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Bullo, Stella (2020) 'I feel like I am being stabbed by a thousand tiny men': the challenges of communicating endometriosis pain. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 24 (5). pp. 476-492. ISSN 1363-4593

**DOI:** <https://doi.org/10.1177/1363459318817943>

**Publisher:** SAGE Publications

**Version:** Accepted Version

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Publisher:

**Health: An interdisciplinary journal for the study of health, illness and medicine**

(First submission June 2018; revised submission September 2018; accepted November 2018)

Title:

**'I feel like I am being stabbed by a thousand tiny men': The challenges of communicating endometriosis pain**

Author:

Dr Stella Bullo  
Manchester Metropolitan University  
s.bullo@mmu.ac.uk

## **'I feel like I'm being stabbed by a thousand tiny men': The challenges of communicating Endometriosis pain**

### **Abstract**

Endometriosis, as a widespread gynecological condition, affects an estimated 1 in 10 women and yet has a worldwide average diagnosis length of 7.5 years. Causing incapacitating pain, among other associated manifestations, the condition severely impacts on women's lives. This article uses online survey data to investigate how pre-diagnosis endometriosis pain is conceptualized and articulated in order to explore communication challenges reported in early consultations that can potentially be seen to play a role in diagnosis delay. The findings of the study indicate that women feel that they do not have the appropriate tools to describe their pain and, in many instances, feel dismissed therefore prolonging diagnosis. The article finds that the majority of the pain descriptors identified use elaborate metaphorical scenarios to convey the intensity of the pain and concludes with some reflections on the issue of metaphorical language in endometriosis pain communication practices whilst calling for interdisciplinary work in order to devise appropriate tools for endometriosis pain communication.

### **Keywords:**

Chronic illness and disability, Experiencing illness and narratives, Discourse analysis

## **'I feel like I'm being stabbed by a thousand tiny men': The challenges of communicating Endometriosis pain**

*Stella Bullo*

### **Introduction**

Endometriosis is a gynaecological condition whereby tissue resembling, and reacting like, the lining of the womb (endometrium) grows in other areas of the body. During menstrual cycles, blood is trapped inside instead of leaving the body (Endometriosis-UK, n.d.). This may lead to the formation of cysts, scars, adhesions and so on and may cause a multiplicity of as yet not fully documented physical and emotional consequences. Despite its high rate of occurrence, affecting 1 in 10 women, the average length of time worldwide from onset of symptoms to a diagnosis of endometriosis is 7.5 years (Endometriosis-UK, n.d.). It is primarily diagnosed when exploring infertility rather than complaints about severe pain and other associated manifestations (Arruda et al., 2003). There are a number of assumptions as to the reason for the diagnosis delay. The invisibility of the condition does not allow for detection of damage in straightforward and non-invasive investigations but rather requires more invasive surgical procedures such as laparoscopic surgery (Hsu, et al., 2010), with all the associated implications thereof. Given that endometriosis symptoms are mostly, but not exclusively, associated with women's menstrual cycles, when some degree of pain is expected, it is not infrequent to find health-care practitioners that dismiss and normalize pain as part of the female condition (Bullo, 2018; Seear, 2009). This dismissal and normalization of pain may therefore prolong referrals for diagnostic treatments (cf. section 2 for further discussion of this issue).

Amongst an array of symptoms, Endometriosis is very frequently characterised by producing life-altering pain in women who suffer from it, which severely restricts their lives (Culley et al., 2013: 635). Endometriosis pain presents characteristics of the two pain types outlined by the International Association for the Study of Pain (IASP) (1994). The first, known as nociceptive pain, is caused by damage to body tissue (e.g. bone fracture) whereby nociceptive nerves sense and respond to parts of the body that suffer from damage. This type of pain is usually limited and lasts until the damaged tissue heals. This type of pain is linked to pain experienced during inflammations. The second type of pain outlined by the IASP is known as neuropathic pain and it occurs when there is nerve damage caused by a primary lesion or dysfunction in the nervous system, such as post-stroke pain, low back pain, and other types of chronic pain (Nicholson, 2006). Endometriosis pain, when diagnosed, can be subdivided into cyclical (i.e. menstrual), non-cyclical or chronic pelvic pain and functional pain, i.e. pain during sexual intercourse, urination, etc. (Bourdel et al., 2015). Therefore, both neuropathic and nociceptive elements are relevant (Howard, 2009), as mentioned above. Further evidence points to the complexity of endometriosis pain and suggests that pain

perception can be affected by stress, hormonal cycles and pain coping strategies, etc. (Morotti, et al., 2016). The latter study also suggests that, given the challenges posed by the nature of the condition and the complexity of the types of pain it causes, the endometriosis pain experience should be assessed holistically. That is, practitioners should measure not only its severity but also the quality of the pain achieved through descriptors that may reflect underlying pain mechanisms (e.g. burning, stabbing, twisting, etc.), as well as the degree to which it affects quality of life. Some medical studies by endometriosis specialists, (e.g. Bourdel et al., 2015), have outlined endometriosis pain assessment tools that map pain patterns to types of endometriosis pain and therefore provide a means to assess response to treatments. Such tools, however, tend to be used by specialists once women have been diagnosed with endometriosis in order to inform treatment. This means that pain complaints prior to diagnosis are not always systematically and holistically assessed, as advised by Morotti, et al. (2016), nor necessarily granted the attention they deserve given their association with the natural menstrual cycle (Seear, 2009). These findings also hint at issues of communication potentially being at stake during early medical interactions.

In this article, I use online survey data to explore the challenges found by women when trying to make sense of, and communicate, pain in order to achieve a diagnosis. I argue that a deeper understanding of the language used in pain communication may have positive implications for pain communication practices and potentially make a contribution towards tackling the alarming endometriosis diagnosis delay issue.

### **The challenges of communicating endometriosis pain**

The communication of pain and its challenges is an issue widely addressed in the health communication literature (e.g. Lascaratou, 2007), as are reports of patients being disbelieved when communicating pain in general (e.g. Kugelmann, 1999). Endometriosis (and, in particular, undiagnosed endometriosis) is no exception. Recent findings (Bullo, 2018) have identified a worrying trend in women, who were later (in some cases, decades later) diagnosed with endometriosis, reporting being dismissed, disbelieved, or even misdiagnosed when complaining about menstrual related pain in early medical consultations.

The issue of the delegitimization of women's pain in medical encounters has been broadly addressed by feminist literature. Malterud (1992), for example, found that issues of communication affected the description of symptoms by women, resulting in illnesses being deemed undefined. The author concludes that gender asymmetries played an important part in the doctor-patient relationship affecting the communication of health complaints and, therefore, the diagnosis. Kaler (2005) reports on a study of dyspareunia, that is pain during sexual intercourse, where 34% of participating women had been told that their problems were of a psychological nature. In fact, dyspareunia falls within the third type of endometriosis pain (i.e. functional pain) mentioned in the introduction to this article. Kaler warns that many pain-characterized conditions

affecting women, amongst which endometriosis is listed, have traditionally been “ascribed to psychological problems” (2005: 35). Echoing Kaler’s findings, Barker (2005) discusses the power of the medical establishment in his/her study on people with fibromyalgia, concluding that, in cases of undefined illnesses, the biomedical failure to provide a diagnosis to symptoms results in the assumption that there are no physical health issues. Instead, symptoms are dismissed as psychological issues. Contrariwise, Barker (2005) sustains that the biomedical establishment provides a rite of passage in cases where doctors are successful in providing patients with the name to their symptoms. This was also acknowledged in Kaler’s (2005) data where the author reported on women being happy with a diagnosis, no matter how serious or critical it was. Along these lines, Bullo (2018) found that women who eventually achieved a diagnosis for endometriosis, after years or even decades of struggle with disbelief over the severity of their symptoms, saw the act of achieving a diagnosis as metaphorically winning a war. Similarly, Greenhalgh (2001), in her journey through a misdiagnosis of fibromyalgia that had severe consequences for her physical and mental health, addresses the methods by which diseases come to be constructed by doctors, the discourses of objectification of the ailed body, the dismissal of symptoms that cannot be quantified, and the dynamics of the doctor-patient relationship. Greenhalgh discusses the influence of power in doctor-patient dynamics and how this may hinder communication, and argues that each of those aspects constitute constraints of biomedical systems to cater for patients with undefined chronic illnesses (2001). A very interesting and appropriate notion put forward by Overend (2014) in regards to undefined illnesses, and how they affect sufferers, is that of a ‘ghost’. Overend argues that, due to the “empirical truths” that modern medicine searches for, illnesses with unclear pathologies become ghosts that haunt both the body of the sufferer and the biomedical practice (2014: 63). The ghosts of such illnesses “call(s) into question the limits of modern biomedicine” (Overend, 2014: 64) not only by virtue of the missing “empirical diagnosis” (p. 70) but also “the ability to account” and, I add, recount “for all those illness experiences that fall outside biomedicine approaches to the sign, symptom and pathology of illness” (p. 63).

The notion of a ghost haunting the body is very relevant to endometriosis given that the disease possesses some of the characteristics of the ‘ghost’ outlined by Overend (2004). The invisibility and lack of defined locality of endometriosis may pose a challenge to the “knowledge frames of biomedicine” (Overend, 2014: 75) when trying to understand the mechanisms of the pain being described by patients when such accounts do not comply with expected approaches to illness, pain in particular, and to symptoms recall. This would explain the frequent cases of misdiagnosis of endometriosis pain (e.g. as UTIs, STDs, etc.) found by previous studies (Bullo, 2018; Seear 2009), where endometriosis becomes a suspect illness by a process of elimination before women are granted access to diagnostic treatments, therefore prolonging delays.

When it comes to the actual accounts of pain by patients, the pain related literature invariably addresses the issue of the subjectivity of the pain experience and the difficulty in communicating pain (e.g. Schott, 2004), including endometriosis pain (e.g. Whelan, 2003). The IASP advises that “the inability to communicate verbally does not

negate the possibility that an individual is experiencing pain...pain is always subjective” (1994: online). Schott points to the paradox that “attempts to truly describe pain indeed appear as difficult as they are frustrating, yet the need to communicate is overwhelming” (2004: 210). Schott (2004) also discusses that the invisibility and unfamiliarity of sensations caused by different types of pain have an impact on the ability to communicate pain. Nociceptive pain, being largely visible and familiar, as most people have experienced burns, cuts, etc., can be conveyed without much difficulty. In contrast, chronic and/or neuropathic pain are more “removed from most people’s experience” (Schott, 2004: 209), which therefore poses a challenge when it comes to describing and qualifying these types of pain. There are normally no visible signs of physical damage that can indicate explicitly the mechanism of chronic and/or neuropathic pain. Pain therefore becomes almost a ghost that haunts the body (Overend, 2014). Given the lack of physical visibility of pain with these characteristics, sufferers are forced to rely on language tools to externalize their internal experience (Lascaratou, 2007). The experience of pain, however, may not only exceed physical boundaries but may also make sufferers step into imaginative linguistic frameworks, leading to a reliance on imagery (e.g. Gosden, et al., 2014) and/or metaphorical language (e.g. Schott, 2004) to communicate internal pain experience/s. In fact, the IASP’s definition of pain hints at the subjectivity of the phenomenon as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (1994: online).

The boundary between real and imaginary, the sensory and the emotional, then becomes a challenge for successful pain communication to take place when metaphorical language is used. By communication, I mean not only the mere act of women describing their pain experience but also the interpretation of the message by doctors in a communicative situation where codes, contextual and socio-interactive elements regulate, and constrain, the interaction hence potentially confounding successful communication (Jacobson, 1960). The locus of effective communication via co-construction, in Jacobson’s (1960) terms, sits in the liminal space between the recognition and use of a shared set of common principles for accessing and collaboratively co-constructing meaning via a shared code. The challenges faced when communicating endometriosis pain are worth investigating given that a mismatch in assumptions where nuance of code, i.e. metaphorical language, is being used, exacerbated by the increasing potential for being unable to decode metaphor usages in pain descriptors outside the expected frames of knowledge (Overend, 2014), can then give rise to miscommunication, potentially resulting in less than adequate or appropriate care. This may, in turn, affect whether sufferers are referred for diagnostic treatment in a timely fashion.

### *Conceptual metaphor theory and pain*

Building on the IASP’s (1994) definition of pain, outlined above, that discusses the description of the phenomenon *in terms of* tissue damage [my emphasis], Semino

(2010) points out that many pain descriptors are used metaphorically “when they convey pain experiences that do not directly result from physical damage” – for example, the use of the metaphor ‘stabbing’ pain to refer to, say, migraine pain (pp. 205).

The description of a perceived subjective or abstract concept in terms of another is the realm of conceptual metaphor theory (CMT) in cognitive linguistics. In CMT, an abstract entity, or conceptual domain, such as ‘love’ (i.e. target domain) is understood or described in terms of another, more familiar and embodied, sensation such as ‘journey’ (i.e. source domain). This is manifested in metaphorical expressions such as ‘it’s been a bumpy road for our relationship’, which demonstrates that the abstract notion of love is understood as a journey. Therefore, ‘love is a journey’, as a conceptual metaphor, is a way of thinking that is manifested linguistically in expressions that contain linguistic metaphors such as ‘to be on a bumpy road’ or ‘to be at a crossroads’ when referring to a relationship (Lakoff and Johnson, 1980).

A parallel concept to metaphor, usually in place in descriptions of pain, is that of simile. Semino defines simile as “an explicit statement of comparison between two different things, conveyed through the use of expressions such as ‘like’, ‘as’, ‘as if’ and so on” (2008: 16). An example of simile in the description of endometriosis pain is ‘[it] feels *as if* I am being stabbed by a long, sharp knife’. Similes are metaphors in that they compare one concept in terms of another. However, similes use explicit comparative devices (e.g. ‘like’), which could be indicative of a more purposeful choice than the understanding of one concept in terms of the other, as in the case of conventionalized metaphors. When referring to metaphors or similes used to describe pain, Semino (2010) points out that neuropathic or chronic pain can be seen as a target domain given its abstract nature, which makes it difficult to explain using concrete and literal language. Pain, however, is also an embodied experience when it occurs in its nociceptive form as a direct result of tissue damage, as in the case of a broken leg discussed above or in the case of, say, a stab or a burn, as also pointed out by Schott (2004) discussed above. Semino (2010) argues that, in cases of neuropathic or chronic pain, pain caused by physical damage becomes a source domain (i.e. a more concrete or embodied experience) and is hence used to explain the more abstract neuropathic or chronic pain. This can be seen, for example, in the case of the description of migraine pain (neuropathic) as ‘stabbing’, which, when used literally, refers to nonceptic pain. Therefore, she argues that “different types of pain (.) are often conveyed via expressions that evoke different kinds of (causes of) physical damage” and adds that “this tendency may be explained as an attempt to enable others to experience something akin to the sufferer’s own sensations” (2010: 207). This view also hints at the importance of the interlocutor in understanding the embodied experience of physical damage and therefore acknowledges the need for a shared code to be at interplay in the co-construction of meaning, as put forward by Jacobson (1960) addressed above. Semino (2010: 210) categorized over 70 one-word pain descriptors found in the standard McGill Pain Questionnaire along with a sample of collocates of the word pain in the British National Corpus of English<sup>1</sup> and found that more than a third of the descriptors and collocates fell under the causes of physical damage source domain.



From this, she derived a taxonomy for the classification of metaphorical expressions used to talk about pain that evoke different kinds of physical damage. In other words, metaphors for physical damage are used to talk about pain that is not caused by such damage but by some form of tissue damage (normally nociceptive pain), which is difficult to describe in terms other than metaphorical expressions. Among these, we find physical damage caused by (1) 'insertion of pointed objects' (e.g. drilling); (2) 'application of sharp objects' (e.g. stabbing); (3) 'pulling or tearing' (e.g. wrenching); (4) 'a malevolent animate agent' (e.g. torturing); (5) 'extreme temperature' (e.g. searing); etc.

In this article, I pose that endometriosis pain, given its abstract, invisible and unfamiliar character, is normally described in metaphorical ways. I use Semino's taxonomy as superordinate metaphors and I codify manifestations of these metaphors in the form of linguistic metaphors as well as similes in the qualitative data used for this study. So, for example, the conceptual metaphor pain as physical damage is manifested in the data in the expression 'stabbing pain' as well as in the simile '[it] feels as if I am being stabbed by a long, sharp knife'.

## **Data and methods**

In this article, I explore endometriosis pain communication challenges by investigating (1) what challenges are associated with pre-diagnosis endometriosis pain communication during early medical interactions, and (2) how endometriosis pain is conceptualized and communicated. The article also addresses the implications of a linguistic approach for endometriosis pain communication practices in early consultation stages to potentially contribute towards tackling the lengthy diagnosis delay.

A mixed-method internet-based pain communication questionnaire was devised. The first part of the questionnaire aimed to establish whether the women sampled found it challenging to communicate pain in early consultations and whether a link between such challenges and diagnosis delay could be seen in the data, which may therefore corroborate qualitative findings of earlier studies hinting at this link, as mentioned above (e.g. Bullo, 2018; Seear, 2009). The questions asked at this stage enquired about the diagnosis length of the participants; whether they experienced difficulties communicating pain to doctors during consultations; whether they felt disbelieved about the severity of their pain and whether they considered that tools for pain description would be of help during consultations. The main part of the questionnaire had open-ended questions that asked participants to describe how their pain feels and what they considered doctors could do to help them overcome the challenges of endometriosis related pain communication.

The questionnaire was distributed via 'The Language of Endometriosis' social media platforms<sup>2</sup>. Participants were UK- and Ireland-based followers of our social media

platforms. The Language of Endometriosis has 535 Twitter followers and 260 Facebook followers. A total of 150 responses were returned; 131 responses answering all questions were used for analysis.

The responses to the first part of the questionnaire were analyzed using basic descriptive statistical tools (cf. table 1). Answers to the second part were coded in relation to the metaphorical meaning of pain descriptors (cf. table 2) and also categorized thematically (cf. table 3) by area of communication challenges identified. In order to identify metaphors systematically, I deployed the renowned Metaphor Identification Procedure (MIP) designed by the Pragglejaz Group (2007). This consists of establishing a contrast between the contextual meaning of an expression (e.g. stabbing pain) with the basic meaning (e.g. stab [v]: to injure someone with a sharp pointed object such as a knife [Cambridge Dictionary online, 2018]). In cases of a mismatch or contrast between the contextual and the basic meaning, the metaphorical meaning is derived. Following this, using an adapted version of Semino’s (2010) taxonomy outlined above, I categorized the metaphorical pain descriptors identified according to the pain as physical damage superordinate metaphor. For example, I look at ‘stabbing pain’ as a metaphorical expression that constitutes a direct linguistic manifestation of the pain as physical damage superordinate metaphor and the ‘pain via the insertion of sharp objects’ subtype. In the case of similes, I also look at the full descriptive extract as a linguistic manifestation of such superordinate metaphor manifested as similes (i.e. signaled by ‘like’ or ‘as if’), for example, ‘I feel like I am being stabbed with a sharp knife’.

## Findings

### *Emerging patterns of pain mis/communication*

The findings below presents the positive and the negative responses to the background questions asked in the first part of the survey which aim to provide a quantitative context to the areas of perceived miscommunication explored qualitatively below. Percentages of respondents are given next to the number of responses. These have been cross-referenced with the average diagnosis length for all participants for further information.

131	Average diagnosis length	Yes / No	N	%
Pain description difficulty	9.7	Y	111	85%
	7.4	N	19	15%
Perceived disbelief	9.6	Y	117	89%
	7.6	N	11	8%
Perceived need for pain description tools	9.2	Y	110	84%
	8	N	3	2%

Table 1: Pain communication by average diagnosis delay

The data presented shows that a high percentage of women claim to have experienced difficulties describing pain during pre-diagnosis medical interactions (85%), to feel disbelieved as a consequence of such difficulty (89%), and that tools for pain description would have been of help during consultations (84%). The data also indicates that diagnosis delay in women who claimed such challenges was higher than those who responded negatively.

It is worth pointing out that, given the size of the sample, these findings cannot be taken as representative of the general experience of women with endometriosis. Further studies with a larger sample would be required to be able to make generalizations and to ascertain a more reliable connection between pain description and diagnosis delay. It is also important to note that this study does not claim that the challenges reported are necessarily directly responsible for the two-year difference in the diagnosis delay identified between women whose response was positive and those whose response was negative. That is beyond the remit of the current study. Even if the sample had been larger, it would still be problematic to make such claims without further ethnographic study perhaps documenting actual consultations and their interactional characteristics. Further to this, some researchers may not consider a two-year difference in diagnosis delay significant enough so as to grant importance to the issues of pain communication I raise in this article. However, it is worth remembering that an additional two years of undiagnosed incapacitating pain can represent life-altering differences to women who live with this condition, let alone the difference that an additional two-year period can make to other associated endometriosis issues, such as fertility. Therefore, the gap is still worth considering, even if only as contextual information in this exploratory phase as background to the qualitative analysis that follows, which is the main purpose of this study aiming to establish the causes for the difficulty in describing pain (as established by 85% of the women surveyed) and the perceived disbelief of the pain severity (as agreed by 89% of the women surveyed) that can be seen as confounding successful communication. Establishing the reasons for this impediment by exploring the ways in which pain is conceptualized and articulated can potentially shed some light on how and why the reported miscommunication happens and how a linguistic approach can help address this issue of delayed diagnosis.

### *Ways of conceptualizing and articulating pain elicited*

In this section, I present an analysis of the descriptions of endometriosis-related pain, as outlined by participants who were diagnosed with endometriosis an average of 8.6 years after first consulting doctors for menstruation-related pain. All 131 responses were collated and analyzed using the MIP procedure outlined above. The data collated indicates that the majority of pain descriptions are metaphorical in nature, deploying either expressions containing metaphors or similes. The metaphorical expressions fall under three categories: (i) pain as physical damage; (ii) pain as physical properties of elements; (iii) pain as a transformative force.

These are explained below with illustrative examples from the data presented in table 3.

Metaphor for pain	Sample pain descriptors	Type and description
Pain as physical damage	(a) A <b>sharp stabbing</b> pain that won't go away	Metaphor: Pain as physical damage caused via the insertion of sharp objects (Semino, 2010)
	(b) it's <u>like</u> someone <b>squeezing</b> your insides	Simile: Pain as a malevolent agent performing actions that cause physical damage
	(c) <u>like</u> someone <b>putting a knitting needle through</b> front to back, just straight through, like someone's <b>cutting</b> you	Simile: Pain as a malevolent agent using objects to cause physical damage
	(d) It feels <u>like</u> being <b>tattooed</b> on the inside	
Pain as physical properties of elements	(e) Sometimes it feels <u>as though</u> I have <b>ball in blown up</b> inside my stomach... that's <b>ready to burst...</b> My uterus <u>feels heavy</u>	Simile: pain is akin to volume  Pain is akin to pressure Pain is akin to weight
	(f) I also get a <b>searing hot pain</b> in my ovaries...	Metaphor: pain as high temperature that has the potential to cause physical damage.
	It feels <u>like</u> a <b>hot poker</b> is sitting off them	Simile: pain is akin to high temperature
Pain as a transformative force	(g) I feel <b>outside</b> of my brain. The pain is so extreme it doesn't feel physical anymore, it's <b>beyond</b> human consciousness	Container metaphor: woman sees herself as outside the bounded region of the body and brain in an alternative location  Directional / container metaphor: human consciousness is centered in space; pain displaces women to an alternative location ('beyond') perceived as unphysical and inhuman
	(h) it feels <u>like</u> I <b>become possessed</b> by pain, <u>like</u> I am <b>something else</b> that takes <b>possession of my usual self</b> , <u>like</u> I am <b>outside</b> my body and my consciousness	Simile: pain is made akin to a force or agent taking control; container metaphor

Table 2: Metaphors for pain and illustration

The majority of expressions used to talk about pain found in the data describe the quality of pain in relation to physical damage that would result from an external object being used to inflict such damage (Semino, 2010), as in example (a) in table 2. In many cases, by means of similes, pain is personified as a malevolent agent inflicting pain by performing actions that cause physical damage (b, and also the quote in the title of this article) or using objects to cause such damage (c, d).

A high number of descriptors that at the basic level of meaning relate to physical properties of objects are used to refer to pain. Some researchers (e.g. Deignan, Littlemore and Semino, 2013) argue that these metaphors can be seen as linked to the physical damage metaphor, given that such properties have the potential to cause harm. In the examples in the table (e-f), pain is described in terms of volume (e), pressure (e), weight (e) and high temperature (f), which helps impart not only a measure of the quality of the pain but also of its intensity by virtue of the dramatic sense of vulnerability and impending danger they convey.

Finally, pain is also seen as a transformative force or process whereby women perceive themselves as shifting into a different location, state or entity. In (g) and (h) directional and container metaphors ('beyond', 'outside') are deployed to create a contrast between humanity as a location and emphasize the perceived abnormality of the pain. The self is a metaphorical model generally used "to conceptualize normal self-control by the subject and lack of it" (Lakoff 1996: 110). Bounded regions are therefore seen as containers. In episodes of pain, women perceive their location as outside or away from the bounded region and hence lacking in self-control, normality (Lakoff 1996) or even humanity. Similarly, in (h), pain is made akin to an external force, possibly a malevolent being echoing previous metaphors, that takes control of the self, which thereby conveys the lack of agency felt by the woman during episodes of pain.

The data extracts in the table also illustrate Overend's (2014) notion of haunting; the conceptualizations of pain outlined make endometriosis "a haunting trace of the barely visible" (a-f) and "a possessive force consuming the body it inhabits" (g-h), without physical trace of symptoms nor familiar or expected ways of describing them (p. 63). As such, endometriosis pain becomes "a specter of death haunting positivist ideals of bodily certainty" (m-o; r below) that, in its lack of visibility and defined location, challenges the standard diagnostic methods (Overend, 2014: 63) in consultations and ways of communicating symptoms.

#### *Further Endometriosis pain communication challenges identified*

The survey also asked what women considered doctors could do to help describe pain. The table below shows a thematic analysis of the responses. Of the 131 responses, two respondents answered this question stating that they were happy with the attention and response of their healthcare providers and had nothing to add. Another two said that the 1-10 scale had been helpful and four said 'I do not know'. Contrariwise, 123 participants answered the question with comments that have been categorized as follows:

Categorization of responses Q5 N=123	N (%)	Sample answers
Provide with tools for symptoms and pain description (incl. descriptive terminology, charts and female anatomy images)	48 (39%)	(i) 'Instead of doing a scale of pain, they could focus on where the pain is, the sensations it creates, and what the severity is throughout the day, including what activities make the pain worse' (j) 'Locations, type (pinching, pulling, stabbing), a better pain severity chart'
Elicit information	11 (9%)	(k) 'Guiding the patient through questions' (l) 'Ask more specific questions about the type of pain'
Listen and empathize	50 (41%)	(m) 'Listen closely and believe what we are trying to communicate to them' (n) 'Be more open minded about the difficulty of describing pain I can't explain well' (o) 'Take me seriously'
Improve knowledge and information dissemination	14 (11%)	(p) 'Have more awareness on the condition and how to treat it' (q) Educate on endometriosis' (r) 'To actually have knowledge about endo and not just tell me it's normal to hurt'

Table 3: Areas for improvement identified

The findings presented in the table also support those presented in table 1 above. The most prominent result is that women feel that are not heard by general practitioners when complaining about pre-diagnosis pain. They feel disbelieved and perceive a general lack of empathy. Further to this, women indicate that tools for pain description would be useful and effective during consultations.

### Discussion of findings

The findings reported above indicate that miscommunication in early endometriosis consultations is a common occurrence. Further exploration of the two areas of miscommunication identified (difficulties articulating of symptoms and perceived disbelief, as reported by 85% and 89% of women, respectively) indicates a connection between the two.

In order to gain an insight into how endometriosis pain is conceptualized and articulated, I took a linguistic approach to the study of pain descriptions, drawing on conceptual metaphor theory (Lakoff and Johnson, 1980). The data analyzed revealed

that the majority of responses use metaphorical expressions to describe pain as physical damage (Semino, 2010). Some metaphors are conventionally used (e.g. stabbing pain), whilst similes appear as more conscious elaborations of that superordinate metaphor. A further exploration into the metaphors used revealed that pain is constructed in three ways: (i) as a corporal transgressor that inflicts pain and harm through violent acts and objects that cause physical damage; (ii) as physical properties of objects where pain is made akin to temperature, pressure, weight, etc. that has the potential to cause physical damage imminently; and (iii) as a force that distances the sufferer from the human condition. In all cases, women convey a sense of helplessness and victimhood. The use of metaphorical narratives for the description of pain brings into question two aspects. Firstly, why are such metaphors consistently used to describe endometriosis pain? Secondly, how can we be sure that they are effective in conveying the communicative purpose intended?

Studies of illness and metaphor, and cancer in particular, have found that journey and violence metaphors are prominent in patients when discussing their condition (e.g. Semino et al, 2017). Similarly, Bullo (2018) found that women also tend to use both metaphors in accounts of endometriosis experiences. I also discussed how physical damage is a common metaphor to refer to pain (Semino, 2010; Schott, 2004; Gosden, et al., 2014). The CMT theory outlined above helps explain that non-visible pain, as an abstract domain, is normally understood in terms of pain caused by physical damage (or nociceptive pain), as a more concrete or experiential domain (Lakoff and Johnson, 1980) given people's experience with the sensations caused by physical damage. We can also understand the use of signaling devices, such as 'like' or 'as if', in cases of similes as conscious attempts to create a powerful image to convey the severity of pain by virtue of the hyperbolic value of the metaphorical narrative constructed.

There has been extensive opposition to the use of metaphors to talk about illnesses, advocating the eradication of metaphors in health communication (e.g. Sontag, 1979/1991) on the basis that the negative effects that certain metaphors (e.g. military, in expressions such as 'aggressive', 'invasion') could have on (cancer) patients who may feel blameworthy if they are 'beaten' by the disease. However, more contemporary researchers argue that "metaphor is a ubiquitous and important aspect of language and thought, which cannot be eradicated" (Demjen and Semino, 2017: 392). Similarly, Loftus advocates that metaphors constitute a way of understanding and dealing with pain (2011), especially if such metaphors draw from meaningful areas of patient's experience (Gwyn, 1999) and they help the patient frame their experience of illness in different ways (Demjen and Semino, 2017). Overend (2014), also supporting the use of metaphors, suggests that they can be especially helpful in cases of undefined or invisible illnesses, such as endometriosis, as they help move "beyond realistic representations of illness experiences" and "help us to understand and articulate the experiences of undefined illness in ways that empirical accounts alone do not" (p. 66). Demjen and Semino (2017) also argue that avoiding the use of metaphors may "marginalize and potentially silence" those who find certain metaphors "motivating and helpful" (p. 392). Demjen and Semino conclude that "different metaphors work differently for different

people at different times in different contexts. Therefore patients should be encouraged and enabled to use the metaphors that work best for them” (2017: 395).

Given that meaning is co-constructed in the interaction between sender and receiver, as Jacobson (1960) proposes, the main issue to consider here is, how women can be certain that their interlocutors understand the use of elaborate metaphorical narratives to frame the experience of pain and are able to make an informed judgment on the symptoms being described. In fact, the survey data analyzed indicates that women indeed feel disbelieved when describing pain (cf. table 1 and 3). It is therefore evident that we need to explore the nature of the disbelief. At this stage, I can only rely on previous literature as well as reports by participants (cf. table 3) to understand the nature of doctors’ disbelief of women’s descriptions of pain. The use of metaphorical language to account for pain experiences is not only a linguistic resource but also a window into how women experience and make sense of pain, which, at the early consultations stage has an unknown source – i.e. it is a ‘ghost’ (Overend, 2014). If we look at the metaphorical descriptions of pain provided in table 2, whilst some may not necessarily find that they explicitly denote the mechanisms of pain, they are still rather indicative of its intensity and life-altering nature by virtue of the hyperbolic force that the metaphorical constructions convey. Still, women report feeling misbelieved and dismissed. This raises the question as to what happens in the interlocutor (i.e. doctors) when faced with such descriptions. That is, whether it may be the case that such descriptions, as Overend suggests (2014), may subvert the dominant or expected models of accounting for illnesses and therefore lead to minimization, dismissal, or even misdiagnoses, as was the case in Greenhalgh’s (2001) and Baker’s (2005) studies reviewed above.

Whether operating within patriarchal models which delegitimize female pain, as the literature suggests (e.g. Malterud, 1992; Kaler, 2005), or perhaps due to lack of adequate education and awareness that might prevent medical practitioners from eliciting the required information that would shed light on evidence of the condition (which may indeed also show evidence of the former), the data suggests that women find it challenging to communicate endometriosis-related pain in early medical consultations successfully. Unsuccessful communication of endometriosis-related pain, in many cases, leads to the normalization of pain (cf. table 3, last entry in column 3). If we consider the literature on pain and metaphor, according to Schott (2004), the use of metaphorical expressions can lead to a number of issues. It may distract from the type of pain felt; it may be considered to be of a psychological nature (Hodgkiss, 2000); it may even recall models associating ‘women’s troubles’ to hysteria and attention seeking (Wright, 2018), which can potentially lead to dismissal and therefore prolonged diagnosis delays. All of these possibilities were implied by the qualitative data (cf. table 3). Then we are back to the issue of identifying exactly *what* is interfering with the successful decoding of the intended message. As established earlier, successful communication relies on the recognition and use of a shared code that allows the collaborative co-construction of meaning (Jacobson, 1960). A mismatch in assumptions can then give rise to miscommunication. Thus, the use of metaphorical language, often a necessity, increases risks of medical professionals being unable to provide their



ultimate extra-linguistic goal, that is, the best and most appropriate medical care to patients in pain, fear, and need.

What, therefore, in a seeming loop in the communication of pain, constitutes an effective, and believable, description of pain? Considering the limited consultation time in some health systems, the lack of education and awareness on endometriosis even in medical professionals (as indicated by the findings in table 3), and the fact that we are fighting against a tendency to normalize and dismiss period pain (cf. tables 1 and 3), as widely evidenced by Bullo, (2018), Seear (2009) and Whelan (2003), how can the pain description of pre-diagnosed endometriosis be optimized in order to contribute towards timely diagnostic treatment? It is clear from the data collected that the standard 1-10 scale alternative is sometimes problematic. Therefore, when prompted, women go from being speechless (e.g. 'when I go to the doctor, I have such a hard time articulating my pain because I am nervous and I freeze') to building a quasi-sci-fi/horror narrative (e.g. the quote in the title of the article). What is, then, an effective and, more importantly, collaborative way to communicate endometriosis pain?

### *A way forward*

Demjen and Semino (2017: 396) advise that "what is required is: attention to one's own and others' language use; responsiveness to the feelings and views expressed by different linguistic choices; acceptance and tolerance of individual variation; and creativity in devising ways of harnessing the potential of metaphor as a resource for individual expression, explanation, sense-making and so on". Similarly, Overend (2014) reminds us that in so long as 'ghostly' illnesses continue to exist and challenge empirical practices of diagnosing them, it is paramount to develop an understanding of their intrinsic prohibition for being accounted for that stops us from coherently speaking about them (Schott, 1992). Understanding will therefore enable those silenced by such prohibition to be visible "within positivist frames of visibility and locatability" (Overend, 2014: 77). This is, after all, what participants call for: empathy (cf. table 3).

To achieve this, a good start might be not to dismiss metaphors altogether but, rather, to understand and catalog them in a way that people may find they "validate a feeling or view they already have, articulate something they have not been able to express before, or provide a new and helpful perspective" (Demjen and Semino, 2017: 396). If we take the physical damage metaphors used to describe pain, like 'stabbing', it is unlikely that most women who claim to have 'stabbing pains' have actually experienced being stabbed (Schott, 2004). Had they had such an experience, the pain produced by such physical harm may have been described in a different way. It is rather the association, or entailments (Kovecses, 2002), related to the act of stabbing (e.g. intensity, depth, abruptness, etc.), that is, the contextual and associated meaning, to which women refer. Therefore, the understanding of pain in terms of the entailments associated to the act of stabbing relies on the conventional association of such characteristics and entailments, as conceptual metaphor theory poses (Lakoff and Johnson, 1980), rather than necessarily on actual experience. Another illustration of this

is provided in table 3 where, when contrasting the metaphorical with the basic meaning of, say 'I have ball in blown up inside my stomach that's ready to burst', we find that pain is described in terms of volume and pressure. Helping women map these sensations to, say, parts of the body where they occur and periods of time in which they take place, would allow an indication as to whether the pain being described is related to endometriosis. Therefore, collaborative work between linguists, doctors and women who suffer this type of pain, would allow for an integrated toolbox where the different types of metaphors identified above, and others, are mapped to different types of pain (nonceptive, neuropathic) and endometriosis pain mechanisms (cyclical, chronic, functional). This integrated toolbox might also include images, gestures, etc. Such a toolbox, which already has a precedent in the form a 'metaphor menu' for cancer patients (Semino, 2014) helping articulate pain in more holistic way, should be made accessible to primary healthcare practitioners in order to allow the elicitation of the information required to detect symptoms in early consultations so as to recommend diagnostic treatments in a timely fashion. It could also be made available to school nurses, teachers and parents by various means of dissemination, including the media, in order to raise awareness and knowledge of the condition, as addressed by the findings.

## **Conclusions**

In this study, I set out to investigate the challenges associated with pre-diagnosis endometriosis pain communication during early medical interactions, including the ways in which endometriosis pain is conceptualized and communicated. I also explored ways in which a linguistic approach can contribute to improving endometriosis pain communication practices in early consultation stages. The article questions pain communication challenges and offers some reflections on the use of metaphorical language in endometriosis pain communication practices, highlighting the value of a linguistic approach in pain communication.

In this article, through an exploration of how pain is described, I have questioned what is the most effective way to describe endometriosis symptoms (prior to diagnosis) to general practitioners with whom lies the power of referral for diagnostic treatment. There are a number of caveats that should be noted. Firstly, the survey relied mostly on UK-based participants who follow the Language of Endometriosis project's social media platforms. A larger and wider sample with more information and demographic data required from participants, along with a wider distribution, would be required to be able to determine significance and make more generalizable claims so as to derive more detailed implications, which was beyond the scope of this exploratory article.

The article has also indicated a number of further avenues for research. The conceptualizations of pain found herein constitute an interesting finding and it would be interesting to extend the research to different kind of pain caused by different illnesses or types of damage. Similarly, ethnographic data documenting doctor-patient interactions may enable the identification of stages of mis/communication by applying the Jacobson (1960) model in full, which would potentially yield interesting findings and

make important contributions to health communication practices. It is also paramount that general practitioners' views are gathered to get a more holistic view of the issues at stake.

For now, though, this exploration has allowed some insights on an area of healthcare that has long been neglected and it is hoped that the issues pointed out by the findings of this study constitute a stepping stone in the right direction towards accelerating diagnosis and finding timely ways to tackle the life-altering pain caused by endometriosis until a more permanent solution is found.

### **Acknowledgements**

I would like to thank all participants for their contributions to the survey. My gratitude also goes to the project's research assistant Zoe Bibbon (née Kent) for her help with the formatting and distribution of the questionnaire, and to Dr Derek Bousfield and Lexi Webster for their comments and feedback. Finally, I would like to thank the article's peer reviewers for their encouraging support and useful feedback.

### **Declaration of conflicting interests**

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### **Notes**

1. Available from <http://www.natcorp.ox.ac.uk/corpus/>
2. Twitter, @endolanguage, and Facebook, [www.facebook.com/TheLanguageOfEndo](http://www.facebook.com/TheLanguageOfEndo)

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