Endometriosis pain and epistemic community: Mapping discourses in online discussions among sufferers

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ABSTRACT

We focused in this study on how the private experience of pain is made public through online discourse by sufferers of endometriosis.

Empirically, we analyse two highly active endometriosis communities on the online social platform Reddit. Drawing on a mixed-methods design, we leverage large-scale social data, and a combination of computational and interpretive approaches for text analysis to study the role and shape of interactions relating to 'pain' for the formation of epistemic community online around endometriosis. The dataset, consisting of 70,817 forum posts and comments, was collected in May of 2021.

Our study shows how pain becomes meaningful for endometriosis sufferers in relation to a multidimensional discursive space of words and concepts that are used to express it. Pain was frequently disguised, underplayed or hidden altogether, from fears of misunderstanding, medical dismissal, and embarrassment.

Clearly, peer validation can be found in the relative anonymity of Reddit discussions. While the experience of pain is individual and subjective, when communities share similar experiences this reinforces patient ownership of the pain, which in turn supports the epistemic authority of the patient collective.

A detailed understanding of how and why pain is discussed in online spaces has much to contribute more broadly to discussions of experiential collective knowledge production among individuals with endometriosis and other chronic illnesses.

1. Introduction

Endometriosis is an incapacitating and under-diagnosed disease experienced by roughly one in ten people assigned as female at birth (Yong, 2020). The condition is a major cause of severe pelvic pain, infertility, bowel and bladder problems, fatigue, and heavy menstrual bleeding in those with the disease (Eskenazi and Warner, 1997; Giudice, 2010). There are well-documented delays in diagnosis and referral to specialist care and treatment pathways for those with the disease, alongside significant levels of stigma and shame attached to the illness (Seear, 2009a). The long delays in diagnosis, the isolating nature of the symptoms, and the complicated relationship between medical and patient communities means that online social media offer one of the few connections available for fellow sufferers (Sbaffi and King, 2020; Shoebotham and Coulson, 2016). This study is set in this context of online peer support among endometriosis sufferers. Our study is particularly concerned with discourses around the notion of pain among endometriosis sufferers online. We analyse how pain is expressed by individuals living with the illness, and how such expressions are responded to by peers.

Pain is clearly the dominant symptom of endometriosis, and the one most frequently reported in the primary care setting (Huntington and Gilmour, 2005). Living with persistent pain and seeking professional help for it poses unique challenges, not the least because the pain comes in many different forms (Evans and Bush, 2017, p. ix). This is especially the case for pelvic pain among women, and research has repeatedly reported how these patient experiences are negated by doctors, as the pain is medically 'extracted' and the existence of organic pathology is questioned, leaving a void that "becomes filled with the specter of neurosis or psychological problems" (Grace, 1995, p. 509). Because of this, it has been suggested that endometriosis is seen through the lens of disability studies, which enables a social constructionist critique that "politicizes pain" and, "demands medical intervention as well as disability accommodations" (Jones, 2016, p. 566, see also Przybylo and

Fahs, 2018).

2. Background

2.1. Living with endometriosis

Endometriosis is a complex and enigmatic disease first discussed in medical literature around 160 years ago by Rokitansky (1860). It is currently understood as a condition in which tissue similar to the endometrial lining grows in places and on organs outside the uterus. The disease manifests with a variety of symptoms, including pelvic and extragenital adhesions, severe pain, infertility, heavy menstrual bleeding, bladder and bowel issues, dyspareunia and chronic fatigue. Symptoms usually begin during young adulthood, but there is notable delay of many years, often up to a decade, between the onset of symptoms and subsequent formal diagnosis and treatment (APPG on Endometriosis, 2020; Hudelist et al., 2012; Husby et al., 2003). The condition affects approximately 10 percent of all people identified female at birth (Greene et al., 2016; Pal et al., 2020). Endometriosis can only be properly diagnosed through laparoscopic surgery, and treatment is limited to analgesics and hormone treatments, or removal of the endometriosis tissue through surgical ablation or excision, which gives the best outcome for respite from the illness (Barra et al., 2019).

However, there is no known cure, and the available treatments are often ineffective or unsuitable in many cases, with the disease returning even after surgery (Duffy et al., 2014). The endometriosis patient must also face a long route to diagnosis, uncertainty, painful tests and multiple surgeries, sexual and relationship problems, and the prospect of living with infertility, alongside the symptoms of pain, exhaustion and low mood. Repeated studies have demonstrated that, for decades, there has been widespread lack of understanding concerning the effects of the condition amongst non-specialist medical professionals (Ballweg, 1997; Dancet et al., 2014; Ghai et al., 2020). This has occurred alongside trivialisation of the experiences and dismissal of the symptoms of endometriosis among primary health practitioners and non-specialist gynaecological staff (Cox et al., 2003; APPG on Endometriosis, 2020; Grace, 1995; Hudelist et al., 2012).

Living with endometriosis is obviously challenging and disruptive, and having a painful and misunderstood, or contested, condition often affects mental health as well as physical well-being (Christian, 1993; Della Corte et al., 2020; Facchin et al., 2017; Márki et al., 2017; Missmer et al., 2021). Research has demonstrated that the symptoms of endometriosis interfere with a patient's ability to carry out many activities of daily living, and can seriously impact working life (Hansen et al., 2013; Nnoaham et al., 2011). It is also a disease that has comorbidities with other pain conditions such as fibromyalgia, interstitial cystitis, migraine and irritable bowel syndrome (Lemaire, 2004; Márki et al., 2017), as well as mental health conditions such as depression, low self-esteem and anxiety (Stratton and Berkley, 2011).

2.2. Epistemological community online

The diagnosis of any chronic illness can mean a "loss of self" (Charmaz, 1983) and a "biographical disruption" (Bury, 1982), likely to also affect the psychological and sociological aspects of the sufferers' lives. Recent research by Marschall et al. (2021) outlines the fact that many with the disease have a disrupted experience of life events, such as education, careers, relationships and even sense of personal agency. In the same study, it was emphasised that when endometriosis sufferers were supported by others and able to express some agency in their experience of the disease, they reported better mental health outcomes. In other words, peer support is powerful (Wingfield et al., 1997), and in the case of endometriosis – as with several other conditions – such support is today increasingly reciprocated in online settings (Neal and McKenzie, 2011; Sbaffi and King, 2020).

The chronic and frequently progressive nature of endometriosis and the impact it has on patient mental health means that a long-term and reliable social support network would help patients to navigate the many obstacles outlined above that exist in the pathway from diagnosis to treatment. Due to the complexity and gendered nature of an endometriosis diagnosis, finding adequate, relevant and accurate information about the disease and treatment options, as well as peer support, is especially challenging. Finding support from people who have experienced the range of chronic pain and disruption involved in endometriosis is invaluable. The need for continuous information and advice when medical support is inadequate or absent, as well as a need to bear witness to the "trauma, distress and anger of not being taken seriously" (Cox et al., 2003, p. 5), means that those diagnosed with endometriosis must become "expert patients" (Seear, 2009b). Whelan (2007) has written particularly about endometriosis patients as an 'epistemological community', and has thus emphasised how the sharing of experiences among chronic illness sufferers can counteract the 'epistemological purgatory' that may follow when there is a lack of objective confirmation of lived experiences. Hankinson Nelson (1993, p. 124) defines an epistemological community as a group or collective that shares and constructs standards of evidence and knowledge and emphasises that "communities that construct and acquire knowledge are not collections of independently knowing individuals; such communities are epistemologically prior to individuals who know".

Various forms of online social media have been argued to be successfully used by endometriosis patients for finding knowledge and exchanging peer support (Shoebotham and Coulson, 2016; Wilson et al., 2020). These technologies are vital for patients who are seeking emotional support, disclosure and validation, as well acting as important sources for information gathering. Endometriosis patients using digital forms of patient support have "sought to reduce feelings of isolation and abnormality. This powerful interaction promoted a sense of belonging and acceptance" (Wilson et al., 2020, p. 5).

2.3. Sharing through the language of pain

Previous scholarship on patient experiences of living with endometriosis clearly emphasises physical pain as the dominant feature of the disease (Bullo, 2020; Bullo and Hearn, 2021; Damario and Rock, 1995; Huntington and Gilmour, 2005; Whelan, 2003). About 80% of those with the disease experience extremely painful menses and chronic pelvic pain as well as pain on urination and defecation (Bulletti et al., 2010; Greene et al., 2016; Stratton and Berkley, 2011), and researchers have noted that these experiences of severe pain have been regularly dismissed as a 'normal' experience of the menstrual cycle by healthcare practitioners (Bullo, 2018; Seear, 2009a). The issue of "the delegitimization of women's pain in medical encounters" (Bullo, 2020, p. 478) is familiar.

Living with chronic pain always means living in a problematic social reality. This is because pain is a private and subjective experience. No one other than the individual experiencing it has direct access to it, especially when that pain is in an area of the body that is both internal, invisible and an unfamiliar location for pain for most people who do not suffer from the disease (Schott, 2004). The pain must be communicated into social existence to be alleviated or coped with (Baszanger, 1992). Previous scholarship on chronic pain has made attempts to formalize various dimensions of how sufferers think about, and express, the pain experience — for example in terms of the Pain Catastrophizing Scale (Sullivan et al., 1995), which highlights the elements of *rumination*, *magnification*, and *helplessness*.

Being able to speak the pain – to verbalise it – is crucial not only for hopefully curing it, but also in the process of coping with it. The description of endometriosis pain for others, in a clinical or personal setting, requires imaginative metaphorical language, in order to seek treatment and elicit appropriate medical and emotional care (Bullo, 2020, p. 487). ". It has been shown that the use of metaphoric language in describing pain can have an impact on the extent to which pain

interferes with patients' daily lives (Munday et al., 2022). As emphasised by Biro (2010, p. 16), pain — as distressing as it may be — provides discursive opportunity as it "urges us to take extreme measures to respond and express ourselves [by] forging novel ways to think and speak through metaphor".

In the gap between the moment when a sufferer identifies the pain, and when they enter "the socially established apparatus of healing", the linguistic and discursive tools at the sufferer's disposal are of crucial importance (Ehlich, 1985, p. 178). This line of reasoning echoes Wittgenstein's view that "words are connected with the primitive, the natural, expressions of the sensation and used in their place" (Wittgenstein, 1953, p. 89). As shown by Lascaratou (2007, p. 9) the notion and experience of pain has been investigated from a range of different perspectives, due to its multidimensional character. It relates to medicine, psychology, anthropology, philosophy, history etc. But like Lascaratou, we are in this article interested in the linguistic and discursive dimension of pain. That is, in how pain is spoken.

Ehlich (1985) has argued, also echoing Wittgenstein, that speaking about pain is among the most difficult of linguistic activities. Previous scholarship concerned with how pain is expressed in language has concluded that there are many words in the English language to describe different experiences of pain, and furthermore that such words fall into different subclasses that are representing varying properties or dimensions of pain experience (Melzack and Torgerson, 1971). In other words, pain is multidimensional, and does not vary by mere intensity. As put by Melzack and Torgerson (1971, p. 50), to "describe pain solely in terms of intensity, however, is like specifying the visual world in terms of light flux only, without regard to pattern, color, texture, and the many other dimensions of visual experience.

3. Methods

3.1. Aim and research questions

The aim of this study was to analyse how pain becomes discursively meaningful for sufferers of endometriosis in online peer support interactions. This article addresses three research questions.

RQ1. What are the most prominent descriptive words in the discursive context around 'pain'?

RQ2. Which discursive dimensions of pain can be identified in posts to r/endo and r/Endometriosis on Reddit?

RQ3. What can these descriptions and discussions tell us about the social and communicative contexts of Reddit and the endometriosis community there?

3.2. Data collection

Our study contributes to previous research about how the epistemological community of endometriosis sufferers develop experiential knowledge around pain through taking part in the "sociolinguistic community" through which they develop "public conceptual schemes" that structure their experience (Whelan, 2007, p. 959). In this article, we approach this community through a study of two highly active endometriosis communities on the online social platform Reddit.

Reddit is a website which at present has approximately 430 million monthly active users (Smith, 2021). The platform contains more than 2.8 million public subforums known as subreddits (r/subject) for posting and discussion, which have a specific theme, that users can subscribe to, and are moderated by volunteers. The subreddits cover a wide variety of subjects including politics, science, art, film, trivia, gossip, comedy, health care and popular culture. These discussions can be openly viewed, read and commented on, and registration for a Reddit account is free and anonymous. Unlike many other social platforms online, discussion text in these subreddits do not have a limited word count, and

redditors (the site's users) can share information and participate in discussions anonymously using pseudonyms. For the purposes of this study, two subreddits were examined. The r/Endo subreddit was established in December 2010 and had 29.2 thousand members at the time of data collection in 2021. The r/endometriosis subreddit was established in November 2013 and had 26.2 thousand members.

A careful understanding of the culture of the platform under examination is especially important with Reddit, since "the sociodemographic characteristics of redditors are not comparable to the general population" (Amaya et al., 2019, p. 4) and participant behaviour on the platform is not the same in each subreddit. The site is especially popular in English and German-speaking countries, with most traffic to the site arriving from the USA, UK, Canada and Australia, with around 3% of traffic from Germany, Austria and other German-speaking nations. Unlike many other popular social media platforms, the relationship between Reddit users as friends or followers is not emphasised, and instead informal participation in conversation, and/or upvoting or downvoting to increase or reduce visibility of each post is common (Thelwall and Stuart, 2019, p. 1545). For the researcher, Reddit is a very accessible data source, as most subreddits are publicly accessible. The wide variety of niche communities, such as those concentrating on issues associated with endometriosis, can be easily and anonymously accessed and studied (Amaya et al., 2019, p. 2).

The data collection was carried out in the late spring of 2021, gathering all posts and comments from r/Endo and r/endometriosis respectively using the *psaw* library for Python (Marx, 2021). This library enables making requests to the Pushshift Reddit API (Baumgartner et al., 2020), which enables data searching and collection from the Reddit database. After collecting the data, the posts and comments from both subreddits were merged into one dataset consisting of 70,817 items.

3.3. Data analysis

To begin to respond to our first research question, about which descriptive words are the most prominent in the discursive context around 'pain', in the subreddits under analysis, we leveraged the Natural Language Toolkit (*nltk*) for Python (Loper and Bird, 2002). In a first step, the English dictionary for removing stopwords (common words, prepositions, etc.) was used for filtering. In a second step, only words occurring in posts mentioning the word 'pain' were retained. In a third step, we applied part-of-speech tagging to extract all adjectives from the posts and comments (Voutilainen, 2003). Finally, by drawing and ranking all bigrams (pairs of consecutively occurring words), we were able to construct a graph where the bigrams were approached as network edges. This means that, in the graph, word co-occurrence, defined as words being consecutive in the posts and comments, was manifested as a weighted relationship between the two words in question. The resulting graph was filtered to include only the edges with a weight of 300 and above, meaning that it contains bigrams that appear in more than 300 posts or comments. When visualizing the graph as a network plot using Gephi (Bastian et al., 2009), the text labels were sized by the betweenness centrality of the words (Fig. 1).

When it comes to the second research question, about which discursive dimensions of pain can be identified in posts to r/endo and r/Endometriosis, we wanted to go beyond the initial overview gained through the analysis described above. Therefore, we analyzed a selection of comments and posts qualitatively.

The data were drawn from a selection of posts and comments from r/Endo and r/endometriosis that were dated between the 29th April and October 7, 2019. These were captured using the Reddit API as outlined above and copied into Excel, where a simple random sample of the discussions was generated using Excel functions. This generated 683 comments and replies that were analyzed. This selection was coded by hand using constant comparative analysis. The data was initially assigned in vivo codes, and these codes were developed as descriptive terms, and compared with other codes throughout the refinement
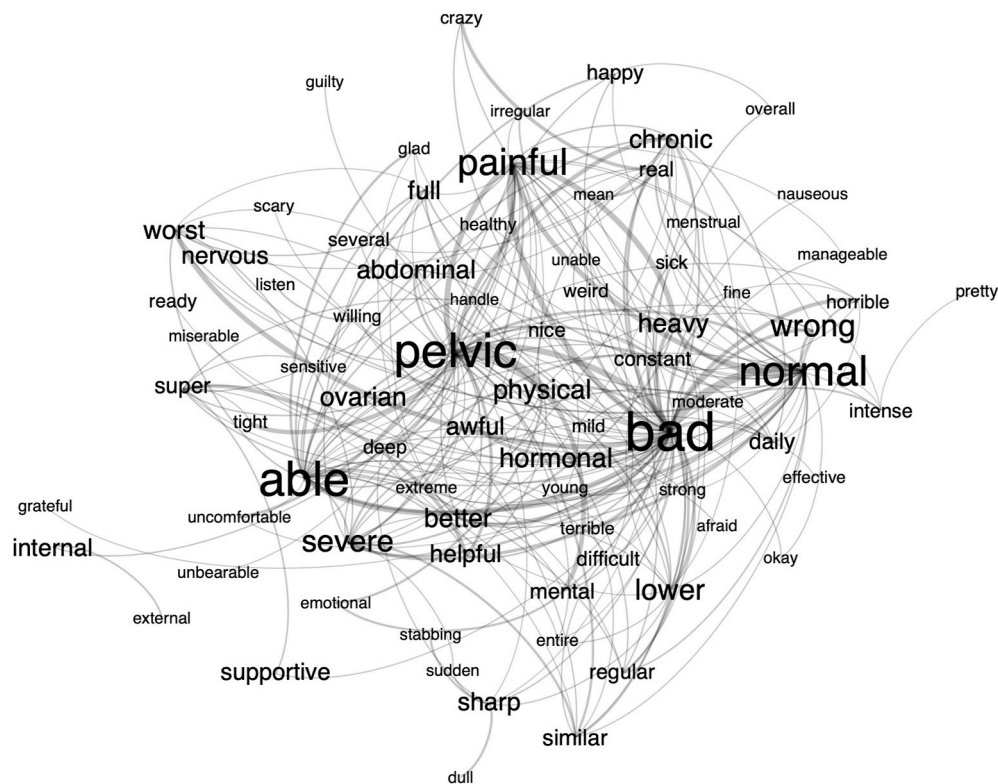
Fig. 1. Network plot showing common word pairs in endometriosis posts and comments mentioning 'pain' on Reddit.

process.

The qualitative analysis for this paper used a Grounded Theory approach. This is a qualitative research and analysis method that was first outlined by Glaser and Strauss, and which supports "the discovery of theory from data" (Glaser and Strauss, 1967, p. 1), through observation of and iterative reflection on social actions, attitudes and participation (Charmaz, 2014). Grounded Theory is especially useful when "the study of social interactions or experiences aims to explain a process, not to test or verify an existing theory" (Lingard et al., 2008, p. 459) and allows the researcher to work closely and reflectively with data, with the aim of understanding both individual contributions and collective concerns expressed in any dataset.

During the Grounded Theory process the researcher "improvises concepts and relationships that emerge from the raw collected data, which are then iteratively organised and reorganised into themes" (Richardson, 2019). These emergent themes combine into a series of concepts drawn directly from the data. Applying a Grounded Theory approach to a research question requires the researcher to undertake an iterative approach to data analysis, and the researcher can focus on the development and refinement of the research questions, as the themes emerge from the topics and social actor. The results of each stage of the conceptualisation and grouping guides the next stage of analysis and supports the refinement of the research questions at each stage (Pickard, 2013, p. 182).

Our close readings, guided by Grounded Theory, produced a set of dimensions that could be derived from the discourse on r/endo and r/Endometriosis. The initial round of coding was a reflexive process, reflecting the expectations of the researcher based on their own lived experience, the research questions and findings from the literature review, as well as identifying explicit phenomena identified in the text. The experiences of pain were allocated codes which reflected whether they were direct descriptions of pain itself, the physical and mental effects of the experience of pain, the stigma attached to the invisibility of pain, or comments on the experience as being a human being who lives through the experience of pain against a backdrop of medical treatment and complex social and cultural contexts.

Having identified these dimensions, and keeping with the general approach of Grounded Theory, we took a set of computational steps to further validate these findings in relation to the entire dataset. We developed a dictionary of key concepts that related to the qualitatively identified dimensions, and approached it as a set of, what is referred to in Grounded Theory as, "sensitising concepts". The idea of such concepts was developed by Herbert Blumer (1954), who argued that researchers must alternately "guide research by theory", and 'assess (…) theoretical propositions in the light of empirical data" (Blumer, 1954, p. 4). One way of achieving that is to approach data openly yet guided by such concepts that "gives the user a general sense of reference and guidance in approaching empirical instances" (Blumer, 1954, p. 7).

Combining this qualitative logic with computational techniques, in order to be able to leverage the full dataset, we first created a word2vec model based on all posts and comments. Word2vec is an approach to text analysis where words are described as numerical vectors (Mikolov et al., 2013). It is based on machine learning through neural networks and is designed to produce a mathematical model of a mass of text. The model, which is trained on the text, makes it possible to predict the degree of probability by which any given word is likely to appear together with another given word in the modelled dataset (Lindgren, 2020, pp. 91–128). In concrete practice, then, a word2vec analysis is a way to automatically find words that tend to frequently appear together in a corpus. In this study, our model which was based on all 70,000+ posts and comments in r/endo and r/Endometriosis, enabled us to extract 'similar' (in terms of proximity) words to those in the dictionary of sensitising concepts. The model was then clustered (using k-means clustering) and plotted using the t-SNE visualisation method. This enabled a refined, and qualitatively guided yet computationally validated, depiction of the discursive dimensions around 'pain' (Fig. 3).

3.4. Ethical considerations

There are several considerations involved in the use of Reddit data.

Subreddit discussions are usually public, and anyone can see the content even if they are not a registered user of the platform. This paper concentrated on original posts and comment threads from these subreddits. Raw data was accessible only to the authors, and all data was anonymised, and the Reddit accounts of the participants were not identifiable. We did not seek individual consent to use these data, as we considered these data public, and all data were anonymised at the point of collection to remove identifiable material from the content of the subreddit before analysis.

The data collection for this paper complied with the Reddit Terms of Service. Individual subreddits may have specific rules about use of the content by researchers, and Reddit also has site-wide user agreements about the use of its API. The subreddits r/endo and r/Endometriosis ask that researchers posting surveys or recruiting for research participants via the subreddits obtain pre-approval. As an anonymised 'Big Data' approach to data collection, we did not fit into these categories and obtaining permission from every account that posted on these subreddits would be an enormous and unnecessary task. Ethical approval for this research project was granted by the Swedish Ethical Review Authority, decision number 2020-00899.

4. Results

In this section, we will first provide a quantitative overview of the most used descriptive words in the subreddits (Fig. 1). Then we move on to the analysis, as described above, where we look closer at the qualitative Grounded Theory analysis and juxtapose it with the word2vec visualisation reproducing a corpus-wide reflection based on that qualitative analysis (Fig. 3).

As can be abstracted from Fig. 1, the networks of descriptive words that surround 'pain' in the discussions about endometriosis hint at a set of dimensions.

First there are words that describe the psychological and mental aspects of living with the pain. These are adjectives such as 'afraid', 'crazy', 'emotional', 'guilty', 'horrible', 'miserable', 'nervous', 'scary' and 'weird'. This bears witness to the fact that words that describe quite strong emotions occur commonly in the discourse surrounding pain of endometriosis sufferers. Feelings of being scared — and of fear and horror — are manifested here. It is also strengthened by our qualitative analysis, that a strong sense of being left to one's own devices, without a clear direction, and with a, sometimes, panic-inducing abysmal feeling of not knowing what to do about one's situation. Furthermore, and relatedly, there are the feelings of going out of one's mind, even questioning one's own experience, as a consequence of not being understood, or even believed, by others. This latter sentiment is manifested through words such as 'crazy' and 'weird'. Additionally, there is the ever-present feeling of guilt. We found in the qualitative analysis, that guilt as related to pain and other symptoms of endometriosis, can come in different forms — one being guilt for not being able to work, another being guilt for being boring among friends who fail to grasp the magnitude of an illness which is largely invisible to others, yet another being guilt for not being able to be intimate with one's partner. There are not only words for negative emotions in Fig. 1, however. As the discussions revolve around the struggle to feel better, words such as 'happy', 'glad', and 'better' naturally also have a place in the discourse. Our qualitative analysis shows that such words are most often used in an aspirational way, such as wishing or hoping to get better and happier in the future. Such patterns must, however, be seen in light of the fact that individuals that do start to feel better, may be less prone to reach out in forums like these.

Second, there are a set of descriptors of the more physiological experiences of pain, such as 'abdominal', 'chronic', 'hormonal', 'intense', 'internal', 'irregular', 'menstrual', 'moderate', 'nauseous', 'ovarian', 'pelvic', 'sharp', 'sick', 'stabbing', 'tight'. Clearly there are overlaps between words in the two categories, as expressions such as, for example, 'constant', 'sensitive' and 'unbearable' indeed may refer to

both mental and physiological experiences at the same time. Pain, indeed, is neither a purely bodily, nor an entirely mental experience.

Finally, a specific category of words bears witness to the fact that the subreddits to some extent enable forms of peer support, as evidenced by the common occurrence of words like 'grateful', 'helpful', and 'supportive'. The qualitative analysis, albeit of a smaller dataset, generally reflects these categories of words. The physical experience of living with endometriosis pain is richly and agonizingly described in the data. The emotional aspects of the experience of pain, such as anxiety, feelings of isolation and despair, and the struggle to feel 'normal', indicate that the process of sharing emotional responses on this subject, a normally taboo discussion topic in everyday life, provides reassurance, is cathartic, and gave a sense of validation to the participants. The platform provides opportunities to share openly, ask questions and compare experiences. The participants provide advice as expert-patients and participants in ongoing treatment with valuable real-life experience to share. Whether that is advocating for pain management treatment, dealing with access to medical care, or negotiating hostile healthcare providers, the qualitative data demonstrates Reddit offers a sense of a reliable, supportive, experienced and robust social network, where "We are here for you if you want to talk, rant or anything else" (Reddit user 2019).

Moving on to the closer analysis, Fig. 2 shows the clusters of topics in the subreddit discussions based on sensitising concepts identified in the first round of qualitative analysis.

The long lists of words that are representative of the five different clusters shown in Fig. 2 give a quite dense, and very high-level, overview of words that have a high probability of occurring together in the corpus that was analyzed. When it comes to single individual words, it must be realized that random factors in the data may have an impact on the precise cluster where a single term gets positioned. This means that plots such as the one shown in Fig. 2 must be interpreted with caution, and more as a kind of sample card of types of words that tend to be used in conjunction, than as clearly delimited categories. Still, the visualisation presented in Fig. 2 gives us a general impression of language-use across the two subreddits.

There were a number of dimensions revealed during the qualitative analysis that speak to the experience of pain associated with endometriosis and its impact on the quality of life. The reports of pain levels were extreme, and the pain was often discussed as an experience of a form of violence, bodily violence, and posts shared extreme descriptions of experience of pain involving sharp objects and adjectives involving horror and torture (cf. The green and purple clusters). The physical experience of this pain was often described as without limits.

The pain was uncontrollable, with discussions about the effectiveness of certain prescribed medication, information was shared about home remedies, and the sense of frustration and fear that surrounds this lack of controlled physical pain. Pain was described as physically as well as emotionally exhausting and energy depleting. The disease and its associated pain was termed as 'one to live with, not recover from'.

From both experienced endometriosis patients and newly or not yet diagnosed, there was a sense that the pain 'will never end', and unlike some medical conditions, there was very little discussion in this dataset of having accepted living with the disease. The experience of torturous pain brings a sense of fear of a loss of control over the body, of bodily functions, and at the same time a fear of loss of dignity and a sense of self. Posts declare significant shame and embarrassment at any outer display of the experience of menstrual or pelvic pain, compounded by the stigma of the almost universal experience of menstrual taboo (cf. Red and teal-coloured clusters).

The experience of long-term chronic pain was an impoverishment of the quality of life, limiting or ending the ability to work, enjoy normal activities, have fun, or maintain intimate relationships. The data indicated a sense of isolation (cf. Teal cluster) in the experience of both the disease as a taboo topic, and the experience of frequent uncontrollable pain (cf. Green and purple clusters). Posts described a sense of loneliness, of being misunderstood by health care professionals, partners,
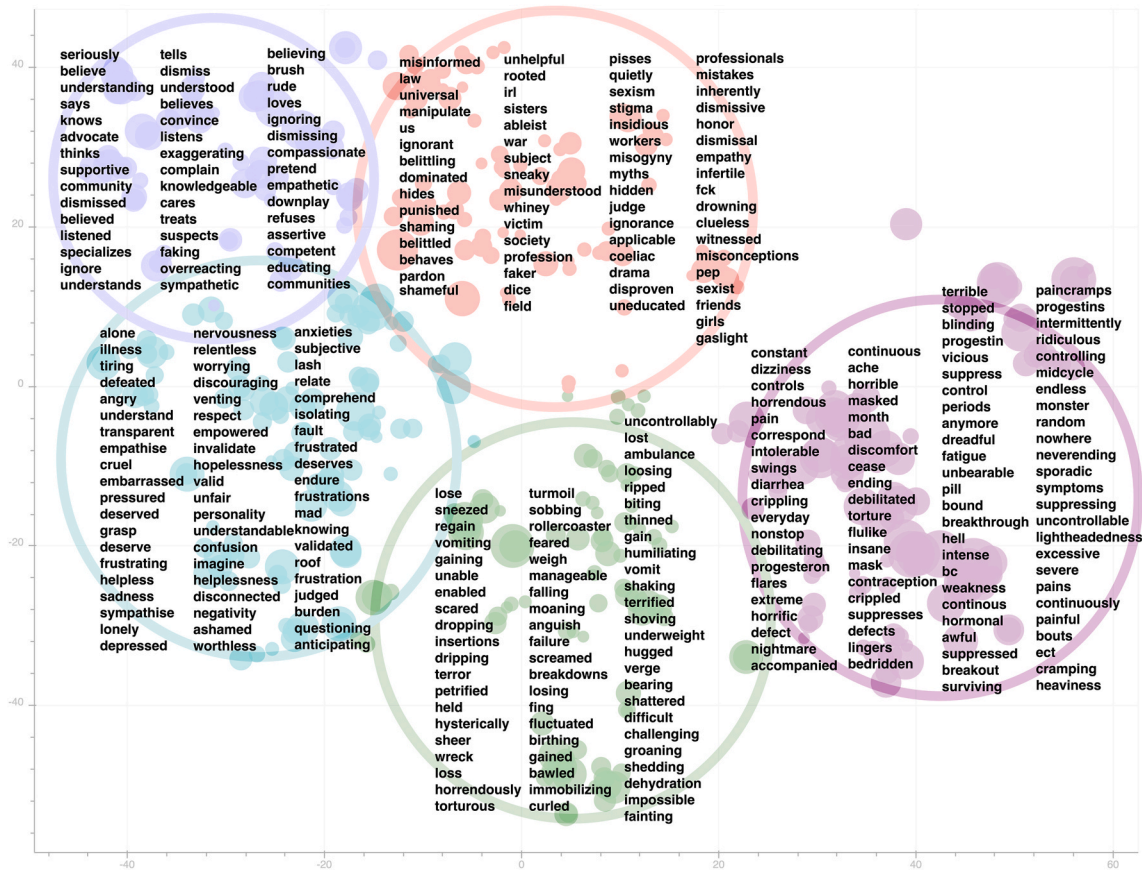
Fig. 2. tSNE plot showing clusters of words with a high probability of occurring together (word2vec), based on a dictionary of sensitising concepts derived from close readings of posts and comments.
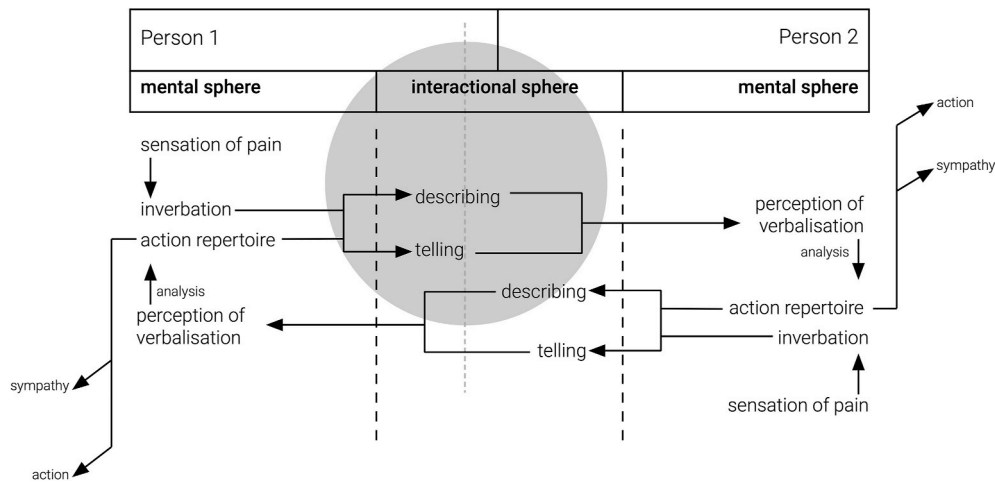

Fig. 3. Social and communicative context around 'pain'. Modification of Ehlich's (1985) model.

family and friends (cf. Teal and red clusters).

A number of posts described how people who don't have endometriosis can't understand the subjective experience of pain, loss and isolation, which led individuals to feel they need their pain validated by others who can sympathise from experience (cf. Pink cluster), and this encourages the use of social media fora for support, especially when in pain.

Many users posted about fear of being perceived as fake, of not experiencing pain to the levels described, and frequently reported not being believed (cf. Pink, red, and teal clusters). Notably, medical

professionals were often criticized by endometriosis sufferers, because of their lack of empathy or understanding about pain levels, or indeed, medical gaslighting in the form of underplaying individual experience, dismissal of symptoms, and refusal to prescribe stronger painkillers (cf. Red cluster). As a result, pain was frequently disguised, underplayed or hidden altogether, from fears of misunderstanding, medical dismissal, and embarrassment. It is therefore unsurprising that validation can be found in the relative anonymity of Reddit discussions and has been positively embraced by the endometriosis community.

5. Concluding discussion

In writing about endometriosis sufferers, Whelan (2007, p. 958) points to the need of exploring *how* they describe their predicament, rather than *why*. This is similar to what Ehlich (1985, pp. 179–180) requests, referencing Wittgenstein, when arguing that it "would be helpful, if not necessary, to look for the *functions* of the language of pain in its *use*. The social and communicative context around pain descriptions is described by Ehlich according to a schematic figure (see Ehlich, 1985, p. 184). According to that model, the *sensation of pain* — which is the initial input of the process — gives rise in the individual to *verbalisation*, i.e., the mental step between the sensation and its linguistic expression. In turn, this urges the sufferer to *describe* or *tell* about the pain in social interaction. The person interacting with the sufferer will *interpret* the verbalisation, *analyse* it (i.e., process it in relation to discursive conventions). In turn, this gives rise — through this interaction — to a certain *action repertoire* as well as potential feeling of *sympathy* and pity. Fig. 3 below represents a modification of Ehlich's original model, with a stronger focus on the processes of peer-support and mutual recognition that are enabled by sharing personal stories on online social platforms (Bambina, 2007; Lindgren, 2014; Lundström, 2018; Naslund et al., 2016). In the figure, the processes envisioned by Ehlich are seen as going both ways in social settings where pain sufferers interact. The one side of the figure thus mirrors the other to reflect the "symmetry of common concern" which is "a major parameter of the self-help group's character" (Jacobs and Goodman, 1989, p. 537). Each participant (Persons 1 and 2) experience sensations of pain, and tell about them in *mutual* interactions, enabling in each participant not only sympathy and/or action to alleviate the pain of the sufferer, but prominently to *reciprocate* the description and telling.

Crucially from the perspective of epistemological community, pain tends to be understood as an experience which is intrinsically individual and personal, and which detaches a pain-sufferer from their social surroundings. Speaking the pain, and to do so in social networks, can therefore provide ways of coping.

Understanding endometriosis sufferers as an epistemological community, and focusing particularly on discursive interactions around pain, means focusing on processes of *sharing* that set social peer support apart from other types of support, for example that given in professional settings e.g., from therapists to clients. It is agreed in previous scholarship about peer support, for example in self-help groups, that the sharing of similar experience plays an important role in corroborating and confirming one's own experiences, as well as those of others. Thereby, the practices of mutual sharing can build a sense of belonging. As Bülow (2004) argues, that while 'sharing' an experience may simply mean to experience similar things, without explicitly sharing – through language – the experience, it is still crucial to approach sharing in terms of it being interactional and mutual. This kind of sharing is especially important in the case of contested illnesses, such as endometriosis, as the difficulties that are entailed in explaining the experiences, e.g., to physicians, often leads to a sense of being mistrusted or delegitimised with the sufferer (Bülow, 2004). It has been shown, in this study and elsewhere, that online peer support can be important to alleviate such feelings (Barker, 2008).

This aligns with the literature on so-called communities of practice, which offers a useful conceptual framework for describing the kind of peer-support interaction that is going on in the analyzed discussions among endometriosis sufferers. The concept of *communities of practice* refers to the informal groups that people form over time through shared enterprises. Wenger (1998) describes three aspects of this relation. To begin with, participants must engage mutually. Practice is not an abstract concept, but something people create as they carry out actions whose meanings they negotiate collaboratively. A community of practice is the result of active interaction and meaning-making — "not just an aggregate of people" (Wenger, 1998, p. 74). The second characteristic of communities of practice is their joint enterprise. Participants negotiate collectively to create this enterprise, which then creates a mutually accountable relationship based on the participants' responses to their situation. The development of a shared repertoire is also an important aspect of communities of practice. Through synchronization of resources, participants construct coherence in "the medley of activities, relations, and objects involved" (Wenger, 1998, p. 82). As a result of this repertoire, participants make and perform meaningful utterances and actions, amongst one another.

In this article, we have shown how discourses around pain are collaboratively shaped by endometriosis sufferers in the online context, where empowering collective processes come into play. While the experience of pain is individual and subjective, when communities share similar experiences, this reinforces "patient ownership of the pain" (Whelan, 2003, p. 475), which in turn supports the epistemic authority of the patient collective. We have focused in this study on how the private experience of pain is made public through discourse. This is from a perspective where private pain is seen as related to physiological responses to unpleasant stimuli, while public pain is part of a social relationship (Waddie, 1996). A detailed understanding of how and why pain is discussed in online spaces has much to contribute more broadly to discussions of experiential collective knowledge production among individuals with endometriosis (see e.g., Neal and McKenzie, 2011).

Credit author statement

Simon Lindgren: Conceptualisation, Methodology, Formal analysis, Data curation, Writing – original draft, Writing – review & editing, Funding acquisition. Lorna Richardson: Methodology, Formal analysis, Writing – original draft.

Data availability

The authors do not have permission to share data.

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