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Exploring disempowerment in women's accounts of Endometriosis experiences

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Abstract

This work explores disempowerment caused by discourses surrounding the life altering gynaecological disease of endometriosis. Despite affecting 1 in 10 women, the worldwide average diagnosis time is 7.5 years and it is mainly diagnosed when exploring infertility rather than complaints about incapacitating pain and other associated manifestations. The aim of this paper is to identify dis/empowerment caused by discourses in the health-care and social environment of women as manifested in their accounts of endometriosis experiences. Having been informed and shaped by a corpus analysis of online forum data, this work explores accounts collected through interviews with women who have endometriosis using discourse analytical tools. Through an examination of the dialectics between micro-level language choices inscribing agency, or lack of, and macro-level discourses in the contexts in which women interact, the findings indicate that disempowerment is mostly a consequence of the perceived lack of agency over achieving diagnosis and knowledge of the condition in order to understand and learn coping strategies. The article concludes with implications for Endometriosis communication practices and suggestions for broader enquiries in the field.

Keywords

Introduction

Endometriosis as an incapacitating gynaecological condition has featured heavily in the public domain at the time of writing this article. This is due to the first NHS issued guidelines asking doctors to 'listen to women' during consultations about 'crippling pelvic and period pain and look out for the symptoms of endometriosis in a bid to speed up diagnosis of a disease that can wreck lives and careers' (Boseley, 2017). The guidelines were put in place as a result of negative experiences of support and information consistently reported by women. The current article is the first output of a

currently unfunded project called The Language of Endometriosis[1] that aims at raising awareness of this surprisingly unknown condition, which nevertheless affects one in 10 women, and draws further avenues for research in this area in order to contribute to the field of health communication and endometriosis in particular.

The present paper represents a pilot exploration that aims to identify disempowerment caused by both the disease as well as discourses in the health-care and social environment of women as manifested in their accounts of endometriosis experiences. Having been informed and shaped by a corpus analysis of online forum data, this work explores accounts collected through interviews using discourse analytical tools.

This work starts by describing the condition of endometriosis and dis/empowerment. It then outlines the research questions, methods of data collection and analysis and preliminary findings. It concludes with a discussion addressing the research questions and deriving implications for health communication.

Endometriosis and disempowerment

Endometriosis is a condition whereby tissue resembling, and reacting like, the lining of the womb, called endometrium, is found elsewhere in the body; each month, instead of leaving the body, blood is trapped inside (Endometriosis-UK, nd). This may lead to the formation of cysts, scars, adhesions, etc. and causes a multiplicity of yet fully undocumented manifestations that have an array of physical and emotional consequences. The primary physical indicator of endometriosis is, in most cases but not exclusively, incapacitating pain during ovulation and menstruation at least, along with other intimate and perceived taboo symptoms usually euphemised as women's problems, (Laws, 1990) such as constipation, urinary infections, etc. The condition affects an estimated 2 million women in the UK. The worldwide average length of diagnosis is 7.5 years (Endometriosis-UK, nd) and it accounts for up to 50% of infertility cases (Bulletti et al., 2010). Endometriosis affects primarily, but not exclusively, women in their reproductive years. There is some conflicting information as to whether ethnicity may have an impact. Some authors (e.g. Acien and Velasco, 2013) suggest that it is more common in Caucasian women than in other ethnic groups; this is nevertheless contested by other sources which consider this claim one of the 'myths' associated with endometriosis (e.g. Streicher, 2014). The optimum diagnostic procedure for endometriosis is laparoscopic surgery which entails a surgical procedure under general anaesthetics with the potential risks that this may cause and the cost that it represents. Despite affecting one in 10 women, endometriosis pain is often dismissed or normalised as a part of the feminine condition. Furthermore, the condition is normally diagnosed as a result of investigating infertility rather than complaints about incapacitating and life altering pain (Arruda et al., 2003). In light of the above, Culley et al., concluded that that the negative impact of endometriosis on quality of life is "complex, multidimensional and pervasive" causing women to feel "that endometriosis controls and restricts their lives, leaving them powerless" (2013: 635). Further studies have also pointed out the insufficient and conflicted knowledge surrounding and constructing the condition and argue that such

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[1] https://www.facebook.com/TheLanguageOfEndo/; @endolanguage

deficit contributes towards further uncertainty, alienation and disempowerment in women (Huntington and Gilmour, 2005; Seear, 2009).

Studies in dis/empowerment in medical settings have mainly focused on patient identity (e.g. Corbin and Strauss, 1987) and experience of illness management (Aujoulat et al., 2007). Paterson et al. (1999), for example, see empowerment as a process of personal transformation or as acquiring the ability to act upon a situation hitherto perceived as overwhelming. Aujoulat et al. (2008: 1228) see powerlessness 'as a threat to their [patients'] senses of security and identity' and pose that empowerment is the state of acceptance where patients embark on a process of negotiation and choice with regards to treatment, and management, etc. enabled by health-care professionals. Finally, Steele et al. (1987) pointed out that empowerment arises when patients become knowledgeable about their bodies, disease and treatment and hence change behaviours. Empowerment in these contexts is seen as a process of learning and understanding and, by default, disempowerment relates to lack of knowledge. From a linguistics perspective, dis/empowerment has been investigated in medical professionals and patients' discourse in palliative medicine (e.g. O'Connor et al., 2010) and has been defined as "an increase or decrease in the degree of agency that the patient has, or perceives him/herself to have" that is manifested in a variety of language choices (Semino et al., 2015: 3).

The above definitions and approaches to dis/empowerment, however, are based on the premise that patients have a diagnosis and medical practitioners are seen as enablers of such knowledge. This work addresses disempowerment prior to diagnosis following repeated visits to the doctor. In particular, it focuses on the lack of agency that women perceive to have when facing a condition whose symptoms are overlooked or dismissed as normal, as is often the case with endometriosis (Seear, 2009). I pose that dis/empowerment is caused by practices that emerge from discourses in the health-care as well as the social environment where women interact and it is evidenced by women's positioning in accounts of endometriosis experiences. By positioning (e.g. Harré and van Langenhove, 1999), I mean the process through which speakers adopt or resist subject positions that are made available in discourses (Benwell and Stokoe, 2006) as manifested in language choices.

This article aims to address the following research questions.

i.   What discourses leading to disempowerment are identified in women's accounts of their experiences of endometriosis?
ii. How do women present themselves as dis/empowered in light of these discourses?
iii. How can the understanding of discourses used by women with endometriosis contribute to advance communication practices around the condition in order to tackle the alarming diagnosis delay issue?

The next section turns to a description of the sequential steps taken to collect the data sampled in this study and the methods used to analyse such data.

A sequential approach to data

The data used for this study were collected with the bigger project of The Language of Endometriosis in mind over a period of two years in two stages. A description of the methodological steps is provided below.

Stage I: Online forum data and bibliographic thematic analysis

The first stage of data selection for this study consisted of a manual collection of online data of women's contribution to English language[2] forums found through searches for 'endometriosis support forums'[3]. The reason for this was to identify 'broad themes and discourse relationships within texts' produced by women with endometriosis as a 'starting point for carrying out qualitative analysis' (Potts, 2016, p.58) and therefore derive the next stage of data collection and analysis. All posts constituting the dataset were written between 2012 and summer 2016, and were publicly available to all Internet users; I omitted data that was accessible only via membership login. The corpus comprises 241,997 word tokens and 9397 word types. It is estimated that over 250 women contributed to the forums from where posts were gathered[4]. In order to "determine whether the most frequent words in the corpus were suggestive of potentially meaningful patterns" (Archer, 2009, p.2) of lexical selection, I performed a semantic tagging of the first 250 words in the Antconc wordlist[5] function using the vertical output style of the USAS online English tagger[6] and identified the semantic domains for each word. The semantic tagging is useful in that 'tags show semantic fields which group together word senses that are related by virtue of their being connected at some level of generality with the same mental concept' (Archer et al, 2002, 1). On the basis of this connection of word sense to a mental concept, in multiple tag cases, the first tag was preserved in most instances. Occasionally, however, the first tag was discarded and alternative relevant tags were prioritised. For example, the first tag for the word 'period' is 'time' (T1); however, given the population and topic, it was evident that in this context the word 'period' referred to women's menstrual cycles. Hence, the second tag corresponding to the domain 'anatomy and physiology' was preserved. This semantic field categorisation procedure was followed by a grouping of the specific semantic domains into the wider USAS '21 major discourse fields' (Archer et al., 2002) from where percentages of tags within each discourse field, illustrated in the table below, were obtained. The process therefore allowed the identification of 'semantic macrostructures' in the corpus indicating 'global meanings, topics or themes' (van Dijk, 2009, p. 68). These, in turn, allowed me to derive an 'objective identification of categories of meaning for analysis' (Potts, 2016, p. 58-60) that provided a systematic way to account for the

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[2] It is assumed that most participants are native speakers of the English language.

[3] Full ethical consent for this project was awarded by the researcher's institution.

[4] This was calculated by counting the average number of entries in each forum with consideration to starters and replies to each post.

[5] This function allows searching for words grouped by frequency of occurrence within a given corpus. In the AntConc corpus tool, word lists are usually sorted by frequency as a default setting. AntConc is freely available at http://www.laurenceanthony.net/software/antconc/ (accessed 19 February 2018).

[6] Available from http://ucrel.lancs.ac.uk/usas/tagger.html

analytical tools for micro-level analysis applied to the interview data. The table below illustrates the percentages of discourse fields and semantic categories identified.

Discourse fields	250 W/%	Includes semantic categories
generally abstract terms	21%	evaluation, degree markers, likelihood, being, getting and possession
language and communication	2%	verbal processes
movement, location, travel and transport	6%	actions
numbers and measurements	8%	quantifiers and frequency markers
psychological actions, states and processes	6%	emotions
social actions, states and processes	3%	actions/processes
the body and the individual	12%	illness
time	8%	time markers
names and grammar	32%	

Table 1: discourse fields and semantic categories

The findings of the corpus analysis were cross-referenced with a thematic analysis carried out with a corpus of over 40 scholarly medical and sociological journal articles on endometriosis (Culley et al., 2013). These were predominantly quantitative studies of the socio-economic, psychological, etc. impact of endometriosis carried out by medical centres worldwide. Key themes identified were diagnostic delay and uncertainty; quality of life and family/relationships impact; economic costs, psychological wellbeing and medical and self-management (Culley et al., 2013). A crossover between the bibliographic themes and the corpus findings was evident. For example, 'uncertainty' can be mapped onto the 'generally abstract terms' ('degree markers', 'likelihood') discourse field above; 'psychological wellbeing' can be mapped to 'psychological actions, states and processes'; 'diagnostic delays' and 'economic costs' can be related to 'numbers and measurements'; 'medical and self-management' to 'the body and the individual', etc. It is worth noting, however, that a more accurate analysis of the crossover between the corpus and the thematic analysis would be reached by performing a semantic tagging of a wordlist sample of the medical articles but that is beyond the scope of this article. The current analysis is considered sufficient enough to corroborate the thematic areas most frequently addressed in discussions of endometriosis experiences (i.e. experiential meanings) and stakeholders' positioning in relation to those areas. (i.e. interpersonal

meanings) in order to derive the main thematic areas for the interview guide development as well as for the selection of analytical tools for the micro-level analysis. The thematic content of the interviews was as follows:

    i.   Description of the condition symptoms/effect
   ii.   Experiences of the condition: (a) symptoms onset to diagnosis; (b) post diagnosis and treatment; (c) impact on various life aspects
  iii.   Perception of self and others in relation to condition

Stage II: Semi-structured interviews

The call for volunteers for interviews launched via social media had an overwhelming national and international response. This study is based on 21 interviews conducted in the UK. Originally 25 interviews had been planned but due to several repeated cancelations, only 21 interviews were conducted, ranging between 40-60 minutes each. A total of over 20 hours worth of interview data (184,620 words) were transcribed. It is important to mention, however, that saturation was reached half way through the process with no new themes being identified in the remaining 10 interviews despite leaving rooms for discussing further or 'other' issues in the interview guide; therefore it is considered that 21 interviews constitute a good sample to analyse qualitatively.

The participants interviewed are women between the ages of 27 and 53, with the majority being in their mid-thirties. All the participants were Caucasian, who on average waited 8 years for a diagnosis, after first seeking medical assistance for their pain and associated symptoms.

Semi-structured face-to-face and Skype interviews were carried out following the themes discussed above. In most cases, very little intervention from the researcher was required as simply asking women to start by telling me of their experiences of the condition addressed most of the prepared questions. They were voice recorded and consent was obtained in advance of the interview after full information had been given to the participants. After being transcribed, anonymised and assigned a reference, the interview data was uploaded onto NVivo for coding.

The first three interviews were closely examined and, in an iterative process between the interview data, the interview guide and the discourse fields and semantic categories identified by the corpus methodology and discussed in the previous section, a list of thematic codes was created to be used as 'nodes' in the NVivo coding process.

Three main thematic areas were coded as main nodes (numbered below) with sub-nodes (indicated in letters) as follows:

    i.   Pain: (a) description/visualisation; (b) effects and consequences
   ii.   Experiences: (a) miscommunication; (b) normalisation; (c) dismissal; (d) misdiagnosis; (e) confrontation
  iii.   Self-perception: (a) negative; (b) positive

As the coding of nodes progressed and new subcategories of sub-nodes emerged, additional levels were added and the coding was adjusted accordingly.

Each node represents a thematic area identified in the interview data which was derived from the cross referencing between the corpus and the bibliographic thematic analysis. No interview data that could not be coded in the thematic nodes listed above (derived from the corpus and thematic analysis) was found. It is therefore considered that the thematic nodes used for analysis in this paper are generealisable to the whole corpus of 21 interviews complied. The extracts selected for analysis in this paper were chosen randomly from the most prominent thematic nodes coded that addressed the research questions of this study presented in section 2.

The next section presents the tools for analysis of the interview data.

Analysis of interview data

The next stage was to derive analytical categories that would allow for a systematic illustration of how the discourse fields identified in the corpus analysis are inscribed in linguistic choices that women made when talking about their experience of the illness and therefore contribute to our understanding of how these linguistic resources play a role in the articulation of discourses of disempowerment.

The qualitative analysis of disempowerment and endometriosis at text, or micro, level is approached by first describing the grammatical choices made by participants in accounts of the experience of illness using tools for Systemic Functional Linguistics [SFL] (e.g. Halliday and Matthiessen, 2004). SFL derived tools were selected given their allowance for examining the different layers of meanings construed by speakers' choices, mostly experiential (explored through, for example, the system of transitivity) and interpersonal (explored through the analysis of modality and appraisal tools), as identified by the corpus analysis above. The analytical tools, derived as described above, consist of:

(1) Transitivity: the discourse fields of 'generally abstract terms', 'language and communication', 'movement, transport, travel' and 'social actions, states and processes' and their corresponding semantic categories involving, for example, 'being', 'getting' and 'possession' as well as 'verbal processes' and 'actions' identified in the semantic tagging described under 'Stage I' above can be illustrated in the spoken data by reference to the SFL system of transitivity. This system allows for a thorough account of the construction of inner and outer experience by the selection of verb processes (material as 'doing', mental as 'feeling', 'sensing', etc. and relational as 'being' or 'having'), among others, circumstances and participants (actors, sensers and tokens respectively) in a clause (Halliday and Matthiessen, e.g. 2004).

(2) Modality: interview data evidencing the semantic categories of 'degree markers', 'likeability' under the discourse field of 'generally abstract terms' can be analysed by reference to the modality system. In other words, the analysis of the participants' choice of likelihood and certainty modality markers in their accounts of medical encounters, for

example, may shed light onto how reliable women perceived the doctors' claims to be during consultations.

(3) Appraisal: the semantic category of 'evaluation' ('general abstract terms') as well as 'psychological/social actions, states, processes' discourse field are illustrated through the analysis of spoken data using the SFL derived appraisal framework (Martin and White, 2005). Appraisal allows for examination of the lexical choices expressing positive or negative disposition towards a stimulus in terms of emotional (affect), aesthetical (appreciation) of moral/ethical dispositions (judgement). Within this framework, the affect subsystem focuses on the selection of lexis to construe feelings of happiness or sadness (un/happiness), confidence or anxiety (in/security) and pleasure/interest or displeasure (dis/satisfaction). Similarly, the subcategory of appreciation construes evaluations of things in terms of their worth or value (valuation), among others. Finally, with the judgement subcategory, judgements of esteem relate to how normal (normality), capable (capacity) or resolute (tenacity) someone is while judgements of sanction relate to compliance with ethical or moral standards (propriety).

(4) Metaphorical expressions: pervading the lexical selection are metaphorical expressions seen as text level manifestations indicating the higher-level underlying conceptual metaphors describing an abstract concept, or domain, in terms of a usually more concrete one, as developed by Lakoff and Johnson (1980). These allow for an insight into the conceptualisation of self and the condition in women's accounts; in other words experiential meanings, manifested across discourse fields[7]. Using the metaphor identification procedure[8] (Pragglejaz Group, 2007), metaphorical expressions were categorized as such through the analysis of basic and contextual meaning of all lexical components of the expressions found.

The micro-level description using the tools outlined above serves as evidence for the arguments made at the next level. The macro-level thus focuses on the interpretation of such linguistic choices in relation to discourses identified in delineating the radius of agency of participants as evidenced in the positioning adopted in their accounts (e.g. Harré and Langenhove, 1999). By discourses, I mean "way(s) of signifying experience from a particular perspective" (Fairclough, 1995, p.135), such as a way of seeing pain as a normal experience in women. These, in turn, act upon practices (e.g. gate-keeping), in relation to how endometriosis, and indeed women who have it, are managed, treated and conceptualised by social agents. By social agents I mean not only medical agents but also women themselves who might perceive their pain as normal and delay seeking help. In so

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[7] The warfare discourse field is not prominent enough so as to figure in the semantic tagging findings outlined above even through the war metaphor is prominent in the interview data in relation to medical encounters. Other discourse fields (e.g. 'movement, location, travel and transport') that are manifested in metaphorical expressions used by participants are the journey and movement metaphor. An interesting avenue to pursue would be to explore whether certain discourse fields are more prone to metaphorical conceptualisations; unfortunately this is beyond the scope of this paper but it is worth further explorations.

[8] The metaphor identification procedure (MIP) proposed by the Pragglejaz Group (2007) allows for a systematic parsing of metaphorical expressions by contrasting the basic and contextual meaning of every lexical component in the expression and identifies those with a clash between both meanings as metaphorical.

doing, we ultimately uncover the positions of dis/empowerment which participants evidence in their accounts.

Discussion of interview findings

This section presents an integrated discussion of a selection of some of the salient findings of the interviews with a focus on the nodes coded in 1 (b), 2 (a-e) and 3 (a-b) above that address the research questions posed for this study.
Each subsection describes language choices by participants in their accounts of endometriosis experiences followed by an explanation of how these micro-level choices are interpreted in relation to macro-level discourses and practices leading to disempowerment.

Disempowerment caused by endometriosis

In the accounts below, participants position themselves in relation to normative discourses of womanhood and respectability. All extracts below (except c), make reference to 'psychological actions, states, processes' (e.g. feel, sense) discourse fields in combination with negative self-evaluation.

(a)
there was a lot of feeling **different** and a bit **freakish** and **broken**… There was something **wrong** with me… in my womb [pointing] and you know I was a bit **repulsed by myself** for a time…

(b)
I feel like I am not a **proper** woman

(c)
I am now **damaged goods** and people treat me like that even though I try my **hardest** not to be

(d)
I have a sense of being **broken**…not a **real** person…**not respectable**…my life is not **worthwhile**…it's an achievement when I get my laundry done

In account (a), the participant recalls her feelings when she was an undiagnosed young woman. Her account is positioned vis-à-vis discourses of normative womanhood with her deviation from it making her feel abnormal, as evidenced by her self-appraisal values of judgement of normality ('freakish', 'different') to culminate in an authorial appraisal of dissatisfaction ('repulsed by myself'). Appraisal values of judgement of normality pervade these accounts consistently ('not real'; 'not proper'; 'damaged'). These

appraisals in (c) and (d) are made in relation to how they perceive others, who presumably comply with standards of normality, see them. And in so doing they self-sanction by projecting a judgement in relation to how others may see them. This is evidenced in values of propriety: 'respectable'. The metaphorical objectification of themselves as 'goods' or as an object that is 'broken' also evidences a self-deprecating positioning vis-à-vis how they perceive others to see them. The social circle is brought into the account in (c) with the struggle with herself in trying her 'hardest' (appraisal judgement of tenacity) to not be treated as a dysfunctional or broken object.

The dominant discourses of the perception of what is normal for a woman to be like against which they position themselves, delineates the extent of agency they should have vis-à-vis what they have as sufferers. Disempowerment arises from the perceived lack of agency that enables them to comply with such societal forces (Davies and Harré, 1990).

Disempowerment caused by disbelief, pain normalisation and misdiagnosis

Disempowerment and vulnerability are also consequences of obstacles encountered by women in the social and medical environment. Below there is an example of one participant's perceived fight against the disbelief caused by the lack of knowledge or understanding of her condition in her social and professional circle. In this passage, we see a combination of 'psychological states, actions, processes' and 'movement, location, travel and transport' discourse fields identified in the corpus analysis.

(e)
…the impact that it has on you mentally, physically, psychologically, is, it knows no bounds, particularly when you're met with just **being pushed back** after **pushed back** after **pushed back .** the **lack of understanding, lack of sympathy, lack of getting your head around it, lack of being believed** . I feel like I've **fought** so many **battles** and I'm **weary** as a result of it .

The parallel structures and repetition serve to convey her frustration and frame the metaphorical construction of war against disbelief. The participant therefore presents herself as a fighter who has been on a quest to make others believe or comprehend the measure of her pain and suffering ('fought', 'battles'). Her failure to do so is mapped to being physically displaced backwards in space by a force or enemy stronger than her ('being pushed back'). The repetition of clauses represents the continuous struggle. Disempowerment is thus constructed as defeat and tiredness of fighting ('I'm weary'). Of interest in this extract as well is the fact that no agent doing the 'pushing' is presented and is difficult to ascertain who is agentive in this passage.
In the extracts below, participants discuss the difficulties encountered in the medical context before the diagnosis was achieved with gatekeeping from diagnostic procedures being reported as the main factor leading to disempowerment. Women's accounts of experiences of pain normalisation normally involve an element of resentment or

frustration at having been told that their pain was normal. Of interest to this particular work is the linguistic mechanisms through which the experience of disempowerment is inscribed in these recollections as illustrated in the excerpts below:

(f)
he said…it's **just** your **natural** cycle. When you have a baby your body **will** change and it will **probably** go away.

(g)
the GPs…who do give you these sort of like a **pat on the head and off you go dear**. **You've just been anxious, off you go**. Well I <u>feel</u> anxious nobody's telling me anything.

The extracts above illustrate the linguistic strategies that allow women to reconstruct past experiences of disempowerment in medical encounters where they felt their symptoms were normalised and dismissed. At stake here is the struggle for knowledge/diagnosis; they know that their symptoms are not natural (f) and nor it is an emotional state that makes them feel like that (g). Yet the doctors refuse to investigate the issues further normalising symptoms.

In (f), the account of disempowerment caused by the normalisation of pain by the doctor is achieved through a selection of appraisal resources and modality markers. The use of the graduation[9] device 'just' in the reported speech of the doctor, as recreated by the participant, may be interpreted as the woman's perception of the doctor's attempt to minimise the symptoms, and therefore normalise her pain. This downscaling of the evaluation of the pain by the doctor helps to construct the woman as overreacting to her perceived normal pain in an 'abnormal' manner therefore leading to disempowerment of women, whose pain complaints are questioned or, at least, minimised. The fact that the stage of having children is mentioned immediately after serves to evidence the normalisation of the pain as natural and intrinsic to the menstrual cycle. The selection of the modal verb 'will' in the woman's recount indicates the categorical assertion of the normality of her pain she perceived in the doctor's response.

Similarly, in (g) the participant constructs a reported speech symbolising the struggle for knowledge and diagnostic treatment in her accounts of the doctors' response to pain. The selection of 'just' once again serves as a graduation device that helps intensify the perceived anxiety (suggesting an appraisal judgement of normality 'anxious'), and minimise the pain experience so as to construct it as an emotional state rather than a symptom of a physical condition. This also leads to the overall effect of normalisation. The metaphor 'pat on the head' and use of 'dear' as a term of endearment come to stand for her feeling of being patronised and dismissed by doctors (note the generic use of GPs in the plural form) and, ultimately her lack of agency and disempowerment.

The final line where she constructs a response to the doctor constitutes a reflection on how she felt (notice the stress on 'feel') as a consequence of the uncertainty caused by the lack of information received and at being told her pain was an emotional state.

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[9] Within the Appraisal framework, the Graduation system deals with 'grading phenomena whereby feelings are amplified and categories blurred' and hence adjust the degree of evaluations (Martin and White, 2005: 35). Further subcategories are available.

Finally, in (h) below the participant constructs a powerful account of lack of agency and disempowerment caused by the recurrent refusal of diagnostic treatment and misdiagnosis or diagnostic procedures for conditions other than endometriosis which took place over a number of years. Here we see an illustration of the semantic categories of 'being' and 'illness' ('generally abstract terms' and 'the body and individual' discourse fields).

(h)
I've been tried and **tested** for an under-active and an over-active thyroid. Anaemia. **I've tried** a gluten-free diet. **I've been treated** for IBS. **I've been treated** for water inflections. **I've been treated** for kidney infections. **I'm** still the same.

A number of linguistic devises aid the participant to construct a powerful account of her experiences reflecting her sense of lack of agency. It is interesting to notice the absence of other parties in her account (e.g. doctors). The extract is structured in a listing of parallel sentences, mostly passivised and with a repetitive topicalisation of herself (i.e. 'I') as the participant in a number of actions involving material processes (i.e. tested), hence constructing herself as the 'goal' with an absent actor. A sense of isolation and disempowerment caused by her passive agency in decisions on diagnostic procedures and treatments arises from the extract.
In all cases above, disempowerment is conveyed by looking back on what happened at medical encounters through the lens of their current position of knowledge of their condition being genuine hence engaging in an interpretation of their past experience (Mishler, 2006).

Shifting self-positioning and dis/empowerment

As an extension of the findings discussed above, particularly (f) and (g) where disempowerment was identified as a consequence of pain (and other symptoms such as extreme pelvic swelling) normalisation in a struggle for knowledge in participants' accounts of past experiences, the extracts below illustrate shifts to empowered personas through gaining knowledge.

 (i)
First thing they thought it might be was an STD. the doctor said oh it's *probably* …*maybe* it's a water infection *that sort of thing* . after that appointment, I kept a record of the painful days, so I went back **armed** with this piece of paper.

This excerpt starts echoing the findings above (f) where the participant uses modality to construct her account of disempowerment caused by pain normalisation or dismissal as gatekeeping strategies. The use of the mental process 'thought' as illustrative of the 'psychological actions, states, processes' discourse field identified in the corpus analysis shows lack of conviction in doctor's diagnosis, perhaps reflective of medical shortcomings when it comes to endometriosis diagnosis. Interestingly, keeping a diary of her symptoms gave her agency to demand diagnostic treatment. The metaphor ('armed')

characterises the participants' conceptualisation of attending her next doctor's appointment as going to a battle; the doctor is the aggressive opponent, the diagnostic treatment is the issue to fight for; the diary of pain is her weapon. Empowerment therefore arises from the knowledge of her body and practice of diary keeping that has equipped her with the tools she needed to achieve her aim. A sense of vulnerability, however, is still present in the need the woman has to be equipped with proof of her pain in order to be taken seriously.

A similar case is recalled in the account below where the same practice of diary keeping allowed the woman to succeed in being believed that her pain was not normal and eventually be referred for diagnostic treatment.

(j)
The diagnosis does give you **the power to your elbow** to say no actually it's not just, it's this **I have a name**. This, you know, this is what it is . I feel like I haven't **fought** as much as I should've done. I should have gone much further in **fighting**. but I did **get** a diagnosis eventually because I was **persistent** and I said this isn't normal. to the point where I wrote everything down here you go, look, this is not normal and I do feel **quite proud of myself** for that. I **took a while to get there**, but **we did get there eventually** . **small victory**. **small victory**.

The battle and journey ('we did get there') metaphor interact here, illustrating the 'movement, location, travel and transport' as well as 'social actions, states and processes' ('fighting' processes) discourse fields. Achieving a diagnosis is mapped to arriving to ta destination ('get there') and the diagnosis is what leads to empowerment in this case. Empowerment here not only arises from the diagnosis in itself but the diagnosis gave this participant agency to be able to explain to people that she had an actual illness with a name hence empowering her with the means to explain to others that her illness is genuine. The relational process 'have' indicating possession of an actual entity (i.e. the disease name) serves to reinforce the empowering feeling of the diagnosis. The 'language and communication' discourse field is also illustrated here embedded in semantic categories indicating linguistic processes ('said, 'wrote', 'look' [i.e. 'read' the name of the condition to people]) in relation to securing diagnosis perhaps pointing out the deficiency in communication processes around endometriosis.

The last extract in this section is a powerful one whereby a woman whose condition has become extremely incapacitating at the age of 29 discusses the dilemma that she faces. She has a young baby who she cannot look after as she would like as she has constant extreme pain due to highly advanced endometriosis which went undiagnosed for 15 years. The only solution to deal with the pain available to her at this stage is regular surgery to remove cysts and adhesions causing it. Her experience of the condition is loaded with uncertainty which pervades her account, as illustrated below.

(k)
But you can **flip it** it's like it's **like a two-sided coin** I want to do as much as I can for him [my son]…cause he's empowered me to be that way. But then **flip-side** of it, *how far do I have to go before it's not worth anymore? Is surgery an answer for endometriosis?* So it's a **catch-22**, *how far do you go with it? Can you put yourself through surgery every*

*single year? Can **we** do that every single year? Is there a limit to how much surgery they can do? Is the answer a hysterectomy?* **Flip it** *. can I do that with my son? Can I let him see me in pain like that?* But I don't want it to **beat me**, it's a **catch-22. I can't win.**

In this extract, the participant presents herself as a disempowered sufferer whom the delayed diagnosis has left with severe consequences. The use of rhetorical questions, repetition and parallel structures are textual devices that help construct the mental state of uncertainty that the speaker is going through. It seems as though by using those devices the participant is going through a list of options that she has been given by doctors (evidenced in parallel structures and repetition) and analyses her options, by means of rhetorical questions, none of them being the optimum option. It is interesting how she constructs different relationships whilst taking this persona, shifting between the first person to the generic 'you' to even include the researcher (who also has endometriosis) in her quest for answers ('can we do that..') hence positioning herself interpersonally as part of a uncertainty ridden community. However, by means of the gambling metaphor ('flip it'), she shifts her positioning to that of a mother who wants to do well by her son. Under this persona, we see a more confident woman who feels that she has no option but to carry on with surgical treatments so that she can care for her baby and bring him up as she would like to. This is evidenced in declarative sentences and mental processes ('I want to do as much', 'I don't want it to beat me'). These shifts are marked by textual devices (rhetorical questions, declarative sentences) and transitivity choices and are triggered by the gambling metaphor ('flip it') which allows her to conceptualise her situation as an unwinnable game where she feels trapped in an unsolvable dilemma ('catch 22') therefore expressing her uncertainty and, ultimately, disempowerment.

Concluding remarks

The article has provided an insight into discourses of dis/empowerment in accounts of endometriosis experiences by carrying out an examination of the dialectics between micro-level language choices inscribing agency, or lack of, and macro-level discourses in the contexts women interact.
The most emergent finding of the study is that disempowerment mainly arises from knowledge deficit around endometriosis not only by health practitioners, who may overlook or dismiss the symptoms as normal or even misdiagnose them as something else, but also from the social/professional circle where women interact and, in many cases, by women who see themselves as 'abnormal'. Disempowerment is therefore seen as a consequence of the perceived lack of agency over achieving knowledge in order to understand and learn coping strategies. It is also a manifestation of uncertainty as to what the future holds for women with the condition.
The article has taken a 'principled approach' to the triangulation of findings (Dörnyei, 2007: 46) allowing for a deeper understanding of 'what' as well as 'how' endometriosis discourses can have a disempowering effect on women who live with it. This was achieved by a systematic application of corpus linguistic techniques to online forum data that allowed me to identify general trends of effects of endometriosis and identify thematic areas for in-depth qualitative exploration. The SFL analysis to the interview

data, in turn, helped illustrate the linguistic realisation of the discourse fields found in corpus analysis. Further to this, the corpus approach provided evidence from a larger population than did the sample interviewed; however, both sets of findings showed similar results about endometriosis experiences. Those findings were further confirmed by the thematic analysis of studies of endometriosis in medical research. Such a systematic approach to data has therefore allowed the advancement of understanding, and raising awareness, of the disempowering effects and consequences of endometriosis in women who live with it.

The application of SFL tools and metaphorical expressions analysis has allowed a deep insight into the experiential accounts of endometriosis as well as the stakeholders' (sufferers, health professionals, social/professional circle) interpersonal positioning in relation to such experiences of endometriosis. By this I mean that, through an exploration into the layers of meaning (experiential and interpersonal) construed by speakers' choices in their accounts of endometriosis experiences, we see exactly how those broader discourses and derived social practices 'constrain and delineate the radius of agency' for women with the condition (De Fina et al., 2006: 7). Hence, we are able to draw implications for endometriosis awareness raising practices as well as avenues for further research. The linguistic analysis has shown that disempowerment is caused by knowledge deficit influenced by pre-existing models or normative macro-discourses of womanhood and reproduction that have manifest impact on multiple levels: (a) making women feel abnormal (as evidenced by the appraisal analysis) and therefore potentially having an impact on timely help-seeking, general well-being, and disease management; (b) making health practitioners dismiss symptoms as normal to womanhood (as evidenced by the transitivity and modality analysis) leading to pain normalisation, dismissal or even misdiagnosis – and, therefore, diagnosis treatment gatekeeping – with irreparable consequences for some women; and (c) making women feel that the right to diagnosis treatment is a battle to win or a long obstacle-ridden journey to embark upon (as evidenced by the metaphorical expressions analysis).

What this paper ultimately argues is that whether symptom dismissal is, unintentionally, caused perhaps by a lack of awareness of the rate of occurrence of endometriosis or prejudices informed by normative discourses or, intentionally as a strategy to gate keep, say, the burden of diagnostic treatment to the health system or other associated issues, the fact remains that women repeatedly and consistently across both sets of (corpus and interview) data report not being able to get past the first point of contact – again, this is also corroborated in medical studies. Therefore, they feel that they either have to accept the situation and follow the suggested alternatives (e.g. being tested for other conditions), assume that pain is natural to their bodies and therefore live with the feeling of being 'abnormal', or 'fight' and devise creative solutions in order to be taken seriously. All such options ultimately lead to disempowerment in women who live with this life-altering condition.

As evidenced in the final section of the analysis, what gave women a sense of empowerment and agency was the acquisition of tools to document their symptoms to take to doctors. Empowerment, therefore, comes from the resistance or rejection of the passive positions created for women (discussed above) and the active adoption of alternative practices. Of course, those discussed in this paper are isolated cases; further research would require an analysis of a larger scale and with a greater number of

subjects/participants. However, the most important issue raised by this work is questioning how women acquire the empowering knowledge of an illness they do not know - or cannot be certain they have - because it is linked to a natural female process and diagnostic treatments are safeguarded, or simply unknown, by primary health-care providers. Hopefully, the newly issued NHS guidelines for GPs will allow practitioners to become more aware of the condition's symptoms.

Future Avenues of Research

This article has only managed to touch on the general issues encountered by women with endometriosis and therefore identifies a number of pathways for further research. Clearly, a view from GPs on their experiences of dealing with women with endometriosis prior to diagnosis would help unveil the intricate web of miscommunication, an avenue that The Language of Endometriosis project seeks to address. Further to this, an exploration of doctor/patient interactions regarding endometriosis symptoms, diagnosis and treatment of the condition would be enlightening, enabling the identification of where and how miscommunication occurs and whether (or how) knowledge deficiency and macro-discourses interact.

A further avenue for research that this project also seeks to address is how young girls are currently being educated on the 'normality' of periods and at what point help-seeking should be a priority. If we consider the fact that one in ten young women do or will suffer from the disease, the incorporation of this knowledge along with tools for self-assessment of the 'normality' of menstrual pain, and other associated symptoms, should be considered in the menstrual health education agenda for young girls in schools – particularly in state education.

Also, an area that grants further research is the problematisation of the word 'pain' in itself and its usual descriptors, normally consisting of dead metaphors such as 'killer/blinding', that have lost conceptual strength (e.g. Gibbs and O'Brien 1990) through overuse and fall short of conveying the magnitude and complexity of pain and associated symptoms, as expressed by some women interviewed when asked to describe their own conceptualisation of pain. This could translate into the development of a toolkit that eloquently allows the articulation of symptoms and thereby result in an empowering strategy to be used, for example, in medical consultations or health education practices; this could easily have an impact on the referral process for diagnostic treatment and thereby contribute towards tackling the significant and alarming delay in diagnosing endometriosis. This is an area already currently being investigated as part of the Language of Endometriosis project.

Finally, a further line of investigation resulting in empowering practices that could potentially aid the referral/diagnosis length issue is the development of awareness raising campaigns aimed at changing public perception of menstrual periods and, more specifically, advocating for a point at which women suffering symptoms should seek professional help. This responsibility should fall on a number of stakeholders including, for example, female hygiene product advertising that could perhaps include a simple a disclaimer as 'extreme period pain is abnormal, seek help' on their products therefore constituting a visible and widespread valuable resource.

An important caveat worth pointing out is the sample population interviewed being mostly Caucasian which is an element of contention, as mentioned in the methodology section. The point I would like to make from this is that, even if endometriosis is predominantly medically recorded in Caucasian women as discussed earlier, it is still worth questioning whether this is due to the fact that gynaecological issues, especially those associated with menstrual and reproductive conditions, are approached differently by different cultural groups. Therefore, a cross-cultural study into how different cultures conceptualise issues of this nature and seek gynaecological help might shed some light onto this issue and, indeed, help further 'demystify' endometriosis further. This is another avenue that The Language of Endometriosis project seeks to address.

As a concluding note, I would like to mention a point that does not arise directly from the findings but from the development of the study in itself. The overwhelming response to the call for interviewees is representative of women's need to be heard. Every single woman that has been in touch to volunteer their participation in the study has wholeheartedly thanked me for carrying out this project and for voicing their 'fight' against the issues addressed in this paper. I would like to finish with a reflection on an anecdote that happened during the data collection stage. An interview was cancelled as the participant had been rushed into A&E due to extreme pain and bleeding. She sent me a text message from the hospital apologising for the cancellation. After I replied reassuring her of my understanding and sympathy, she responded saying that she was moved by my message because that was the first time she had ever received empathy after having to cancel a scheduled activity due to endometriosis symptoms. This is not an isolated instance, unfortunately.

Acknowledgments

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