



# Parallel worlds and personified pain: A mixed-methods analysis of pain metaphor use by women with endometriosis

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**Objectives.** Endometriosis is a long-term condition in which endometrial-like tissue grows outside of the womb, causing intense chronic pain. Previous work has demonstrated the physical and emotional impact on women who live with endometriosis, and metaphors can play an influential role in communicating the experience of pain, but there exists little understanding of the role and impact of such language for women with endometriosis.

**Design.** A qualitative, semi-structured interview design.

**Methods.** Conceptual Metaphor Theory (CMT) and Interpretative Phenomenological Analysis (IPA) were utilized in a mixed-methods study to examine the prevalence, types, and meaning of metaphors and metaphor use as a health communication strategy. Twenty-one women aged between 23 and 53 years (mean age 36.1 years) with endometriosis took part in audio-recorded interviews.

**Results.** The women reported experiencing symptoms for an average of 11 years before receiving a formal diagnosis of endometriosis, and the mean age of diagnosis was 27.6 years. Seven distinct conceptual metaphors were identified in 221 metaphorical expressions used across all participants, with most common ones referring to pain as physical properties of elements such as temperature and pressure, physical damage, and an external attacker. IPA revealed three themes pertaining to the feeling of vulnerability and helplessness, pain being incomprehensible, and a drive to manage and conceal pain simultaneously.

**Conclusions.** This study demonstrates the power of language in facilitating understanding and empathy in the listener, alongside the challenge of communicating endometriosis pain to others. Imagery-based techniques may assist in adaptation to, interpretation, and acceptance of pain to reduce pain-related distress.

## Statement of contribution

### *What is already known on this subject?*

- Endometriosis is a debilitating gynaecological condition causing incapacitating pain that is reportedly difficult to describe.

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- This challenge means that women are forced to rely on language tools (such as metaphors) to externalize their internal pain experiences.
- Limited work has explored how endometriosis pain is communicated, and the functions of that communication, utilizing a conceptual metaphor approach.

***What does this study add?***

- Across 21 women, pain metaphors (including repetitions) were used 221 times, with a range of seven different conceptual metaphors.
- Most commonly, endometriosis pain was referred to as physical property of elements (such as temperature and pressure), physical damage, and an external attacker. Pain was described as a distressing agent, often conceptualized as an external entity exercising intrusive control over their experiences.
- The analysis conveys the perceived loss of control, feelings of helplessness and fear, and attempts to escape and conceal pain.

## **Background**

Endometriosis is a debilitating gynaecological condition, affecting one in ten women of reproductive age (Endometriosis UK, 2017), in which tissue similar to the uterine lining is found outside the uterus.

Symptoms include heavy and/or painful periods, fatigue, and bowel and bladder problems, with long-term effects such as risk of infertility and chronic pain. Treatment is complex and can involve analgesia, hormone treatments, and surgery to remove small patches of cells, or in some cases the entire uterus (American College of Obstetricians and Gynaecologists, 2010; National Health Service, 2017). Endometriosis pain can be incapacitating and has various mechanisms, that is, cyclical (i.e., during menstruation and ovulation), functional (i.e., during urination, sexual intercourse), and chronic (Bourdel *et al.*, 2015) with both neuropathic and nociceptive characteristics (Howard, 2009).

Evidence examining the experience of endometriosis highlights the negative impact of the condition on work, relationships, well-being, and quality of life, with pain being a major contributor to this impact (De Graaff *et al.*, 2013). Indeed, work has demonstrated that women experiencing endometriosis pain had significantly poorer quality of life and mental health compared with women with asymptomatic endometriosis (Facchin *et al.*, 2015). Interview data highlight that this impact is further complicated by the perceived normalization, trivialization, or disbelief of pain by medical professionals and families, and diagnosis delays, both of which are key sources of distress (Bullo, 2018; Facchin, Saita, Barbara, Dridi, & Vercellini, 2017). Likewise, this is echoed in a recent systematic review of qualitative research with women with endometriosis, summarizing that endometriosis and its associated pain poses significant risk to women's well-being and quality of life (Young, Fisher, & Kirkman, 2014).

The challenges of communicating pain are widely addressed in the health communication literature (e.g., Lascaratou, 2007), which normally address the subjectivity of the pain experience (e.g., Schott, 2004) and patients' reliance on language tools to be able to externalize their internal experience (Lascaratou, 2007). This also means that patients need to resort to imagery (e.g., Gosden, Morris, Ferreira, Grady, & Gillanders, 2014) and/or metaphorical language (e.g., Schott, 2004; Semino, 2010) to communicate their pain experience/s. The reliance on metaphorical language to describe pain is actually acknowledged by The International Association for the study of Pain's (IASP) (Merskey & Bogduk, 1994) definition of pain as 'an unpleasant sensory and emotional experience

associated with actual or potential tissue damage, or described in terms of such damage'. This definition parallels that of metaphor as the conceptualization of one (abstract) phenomenon in terms of another (more concrete) one (Lakoff & Johnson, 1980) (c.f. Methodology section below).

Studies in metaphor and illness have found that journey and violence metaphors are prominent in cancer patients discussing their condition (e.g., Semino, Demjén, & Demmen, 2017). The use of military metaphors in health communication, however, has been critiqued on the basis that they could have negative effects on patients who may feel blameworthy if they are 'beaten' by the disease (Sontag, 1991). Contrariwise, linguists have argued that avoiding the use of metaphors may 'marginalize and potentially silence' those who find certain metaphors 'motivating and helpful' (Demjen & Semino, 2017: 392). As an important aspect of language and thought, metaphors frame the experience of illness in different ways (Demjen & Semino, 2017) by drawing from areas of experience and therefore help understand pain in meaningful ways (Gwyn, 1999; Loftus, 2011). Similarly, Shinebourne and Smith used Interpretative Phenomenological Analysis (IPA) to explore metaphors in accounts of experiences of addition and conclude that such an approach can shed light into how participants make sense of 'unexpressed or unexplored dimension of experience, such as emotions' (2010: 60). Further to this, Overend (2014: 66) suggests that metaphors have special added value in cases of undefined or invisible illnesses, such as endometriosis, as they allow patients to 'understand and articulate the experiences of undefined illness in ways that empirical accounts alone do not'. Indeed, the use of pain measurement tools, such as the NRS or VRS scales, normally used in suspected endometriosis consultations, has been argued as a factor in restricting pain expression in consultations (Bourke, 2014). The McGill Pain Questionnaire (MPQ; Melzack, 1975), however, offers patients a selection of metaphorical descriptors such as 'drilling', 'tearing', etc. to choose from in order to describe what their pain 'feels like'. Semino (2010: 210) therefore points out that the MPQ 'provide(s) evidence of the pervasiveness of metaphorical descriptions of pain in English'. Indeed, the use of metaphor can facilitate in communicating sensorimotor qualities that others may not personally understand or visibly see (Radley & Chamberlain, 2001). From this, shared understandings may be invoked, which can then act as a pathway to enhanced support (Howe, 2008). Metaphor, therefore, may be highly suited to the expression of endometriosis pain (Bullo, 2020), and reviewing interview data to explore the type and function of language used can provide a foundation for evidence-based integration of language and imagery in diagnostic discussions and consultations (Jamani & Clyde, 2008). For example, existing literature on pain metaphor demonstrates some commonalities in metaphor choice, such as 'burning' and 'pins and needles', which can be seen in people with neuropathic pain after spinal cord injury (Hearn, Finlay, & Fine, 2016), HIV, diabetes, and post-stroke (Freeman, Baron, Bouhassira, Cabrera, & Emir, 2014). Further, work has demonstrated a link to negative cognitions, which is associated with higher emotional distress and pain intensity (Philips, 2011) and may highlight pain-related fear, and perceptions of pain as permanent and deserved, particularly when pain is described as 'torture' (Hearn et al., 2016). Such use of metaphor is argued to reflect catastrophic thinking, a cognitive coping strategy in which focus is on threatening appraisals of events, and is motivated by proximity and support seeking, which may lead to hypervigilance (Villemure and Bushnell, 2002).

Despite this evidence, the communication of endometriosis pain via metaphor has received little attention and is not often the primary focus of analyses. Indeed, previous qualitative work has set out to explore the lived experience of endometriosis pain (Bullo,

2020), quality of life (Jones, Jenkinson, & Kennedy, 2014), social support (Cox, Henderson, Anderson, Cagliarini, & Ski, 2003), and the diagnosis delay (Ballard, Lowton, & Wright, 2006), with a recent systematic review of qualitative work exploring experiences of endometriosis in general summarizing such work (Young *et al.*, 2014). By making it the central focus of analyses, such work can enhance the understanding and ability of health care professionals to identify those with greater risk of distress and offer timely, tailored support. This study, therefore, aimed to examine the use of metaphor in communicating pain in women with endometriosis.

## **Methods**

### **Participants**

Participants were self-selecting, in a purposeful sample that has lived, experiential knowledge of endometriosis (Smith & Osborn, 2003). Inclusion criteria were as follows: lived experience of endometriosis for at least one year, and 18 years old or over. The final sample consisted of 21 women, all of whom had a diagnosis of endometriosis. Ages ranged from 23 to 53 years old ( $M = 36.1$ ,  $SD = 8.5$ ). The mean age at diagnosis was 27.6 years ( $SD = 8.4$ ), and the average time that participants experienced their symptoms before they were formally diagnosed with endometriosis (i.e., time to diagnosis) was 11 years ( $SD = 7.5$ ). Pseudonyms are used to preserve participant anonymity.

### **Procedure**

A call for participants was shared via social media channels. Those who were interested in participating were directed to contact the researcher (SB) and were provided with further detailed information, and an opportunity to ask questions, after which times, dates, and locations of interviews were confirmed. Written, informed consent was obtained prior to interviews, which were conducted in public places or participants' homes via Skype. Interviews were conducted by the first author and lasted 60 minutes on average. An encrypted audio-recording device was used to record the interviews, which were then transcribed verbatim, prior to analysis.

### **Data collection**

Data collection followed a systematic approach as recommended by Smith, Flowers, and Larkin (2009), with interview questions guided by an open-ended, semi-structured interview schedule. Participants were given freedom to lead the interview, focusing on topics deemed most important to their lived experiences of endometriosis. Participants were asked to narrate their journey through endometriosis through the use of open questions such as 'Can you tell me about your journey through endometriosis from symptom onset to diagnosis?' One specific question required women to describe how their pain feels. When interviewees felt unable to describe their pain, they were encouraged to start sentences using 'it feels like...'.

### **Analysis**

In order to obtain a rounded perspective of endometriosis pain as experienced not only physically and cognitively but also socially, a novel mixed-methods approach by

combining Conceptual Metaphor Theory (CMT; Lakoff & Johnson, 1980) with IPA (Smith *et al.*, 2009) was conducted and audited by all authors. The first stage consisted of identifying metaphorical language across participant transcripts, which were coded in line with CMT using Metaphor Identification Procedure (MIP; Pragglejaz Group, 2007). This utilized the definition of conceptual metaphor as understanding one domain of experience (typically abstract e.g., pain) in terms of another (typically concrete e.g., temperature). That is, any reference participants made that linked their pain (the target domain) to another domain of experience (a concrete, source domain) was included in the analysis. Frequently used examples of metaphorical expressions are ‘it’s been a long and bumpy journey for our relationship’, ‘long and bumpy journey’ as ways of conceptualizing a relationship as a journey; therefore, the conventionalized conceptual metaphor is LOVE IS A JOURNEY<sup>1</sup>.

Conceptual metaphors were systematically identified in the data by reference to the well-established MIP (Pragglejaz Group, 2007) which allows for a systematic parsing of metaphorical expressions by contrasting the basic and contextual meaning of every lexical component in the expression and identifying those with a clash between both meanings as metaphorical. For example, in the expression ‘stabbing pain’, the contextual meaning of ‘stabbing’ in the data refers to pain that is likely sudden, intermittent, deep, intense, etc. This contrasts with the basic meaning of the word, that is, the dictionary meaning, ‘to stab’ [v]: to injure someone with a sharp pointed object such as a knife [Cambridge Online Dictionary, n.d.]. In other words, when there is a contrast between the basic meaning and the situated contextual meaning, or usage of a particular word (or string of words) then such word is considered metaphorical according to MIP (Pragglejaz Group, 2007). This procedure was applied to all pain descriptors used by participants. Once the contrast between basic and contextual meaning was established and a descriptor considered metaphorical, for example, ‘stabbing pain’, it was allocated to a conceptual category. In the case of the example at hand, ‘stabbing’ pain is seen in terms of PHYSICAL DAMAGE as result of the application of a sharp object. Summative scores were calculated for individual participants, and multiple occurrences of the same conceptual metaphor in the form of different metaphorical expressions were counted individually. For example, ‘stabbing pain’ and ‘twisting pain’ are two metaphorical expressions reflecting the PAIN AS PHYSICAL DAMAGE conceptual metaphor. The metaphorical expressions were then grouped by conceptual metaphor they entailed (cf. Table 1).

Secondly, IPA was utilized, with a focus on interpretation of metaphorical language. Each transcript was read, with notes pertaining to linguistic, descriptive, and conceptual features made in order to develop themes based on psychological concepts and abstractions representing key concerns surrounding pain for each individual. This resulted in a table of themes, within which corresponding quotes providing illustrative content of each theme were provided. In the cross-case analytical process, themes across the sample were reviewed and clustered according to conceptual parallels, examining convergences and divergences in experiences in an iterative process, with the researcher

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<sup>1</sup> Cognitive linguistics distinguish between metaphorical expressions, for example, ‘bumpy road for our relationship’ (i.e., way of speaking) and conceptual metaphor (i.e., way of conceptualizing the abstract idea of love) that such metaphorical expressions entail. Conceptual metaphors are normally coded in in SMALL CAPS to distinguish them from metaphorical expressions. Therefore, it is important for the reader to bear in mind that when we make reference to ‘metaphorical expressions’, we refer to the former whilst ‘metaphors’ or ‘conceptual metaphors’ and their graphical representation in SMALL CAPS refers to the latter. Lakoff and Johnson refer to conventional metaphor as those commonly used in everyday language in a given culture to structure certain domains of experience, such as LOVE IS A JOURNEY, as opposed to novel or unconventional metaphor that are beyond social conventions and ‘are capable of giving us a new understanding of our experience’ (Lakoff and Johnson, 1980, p. 139).

constantly moving between part and whole to ensure that interpretations remained grounded in the data (Smith *et al.*, 2009). Those themes that were endorsed by more than half of the sample were considered ‘common’ and key to the experience and communication of endometriosis pain, in line with recommendations by Smith (2011). This approach has been effectively utilized to examine the role of metaphor in the experience of neuropathic pain in spinal cord injury (Hearn *et al.*, 2016).

In order to ‘bracket off’ any prejudgements and assumptions, a reflective diary was utilized to ensure the analysis reflected each individual’s account (though it is acknowledged that the epistemological stance of the researchers may have played a role in the interpretations). SB, who has lived experience of stage 4 endometriosis, acted as an auditor of the analysis, checking the super-ordinate themes and the corresponding quotes through discussion, and helped to ensure that themes remained grounded in the data. As such, the interpretations presented here are a result of the researchers’ interpretations of participant accounts and are considered credible and meaningful reflection of living with endometriosis.

## Results

### Metaphor identification

All participants used metaphorical language when describing their experiences of endometriosis. Metaphorical expressions, including repetitions, were used 221 times across participants, with seven distinct conceptual metaphors used across the data set. The mean number of metaphorical expressions used was 10.5. Table 1 lists the metaphors by percentage of occurrence, and Table 2 describes each conceptual metaphor with examples from the data.

The highest percentage of metaphorical pain descriptors found in the data conceptualizes PAIN AS PHYSICAL PROPERTIES OF ELEMENTS (e.g., ‘like my womb is going to explode’). This was followed by expressions that describe the quality of pain in relation to PHYSICAL DAMAGE that would result from an external object being used to inflict such damage, such as ‘stabbing pain’. In many cases, by means of similes<sup>2</sup>, pain is personified as an EXTERNAL ANIMATE AGENT inflicting pain by performing actions that cause physical damage or using objects to cause such damage, for example, ‘like someone is cutting you’. Such descriptors clearly reflect the physicality and the psychological conceptualization of endometriosis

**Table 1.** Results of metaphor identification procedure

Metaphor PAIN AS...	Proportion of metaphors (%)
a. PHYSICAL PROPERTIES OF ELEMENTS	41
b. PHYSICAL DAMAGE	27
c. EXTERNAL ANIMATE AGENT CAUSING PHYSICAL DAMAGE	18
d. TRANSFORMATIVE FORCE	8
e. EXTERNAL INANIMATE ENTITY	4
f. SENSORY EXPERIENCE	2
g. ANIMATE AGENT	2

<sup>2</sup> Similes are also considered metaphors in that they explain one concept in terms of another but in using explicit comparative devices (e.g. “like”) they could be seen as indicative of a more purposeful choice than is the case with conventionalized metaphors (Bullo, 2020). Such intentionality should also be considered in the study of metaphorical language in pain description.

**Table 2.** Conceptual metaphors, with descriptions and examples from the data

Conceptual metaphor PAIN AS . . .	Description	Example of metaphorical expressions
a. PHYSICAL PROPERTIES OF ELEMENTS	Pain is seen as an intrinsic feature that happens in its own right and is made akin to physical properties of elements such as pressure, temperature, volume, weight, etc. and that have the potential to cause physical damage (e.g., if something explodes from pressure) but the damage is not made explicit	'like my womb is going to explode' (pressure), 'hot', 'like a burning golfball', (temperature), 'heavy' (weight), 'like everything was drawing into the centre' (magnetism), 'electric sparky' (electric force), 'sharp' (hardness), 'tight' (tension), 'lumpy' (volume)
b. PHYSICAL DAMAGE	Pain is described in relation to physical damage that would result from an external object being used (e.g., knife) or actions performed (e.g., twisting) to inflict such damage (but no agent causing such damage is made explicit)	feels like 'stabbing', 'twisting'
c. EXTERNAL ANIMATE AGENT CAUSING PHYSICAL DAMAGE	Pain is personified as a malevolent agent performing actions that cause physical damage	'like someone cutting you', 'someone putting barbed wire in your belly button in a figure of eight'
d. TRANSFORMATIVE FORCE	Pain is seen as a transformative force or process whereby women perceive themselves as shifting into a different location, state, or entity	'doomed', 'beyond human consciousness', 'like someone possesses you'
e. EXTERNAL INANIMATE ENTITY	Pain is made akin to inanimate and unnatural elements inside the body	'like metal wool inside', 'it feels machine like'
f. SENSORY EXPERIENCE	Pain is qualified as an experience that is sensed, mostly in terms of sound	'buzzing', 'like a car alarm', 'loud', 'like nails against chalk board'
g. ANIMATE AGENT	Pain is given the characteristics of animate beings, human, or animal	'nagging pain', 'my womb is angry', 'it kicks in'

pain and may reflect experiences (such as cuts) that individuals without endometriosis have experienced, potentially facilitating shared understanding and reflecting the embodied aspect of conceptual metaphor.

Other metaphorical expressions denote a more ontological quality to the conceptualization of pain. These include PAIN AS TRANSFORMATIVE FORCE where women see themselves as becoming a different entity or in a different location during episodes of pain. In the 'beyond human consciousness' expression, the 'normal' self is seen as contained within a bounded region. In episodes of pain, women perceive their location as outside or away from the bounded region and hence lacking in self-control, normality, or even humanity. Similarly, in 'like someone possesses you', pain is compared to an external force or being taking control of the self thereby conveying a lack of agency felt during episodes of pain. Linked to this, expressions that conceptualize PAIN AS SENSORY EXPERIENCE, for example, 'like nails against a chalk board', still denote an embodied phenomenon but one that detaches pain from its physical experience.

Finally, the categories with the lowest percentage of occurrences also present an ontological aspect conceptualizing PAIN AS ANIMATE AGENT by means of personification, for

example, 'it feels like my womb is angry', or EXTERNAL INANIMATE ENTITY 'it feels like a machine'.

The conceptual metaphors identified above demonstrate a number of ways in which women with endometriosis conceptualize their pain. The bulk of metaphorical pain descriptors selected by participants were within the PAIN AS PHYSICAL PROPERTIES OF ELEMENTS, PAIN AS PHYSICAL DAMAGE, and PAIN AS EXTERNAL ANIMATE AGENT CAUSING PHYSICAL DAMAGE metaphors. A lesser percentage of descriptors relate to PAIN AS TRANSFORMATIVE FORCE, ANIMATE OR INANIMATE ENTITIES, and SENSORY EXPERIENCE. Such descriptors are revealing of a number of aspects of the pain experience that go beyond its severity but they also hint at how pain affects women physically and emotionally as well as its impact on quality of life. A further in-depth qualitative exploration can therefore provide a more thorough insight into such dimensions of the endometriosis pain experience and aid the development of clinical implications. To that end, we now offer such a perspective through the IPA lens.

### ***Interpretative phenomenological analysis***

Participants' descriptions acted as windows to the experience, demonstrating the use of metaphor to convey sensory qualities of endometriosis pain, and associated emotional distress. Three themes are presented: (1) *Losing agency to an externalised attacker*, (2) *A fearful liminal space of pain*, and (3) *Concurrent coping and concealment of pain*. The themes convey the perceived loss of control to an external entity distinct from themselves, which fed into participants' sense of helplessness and fear.

Driven by pain intensity and pain-related fear, participants discussed their multiple attempts to escape and conceal pain. Themes are presented alongside the conceptual metaphors identified in order to further illuminate the understanding that metaphorical communication can offer to experiential meaning making, therefore providing a more vivid and richly textured analysis of experiences of endometriosis pain.

#### *Theme one: Losing agency to an externalised attacker*

The most common understanding of pain was in terms of feeling controlled by a force distinct from their own bodily representation, often personifying pain as an external entity intrusively exercising control over their bodies, as manifested by the use of the PAIN AS ANIMATE AGENT CAUSING PHYSICAL DAMAGE metaphor:

... it just feels like someone is in your insides, pulling everything to bits. (Gail)

Gail demonstrates her personification of pain as a person inside her and the actions they are taking to induce pain, with an emphasis on pulling sensations. The invasive nature of this metaphorical reference reinforces the loss of control and autonomy induced by the pain.

Reflecting Gail's experience, Eleanor described pain as heat and damage caused by insertion of a sharp object (combining both the PAIN AS PHYSICAL PROPERTIES OF ELEMENTS and the PAIN AS PHYSICAL DAMAGE metaphors) that, despite passing, would occur repeatedly and unpredictably:

The pain for me is like, is a hot poker or a knife being shoved inside me. Or two being shoved inside me. Uhm, it will, it's a completely overwhelming pain that will pass, but will happen again ... and it will be absolutely enormous pain and again maybe an hour later, or maybe days later (Eleanor).

Eleanor's communication of pain underscores the intensity with which endometriosis pain is experienced, with a description graduating from a single hot poker or knife, to two of the same, thus emphasizing the original description as insufficient in conveying her experience. Her quote also illustrates her loss of autonomy, with enormous pain overwhelming her in an unpredictable manner.

Further highlighting the sense of helplessness echoed across all participants, Sasha and Sue recall similar metaphors to describe the constancy of their pain, marked by the time references 'continuously' and the 'wait for it to pass' and their inability to mitigate it:

I had what felt like someone gripping the bottom of my spine and crushing my spine continuously for two years. (Sasha)

It's as if somebody's taken a uhm, someone's driven a knife into my side, or, hammered or screwed something in and it just gets tight and I have to wait for it to pass. (Sue)

Echoing the above views of pain, Sasha and Sue also underscored feelings of helplessness and resignation in waiting for the pain to pass, leaving them feeling like passive victims of pain.

Jo described the punishing nature of her experience of pain through a vivid and visceral description by means of the PAIN AS EXTERNAL ANIMATE AGENT causing PHYSICAL DAMAGE metaphors:

... it feels like somebody putting barbed wire through your belly button in a figure of eight around your pelvis and they're twisting it and pulling it and all your insides are just being squeezed and sort of pushed and pulled and everything is just being twisted. And then they set fire to the barbed wire and it starts getting hot and everything's just being squished inside you basically. (Jo).

The externalized attacker is described in excruciating detail, the description graduating by use of the PAIN AS TEMPERATURE metaphor, a subcategory of the PAIN AS PHYSICAL PROPERTIES OF ELEMENTS, in order to convey the intensity. Through the use of such metaphors, the descriptions portray pain as a malevolent, punishing, uncontrollable, embodied being distinct from their self-identity. Such conceptualization of pain may have implications for pain acceptance and could constitute a catastrophic perception of pain.

#### *Theme two: A fearful liminal space of pain*

Enhancing the potential for shared understanding to be reached, participants also offered further detail that illustrated the emotional and cognitive impact of pain:

I just remember that like flames and like it's just all-consuming (Sue)

Sue used the PAIN AS TEMPERATURE metaphor (PAIN AS PHYSICAL PROPERTIES OF ELEMENTS) in heat-related metaphorical expressions to convey her pain alongside conveying the cognitive, emotional, and physical impact of her pain. Her use of the PAIN AS TRANSFORMATIVE FORCE metaphor ('all-consuming') demonstrates the incapacitating and overwhelming experience of pain; demanding her whole attention, highlighting the cognitive impact and her inability to divert her attention away from it.

Further, affective descriptions honed in on participants' fear, sense of doom and entrapment, also by means of the PAIN AS TRANSFORMATIVE FORCE metaphor:

I was in absolute agony . . . I thought I was dying. (Alice)

. . . if you didn't know what was going on, you'd go to the hospital and you'd think you were dying. (Sue)

Sue and Alice use language that demonstrates their fear of pain indicating impending death, with pain viewed as outside of the 'normal' parameters within which it should be tolerated. The sense of pain being a liminal space before death forced participants to confront their mortality and potentially induced further distress.

In a similar vein, Amanda highlighted the pain's complex connection to her sense of self and identity:

It's like I lose my sense of self . . . You can't hear. You can't see. When it's at its worst you do just become almost like transcendental . . . nothing else matters. But not in a good way. (Amanda)

And in a public building even sometimes just on my knees just you know crouched and . . . in another world just in agony. (Amanda)

Amanda's referral to losing her sense of self illustrates the perceived TRANSFORMATIVE FORCE of pain, and her loss of an awareness of herself and her body in space and time. Her pain overpowers her senses, as she experiences a loss of connection to her physical world, entering a parallel world or liminal space, with pain being the only thing that matters.

Kim and Mel also reflected a sense of being overwhelmed by their pain, with it becoming their sole focus:

When it's really bad, and if the painkillers haven't kicked in, you know, you can literally be on all fours in the bathroom just in a ball because it hurts, because you can't do anything. It's quite hard to describe the pain actually, it is, because it's just . . . You feel quite closed down and closed in, so you feel like it, it's almost like tunnel vision. (Kim).

You go from enjoying yourself to being in extreme pain . . . You can't do anything; it clouds your whole mind. (Mel)

Kim demonstrates the impact of her pain when unmanaged by analgesic medication, with her being reduced to the floor by the pain and unable to continue her daily activities. Mel also underscores the impact on her daily life, with sudden fluctuations in pain dominating her mind. Both Kim and Mel, through the PAIN AS TRANSFORMATIVE FORCE metaphor, echo the difficulty in adequately describing pain, and the sense of disconnection from everything external to themselves. Pain leads to a loss of peripheral and external focus, forcing both Kim and Mel to direct all of their attention on it and dominating ('clouding') their cognition with 'tunnel vision'.

Similarly, Susie echoed the otherworldly nature of pain, acknowledging that description becomes impossible when pain exceeds a certain level:

But like, after a certain point it's so extreme that I kind of don't experience an analogy of it anymore, like it's sort of beyond human consciousness or something, sounds ridiculous but it's true. (Susie)

Susie's experience, through an ORIENTATIONAL METAPHOR 'beyond human consciousness', reflects her understanding of pain as a location (indicated by the adverb 'beyond') as outside or away from the perceived bounded region of normality or even humanity. This suggests the loss of self-awareness and conscious agency caused by the pain experience. The extreme nature of this description is acknowledged, but Susie reinforces that this is her reality. This demonstrates the intrusive and distressing nature of endometriosis pain, and those who live with endometriosis also live with their imagery far beyond providing explanation to health care professionals, family, or friends.

*Theme three: Concurrent coping and concealment of pain*

There was acknowledgement of the various strategies participants used in attempts to manage their pain, whilst also trying to maintain a socially desirable view of oneself as pain-free. Driven by the intensity of their experiences of pain and pain-related fear, discussions often migrated to focus on the influence of pain on their behaviour and steps taken to cope with and manage the pain:

Like I've literally, not overdosed intentionally, but taken so many painkillers that I haven't even touched it . . . I would have to like really plan my day or like where I was because if I came on period while I was at university or if I was out somewhere or I hadn't got any painkillers with me, I'd just be in agony. So yeah you have to like plan, you have to plan around your uterus. (Annie).

Annie's experience underscores pain experiences so intense that she has felt driven to self-manage with analgesic medication, highlighting her desperation to escape the pain by taking so much medication despite it not having any impact ('haven't even touched it'). She also describes anxieties around being without analgesia to manage any potential flares in pain, reinforcing the sense of endometriosis pain exerting control over her body and life. Such fears lead to her meticulous planning behaviour 'around her uterus' to compensate for the impact of pain should it flare-up. The uterus is thus personified as an ANIMATE AGENT and therefore given agency and control of her life and activities.

Whilst use of analgesia to manage pain was common, other less conventional strategies were discussed:

The cramps, it feels like, you know, have you ever landed on your coccyx? It's like that, and it radiates all through my abdomen and I sometimes have to stand up on tippy toes just to try and get away from it. (Margaret)

Margaret's quote starts with the comparison of her endometriosis pain to something that may have been a shared painful experience; falling and landing on the coccygeal level of the spine. This attempt to induce shared understanding with the interviewer highlights the difficulty in describing the sensation of pain, allowing for the listener to simulate the experience based on something they can understand. Endometriosis pain is therefore made akin to PHYSICAL DAMAGE of a different body part of which is presumed most people will have experience of and can therefore relate and understand the pain being described. Margaret also describes her attempts to escape from pain, with attempts to physically distance areas of her body from the area of pain in the hope of finding some relief, perhaps indicating a perception of pain as separate from herself, as an EXTERNAL AGENT to be avoided.

This serves to highlight the extent of the pain experienced and the measures taken to mitigate it.

Eleanor also described steps taken to manage the impact of the pain on her body, whilst also highlighting her anxieties around mitigating the visibility of its impact to others:

I can't move. So, you can't hide it either which is the other thing. Like I say at work, I used to sit typing and then I'd just go like there, I'd hold onto the side of the table and stiffen up, wait for it to pass and then just carry on typing again. Cause your entire body is rigid from it . . . there is a paralysis. (Eleanor).

For Eleanor, pain is also conceptualized as a TRANSFORMATIVE FORCE, in this case one that paralyses and renders her unable to continue with her work until a flare-up passes. The PAIN AS TRANSFORMATIVE FORCE metaphor allows her to express the incapacitating nature of her flares that cause her to 'stiffen up', become 'rigid', and experience 'paralysis'. Being incapacitated by the pain gave rise to Eleanor's concern around hiding it, a concern that underscores her sense of caution surrounding revealing her pain to others around her. Her efforts, involving gripping her desk in order to retain her composure, highlight her selective concealment, and her decision to conceal her experience from peers, a potential source of psychological stigma should her colleagues not understand the extent of her pain, or her experience not be perceived as legitimate.

Likewise, Carol's strategy also reflects coping strategies for pain management:

It's just really hard to describe it, really, it's just very overwhelming and it's really bad. And all you want to do is lie down with a hot water bottle and [...] just hide from the world basically. Which is what I end up doing most of the time. I'd just disappear. (Carol).

Carol's quote also alluding to PAIN AS A TRANSFORMATIVE FORCE highlights the difficulty in describing endometriosis pain and its overwhelming nature to the listener. Her desire to withdraw when experiencing a pain event reflected her attempts to take control and cope with pain draining her of ability, energy, and motivation to engage in her everyday activities, as well as her avoidance of others when experiencing pain, concealing her experience from the outside world as a form of self-preservation.

## Discussion

The present study used a novel, mixed-methods design, combining CMT with IPA, to examine metaphors in the communication of endometriosis pain, with qualitative findings complemented by quantitative findings. All participants referred to their pain through metaphor, using a wide range of metaphors consistently. IPA revealed three themes pertinent to the experience of endometriosis: (1) *Losing agency to an externalised attacker*, (2) *A fearful liminal space of pain*, (3) *Concurrent coping and concealment of pain*. The MIP and IPA revealed that conceptual metaphors adopted to describe endometriosis pain were wide ranging, most often emphasizing the sensory qualities and perceived threat of pain, which may offer women a way to make sense of and qualify their pain experience. The following discussion considers the results of both the MIP and IPA analyses in conjunction with one another.

Pain was frequently discussed in terms of a malevolent external attacker (PAIN AS EXTERNAL ANIMATE AGENT metaphor), a description that may reflect a conceptualization of pain

as distinct from the self. This is reflected in a study conducted by Munday, Newton-John, and Kneebone (2020), in which a large corpus of self-reported descriptions of pain by 247 people with chronic pain (not endometriosis-specific) was reviewed for common overarching source domains. This work indicated that the domain of an external attacker was the most frequent metaphorical reference to pain and demonstrates the shared experience of such conceptualizations across people with endometriosis pain and non-endometriosis pain, with personification of pain potentially creating a separation from a healthy, pain-free self (Munday *et al.*, 2020).

Many metaphorical expressions were used that can also be found in standardized pain assessment tools such as the McGill Pain Questionnaire (MPQ; Melzack, 1975), including references to pulling, squeezing, crushing (PAIN AS PHYSICAL DAMAGE metaphor), the presence of objects with PHYSICAL PROPERTIES (TEMPERATURE) that have the potential to cause damage such as hot poker and coals inside them. However, there were further metaphorical expressions entailing the same conceptual metaphors, adopted that are not present in the MPQ, including stretching, twisting, punching, insides being carved 'like a pumpkin'. Similarly, metaphorical expressions reflecting other conceptual metaphors such as the PAIN AS AN EXTERNAL INANIMATE AGENT (MACHINE), for example, metal against metal, cogs/gears grinding, scraping, PAIN AS A SENSORY EXPERIENCE metaphor, such as nails against a chalkboard, were found in the data set but not in pain assessment questionnaires. This indicates that metaphor use goes beyond standardized pain descriptors to add depth to experiences, highlighting both the physical as well as the cognitive, emotional as well as social impact on the individual. The descriptions used may have been attempts to emphasize the urgency of pain and provoke emotional responses, care provision, empathy, and understanding from the listener (Semino, 2010). This could provide a basis for prediction, in which introspection of one's cognitions and emotions allows conclusions to be drawn (Barsalou, 2008), thus facilitating perspective-taking.

Participants also described pain in ways potentially difficult for a listener to embody. For example, pain was often described as a malevolent external agent damaging and controlling their bodies and lives (mostly through the PAIN AS EXTERNAL ANIMATE AGENT CAUSING DAMAGE metaphor). Such metaphors could exacerbate distress by highlighting perceptions of endometriosis pain as 'punishment', especially when described as an unknown enemy, a view opposed by some researchers (e.g., Sontag, 1991), as discussed earlier. Such catastrophic imagery could predict pain behaviour (Thibault, Loisel, Durand, & Sullivan, 2008), leading the communicator to pay increased attention to pain and increasing the risk of negative emotional states (Holmes, Arntz, & Smucker, 2007).

Pain was also described as a liminal space of disorientation, fear, uncertainty, and death, through the PAIN AS TRANSFORMATIVE FORCE metaphor. This may be reflective of endometriosis as an 'invasive' condition, alluding to the view of a lack of control in managing the condition, which may be particularly true for women experiencing significant diagnosis delay. Further, this perception could represent the belief in pain as punishment and that they are passive 'victims' (Graham, Horne, & Brown, 2019), which may pose a threat to the well-being of those who perceive their endometriosis in this way and may even cause women to delay seeking medical assistance thereby prolonging diagnosis even further. Indeed, references to being in so much pain 'you'd think you were dying' may reflect a perception of pain being so intense that it could only be communication through death itself (Munday *et al.*, 2020). Such negative personification of pain is a demonstrated predictor of pain-related distress, depression, and illness intrusiveness (Schattner & Shahar, 2011) and could indicate catastrophic thinking and

concerns that warrant additional attention, therefore highlighting targets for future work to examine.

Finally, metaphor use went beyond the description of pain to demonstrate its physical impact, participants' desperation to escape pain, and their attempts to reduce its visibility to others in order to maintain a socially desirable view of oneself as pain-free. This frequently manifested in discussions surrounding preventing pain from becoming visible to others, with participants engaging in active concealment of their pain flares. Such self-concealment can be defined as the tendency to hide negative or distressing personal information from others (Larson & Chastain, 1990), and pain has been demonstrated as a potential source of stigma (Slade, Molloy, & Keating, 2009) or burden to close others (e.g., Hearn, Cotter, Fine, & Finlay, 2015), which may lead to such selective concealment of pain experiences (Uysal & Lu, 2011). Indeed, this is reflected in previous work with women with endometriosis, with participants reporting feeling 'judged' and challenged by work colleagues after disclosing the experience of endometriosis pain (Seear, 2009). However, motivations and consequences of concealment may vary according to the audience and may reflect and magnify pain vigilance, feeding into a fear-avoidance cycle (Vlaeyen & Linton, 2000), which may warrant further investigation.

### ***Clinical implications***

As far as we are aware, this is the first study to formally approach analysis with both CMT and IPA in endometriosis research. The present study highlights the benefits of this innovative merging of disciplines of cognitive linguistics and psychology, demonstrating a more vivid and richly textured analysis of experiences of endometriosis pain. Sensitivity to the role of language in clinical and social encounters is vital in ensuring that women with endometriosis feel heard. Making health professionals aware of the valuable insights presented in this study may help to enhance doctor–patient communication, with health professionals being less likely to dismiss, minimize, or misunderstand pain when it is expressed through metaphor (Munday *et al.*, 2020). The integration of metaphor in endometriosis pain education and assessment tools could provide benefits in understanding and communicating pain to others, by going beyond single word descriptors (e.g., the MPQ) and providing a richer range of metaphors to choose from, as reflected in Semino's (2014) work with the 'metaphor menu' for pain communication in cancer patients.

Identifying problematic language and cognitions that maintain pain and pain-related distress may aid in directing women with endometriosis to interventions such as Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 2011) and image rescripting (Van der Kolk & van der Hart, 1989), both of which utilize metaphor to facilitate positive change in pain conceptualization and well-being. Whilst more evidence is required to understand the role of metaphor as a communicative tool, an appropriate first step is to acknowledge such expressions, exploring them further in consultations to better understand women's experiences of endometriosis pain.

### ***Limitations and future research***

The nature of IPA means that the results presented are representative of a small, self-selecting sample, studying women's personal experiences, rather than definitively generalizable (Smith *et al.*, 2009). The range of metaphors used may be reflective of unique experiences and contexts. However, the commonalities indicate shared

experiences in terms of fear and helplessness and contribute enhanced understanding and insight into these experiences. Future research should explore quantitative measures of metaphor use and pain personification, and their association with pain-related distress and catastrophizing in women with endometriosis. It would be valuable to investigate the role of the language used and perceptions of pain in women's beliefs in their abilities to manage endometriosis (self-efficacy), examining ways to enhance self-efficacy and health care professional understanding.

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## Conflicts of interest

All authors declare no conflict of interest.

## Author contributions

Stella Bullo (Conceptualization; Data curation; Formal analysis; Methodology; Project administration; Resources; Validation; Writing – original draft; Writing – review & editing)  
Jasmine Heath Hearn (Formal analysis; Methodology; Writing – original draft; Writing – review & editing)

## Data availability statement

Research data are not shared.

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