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## ARTICLE

# Visual reconstructions of endometriosis pain: An interdisciplinary visual methodology for illness representation

Stella Bullo<sup>1</sup>  | Jasmine Heath Hearn<sup>2</sup> <sup>1</sup>Plymouth Marjon University, Plymouth, UK<sup>2</sup>Manchester Metropolitan University,  
Manchester, UK**Correspondence**Jasmine Heath Hearn, Manchester Metropolitan  
University, Brooks Building, 53 Bonsall Street,  
Manchester, M15 6GX, UK.  
Email: [j.hearn@mmu.ac.uk](mailto:j.hearn@mmu.ac.uk)**Abstract**

**Objectives:** Endometriosis is a chronic condition in which tissue resembling the endometrium grows outside of the womb, causing severe chronic pain. Research demonstrates the physical, emotional and quality of life impact on people with endometriosis, but pain is reportedly difficult to communicate, resulting in lengthier diagnosis. This work aimed to gain insight into the value of imagery production as a pain communication strategy through a novel synergy of psychological and linguistic/socio-semiotic approaches.

**Design:** A qualitative, multimodal, participant-generated imagery study.

**Methods:** Interpretative phenomenological analysis (IPA) and conceptual metaphor and metonymy analysis were utilized to examine visual representations of endometriosis pain. Data were collected in two focus groups with four and six women, respectively; all with a diagnosis of endometriosis, aged 25–40 years old ( $M = 34.5$ ,  $SD = 4.2$ ) and a mean diagnosis delay of 8.4 years ( $SD = 3.6$ ).

**Results:** The overarching theme across visual representations was ‘Pain as Physical Violence’ with ‘colour as emotional representation’, ‘texture as sensory qualities’ and ‘materials as sensation’ as sub-themes. These are realized through metaphorical and metonymical relations in both the visual representations as well as the accompanying linguistic representation of the process.

**Conclusions:** This study demonstrates the value of a creative mixed-methodologies approach to capture experiential aspects of pain and its impact that are not verbalized in linguistic accounts alone. This can facilitate a deeper understanding of one's pain, acting as a medium for therapeutic

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adjustment to occur, while facilitating effective and empathic patient–professional conversations surrounding pain.

#### KEYWORDS

arts-based approaches, chronic pain, creative research methods, linguistics, pelvic pain, qualitative, women's health

### Statement of Contribution

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

- Endometriosis is a chronic gynaecological condition causing severe chronic pain that is reportedly difficult to describe.
- 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 utility of imagery production as a pain communication strategy remains unexplored.

#### What does this study add?

- Visual representations of endometriosis pain capture the experience in depth not previously provided through verbal accounts alone, with colour, texture and materials used to enrich the sensory, psychological and physical understanding of the participants' lifeworld.
- Visual representations can highlight the complexity of endometriosis and its significant physical and psychosocial impact.
- Creative mixed methodologies may facilitate a deeper understanding of one's pain, and artefacts may act as a medium for therapeutic adjustment to occur while facilitating effective and empathic patient–professional conversations surrounding pain.

## INTRODUCTION

Endometriosis is a debilitating reproductive condition, affecting 1 in 10 women of reproductive age, in which tissue resembling and acting like the uterine lining is found outside the uterus causing, in many cases, severe pain with both neuropathic and nociceptive characteristics (Howard, 2009). Other 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. Despite affecting 1 in 10 women, endometriosis takes almost 9 years to diagnose (Endometriosis UK, 2024).

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). 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). This is further complicated by the perceived normalization, trivialization or disbelief of pain by medical professionals and families, and diagnosis delays, all of which are key sources of distress (Bullo, 2018). Research also suggests that women find it difficult

to communicate endometriosis pain effectively and this is argued to have an impact on the speed of diagnosis (Bullo, 2020). Indeed, the use of pain measurement tools, such as the numerical rating scale, normally used in suspected endometriosis consultations, has been argued as a factor in restricting pain expression in consultations (Bourke, 2014), thereby limiting the depth of conversations about pain.

A wealth of research addresses the difficulties of communicating invisible pain (e.g., Schott, 2004) and endometriosis in particular (e.g., Bullo & Hearn, 2021). Various studies have focused on the language tools used in order to externalize the pain experience (e.g., Lascaratou, 2007), such as the use of metaphorical language in the expression of pain (e.g., Hearn et al., 2016; Semino, 2010) and endometriosis (Bullo & Hearn, 2021). However, the linguistic expression of pain can be limiting in that it relies solely on the proficiency and fluency of the participants (Gameiro et al., 2018). This disadvantages not only those who lack such skills but also limits expression of people who respond better to alternative modes of communication, such as visuals. In this work, we explore the use of an alternative and complementary way to represent endometriosis pain. We explore how this can offer an opportunity for expression when linguistic resources are lacking and the ability to account for, and recount, endometriosis pain meets the boundaries of the commonly deployed approaches to signs, symptoms and pathology of illness (Overend, 2014).

## The case for visual research methods

A growing body of research suggests that pain may be helpfully communicated through visuals such as paintings and drawings to reveal some insight into the internal world of the person living with pain. Systematic review evidence suggests that larger drawings of conditions, such as cancer, cardiac conditions and pain, are associated with more negative illness perceptions and worse symptomatology (Broadbent et al., 2009). Expanding on this, art forms created by people with long-term health conditions may be considered a physical manifestation of their illness and risk perceptions, thereby giving physicality to 'invisible' cognitions surrounding health, illness and their physical, psychological and social manifestations.

Using image-based approaches, Gameiro et al. (2018) explored how women from various ethnic communities experienced infertility through drawings, concluding that such creative methodologies afford people an empowering experience. Similarly, Padfield et al. (2018) examined the dynamics of images co-created between patients and British artist Deborah Padfield in pain consultations, concluding that images help patients to better disclose the emotional impact of pain in their lives than exclusively verbal accounts do. Likewise, Kirkham et al.'s (2015) use of paintings for the visualization of pain captured the temporality of the pain experience, identifying participants' shifts in identity and future aspirations. The active creation of multidimensional artefacts to communicate endometriosis pain, however, offers opportunities to add depth to our understanding of lived experiences of pain, with participants in previous work demonstrating a remarkable ability to employ tangible materials creatively and reflectively to express their pain experiences (Fyhn & Buur, 2019).

Informed by the notion that relying upon words alone may obscure meaning and complexities associated with an experience (Mannay et al., 2017; Ray & Smith, 2012), in this work we adopt a nuanced and innovative approach to understanding women's lived experiences of endometriosis and its associated pain. This is achieved through utilization of a novel visual research methodology and a synergy of psychological and linguistic/socio-semiotic approaches whereby we investigate participant-generated visuals approached as multimodal devices. That is, the visual messages interact with the verbal description of the process so that both modes 'intermesh and interact at all times' (Kress & Van Leeuwen, 1996: 40). This multimodal approach may therefore facilitate the articulation of meanings that language falls short of realizing (Kress, 2000), as is the case of experiential meanings that are difficult to communicate, such as invisible pain.

We argue that the spatial configuration of artefacts produced by participants allows for greater value of representation of the way in which pain is conceptualized, the elements or mechanisms potentially

involved and their relation to each other (Kress, 2000). This, in turn, can help facilitate the process of sense making surrounding a fragmented and individual experience, which may be particularly relevant for invisible afflictions like endometriosis pain. This study therefore aimed to explore the utility of imagery production as a pain communication strategy through the use of a novel synergy of psychological and linguistic/socio-semiotic approaches.

## MATERIALS AND METHODS

### Participants

Participants were self-selecting through a social media call<sup>1</sup> and an advert by partner organization Femedic,<sup>2</sup> in a purposeful sample that had lived, experiential knowledge of endometriosis (Smith & Osborn, 2003). Those who were interested in participating were directed to contact the research team and were provided with further detailed information, and an opportunity to ask questions. Written, informed consent was obtained in advance. Inclusion criteria were as follows: lived experience of endometriosis for at least 1, and 18 years old or over. The final sample consisted of two groups, one with four and another with six women from different ethnic backgrounds (white, black and Asian), all of whom had a diagnosis of endometriosis. Ages ranged from 25 to 40 years old ( $M = 34.5$ ,  $SD = 4.2$ ), with a mean diagnosis delay of 8.4 years ( $SD = 3.6$ ). Responses have been anonymized.

### Data and aims

Two 90-min-long focus groups with the purpose of collecting visual and textual data about endometriosis pain were conducted. The visual data consisted of artefacts produced by women using materials, such as plasticine, needles, pegs and wire. The textual data relate to the transcripts of the recorded conversations that took place during the focus groups as participants were discussing pain and handling materials. The aim of the focus groups was to explore how participants expressed their pain experience through using art materials while discussing the process. As such, the artefacts in this study are considered the main data source, rather than stimulus. This is because the analysis is not based predominantly on the verbal responses but rather they complement the art production (this being the main driver towards examining how women imagine, conceptualize and externalize their pain experience).

The use of physical materials to create visuals of endometriosis pain was considered a way for participants to better explore and communicate their life worlds by tapping into multiple sensory registers simultaneously (Boden & Eatough, 2014). This strategy was combined with a discussion in a talk-and-create approach, with art materials provided in a live discussion to support participants in expressing and reflecting upon the complexity, subtlety and intensity of their experiences. This combination of direction and flexibility for creating a visual representation of pain is argued to allow the unsayable to reveal itself (Kirova & Emme, 2008) and can provide a shared focus for parallel or subsequent verbal discussion.

The creations were considered mediators that served as 'material go-betweens' (Prosser, 2012: 484) to help express difficult and elusive emotions and experiences. Along with words, the visuals are argued to give shape and voice to ideas and experiences (Luttrell & Chalfen, 2010). Like metaphor then, artistic creations serve to create a bridge to connect one person's embodied experience to another without the need for translation. As such, this was considered a suitable approach for the present study.

<sup>1</sup>Through the project's 'The Language of Endometriosis' social media accounts.

<sup>2</sup><https://thefemicom.com/>.

## Procedure

Prior to the study, ethical approval was obtained from Manchester Metropolitan University. The materials were provided at the beginning of the event by the research team. These were pre-selected by the facilitator prior to the event by reference to elements featuring linguistic metaphors used to describe endometriosis pain collected through the Language of Endometriosis project. Linguistic metaphors containing these elements feature in our 2021 article on metaphorical endometriosis pain description (Bullo & Hearn, 2021).

The focus groups took place in Manchester and London. The Manchester focus group took place on Manchester Metropolitan University premises. The London workshop was hosted at a private function room purposefully rented for the event with the help of Femedic, an organization devoted to supporting women's well-being. The focus groups were facilitated by a hired art educator and supported by the research team who introduced the project and the event and collected feedback. The facilitator was a local artist hired as an independent consultant with experience in collaborative work and art production reflecting experiences of pain. This involved introducing the aims and methods, guiding participants through materials and activities, keeping the discussion focused on experiences of pain and the materials being used, encouraging participation, checking understanding and summarizing discussions.

The data collection exercise took around 60 min, and the introduction and feedback took an extra 15 min each at the beginning and end of the session respectively. The host organization offered a meditation session after the focus group activity to help women cope with any potential stress caused by externalizing their feelings during the event and participants were signposted to ongoing support during the debrief.

The participating women at the Manchester event worked together as a group, while at the London event, as the group was bigger, the participants were split into two groups and sat at two separate tables. A member of the research team joined each group, whose role was to observe, take notes, ensure that the brief was understood and encourage discussion. They also took pictures of the artefacts, ensured that participants felt comfortable and managed any distress or discomfort surrounding the exercise. Table 1 outlines the structure of the data collection exercise.

The discussion was recorded on an encrypted audio-recording device and photographs of the artefacts were taken (with consent from participants). Even though the session was carefully structured, the format also allowed for and encouraged, spontaneous interactions at any time between all members of the group, individual tables or even subgroups within a table. Participants were allowed the freedom to create visuals that they felt best expressed their experiences of endometriosis pain. In addition to the encrypted audio recordings, observational notes were taken by members of the research team in order to support the transcription process when pairing the conversations to the artefacts.

Focus group was selected as a methodology to allow access to participants' negotiated accounts of the subjective experience of pain (Bullo, 2014) to arrive at a consensus on how an invisible phenomenon can be made sense of. Indeed, the participants' interaction formed a dialogic space in which they were able to view and acknowledge others' artefacts, mostly marked by backchanneling discourse markers (e.g., 'OK', 'uh-huh', 'right' and 'I see' indicating understanding, sympathy or agreement). Interactions between participants were therefore monitored to inform understanding of how artefacts were developed (Tomkins & Eatough, 2010). As such, these interactions are acknowledged within the analysis.

## Analysis

The approach taken encouraged participants to describe and reflect on the pain experience, with a focus on the language used to accompany the visual representations as a source of rich, nuanced description

TABLE 1 Structure of the data collection exercise.

1. Introduction to materials (10 min)	Participants were asked to touch and handle the materials in order to familiarize themselves with them, their textures and their potential for manipulation and handling for creative purposes.
2. Plasticine and pain (15 min)	Participants were encouraged to think of words they use to describe their pain while handling plasticine. They were encouraged to think about how plasticine can be used to express such sensations. Participants were then asked to say those words out loud if they felt comfortable so doing and the facilitator wrote down such words on a whiteboard.
3. Creating personal artefacts (20 min)	Participants were provided with time to handle and select materials that they felt drawn to or that resonated with them and their personal experiences. They were asked to use their chosen materials to externalize their endometriosis pain in ways that felt appropriate for them, considering sensation along with broader considerations such as their emotional responses to pain or pain's impact on their lives. Participants were encouraged to talk and create at the same time to support participants to express and reflect upon the complexity, subtlety and intensity of their experiences.
4. Show and tell (15 min)	Participants were asked to show and explain their finalized artefacts and encouraged to reflect on whether working with materials impacted in any way their description or association of pain and their feelings about this. They were also asked to reflect on how useful this had been in understanding their own pain experience and what they could take from this when discussing their pain with various other stakeholders (family, friends, strangers, doctors, etc.)

and meaning (e.g., Smith, 2011). Such approach adds depth to analytical procedures thanks to their multidimensional and multimodal characteristics. That is, working across different sensory registers as well as modes of communication (i.e., verbal and visual) to situate a bodily experience that can be translated into a reflective, verbalized account (Kress, 2010; Stelter, 2000).

We analysed meanings created by means of selection of materials, colours and shapes alongside participant descriptions of the process of engaging with the materials and the artefacts they developed. The verbal transcripts (which were also captured within group interactions) were analysed following a conventional interpretative phenomenological analysis (IPA; Smith et al., 2009) approach, with adaptation to capture the hermeneutic cycle between the visual creation and the verbal accounts in the initial coding steps. While usually used for in-depth interview data, IPA was utilized in a complementary manner to help make sense of the visual creations and the convergences and divergences in the creations, with the central focus of the analysis remaining on the visual creations.

We randomly selected 9 (of 26) artefacts corresponding to the IPA-identified theme for visual analysis for the present article. The artefacts were visually analysed individually in terms of the conceptual representation they stand for and approached as metaphors and metonymies of pain alongside the verbal descriptions. We approached these by reference to conceptual metaphor theory (CMT) and conceptual metonymy (Lakoff & Johnson, 1980).

Conceptual metaphor is the understanding of one (generally more abstract) domain in terms of another (generally more concrete, embodied) domain, referred to as target and source domains. For example, in the context of pain description, the understanding of pain in terms of tissue damage that can be seen (e.g., a stab) represents a conceptual metaphor, whereby endometriosis pain is the target domain mapped into the source domain of the act of stabbing. A similar concept is metonymy which involves the selection of certain elements within one domain to describe a concept. For example, in a scenario where a participant chooses a needle piercing through plasticine to compare it to their pain experience, the needle comes to stand for the action that it represents, that is, piercing, which is ultimately how the participant perceives her pain. In this way, the object stands metonymically for the action that is ultimately being alleged. So, while metaphor allows us to understand pain as a general act of physical

damage, metonymy helps us understand the more specific sensation of piercing by association with the needle, that is, the product that causes the piercing sensation.

Although originally used to account for linguistic meanings, CMT has also been applied to other modes of communication such as advertising, film, music (e.g., Forceville, 2002, 2008; Forceville & Urios-Aparisi, 2009; Pérez-Sobrino & Julich, 2014) and gesture (e.g., Cienki & Müller, 2008), thereby recognizing the utility of such an approach to accommodate the culturally specific nature of such communication modalities and preferences. Visual metaphors also work by means of a target domain being visually represented in terms of a source domain (Forceville, 2008). The scope of the article does not allow for a linguistic analysis of the metaphors identified in the verbal data but we highlight the relevant metaphorical descriptions to aid the reading of the visual analysis and therefore facilitate a multi-, or rather, trans-modal representation of the experience of endometriosis pain in participants.

## Methods to ensure rigour

To address the issue of trustworthiness of the study findings, credibility, transferability and confirmability were taken into consideration (Shenton, 2004). Credibility was enhanced by building rapport with the participants which helped them develop a sense of self-determination (autonomy, competence and relatedness; Martin, 2017) to ensure honesty in data collection (Shenton, 2004) and using participants' extracts to report the study findings. To ensure study transferability, detailed contextual information is presented in addition to an information-rich sample of participants. To enhance the confirmability of the research, the research team allowed participants to lead discussions, asking for clarifications from the participants when needed and taking notes regarding personal feelings and insights from the discussions.

## RESULTS

The data collection strategy and analytical approach quickly illustrated complexity and context within which participants' experiences of endometriosis pain were situated. While the artefacts were unique to the individuals creating them and need to be considered wholly to gain a full appreciation of their representations of pain, the overarching theme of 'Pain as Physical Violence' was captured in sub-themes of 'colour as emotional representation', 'texture as sensory qualities' and 'materials as sensation' as the most prevalent themes within the data. These are mostly realized through metaphorical and metonymical relations in both the visual representations as well as the accompanying linguistic representation of the process.

It is worth pointing out that an underlying sense of frustration due to the invisibility of the pain was also present, as in the example below:

That is the frustration, to be in that significant pain and not be able to see what... It's not like when you cut yourself, and you're like "oh that hurts, I've cut myself," it's like, I'm in pain and I can't see why that is.

### Pain as physical violence

The participants' artefacts demonstrated the powerful threat of pain in their internal worlds; a threat to their sense of self and identity, with metaphor acting as an authoritative resource to help illustrate the conceptual layers and dimensions of pain. The creations were strong, vivid and abstract representations that captured pain and its meanings in colour, texture, shape and materials. Consistent with the current literature on endometriosis pain (Bullo, 2020; Bullo & Hearn, 2021), as well as with the wider literature





IMAGE 1



IMAGE 2

on pain and metaphorical language (e.g., Semino, 2010), the representations consistently referred to pain as physical damage in the form of piercing, cutting, pinching, etc. (Images 1 and 2), which are present in both visual and verbal accounts. The green plasticine in Image 1 represents the participant's insides, and the cotton wool represents their insides that feel as though: 'in my head it's like, someone's got a spoon and they're like carving me out from the inside, proper pumpkin' and 'it feels like you're being, like a cheese grater type thing, it's like literally being grated almost, like your insides are being grated'. Descriptions captured the sense of damage being inflicted within their bodies, with endometriosis seen as a malevolent animate entity in control of this violence, as seen in Image 2 wherein string becomes a visual representation for endometriosis wrapped around internal organs: 'It basically has entwined itself



IMAGE 3

round my ovaries, and they rip them to shreds whilst doing so. The endo is kind of like wrapped around it (the ovary) and like torn it to shreds'. In a more extreme sense of pain as physical violence, one participant summarized their experience using the metaphor of being at 'war' with endometriosis: 'It just destroys your entire body, it's crazy. But then at the same time I'm like, I see everyone else and myself and, and you, you're trying to do all these new things, and then you beat yourself up for the one time like actually I, I can't come tonight, I'm too ill, you beat yourself up for it because you're like I should be the same as everybody else, but actually your body is in a war against itself'. Providing clear reference to the overwhelming physical, psychological and social impact of living with endometriosis, this quote demonstrates the way in which endometriosis and the body *with* endometriosis become so conflated that the 'war' represents not only illness against body and self but also of the self against the body ('you beat yourself up') and of the body against itself ('your body is at war against itself').

### Colour as emotional representation

Kress and van Leeuwen (2002) discuss that colour is primarily related to affect and fulfils an interpersonal function. That is, it allows speakers to express attitudes and judgements (Halliday, 1978). In this study, colour was used creatively to emphasize meaning of the pain to the individual. Pinks were often utilized as representations of internal organs or soft tissue through a metonymic relationship of part for whole, that is, the colour of the organ. Contrariwise, green is used metaphorically to represent the affected and affecting force of the pain/endometriosis, potentially signalling representations of the body as rotting, decaying, dysfunctional and out of their personal control. For example, according to the verbal description for Image 3, the green plasticine wrapped around the pink balloon represents the interaction between endometriosis and the participant's stomach: 'this is like my stomach through all the way down to my bowel and like every time I eat my, my stomach or my bowel like it just can't function properly because there's endometriosis all over, inside of it, outside of it, wrapped around it, uhm, and the bloating. And then I get uhm these really fun stabbing pains as well, hence the stabbed pin through it, and yeah it kind of just falls apart'. The artefact illuminates this verbal description, the green seen as the affecting entity (endometriosis tissue), tied around pink as soft tissue (i.e., the stomach) in a strangling

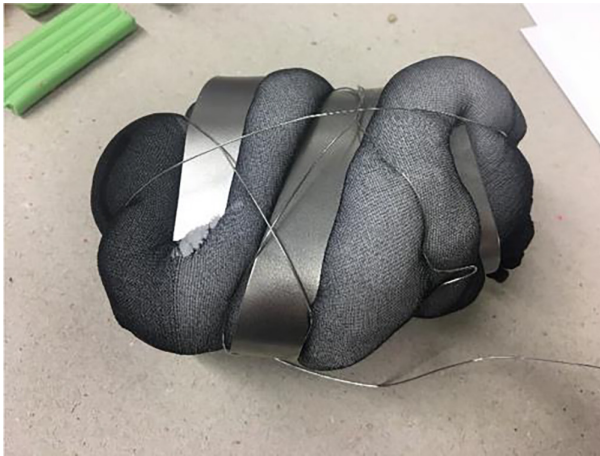


IMAGE 4

and suffocating manner. The pain appears as an agent exerting control, underscoring the multidimensionality of pain ('And then I get uhm these really fun stabbing pains as well') and perceptions of pain as a toxic threat to the internal world, invading and eroding the body and materializing the entity that is believed to cause organ malfunctioning ('can't function properly'). This is also manifested in the participant's reflections on the impact of endometriosis on their sense of self, thereby underscoring the physical and psychological impact: 'I'm really, really negative, I was for quite a long time, really, really negative about pain, I find it a really negative thing'. Other participants also reflected on the description above of everything falling apart: 'I feel fragmented', revealing feelings of existing or functioning in a way that is broken, disjointed or disunified, broken apart by the experience of endometriosis.

In contrast to a large majority of the artefacts, [Image 4](#) demonstrates how this participant cloaked their pain in darker, more oppressive colours of black. Metaphorically used as 'dark is bad' (Forceville & Renckens, 2013), the metaphor signifies the participants' conceptualization of pain as an oppressive, hostile and malevolent entity within the body, which was also reflected in the participant's verbal account: 'there's something that's not, not human, not organic'. Interestingly, within the verbal descriptions, participants did not discuss the choice of colour in the representation but rather they focused on the metaphorical physical actions to which they relate, as in [Image 4](#) wherein the soft insides are cloaked in darkness and under pressure from constricting materials that represent endometriosis: 'like someone wringing my insides out ... immense pressure and it's just kind of like metal, like something like this, like very hard materials constricting very soft material'. Taken alongside the artefact, these descriptions complement the perception of endometriosis as a dark and oppressive condition, existing in extreme contrast to the softness of the body ('like very hard materials'), causing physical harm ('wringing') and leading to a sense of fear and despair. This demonstrates, as discussed above, how the use of visuals can help unveil experiential aspects that are not verbalized in linguistic accounts alone.

### Materials as sensory qualities

Along with colour, participants utilized a range of tools to create texture in the artefacts. This often depicted the perceived brutality of endometriosis and its associated pain, capturing the multiplicity of pain in its overlapping but distinct qualities. Texture may also metaphorically represent the pathophysiology of the different pain types that may be experienced in endometriosis. The materials stand metonymically for the action they are represented to perform (i.e., pull and squeeze). In other words, the visual representation of pain is based on the material that the participants associate with causing the action they visualize to cause their pain (as per the superordinate theme, i.e., 'pain as physical violence'). In



IMAGE 5

metonymical terms, this refers to an object for its action relationship, that is, the needle stands for the piercing action that metonymically, links or associates parts of an entity with its feeling.

For example, the artefact represented in [Image 5](#) was described as: 'so I've kind of got this area that, you know where pain maybe starts in the centre and then spreads outward, that can be, like in a bigger area down my legs, uhm, the idea of sort of clamping or something holding on with the pegs and the pins, uhm, some dragging kind of marks, to, to describe those dragging feelings. Uhm, I always feel like there's a burning, gnawing hole, which is why there's the hole... and the thread to sort of, that, that, uhm, really thinking about the disconnection between what you imagine and what is actually there... and the, the thread sort of shows maybe what I imagine it looks like inside'. When taken alongside the artefact, it is possible to see this depiction in the puncture marks as a representation of sharp, stabbing pain, along with strings sewn throughout the soft tissue which may represent the visceral depth of pain and the idea of it as a restrictive, controlling force. The pegs along the outer edge reflect the tight, 'clamping' nature of pain, while the imprints of the same pegs having been pulled outwards from the centre of the artefact capture the often-used reference of 'dragging' pain. The hole in the centre stands for a 'burning' sensation. Finally, the cross-hatched imprints that centre on the green distinguish it as an invasive and penetrative presence that is separate from the rest of the soft tissue, further underscoring the idea of the green as a toxic invasion of the body (as described in the previous theme). Taken as a whole, the image and description present a powerful visual representation of a womb victim to trauma, ravaged by endometriosis and pain, the powerlessness and persecution endured and the frustrating invisibility of the experience, which is acknowledged in the verbal description.

Materials are also used to represent the symptoms of endometriosis and the emotional consequences of these. In [Image 6](#), the participant uses cotton wool as a metaphor for the bloating she feels in order to express the frustration that causes in her: 'This is my bloated stomach and uh my full bowel, with white cotton wool... but uhm yeah I was just wanting to express, I always feel so bloated, I can't wear certain clothes... like all the time, and it's very frustrating, and uhm yeah, that's my tummy'. The volume of wool constitutes the source domain onto which the fullness sensation is mapped. This is supported by



IMAGE 6



IMAGE 7

the participant's statement of frustration at the inability to conduct a normal life due to the pain (i.e., unable to wear the clothes she might like to) and in her reflection: 'it's just, it's very wearing and tiring'.

Similarly, in [Image 7](#), the ovary is represented by cotton wool: 'my ovary there and these sort of like radiating pains shooting, just, you know they're, they're not like constant but just as I'm moving...'. Metonymically this relates to the softness (see below), while metaphorically, the cotton wool is assigned the quality of delicate that is mapped onto the ovary as target domain. This works *vis-à-vis* the pins and plasticine whose qualities of vertically shaped and piercing properties (in the former) and redness (in the latter) are mapped onto the quality of pain as radiating and shooting intermittent (i.e., 'not constant')



IMAGE 8

pain in the target domain. In turn, red/pink as a colour works metaphorically to represent pain (as above). When asked if they saw their ovaries as soft and delicate, as in the visual artefact, the participant responded: ‘Sadly not, not so much anymore, but yeah, that is, yeah, what I’d imagine it to be’, reflecting her sadness and perception of the body having been physically transformed by endometriosis.

### Texture as sensation

Other participants opted to use materials based on their texture, that is the feel, appearance or consistency of materials, to express how pain feels. For example, cotton wool is used as a representation of the soft tissue affected by endometriosis in [Image 8](#), while the texture of the other materials used comes to stand for the physical sensations caused by endometriosis pain: ‘the cotton wool is like bits of your tummy, and it’s kind of interfering, one is interfering with the other... I feel like, this is kind of my soft tummy and this is it being interfered with, it’s quite stabby. I always think of my pain as something that was, yeah, painful, but I mean, really, really delicate. Made me feel really delicate and really, like I was scared, to kind of walk out of the house in case someone bumped into me or if someone knocked into me or if I tripped or if I fell and it would make everything twenty times worse because I felt like I was so, such a delicate, you know like a really little frail old woman is how I felt ... a real fragility’. The descriptions are based on the juxtaposition of the softness versus the hardness of the materials chosen *vis-à-vis* the conceptualization of the pain felt and the qualities attributed to it in relation to the physical damage metaphor for pain. For example, pins stuck into the soft cotton emphasized the sharpness of pain conceptualized as piercing (‘stabby’). This works in juxtaposition to the cotton wool whose soft texture stands for the afflicted womb. The softness of the cotton wool metonymically represents the sensitivity of the womb and metaphorically maps to the softness of the organ and tissues (‘really delicate’). The pipe cleaners surrounding the represented womb area, also soft in texture, may be seen to represent the reproductive area and function to isolate or contain the affected area and the pain while also reflecting the sense of fear and fragility brought to the fore in the participant’s reflections, and a need to be protective of oneself and one’s body to minimize risk of further harm or pain.

As opposed to the examples above where organs were represented through the use of soft materials, in [Image 9](#), a sharp element, that is, a metal blade, was chosen to stand for the womb: ‘that sharp thing (is) the pain... and then these pipe cleaners, just trying to protect it a bit... almost to kind of protect it, I feel like, you need something there to protect you... for years I literally walked round everywhere with a hot water bottle attached to me or a heat pad or a something and it felt like it was there because it helped



IMAGE 9

but it was there as a kind of form of protection as well... a barrier... and then these pipe cleaners, just trying to protect it a bit I suppose'. In this metaphorical scenario, the organ is seen as sharp and in need of protection by soft materials. The sharp texture of the blade stands for the sensation that the organ experiences in an episode of pain. Therefore, the sharp property of pain is linked to the property of material used in a metonymic relationship of part or quality for the whole. The womb and endometriosis merge into the blade because the organ has taken on the property of the pain as sharp and then the material becomes a metaphor for the organ based on its quality of sharpness. The velvet pipe cleaners are chosen for their softness quality and wrapped around the sharp blade as a barrier to shelter from the pain, a visual aid to the description of the participant's use of a hot water bottle.

## DISCUSSION

The present study utilized a novel visual research methodology and a synergy of psychological and linguistic/socio-semiotic approaches to explore the visualization and lived experience of endometriosis pain. The results demonstrate the significant depth of understanding that such a novel methodology offers and captures the artistic and creative representations of endometriosis pain that help to make an invisible and elusive condition visible. Through such in-depth exploration and external expression of the internal world, the artefacts created capture the diversity, depth and breadth of pain to enrich the sensory, psychological and physical understanding of the participants' lifeworld. Indeed, the artefacts appeared to be related to participants' physical experiences of endometriosis, along with their beliefs about their endometriosis pain (in terms of appearance, character and urgency), as well as their personal fears and concerns.

The key overarching theme within the study represented the view of pain as physical violence, which manifested in core commonalities in colour, texture and shape through metaphorical and metonymic relationships. Colour was used in an intentional manner throughout the focus groups; pale and lighter, more flesh-coloured materials were used in order to represent healthy tissue, while green was often utilized as a visual representation of pain and the invasive nature of both endometriosis and endometriosis pain. Likewise, black was utilized in a way that demonstrated the distress and oppression associated with the pain. This is reflected in work by Broadbent et al. (2009), who studied people living with chronic headache pain and found that darker drawings were associated with greater emotional distress and greater pain intensity. Likewise, work on drawings of pain demonstrated use of the colours of red

and black to emphasize the threat and hostility experienced in relation to pain (Kirkham et al., 2015), emphasizing colour as an important tool for emotional representation.

The diverse use of materials and texture was present across all artefacts and illustrated the extent of the pain experienced as well as perceived organ damage as a result of endometriosis more generally. Those with greater use of different materials and textures appeared to capture the multiplicity of pain and served as powerful representations of soft tissue being controlled and invaded by endometriosis. This could reflect more negative perceptions of the condition and the individual's health status (Broadbent et al., 2009). Indeed, prior work has suggested that visual representations of illness that capture greater perceptions of damage are associated with perceptions of poorer chance of recovery and lower control over the condition (Broadbent et al., 2004), which may be reflected in the present study.

Through this work, participants' external expression of their internal worlds has provided insight into deeply personal accounts, which on one hand capture the diverse sensory and psychological impacts of endometriosis, while on the other do not explicitly capture possible sociocultural issues, such as concerns surrounding fertility. While this was not a primary focus of the present study, one person acknowledged the impact of endometriosis on their social life through their artefact (often having to cancel plans due to pain). There is merit in examining the extent to which visual methods capture and elucidate understanding of these broader sociocultural issues in future research. Given the limitations of relying solely on linguistic expression of pain (such as the need for proficiency and fluency of participants; Gameiro et al., 2018), this work provides a significant and novel addition to the understanding of methods to communicate pain, providing a springboard for making sense of such creative artefacts and their potential use in pain management. Indeed, while many descriptors seen in the present study are also reflected in commonly used pain assessment questionnaires (such as pulsing, sharp and punishing), the use of colour, materials and texture is not. This study provides an important foundation upon which the use of colour, materials and texture in describing endometriosis pain and its impact may be better understood.

## Clinical implications

This work has important implications for illness perception and management interventions. To date, assessment of illness perceptions, and endometriosis specifically, has relied upon questionnaire measures and qualitative work limited to verbal discussions. The work presented here allowed participants to engage in research in a more participatory manner, shaping the data in ways they felt best captured their experiences and allowing for increased agency in the research. As a result, the findings present elements of endometriosis pain that may be overlooked, ignored or not conceptualized by other research methods. Participants found that engaging in the research in this participatory way enhanced their sense of self-understanding, and was 'healing', benefits that have been recognized in previous work (see Majid & Kandasamy, 2021, for a review). Indeed, as one participant reflected:

I think it's a bit of like a relief to see, because in my head I'm just like, that is probably what my internal organs look like. It's, it's kind of like, a relief to make that something physical in front of me.

Cognitive behavioural techniques have been the primary interventions utilized to change illness perceptions and to support adaptive self-management and adjustment to illness. However, it is entirely possible that interventions that capture more artistic approaches to understanding illness could add depth to understanding and thereby act as a medium for therapeutic adjustment to occur, while also recognizing and valuing the unique and individual nature of pain and a way of making the abstract concrete. This suggests potential alignment with, and utility of, the discipline of art therapy alongside formal psychological intervention, through which one can express their experience through art for therapeutic benefit. However, much work is still required prior to diagnosis to improve the initial



care pathway and diagnosis delays seen in endometriosis. Indeed, previous work suggests that health professionals (specifically gynaecologists and general practitioners) may struggle to understand and support people reporting endometriosis and/or endometriosis pain, often limiting its impact to menstrual pain (Young et al., 2017). Most health professionals in this study assessed themselves as not adequately trained to understand and provide care for psychosocial aspects of endometriosis; indeed, half of the gynaecologists did not believe it was necessary for them to do so.

The present work, along with previous in-depth considerations of the role of language in the communication of endometriosis (Bullo & Weckesser, 2021), highlights the complexity of endometriosis and its significant psychosocial impacts. Because of this, it is essential that focus is placed on the development of high-quality, practical training and tools that capture the biopsychosocial experience of endometriosis and develop patients' and health professionals' confidence in having effective and empathic conversations around the impact and management of endometriosis. For example, GPs have reported finding the use of visual cues by people with endometriosis a helpful communication tool for understanding their experience (Bullo & Weckesser, 2021). The present work may be useful in supporting diagnostic conversations and enhancing empathy through the use of metaphor and imagery to improve the communication of sensorimotor qualities that others may not personally understand or visibly see (Radley & Chamberlain, 2001). Understanding common visual and metaphorical representations of endometriosis pain may therefore help to reduce instances of misdiagnosis, diagnosis delay, pain dismissal or normalization (Bullo, 2020). This demonstrates the potential utility of a linguistic and visual taxonomy of endometriosis pain in helping patients to better disclose the impact of pain and to facilitate effective diagnosis and management of endometriosis, something which future research could explore further.

## Limitations and future research

The use of visual methods can be challenging, particularly in relation to issues associated with the multiple meanings attributed to images created (Prosser, 2012; Reavey, 2012). While striving to keep the research design and guidance given to participants prior to the workshop flexible and open, there still is an element of guidance provided through the participant information documentation. However, the utilization of the creative methodology encouraged agency and control in the generation of knowledge. This resulted in powerful creations and discussions that add further to our understanding of the experience and impact of endometriosis pain, and which are versatile to a range of analytical approaches. The present work also highlights the potentially therapeutic outlets for the expression of pain and creative methodologies for further research to utilize across health conditions. Future research would benefit from utilizing the methodology described here to examine its utility across health conditions in improving understanding and potential for therapeutic change, beyond what traditional quantitative and interview-based qualitative research can offer.

## AUTHOR CONTRIBUTIONS

**Stella Bullo:** Conceptualization; investigation; writing – original draft; methodology; writing – review and editing; formal analysis; project administration. **Jasmine Heath Hearn:** Writing – original draft; methodology; writing – review and editing; formal analysis.

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## CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

## DATA AVAILABILITY STATEMENT

Research data are not shared.

## ORCID

Stella Bullo  <https://orcid.org/0000-0002-7402-0819>

Jasmine Heath Hearn  <https://orcid.org/0000-0001-5988-5278>

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