



The Language of Endometriosis

Introduction

The Language of Endometriosis project explores ways to improve communication about the medical condition.

The project is run by Dr Stella Bullo, a researcher at Manchester Metropolitan University and supported by Zoe Kent as research assistant.

This report has been put together to disseminate our findings so far.

What do we know about Endometriosis?

- Endometriosis is a condition whereby tissue resembling, and reacting like, the lining of the womb, called endometrium, forms elsewhere in the body.
- Each month, instead of leaving the body, the blood remains trapped inside causing, in most cases, incapacitating pain during ovulation and menstruation. As the blood is unable to escape, it forms into cysts, scars and adhesions in the abdomen. Many sufferers also experience other symptoms such as constipation, urinary infections, etc. The condition has a significant emotional impact on women.
- It affects 1 in 10 women, an estimated 2 million women in the UK.
- The worldwide average length of diagnosis is 7.5 years and it accounts for up to 50% of infertility cases¹.

What we set out to investigate and how

We conducted 21 face-to-face and Skype interviews with women that responded to our call for volunteers through mailshots and social media.

We asked our participants to tell us about their journey through endometriosis from early symptoms to diagnosis and the impact that it has had on their lives.

Our findings:

The main finding from this study is that women feel powerless, or disempowered, as endometriosis controls and restricts their lives. We have

narrowed this down to a number of aspects, ranging from the symptoms of the condition and communication skills to interaction with the social and medical environments. We address each one in detail below.

Feeling abnormal

Some women feel or have felt abnormal in comparison to peers or women otherwise perceived as 'normal'. This is what our participants report to feel or felt like when they were growing up with (undiagnosed) endometriosis.

Below are some examples from interview quotes:

- *'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...'*
- *'I feel like I am not a proper woman'*
- *'I am now damaged goods and people treat me like that even though I try my hardest not to be'*
- *'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'*

Very interesting for our project is the use of strong words such as 'repulsed by myself', 'not respectable'. These are all quotes by different women, which means that this is a common feeling in women with endometriosis yet, they feel 'abnormal' due to, perhaps, lack of peer support and standards of what is normal for a woman to be like in our society. This feeling of 'abnormality' is possibly being enforced by lack of awareness in how common endometriosis is for women. Many of our participants were not able to discuss the severity of symptoms with friends and family for fear of being dismissed or feeling embarrassed which can lead to isolation and loneliness.

Lack of support and understanding

A consistent finding in our interviews is that Endometriosis symptoms are often dismissed or normalised as a part of the feminine condition by family,



The Language of Endometriosis

friends, employers, etc. whose lack of knowledge of the condition leads to lack of empathy.

- *'...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'*

As linguists, what calls our attention in this passage is the metaphor where this participant 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'). Although it is very common to compare illnesses to war or battles, in this particular quote we can see the frustration felt by this woman at her inability to be taken seriously, which ultimately makes her feel isolated and defeated.

Pain dismissal and misdiagnosis

Most participants have talked to us about difficulties encountered before diagnosis was achieved. The most common issue reported is the normalisation of pain. In other words, women were told that pain is normal and it was therefore dismissed. For example:

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

A good number of participants have been misdiagnosed at some point or another.

- *'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'*

Although we cannot be certain that these were the exact words used by the doctors, we can assume that, by using words such as 'probably' and 'maybe',

the participant recalls coming out of the consultation feeling very uncertain about what was wrong with her.

The extract below shows something similar where we get a sense of hopelessness and ultimately disempowerment.

- *'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'*

Knowledge is power

Some other data revealed that what gave women a sense of empowerment and control was the acquisition of tools to document their symptoms. For example:

- *'after that appointment, I kept a record of the painful days, so I went back armed with this piece of paper'*

Interestingly, keeping a diary of her symptoms gave this participant the tools to feel in control in order to assert her need for diagnostic treatment. Again, we see the war metaphor used here ('armed') which implies that she saw attending her next doctor's appointment as going to a battle and the diary of pain as her weapon. From this we can conclude that empowerment, therefore, comes the active adoption of practices that allowed the participant to understand her body and her symptoms by diary keeping. Once again, this stresses the importance of awareness and knowledge to help women get diagnosed and treated.

Communicating pain

In most interviews conducted, women have expressed how difficult they find describing their pain. Most women were initially wordless, using hand gestures and explicitly acknowledging this difficulty:

- *'that (describing pain) to me has been the most difficult thing to try and describe to people actually, I struggle to describe it'*
- *'It's just really hard to describe it really it's just very hard'*



The Language of Endometriosis

As chronic pain is abstract in nature and thus very difficult to describe, it is often compared to damage caused through physical harm. For example, very common words found in descriptions of pain are 'stabbing', 'burning', 'cutting', etc. Other times, when we asked women to describe their pain by starting sentences with 'it feels like../as if..', we found that they used descriptions such as:

- *'as if someone was wringing my womb out like a dish rag'*
- *'like a thousand tiny men stabbing at my womb'*
- *'it feels like my womb is going to explode'*

This makes us question what is the best way to describe pain? Women go from being unable to describe pain to describing a horror-like narrative. Is there a middle ground? And how can we provide women with the linguistic toolkit to describe that middle ground? This is something that we will be focusing on in future research. We will be aiming to develop a linguistic toolkit that eloquently allows the articulation of symptoms, given that the word 'pain' and its qualifiers (for example, severe) fall short of conveying their magnitude and complexity. Watch this space.

What else could we do to help?

We have found that disempowerment is mostly caused by knowledge deficit at various levels ranging from women themselves, who may not realise that extreme period pain and associated symptoms are not normal, therefore postponing seeking help and diagnosis, to some doctors who may dismiss symptoms by normalising them or even misdiagnosing them.

We saw from the interviews that what gave women a sense of empowerment was the acquisition of tools to document their symptoms. Empowerment comes from knowledge. Therefore, the most important issue raised by this project is questioning how do we educate about a condition that is linked to a natural female process that is often dismissed as 'women troubles' and potentially seen as taboo?

The aim of the Language of Endometriosis project is to empower women by providing them with tools to describe symptoms, and pain in particular, and to ask the right questions.

We would also like doctors' views on what they think would help them spot endometriosis symptoms more effectively in terms of how women communicate symptoms.

We also need to explore how young girls are currently being educated about menstrual periods. If we consider that one in ten young women do or will suffer from the disease which can potentially lead to infertility and a highly diminished quality of life affecting relationships, careers, etc., then education on menstruation should be a priority of the health education agenda. This should consider tools for self-assessment of the 'normality' of menstrual pain, and other associated symptoms, and stress the importance of seeking help early on.

Finally, we also need to work on changing public perception of menstrual periods and advocate for a point at which women suffering endometriosis symptoms should seek professional help. Endometriosis-UK is doing a great job development of awareness raising campaigns. The NHS has issued guidelines for GPs. This is very promising. However, perhaps we could involve the wider community. Other stakeholders, such as for example, companies that produce female sanitary products could be involved. A simple disclaimer as 'extreme period pain is abnormal, seek help' on their products, for example, could constitute a visible and widespread valuable resource.

A final note:

We wholeheartedly thank our participants for sharing their stories with us. We hope that this initial report will give them an indication of what their interviews with us have allowed us to achieve so far. We also want to reassure those participants who sadly had to cancel their interviews due to being unwell with endometriosis that we understand and sympathise. One woman, in particular, who contacted us from the hospital apologising for the



The Language of Endometriosis

cancellation, responded to our message expressing our sympathy and thanked us for our understanding. She said that she was moved 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, unfortunatelyⁱⁱⁱ.

Please do not hesitate to contact us with any questions:

www.facebook.com/TheLanguageOfEndo; @EndoLanguage

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ⁱ Endometriosis-UK. Available at <https://www.endometriosis-uk.org/information>.

ⁱⁱ Bulletti C, Coccia ME, Battistoni S and Borini A (2010) Endometriosis and infertility. *Journal of Assisted Reproduction and Genetics*, 27(8): 441–447.

ⁱⁱⁱ A full version of this article has been accepted for publication in the *Journal of Discourse and Communication* (12, 6) available online in May 2018.