



"Allow us to show them the pain by
squeezing their hand":

The study of pain communication and the
diagnostic delay of endometriosis

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Abstract

Endometriosis is a gynaecological disorder that affects an estimated 176 million women worldwide. Endometriosis causes serious societal impacts, such as loss of work productivity and effectiveness of non-work-related activities. Regardless that a significant number of women are impacted, many clinical questions remain unanswered, treatment failures are common, diagnosis takes an average of seven and a half years, and there is little investment in investigating disease mechanisms. At the same time, in the last few decades, endometriosis has been repeatedly mislabelled, which still presents indications on the current endometriosis care. Furthermore, there is still a tendency to exclude women's experiential knowledge, which presents one of the biggest burdens of endometriosis.

The Degree Project demonstrates communication barriers to early diagnosis from 262 women using survey data and aims to understand women and medicine's power relations. Through this analysis, women's perspective is presented and discussed. The analytical discussion is divided into four chapters: medical knowledge, pain communication, desired communication support and experiential support.

The study identifies how the relationship of knowledge and power impact pain communication and consequently the diagnosis of endometriosis. This study contributes to endometriosis, gender and communication for development studies by suggesting the incorporation of women's experiential knowledge to address the challenges of pain communication and the diagnostic delay.

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I. INTRODUCTION

1.1 THE CONTEXT AND THE SCOPE OF THE STUDY

Endometriosis is a condition where tissue similar to the lining of the uterus starts to grow in other places, such as the ovaries and fallopian tubes. During menstrual cycles, the blood is trapped inside instead of leaving the body (Endometriosis-UK, n.d.). Endometriosis is a long-term condition that affects 176 million women worldwide (Young, Fisher, Kirkman, 2019). However, endometriosis is not exclusively a female disease; everyone born with a uterus is exposed to it, even though the evaluation for endometriosis with dysmenorrhea is limited in the transgender population (Kronemyer, 2020).

Endometriosis became identified around eighty-five years ago (Groff, 1989 in Whelan, 2009); nonetheless, numerous medical experts still consider it an enigma (Whelan, 2009). While the estimated global burden of endometriosis has been decreasing (since the 1990s), this decline is explicit due to limited data, lack of reports across global regions and diagnosis difficulties, according to recent research (Zhang, Gong, Wang, Zhao, Wu, 2020). There is little established relation between the lesion (number, size and infiltration) and the pain level (Stratton & Berkley, 2011), and women do not experience the same symptoms and the same level of pain. The associated pain, infertility and pelvic masses can impact general physical, mental and social well-being, and symptoms may persist despite seemingly adequate medical or surgical treatment of the disease (Kennedy, Bergqvist, Chapron, 2005, p.3). The condition can cause further severe societal implications, such as loss of work productivity and effectiveness of non-work-related activities, which are significantly impaired by flare-ups' pain (Endometriosis.org, 2021).

It was widely argued in the gynaecological field that patients' personal and social characteristics play a causal role in developing or presenting their symptoms. While today these are contradicted and explained by previous flawed research and biased assumptions, "acknowledging these biases and artefacts does not make the variation in the endometriosis patient population any more comprehensible" (Whelan, 2009, p. 1490). For example, menstrual disorders are quite common among adolescents and young women (Armour, et al., 2021). Furthermore,

at the individual level, normalisation of pain can start when women start having menstruation.

Unfortunately, limited data are discussing young women's knowledge about endometriosis and menstrual health in general. However, a recent global study conducted across low/middle-income countries (LMICs) and high-income countries (HICs) demonstrates that menstrual health issues such as dysmenorrhea were normalised, leading young women to avoid seeking help from medical professionals or parents. In both LMICs and HICs, menstrual health is still associated with negative connotations leading to a lack of open communication at school and home (Holmes et al., 2021). An Australian study also showed that most young women were unable to identify the symptoms of primary dysmenorrhea. As a result, they do not know what could cause pain and do not use pain medication appropriately to attain optimal pain relief. Thus there is less use of preventative health care. In remote areas (due to further cultural and economic barriers), the issue is even more significant as they mainly rely on schools to provide reliable and accurate education.

Despite the severity of their pain, many young women consider that their pain is normal due to the "widely accepted idea" that painful menstrual symptoms are just part of becoming or being a woman (Armour, et al., 2021). In the United Kingdom, the Plan International UK survey presented that some of the critical issues in the UK do not dramatically differ from those experienced globally, such as menstrual stigma, taboo, access to menstrual products and the challenge of pain management being universal issues (Tingle et al., 2018). Furthermore, regardless of societal implications, symptoms are often referred to as psychological issues similar to many pain-characterised conditions affecting women (Kaler, 2005).

Regardless of the technological advances in biomedicine, the average time of diagnosis is still seven and a half years (Endometriosis UK, 2017). Some of the symptoms of endometriosis overlap with other conditions such as Irritable Bowel Syndrome (IBS) or chronic pelvic inflammatory disease (PID). Additionally, many women with chronic pelvic pain will never receive a complete diagnosis (Ballard, 2010). At present, the only definitive way to diagnose endometriosis is a surgical

procedure called laparoscopy (APPG, 2020), recommended by the Royal College of Obstetricians and Gynaecologist guide (RCOG, 2006). However, the diagnostic accuracy largely depends on the surgeon's skill, aptitude and interest in the condition (Zhang et al.).

A report of the All Party Parliamentary Group on Women's Health (WHAPPG) in the UK further highlights the complications of diagnosis and, in particular, the insufficient care. For instance, there is unsatisfactory information about treatment options, lack of dignity and respect (Endometriosis.org, 2020). There is also a tendency to exclude women's experiential knowledge, which is equal to ignoring a "large piece of the healthcare puzzle that addresses the complexities of endometriosis" (Young et al., 2019, p. 351). This exclusion presents one of the biggest burdens of endometriosis.

Bullo (2020) defines limited consultation time, lack of education and awareness (at the public and medical level), and the normalisation of pain as the main barriers to timely diagnosis. The lack of consensus of what is considered a normal period and the lack of public awareness of endometriosis often intertwine with the unknowing of endometriosis symptoms along medical professionals, which further delays the diagnosis (APPG, 2020). Krebs and Schoenbauer (2020) argue that another reason behind a diagnostic delay is that diagnosing an illness is not entirely a scientific and medical process. Diagnosis should be considered as a social process as "diagnoses are formed through dialogic interaction between patients and providers" (Geist & Dreyer, 1993, cited by Krebs et al., 2020, p.1013). Given the interplay of the facts that chronic pain is one of the most common symptoms of endometriosis while measuring pain is somewhat subjective, effective pain communication between patient and provider is indispensable for timely diagnosis. However, "within this increasingly depersonalised system, the role of in-person patient-provider communication is often marginalised, if not altogether seen as unnecessary for the diagnostic process" (Krebs and Schoenbauer, 2020, p. 1014).

The medical world still does not fully understand the mechanism of the disease. In addition, the number of specialists with the necessary surgical skills is limited. While such difficulty is the main diagnostic barrier, through the close reading of

discourses surrounding endometriosis, broader sociocultural barriers become apparent. Combining communication, social feminist linguistics and development studies, the Degree Project aims to understand the power relations between women and the traditional medical knowledge by identifying how these relations impact the diagnosis of endometriosis and how the integration of women's experiential knowledge could present a positive change. The Degree Project analyses how women navigate knowledge and power and argues that women not only should have access to information about their bodies, but they should also help to create this knowledge. As there is a historical relationship between scientific knowledge, women's bodies and medical care, this study may challenge the authoritative knowledge of Medicine and its historical androcentric biases. As a communication for development study, this paper demonstrates the potential to highlight communications barriers based on ideology and present solutions to these barriers by placing women at the centre of research.

1.2 PERSONAL MOTIVATION

For some women, their stomach hurts. So much so that even if they take a handful of medication, they still curl up from the severe cramp and find it hard to go into works. For weeks. Every month. Other women lose so much blood that it hurts when they go to the toilet, and it hurts when they are with their partner. Some women try to get pregnant for years, but it does not work, nothing work, studies show that everything is fine, but even if they try artificial insemination, they run out of time slowly, they are helpless. At the same, they go to several doctors with all these complaints, but all they say that it is normal, part of women's life or get referred to a psychologist while all they want is the constant pain that destroys their femininity and quality of life to go away. Not to be afraid every month. They all have endometriosis.

On a personal level, I suffer from dysmenorrhea and severe pelvic pain in the last five years. It took me years to realise that along with my gynaecologists, I also normalised my pain, believing that behind this pain, there is one simple explanation: I am a woman. While I do not draw any conclusion from my own experience, it made me curious to know why so many other women go through similar experiences. My professional background in the public health non-profit sector and my

academic interest in communications and development made me start researching the diagnostic barriers. The communication lens quickly showed that even though the representation and comprehension of endometriosis have significantly improved over the last few decades, gendered labels still present implications on various levels. For this reason, I decided to study these implications in my Degree Project.

1.3 AIMS AND OBJECTIVES

The Degree Project studies the relationship between diagnostic barriers and communication practices to confirm the potential of the inclusion of women's experiential knowledge. As effective pain communication is key to achieving a timely diagnosis, while pain communication is affected by power and knowledge between health care providers¹ and patients, it is essential to explore the broader context of communication practices concerning endometriosis pain. For this reason, the main objective of the Degree Project is to answer the following research questions:

- 1) *How does the relationship of knowledge and power between patients and health care providers affect the diagnosis of endometriosis?*
- 2) *How endometriosis pain is communicated, and what are the challenges of pain communications during medical interactions?*
- 3) *How could pain description be optimised in order to contribute toward timely diagnosis?*

II. LITERATURE REVIEW

The literature review contextualises the power of Medicine as authoritative knowledge and explores the role of gender and language through gender and communication studies which gave the basic structure of the Degree Project. It

¹ Throughout the Degree Project, health care providers, providers, doctors and medical professional are used interchangeably.

also explains the concept of online support groups as epistemological communities, which becomes essential in the study of pain communication to reduce the length of the diagnosis.

2.1 MEDICINE AS AUTHORITATIVE KNOWLEDGE

Krebs (2020) defines biomedical Medicine as an ideological system of social control and argues that patriarchal influences often infiltrate biomedical care and knowledge by marginalising women's voices in the sociocultural aspects of care. Western Medicine holds authoritative knowledge of the human body (Lupton, 2012 in Young et al., 2019). Lupton (1994) also emphasises the ideology behind traditional Medicine, which defines the relationship between patients and providers as the voice of scientific expertise over a patient. Ideology could therefore be also seen as a diagnostic obstacle since it affects communication practices within medical encounters. In the case of endometriosis, the severity of pain often does not correlate with the stage of the disease (i.e. observable extent); thus, the enigmatic nature creates a contradiction between patients' and providers' account.

According to the World Health Organization (WHO, 2021), in many countries, the general public and many front-line healthcare providers are unaware that distressing and life-altering pelvic pain is not normal, leading to normalisation and stigmatisation of symptoms and significant diagnostic delay. Furthermore, healthcare providers could have different ways to determine what is normal regarding menstrual pain and what is considered dysmenorrhoea, ovulation pain (mittelschmerz), and dyspareunia. Grundström et al. (2016) conducted interviews with medical professionals such as gynaecologists (GYs) and General Practitioners (GPs and midwives) to describe their experiences with endometriosis patients. The study defines the requirement of a high amount of responsiveness from providers, which can be achieved through supportive consultations by acknowledging the women, confirming their symptoms, and considering the physical and mental aspects of experiencing pain. At the same time, the study showed different levels of ability to suspect endometriosis between professionals. The GYs considered endometriosis enigmatic and this patient group challenging, but they suspected endometriosis if the symptoms were presented. The GPs and midwives stated that their knowledge was limited and agreed that women would

get better treatment from GYs. This result indicates that medically unexplained symptoms could be challenging for medical professionals, which may explain the possible gap between the experiences of patients and providers. In this epistemological conundrum, the lived experiences of illness are questioned by a lack of objective confirmation, and medical professionals may disbelieve the reality of these experiences as a result (Barker, 2002, in Whelan, 2007).

According to Foucault, the power of Medicine is defined by its institution, individual clinicians, patients and authors who participate in its dissemination and perpetuation.

"For clinical experience to become possible as a form of knowledge, a re-organisation of the hospital field, a new definition of the status of the patient in society, and the establishment of a certain relationship between public assistance and medical experience, between help and knowledge, became necessary; the patient has to be enveloped in a collective, homogeneous space." (Foucault, 2003, p.196)

Even though the subordination of patients is not always intentional, clinicians can embody and maintain the social power of the medical institute through their everyday clinical practice (Carsten, 2017). In the past, endometriosis has been repeatedly labelled as "hysteria" or "career women disease". Although its representation and comprehension have significantly improved over the last few decades, these labels still present implications on various levels. Thus, careful consideration of the complex social interaction between doctor and patient is necessary (Westerhaus, Finnegan, Haidar, et al., 2015).

Whelan (2009) argues for an extensive experience that builds on learning from experienced medical professionals, practice of case presentation, and the requisite of interacting and negotiating with patients regarding best practices of endometriosis care. However, it is argued that women not only should have access to information about their bodies, but they should also help to create this knowledge. However, "women with endometriosis present a threat to Medicine's knowledge of the body, and that, instead of acknowledging the inherent limitations of androcentric medical knowledge, the fault is established within women (usually, their choices and their bodies)" (Young et al., 2019, p. 341). For this

reason, the contextualisation of the relationship between scientific knowledge, women's bodies and medical practice is key to understand gender inequities of medical care (Wendy, 2010). By studying the historical relationship between scientific knowledge, women's bodies and medical care, the authoritative knowledge of Medicine may be challenged.

2.2 GENDER AS SOCIAL DETERMINANTS OF HEALTH

While there is a socially constructed connection between sex and gender, Phillips (2005) makes a distinction by referring to sex as "unchanging biology of being male or female" and gender as "roles and expectations attributed to men and women in a given society which change over time, place and life changes" (p.15.). Due to these socially constructed assumptions, women tend to have less access and control over their bodies and lives at a population level. Furthermore, gender has often an effect on the access to education or health care in the measure of women's health (Phillips, 2005, p.15).

The World Health Organization determines the Social Determinants of Health as "the non-medical factors that influence health outcomes" (WHO, n.d.). These social factors have tremendous implications concerning whose health needs are acknowledged and who has the power over his/her health. Sen and Ostlin (2008) argue that along with economic and racial inequalities, gender is one of the most influential intermediary factors which could result in biased and inequitable health outcomes. The "unconscious gender bias" has been examined across the health system. For example, along with gynaecological conditions, studies highlighted gender discrepancies in medical decisions involving bypass surgery (Travis, 2005) and gender disparity in analgesic treatment of emergency department patients with acute abdominal pain (Chen et al., 2008). Gender imbalances are equally present in health research due to the poor recognition of health problems and the relationship between gender (Sen et al., 2008) and limited funding. For example, 70% of chronic pain patients are women, but 80% per cent of pain studies are conducted on men or male mice (Jackson, 2019).

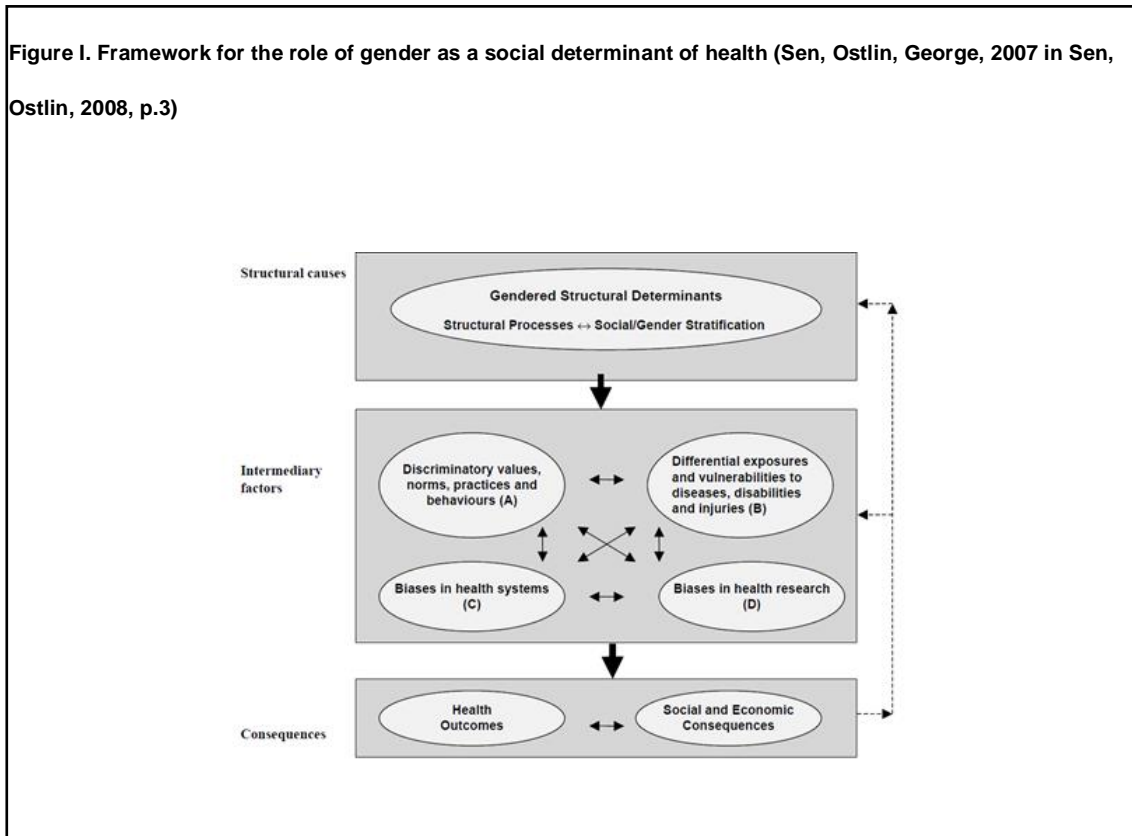
Why do health care systems and health research reproduce inequalities instead of resolving them? (Sen et al., 2008, p.11). Regarding biomedicine, how women

were treated in the past could also explain the inefficiency of diagnosing endometriosis.

Since ancient times, the man was considered as default human being opposed by abnormal deficient women. In the case of gynaecological disabilities, the "wandering womb" was blamed for a long time, followed by the failure of hormones. The concept of "mad women" (during their period) is well-established in Western society, even though it is not more than a confirmation bias. Having female reproductive organs with "raging hormones" was enough to be excluded from education, professions, religious and public places. Since then, women learned to blame themselves (Jackson, 2019).

"Gender inequality and equity are socially governed" (Sen et al., 2008, p. 2); thus, addressing its problems requires multidisciplinary approaches both outside and within the health sector. A Special Supplement created by the Women and Gender Equity Knowledge Network (WGEKN) of the World Health Organization (WHO) Commission on Social Determinants of Health (CSDH) concludes that a normative framework should be applied in order to protect and promote women's health rights, placing the focus on empowerment (i.e. claiming and exercising their rights). This framework proposes an explanation of the role of gender as social determinants of health (Figure 1). The analysis of the structural causes and intermediary factors in the case of endometriosis calls upon a question about structural gender inequalities: how much women's suffering from endometriosis is due to female biology, and how much can be attributed to women's lack of power and access?

Figure 1. Framework for the role of gender as a social determinant of health (Sen, Ostlin, George, 2007 in Sen, Ostlin, 2008, p.3)



Hirschmann (2008) argues that social construction frames individuals who are not aware of their domination and, at the same time, imposes a set of norms and values which establish women's lack of power. Women are expected to have children and participate in activities that are appropriate to the feminine gender identity. According to Hirschmann, women also think about themselves in a particular way that is more aligned with certain choices as they are subjected to a male-dominated society. The gender divide in societies is not based on biological characteristics, nor can it be explained by a non-intermediate biological difference. Social positions are to be found in a culture that helps to maintain inequalities in a contemporary form (Hirschmann, 2008, p).

2.3 GENDER AND LANGUAGE

Holmes (2007) claims that we need to put women back at the centre of language and gender research. She argues that linguists can highlight discursive behaviours which penalise women and, on the other hand, document active discursive resistance to behaviours influenced by the masculinised knowledge. Gender is an aspect of social identity conveyed, usually indirectly, by linguistic features that

may concurrently convey other meanings. For this reason, particular attention needs to be paid to participants' interpretations within a specific community of practice for contextual analysis (Kovacs, n.d.). From a feminist perspective, Wodak (2015) sees language as a symbolic reflection of androcentric cultures that reflects upon Western societies' patriarchal structure and manifests and constructs social practices.

"Feminist linguistic does not accept phenomena as given, but seeks alternatives in keeping with the principle of the linguistic equal treatment of women and men. It pursues explicitly political goals by criticising ruling linguistic norms and understanding the linguistic change it advocates as part of an overall change in society" (Wodak, 2015, p. 700)

Endometriosis has attracted feminist scholars as a "metaphorical meeting point" for gender knowledge and power (Carsten, 2007). The language used by health care providers constructs power structures within Medicine and has significant implications for women with endometriosis regardless of whether these constructions endorse or challenge historical discourses (Young et al., 2019). A deeper understanding of the language used in pain narratives may positively impact communication practices and potentially contribute to tackling the alarming endometriosis diagnosis delay issue (Bullo, 2020, p. 478).

3.3 ONLINE SUPPORT GROUPS

Regarding online communication practices, personal experiences shared on different social media channels are increasing. This phenomenon can be explained by the technological changes in health communication along with the fact that women's experiences shared in private with other women are regarded as acceptable, while the public discussions challenge medical authority. There is a growing literature discussing endometriosis patients' frustration with medical professionals. These contend that disease is not taken seriously due to gendered biases, normalisation of pain and disbelief in women's account. The "highly gendered delegitimation theme" (Whelan, 2007, p. 958) also justifies why there is growing online endometriosis activism.

Once invisible, endometriosis started to appear across various media platforms. According to Clammer (2010), social movements challenge ideological power relations; thus, they generate alternative knowledge of what is shaped by culture. Disregarding whether a social movement is successful, the discovered alternatives present long-term effects, such as new forms of discussions. Celebrities' testimonies, social media support groups, digital life stories, hashtag movements such as #endowarrior, #endowhat, and #EndoActive represent collective illness narrative and social activism. There are visible implications of endometriosis-related social activism, awareness campaign and national action plans that have been launched in several countries. However, studies continuously show that public awareness and medical perception of women with endometriosis-related symptoms have not changed visibly and similarly, there is a lack of appropriate health care policies addressing the disease of one woman in ten. For this reason, the Degree Project uses postcolonial studies' innovative way of studying more diverse forms of text (Clammer, 2012). The study of different narratives shared on various social media channels, from which the discursive categorisation can illuminate communication barriers of timely diagnosis, increase social movements and "offer a unique entry point for endo advocacy efforts among both the general public and healthcare providers" (Krebs et al., 2020, p. 1015).

Within endometriosis activism, online support groups draw upon online contemporary illness narratives when tellers demonstrate awareness and position themselves as moral and knowledgeable endometriosis patients. Thus, personal experiences are tied to larger stories and understandings of health. Since the discussion has an online presence, it creates new spaces for sharing experiences and invite for an understanding of the reality behind the disease (Melander, 2019). Nelson defines these patients' groups as epistemological communities which are to "not only share knowledge but collaboratively formulate and defend an understanding of what counts as 'good knowledge' in order to challenge medical authority and develop patient-centred knowledge claims" (Nelson, 1993, in Whelan, 2007, p. 959). The collective experiential illness narrative equally generates a sense of belonging and acknowledgement which is seen as incredibly helpful in coping with the physical and mental aspect of the disease. Wilson ar-

gues that there are different opportunities to improve understanding of how endometriosis patients cope, online support group is one of them. Health care providers' participation in these groups could help them identify emotional struggles and coping mechanisms and develop appropriate discussion strategies (Wilson et al., 2020).

III. THEORETICAL FRAMEWORK

3.1 FEMINIST SOCIAL CONSTRUCTIVISM AND FEMINIST LINGUISTICS

The feminist theoretical framework enables a detailed analysis of endometriosis narratives that ultimately highlights hegemonic ideologies at the societal level (Mills, 2011). The application of this framework leads to an analysis of gender and demonstrates the implications of language about gender relations.

The feminist perspective has a liberating potential as it can recognise human relations' distorted and inhuman nature and ultimately create opportunities to change them (Hartsock, 1998). Thanks to applying a feminist social constructionist perspective, Medicine can be seen as a system of knowledge that is a product of evolving social constructions and power relations dependent on their historical context (Irwin, 2010). As the Degree Project aims to understand power relations between endometriosis patients and medical knowledge, feminist social constructivism offers a valuable perspective to frame the analysis as well as to document change.

Narratives and social constructions influence psychosocial aspects of health, bodies, reproduction and sexuality. Social construction theory is based on the belief that knowledge is created not as a reflection of one "true" reality but as a product of humans' collective assumptions about the world shared through language. The language used by medical professionals constructs power structures within Medicine and have significant implications for women with endometriosis regardless of whether these constructions endorse or challenge historical discourses (Bullo, 2020, p. 478).

"The socio-linguistic frame focuses on "plots" or the structure of narratives, and how they convey meaning" (Bryda, 2020, p. 137). Social and cultural influences

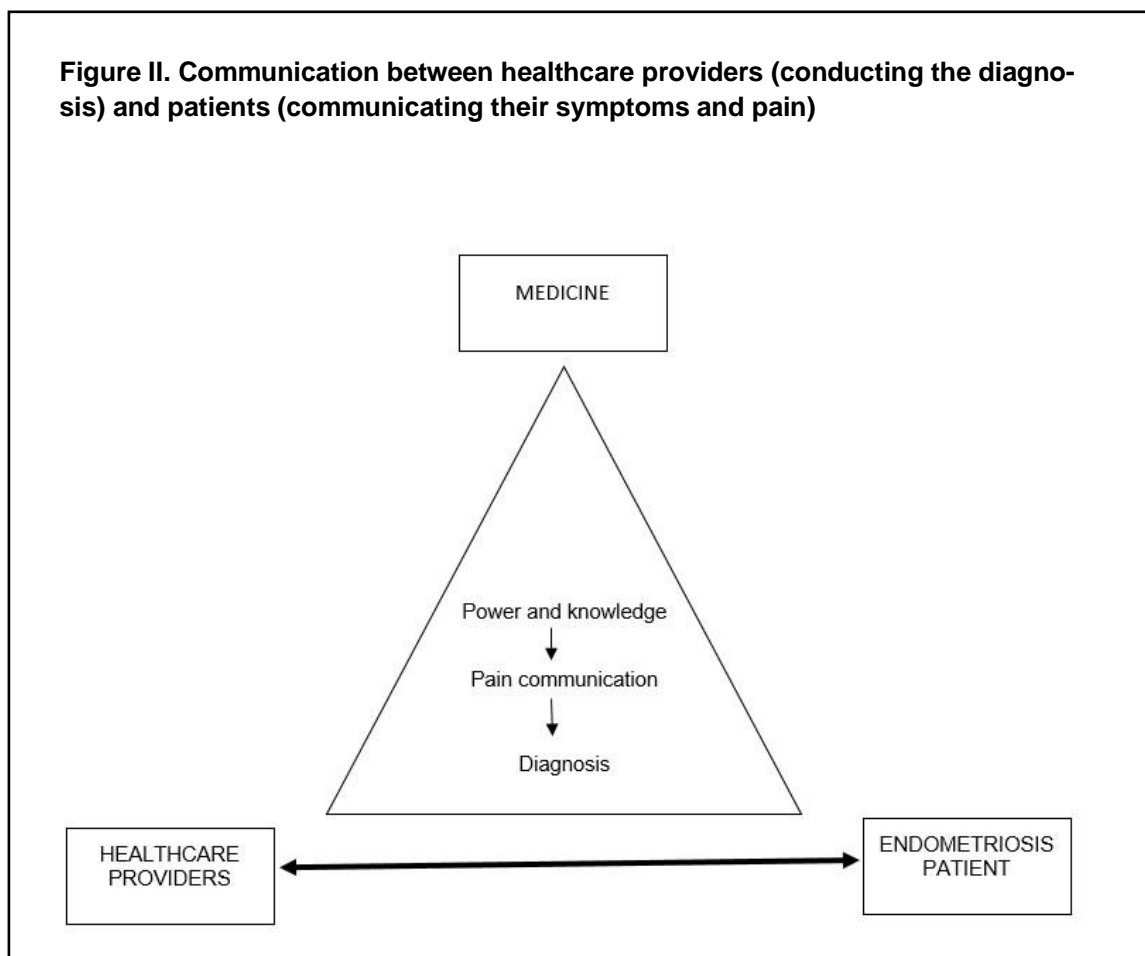
such as race, class, gender, education, or hierarchy became visible through the sociolinguistics frame. Social feminist linguists could extend the project's theoretical framework in terms of language and the social constructivist approach, as in the medical field, gendered expectations about normative ways of speaking still persist. Social feminist linguistics can observe subtle and apparent patterns in discourses and argue for its repression. Feminist linguistics approaches give insights into inequality (specific political objective) as language can trace the working ideologies and their stereotypes (Mills et al., 2010)

3.2 COMMUNICATION BETWEEN HEALTH CARE PROVIDERS AND PATIENTS

Diagnoses are formed through dialogic interactions between patients and providers (Geist & Dreyer, 1993 in Krebs et al., 2020, p 1013). Malterud (1992 in Bullo, 2020, p. 478) emphasises the key role of gender asymmetries in the doctor-patient relationship, affecting the communication of health complaints and, therefore, the diagnosis. As endometriosis is a silent epidemic (physical examination often does not show any evidence of endometriosis), its diagnosis should include women's personal history and experience. However, women's experiential knowledge is often dismissed, and the symptoms normalised, which sheds light on androcentric medical biases.

The study of power dimensions as part of a communicative relation and interaction between women and medical professionals can explain how the relationship of knowledge and power between patients and health care providers affects the diagnosis of endometriosis. Foucault claims that knowledge and power are deeply interconnected:

"There is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time, power relations" (Foucault, 1977, p. 27).



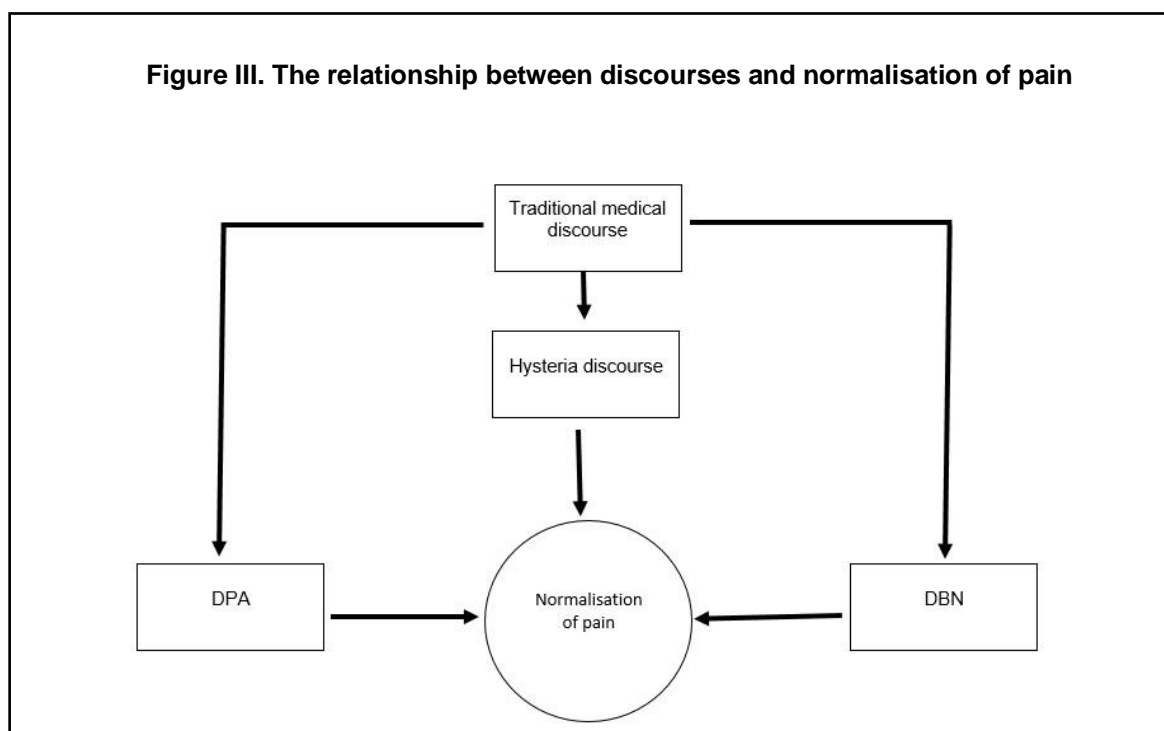
Considering the delay between the onset of the symptoms of endometriosis and diagnosis (Deal, DiBenedetti, Williams, Fehnel, 2010), several discourses could be examined to gain a deeper understanding of communicative relation and social burden of endometriosis. The traditional medical discourse around women bodies can be seen as a discourse building on androcentric knowledge and practices incorporating themes of volatility and control (Young et al., 2019). This authoritative medical knowledge revokes the hysteria discourse in Medicine defined by Jones as "women's illnesses are a product of their psyche, stemming from their reproductive system, as a failure to uphold their 'biologically destined' role of mother" (2015 in Young et al., 2019, p. 342). The cause of hysteria was medicalised and defined with different factors of the reproductive system, nervous system, and masturbation or women's desire to pursue higher educational studies, to mention a few. Today, these historical discursive diagnoses still impact medical and public beliefs of women's health (Jackson, 2019).

In addition, Shohat (1992) revealed evidence that endometriosis has been presented due to disordered female biology and disordered personality and behaviour, such as delayed marriage and pregnancy. "For decades, it was known as the "career woman's disease" on the assumption that it predominantly affected white, middle-class, educated women" (Carpan, 2003; Nezhat et al., 2012 in Young, 2019, p.). Nowadays, women with "unexplained" symptoms are often considered "difficult patients", which is simply the perpetuation of the hysteria discourse (Young, 2019). While the representation and comprehension of endometriosis have significantly improved over the last few decades, undiagnosed endometriosis patients are still often considered to be suffering from "somatisation" or other psychological factors that cause symptoms of a disease without apparent physical pathology (Cox et al., 2003).

A study (Krebs et al., 2020) analysing women's experiences of endometriosis diagnoses through online posting revealed two main additional centripetal discourses: the discourse of psycho-abnormality (DPA) and the discourse of biological normality (DBN). While DPA disqualifies women's suffering as imagined and "all in their heads", the DBN naturalises women's suffering as "just part of being a woman". The study argues that both discourses are rooted in patriarchal influences and, for this reason, prevent timely and accurate diagnosis. The DBN has historical literature as well as scientific roots and naturalises dysmenorrhea from a young age in educational, medical, and home settings through sexual education, early visits at gynaecological practices and mother-daughter communication. The DPA sees women as weak, neurotic and attention seekers and highlights broader patriarchal histories of biomedicine. The DPA and the DBN are inherently paradoxical, but at the same time, "each had the power to silence endo sufferers' concerns" (Krebs et al., 2020, p.1019).

The above-described discourses demonstrate that the relationship of knowledge and power between women and providers impact pain communication in medical consultations. The traditional medical, hysteria, DPA and DBN discourses suggest communicative reasons for the diagnostic delay by highlighting pain communication challenges such as the normalisation of pain. The normalisation phenomenon can be explained by minimising symptoms in communications practices at home and medical settings, along with the lack of education and awareness at

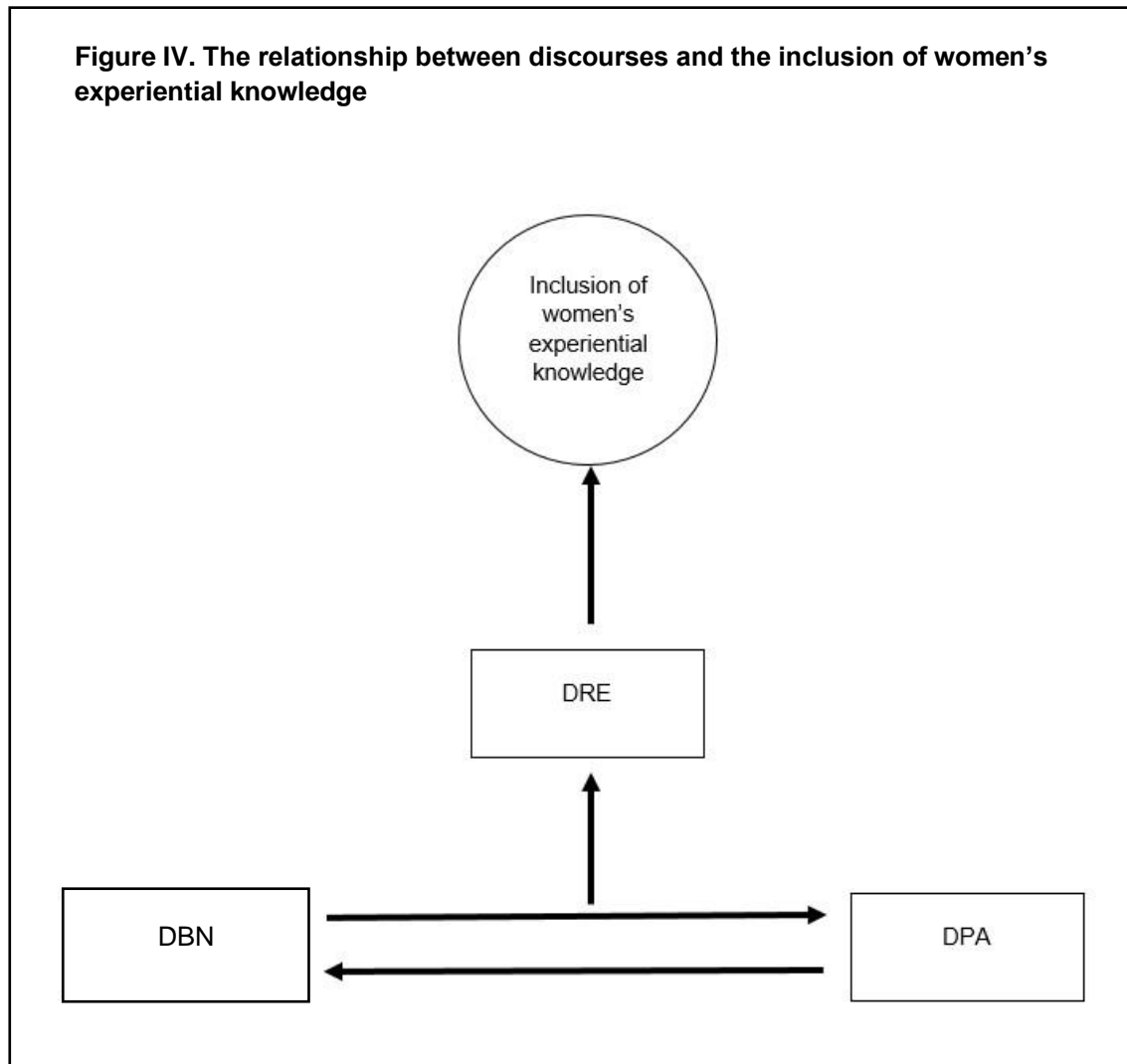
school. Thus, the normalisation takes place in two levels: at the individual level where women normalise their own pain due to the difficulties of determining what abnormal menstrual pain (dysmenorrhea) is, and at the medical level as there is a tendency to dismiss the severity of the pain (Grundström et al., 2016). At both levels, there are broader sociocultural barriers to timely diagnosis and adequate medical care.



The communicative challenges illuminate the necessity of the optimisation of pain description in medical consultation. In the case of endometriosis, pain and measuring pain is subjective; thus, there is often a discrepancy between women and providers' account.

A third emerging discourse, the discourse of remaining expertise (DRE), underlines the significance of such inclusion as it brings attention to the paradox DPA and DBN discourses and empowers marginalised voices via (often web-based) endo-related activism.

"DRE holds much less power than the centripetal discourses it challenges, but remains an important discourse. Through the DRE, women accredited embodied knowledge and encouraged one another to seek better medical care if healthcare professionals incited the DPA or the DBN" (Krebs et al., 2020, p. 1019).



3.4 COMMUNICATION FOR DEVELOPMENT

Communication is key to establishing trust and collaboration between patients and healthcare providers to eliminate or significantly reduce diagnosis complications. In the case of endometriosis, as social and health issues should not be exclusive to specific ideologies or dominant discourses, it is critical to shifting the paradigms towards better inclusion. Combining communication, social feminist linguistics and development studies, the Degree Project aims to understand communication practices between healthcare providers (conducting the diagnosis)

and patients (communicating their symptoms and pain) by exploring power relations between female patients and the dominantly masculinised medical knowledge and identifying how these relations create pain communication challenges and therefore impact the diagnosis of endometriosis. By making women's perspective on pain communication the central point of the analysis, this study uncovers that integrating women's experiential knowledge is crucial to present a positive change. This perspective puts "the focus on citizen engagement, processes of empowerment and particularly the ability to control the direction of one's own life trajectory" (Tufte, 2017, p. 109). It considers knowledge as a "strategic weapon" essential for gaining control of our quality of life (p.111).

IV. RESEARCH METHODOLOGY

4.1 QUALITATIVE RESEARCH DESIGN

The Degree Project builds on internet research and other mixed methodologies within the qualitative research design, namely survey study and in-depth interview. The study uses the interview method to gain professional insight into endometriosis and survey to explore diagnostic barriers from women's perspective by highlighting endometriosis patients' communication difficulties and studying the beneficial qualities of online support groups, placing a particular focus on pain communication. Within a two-week period, 262 women participated in the survey.

Critical discourse analysis (CDA) and narrative analysis are applied within texts following a three-dimensional approach (text, discursive practice and context) to make sense of the qualitative results of the survey. "In line with the CDA's explicit commitment to furthering social justice, most investigations start by identifying a social problem that has a discursive aspect" (n.p). As Weninger explains here, CDA is inductive, so it uses fundamentally qualitative research methods. The inductive logic means that CDA is not a research method that tests hypotheses. Instead, it aims to define ways of resisting or changing oppressive discourse practices. From this point of view, CDA is an appropriate choice to provide constructivist theoretical insights into the analysis of knowledge and power relations between women and medical professionals. The close reading of discourses explores the challenges of pain communication, thus explains the social aspects of

the diagnostic delay. The Feminist Critical Discourse Analysis further proves the governing societal gendered expectations.

The narrative analysis serves as a tool to analyse communication practices and determine the diagnostic barriers of endometriosis from the patients' perspective. The analysis is inductive with exploratory orientation and follows the thematic approach discovering themes and similarities between patients' responses and experiences. A particular focus is placed on the communicative relationship between medical professionals and patients by exploring the intervening relationship between dimensions of power, pain communication, and diagnosis processes. According to the Applied Thematic Analysis' instructions, codes were developed to represent the identified themes, and quantitative findings are presented in the discussion section in addition to the narrative analysis to confront the research problem (Guest et al., 2012).

4.2 INTERNET RESEARCH

"Depending on the role the internet plays in the qualitative research project or how it is conceptualised by researchers, different epistemological, logistical, and ethical considerations will come into play" (Markham, 2008, n.p.)

The study of communication barriers of endometriosis uses the internet as a tool to collect, sort, store, or analyse the gathered information. In this study, the internet is defined as a tool for managing information and contacting women and as a field site for observing interaction practices and norms among participants (Markham, 2008).

In terms of logistics, the internet allows me as a researcher to conduct a survey asking for women's opinion worldwide. It became handy given the current circumstances presented by the pandemic. Internet also facilitates the selection of the participants and adds valuable qualitative data that can present powerful evidence for advocacy purposes and decision making (Westerhaus, 2015). Multiple modes of communication via the internet operate on the users' sense-making practices (Markham, 2008), which justifies the application of critical discourse analysis and narrative inquiry.

4.3 INTERVIEW

"More knowledge about the experiences of gynaecologists when meeting with women with these symptoms might result in faster diagnosis, consequently leading to better care and an improvement in the women's quality of life" (Grundström et al., 2016, p. 65).

To explore the medical point of view of communication and other barriers of timely diagnosis in-depth, I contacted Dr Sue Ward, the Vice President for Education Royal College of Obstetricians and Gynaecologists. The Q&A interview was conducted via email. Dr Ward provided expert insights about diagnostic barriers, pain assessment, learning requirements concerning endometriosis in Gynaecologic Medical Education and Training and shared her professional opinion about adolescents' menstrual health literacy, gynaecologists' communication skills and pieces of training.

4.4 SURVEY

Due to diagnosis and unsatisfactory information complications, there is great frustration among women living with endometriosis. However, there is an increasing number of online support groups where participants share their personal experiences and provide recommendations which shows awareness and represents women as knowledgeable endometriosis patients.

The survey was posted on *Nancy's Nook Endometriosis Education* Facebook group. *Nancysnookendo* website and the social media group are created by Nancy Petersen, a retired nurse living with endometriosis. Her objective is to empower women with knowledge by providing up-to-date resources (journal articles and key facts on endometriosis, symptoms, treatment opportunities, guiding questions that patients can use in medical consultations and a list of experts).

The survey was developed by following Ball's guideline (2019), covering question validation based on previous studies, data gathering, processing, analysis and interpretation of the raw data. In addition, since the Degree Project studies diagnostic barriers from a communications perspective, the survey questions (Appendix 1) were developed to highlight endometriosis patients' communication difficulties, emphasising pain communication. The survey also included questions about

the beneficial qualities of online support groups. Within a two-week period, 262 women participated in the survey.

4.4.1 RECRUITMENT AND PROCEDURE

In addressing the research questions, a mixed-method Internet-based survey was applied. By devising the survey, securing anonymity and talking to different age groups of women to reach broader communication practices were considered priorities. The volunteer recruitment took place via Nancy's Nook Endometriosis Education Facebook group. The participants were directed to an online questionnaire created on SurveyMonkey.com. Most of the questions addressed in the analysis relate to pre-diagnosis experiences.

Half of the survey questions intended to quantitatively determine whether the participants found their communication and relationship with medical professionals challenging and whether their experiences and knowledge to be considered to address the diagnostic delay present in the data. Ultimately, the survey attempted to show whether the results authenticate or confirm earlier studies implying such challenges. The questions asked at this level explored:

- *their age;*
- *the length of diagnosis (if they have been diagnosed) and the duration of experiencing symptoms;*
- *how they educate themselves about endometriosis;*
- *whether the participants received sexual health education which included menstrual health;*
- *whether they found it challenging to discuss pain;*
- *whether they think tools for pain description would have been of help in early consultations;*
- *whether they felt disbelieved about the severity of their pain in early consultation with a general practitioner;*
- *whether their gynaecologist took into consideration their quality of life and their experiential knowledge during pre-diagnosis consultations;*
- *whether they think that the inclusion of this knowledge could improve the diagnostic delay.*

These answers were analysed by the application of descriptive statistics. Table one shows the proportion of negative and positive responses to some questions, providing a quantitative background to the qualitative thematic analysis.

Table I. Practices of medical consultations			
Quantitative results Q8, Q9, Q10			
N=262	Yes	No	Skipped
Experienced disbelief	109	15	138
Consideration of quality of life	59	180	23
Consideration of experiential knowledge	41	196	25

The other part of the survey questions also had an open-ended answer option that enquired into participants' view on diagnostic barriers, their expression of pain in medical consultations, their expectations from medical professionals to overcome the challenging pain communication and the advantages they believe online support groups offer. The comments were coded referring to diagnostic delay, communication challenges, and online support then categorised thematically. The thematic analysis revealed four themes such as medical knowledge, pain communication tools, desired communication support and experiential support, which includes the following subthemes:

- *Medical knowledge: [1] medical education, [2] dismissal, [3] prejudice, [4] inadequate care.*
- *Pain communication tools: [1] figurative language, [2] experience comparison, [3] factual characteristics of pain, [4] diary, [5] quality of life and [6] rating scales.*
- *Desired communication support: [1] patients' perspective questionnaire, [2] acknowledgement, [3] language and [4] taking the time.*
- *Experiential support: [1] togetherness, [2] validation, [3] sharing experiences, [4] education and [5] mental health.*

4.4 LIMITATIONS

This study builds on the growing literature on pain communication and diagnostic barriers of endometriosis and uniquely combines and reinforces its claims to explore how the integration of women's experiential knowledge could improve the

diagnostic delay. As this is a communication for development degree project, it cannot address the diagnostic delay from a medical perspective. However, thanks to the communication for development focus, the degree project demonstrates the potential to highlight communication barriers based on ideology and present solutions to these barriers by placing women at the centre of research.

4.5 ETHICAL CONSIDERATIONS

While the Degree Project studies women's experiences and the Facebook group's members are predominantly assigned female at birth, the survey's language was adjusted to be gender neutral to ensure it is inclusive for all members, including transgender individuals. During the analysis, "women" and "patients" are used without distinction.

Given the sensibility of the endometriosis, the survey gave the possibility of skipping questions to make sure participants do not feel uncomfortable.

V. RESULTS AND DISCUSSION

5.1 SURVEY RESULTS

The thematic analysis explores what challenges women face in medical consultations and how women navigate knowledge and power within medical interactions and online support groups by investigating what the competing discourses in contemporary health communication are, how endometriosis pain is conceptualised and can be optimised and finally, how digital platforms can correct incomplete and inaccurate medical knowledge. In addition, the analysis engages in the indications of communications perspectives for pain communication practices, especially in pre-diagnosis consultations, to potentially address the timely diagnosis.

5.1.1 MEDICAL KNOWLEDGE: BIASED DIAGNOSTIC BARRIERS

In order to gain more understanding of how the relationship of knowledge and power between patients and medical professionals affect pain communication and consequently the diagnosis of endometriosis, I revealed medical knowledge

as a primary thematic category. I further divided medical knowledge into subcategories: medical education and inadequate care, which affects the diagnosis at the medical level and results in *dismissal and prejudice* at the patients' level.

Thematic categorization of responses Q5			
N=43	N	%	Sample answers
Medical knowledge (including concerns over medical professionals' knowledge, education, awareness, ability to operate, medical research as well as to lack of collaboration within different medical field)	18	42%	<i>"Medical professionals not wanting to make a diagnosis because they are not comfortable with the treatment that comes with it (excision)."</i>
Inadequate care (treating symptoms rather than diagnose, overusing birth control and lack of accurate information provided)	10	23%	<i>"I have been told that I likely have endo but the only treatment is birth control."</i>
Dismissal (concerns over the dismissal of symptoms, normalization of pain and " <u>gaslighting</u> " patients)	8	19%	<i>"When I started having symptoms I didn't know what it was and when I talked to my doctor they just blew it off until my symptoms became more severe and had difficulty conceiving."</i>
Prejudice (concerns over medical view on patient's lifestyle choices, age, gender and race)	7	16%	<i>"I also had trouble seeing a doctor because I was so young. My mom couldn't get an obgyn to agree to see me."</i>

Similar to the quantitative findings, these thematic categories highlight androcentric medical biases and the social power of medical knowledge.

Quantitative results Q5		
N=262	N	%
Dismissal of symptoms and/or normalization of pain	232	89%
Insufficient medical knowledge of the disease and its mechanism	197	75%
Lack of awareness among medical professionals	193	74%
Insufficient menstrual health education and lack of public awareness	125	48%
Exclusion of patients' experiential knowledge	103	39%
Limited consultation time	45	17%
Skipped	10	4%

Many participants identified concerns about gynaecologists' knowledge, ability to operate and willingness to collaborate within different medical fields. In terms of *education*, women think that their doctor's knowledge is defined by medical research and their curricula, but they also established a direct link between knowledge and patriarchal influences of Medicine itself. For example: "Paternalism in medicine combined with lack of research and education for medical personnel". According to Dr Ward, [in the UK] RCOG has many resources related to endometriosis such as pelvic pain and its causes, guidelines, special library resources; however, the number of pelvic pain clinics with multidisciplinary experts is far from ideal. At the same time, Dr Ward highlighted that the diagnostic delay is due to lack of referral in the first place rather than gynaecologists' lack of knowledge. While both Dr Ward and the women observe an insufficient number of experts in the field, the obstacle of understanding symptoms for diagnosis was only seen in the patients' account. In opposition to Dr Ward's point of view, this account correlates with the finding of a previous study claiming that the dependence of medical professionals' knowledge, skills and interest in the condition impact the length of diagnosis (Zhang et al., 2020). The lack of these could result in women losing trust in Medicine and turning to their peer's knowledge. For example:

"My first OBGYN was the same OBGYN that my Mom, Aunt, and Grandmother all went to. We had a high level of trust in her skill and knowledge. During my first appointment my Mom told her that she thought I had some endometriosis (because my cramps were so terrible). The doctor replied "that's probably true" and that was the entire discussion. It was so easily dismissed that I never thought to research it, look for treatments, and I certainly didn't understand the impact to my reproductive system. It wasn't until my sisterinlaw told me last year that she was having excision surgery for her endometriosis that I started to understand that there was a treatment and medical professionals who can help."

This response demonstrates the unbalanced interaction dynamics between patient and provider. "The exchange of information is driven by institutional agendas" (Menz, 2010, p.) as the gynaecologist confirms the possibility of endometriosis but does not provide any further information, thus eventually delimits the patient's participation and opportunity to pose further questions. Thus, the emphasis is placed more on gynaecologists' authoritative attitude and communication competencies than their knowledge.

Many participants claimed that gynaecologists are reluctant over the laparoscopy procedure, even though it is the only definite diagnosis method. One patient notes that: "Many physicians likely want to avoid surgery for diagnostic purposes and wait until there is more to do (e.g. Cyst removal) and then the diagnosis comes secondary". Dr Ward's statement confirmed the participants' claim: "General gynaecologists all do a lot of laparoscopies with normal findings in older women [...], most gynaecologists use MRI for diagnosis if deep endometriosis is suspected". Given the interplay of the facts that two out of three women with endometriosis noticed symptoms before age 18 (Endometriosis.net, 2018) and MRI often does not show visible results, inadequate care is identified as another significant diagnostic barrier flagged by many women.

In terms of care, women also recalled doctors' desire "to treat with medication without pursuing diagnosis" and overusing contraceptives: "I was told that I likely have endo, but the only treatment is birth control". The lack of information provided about treatments options contributes to *inadequate care*, which was also highlighted as a diagnostic complication in the mentioned WHAPPG report. Women's claim about gynaecologists' preference of hormonal treatment over laparoscopy sees oppression over women's bodies: "Insurance companies forcing to try multiple birth control pills as if they would fix all your issues without even considering surgery". This last statement is not just a reaction against medical mismanagement but also suggests a profitable interaction between insurance companies, the pharmaceutical industry and the medical field. It is an important connection that places profit over adequate care; however, there is limited research discussing this relation.

Women's desire for better collaboration between different specialities also constituted a recurring factor, and generally, the absence of this cooperation. For example, participants noted that "disease affects multiple organ systems, crosses specialities and specialists don't collaborate" and "Every doctor has his own island. They don't look any further. If I didn't search myself, I still wasn't aware of endo". As diagnosis is a turning point, medical professionals' unwillingness to collaborate with other specialities could delay the diagnosis.

The implications of *medical education* and *inadequate care* can be defined with *dismissal* and *prejudice*, seen as significant diagnostic barriers by many participants. Responses demonstrated concerns over lifestyle choices, gender and age seen as medical biases of broader societal discourses about gender. Sen's framework of the role of gender as social determinants of health is applicable here. The consideration of gender as social determinants of health explains how much women's suffering from endometriosis is due to female biology and how much can be attributed to women's lack of power and access. Women do not receive the care they need due to gendered biases: "medical professionals labels women as 'hysterical'" or lifestyle choices: "Gynaecologist kept telling me to 'just lose weight". The feminist social constructivist approach yet offers proofs that gendered biases are based on stereotypical behaviours which are socially constructed. The word hysterical is a recurring sociohistorical construction of women bodies that prefers psychogenic over biological explanation of symptoms. In the second quote, instead of considering other societal factors, "the moralising discourse" is focused on "individual failure". (Young et al., 2019). This also suggests that the connection between endometriosis and delayed pregnancy is continuously presented to explain the disease's development.

Participants also identified "gaslighting patients" as a recurring phenomenon in medical consultations. One participant noted: "Gaslighting patient pain and other symptoms. Doing things such as offer ultimatum treatment choices, and dismissing patients from the practice when there is no improvement." Another woman recalled: "When I started having symptoms, I didn't know what it was and when I talked to my doctor, they just blew it off until my symptoms became more severe and had difficulty conceiving". Along with the normalisation of pain at the medical level, responses revealed the normalisation at the individual level. For instance, participants wrote:

"The acceptance that symptoms were normal but I never got them checked"

"I actually never really said how bad it was because I was always told I was very weak and I didn't want to appear weaker."

The women's responses above illuminate both DPA and DBN discourses. Women feel that their suffering is naturalised and their symptoms considered "just

part of being a woman" (DBN). At the same time, some women do not even mention their pain to avoid being seen as weak (DPA). If the barely tolerable physical pain would not be enough - those affected still suffer because doctors do not seem to examine them thoroughly and do not understand what it means to live in constant pain.

In the case of young patients, the two thematic subcategories closely intervene. According to several participants, they have been dismissed as well as experienced disbelief due to their age. For example: "Doctors are not believing younger people and saying things like 'you're too young". When I asked Dr Ward about the diagnostic barriers, she agreed with the barriers I defined but stressed that it is difficult to unpick. However, she highlighted one reason:

"One of the issues is possibly that it used to be taught that endometriosis was a problem affecting women in their 30s and 40s whereas it is becoming more obvious that is not the case. Even on the NHS website page on period pain, it says that "period pain linked to an underlying medical condition tends to affect older women. Women aged 30 to 45 are most affected."

The fact that gynaecologists do not have up-to-date knowledge about the impacted age group and a national health care organisation links period pain to older women further highlight medical bias over age. It also recalls the historical representation of endometriosis (career women disease) even though it is well-established today that endometriosis can affect women at any age. The quantitative survey results also reinforce this claim as 51.52% of participants are under 35 years old. It is worth to note that this percentage is likely even higher as nearly half of the participants waited more than eight years to get diagnosed.

In conclusion, medical knowledge is the first thematic category, demonstrated the recurring paradox of DPA and DBN discourses which recalled the constant presence of the traditional authoritative medical discourse. The competing discourses in pre-diagnosis consultations show the necessity of multilevel interventions: at the medical level, there is a need for the willingness of the profession to train more surgical specialists and improve interpersonal communication competencies. At the patients' level, women need a more comprehensive menstrual education to be better equipped against the normalisation of pain. As Rubinsky concludes:

"Communication is the vehicle through which women learn what menstruation is, make sense of the meaning of menstruation for themselves and other people who menstruate, and form attitudes about menstruation. [...] Thus, the way we communicatively socialise women and girls into menstruation has lasting effects on their personal well-being and sexual health" (Rubinsky et al., 2020, p. 242).

5.1.1.2 PAIN COMMUNICATION

"The description of pain is a central diagnostic tool used to distinguish severe from less harmful complaints and thus to assess the necessity of (life-saving) measures, verbal representation plays a central role that is not to be underestimated" (Menz, 2010, p.10).

Medical professionals could have different views regarding what is normal pain. Furthermore, the description of pain is based on numerous distinct patterns. Measuring pain is subjective. The way pain is described and how descriptions are interpreted varies significantly between patients and medical professionals. At the same time, the role of in-person patient-provider communication is often marginalised, while diagnoses are formed through dialogic interactions. In the following two sections, I discover the ways women communicate about pain, then their desired communication support to overcome the challenges of pain communication.

While the question (How do you describe and discuss pain in medical consultations?) only asked about how participants discuss pain in medical consultations, 25% of the analysed responses expressed concerns over *dismissal* and *prejudice* as biased diagnostic barriers related to pain assessment. Similar to previous studies, the overall lack of communication about pain results in delayed diagnosis. Consequently, it is necessary to understand what is considered normal period pain and what endo-pain is (dysmenorrhea, deep dyspareunia, and non-menstrual chronic pelvic pain) to advance diagnosis. Alike, the qualitative categorisation of responses reports the necessity of a better comprehension of endometriosis-related pain to help women discuss such symptoms and help medical professionals interpret and assess pain.

Table IV. Pain communication tools identified			
Thematic categorization of responses Q12			
N=39	N	%	Sample answers
Illustrative language (figurative language, metaphors, cause-effect sensation)	9	23	<i>"Usage of specific pain related terms (throbbing, radiating, pulsing, stabbing, sharp, aching)."</i>
Factual characteristics of pain (Pain location, type, frequency, duration and required quantity of pain communication)	6	15	<i>"How much pain medication is required to get through a day"</i>
Quality of life (impacts on quality of life)	4	10	<i>"Explaining associated symptoms and effect on my wellbeing, lifestyle and daily routine."</i>
Experience comparison (pain and effectivity of medication over the years)	3	8	<i>After having a caesarean section I compare it to the 3rd day post op pain. That's exactly what my cramps feel like during menstruation.</i>
Diary (pain or other diaries)	3	8	<i>"I kept a diary with the pain levels, symptoms and severity."</i>
Physical representation	3	8	<i>"Allow us to show them the pain by squeezing their hand or something."</i>
Rating scale	1	3	<i>"I can function pretty fully at level 4. I am pretty incapacitated by level 7. "</i>
Recurring thematic categories:			
Dismissal	4	10	
Prejudice	4	10	
Medical knowledge	2	5	

Metaphors and other forms of illustration may be used for resources in information exchange between experts and laypersons. From the endometriosis patient's perspective, these are employed to illustrate the experience of pain that is otherwise difficult to express (Metz, 2010). However, Semino (2010) points out that chronic pain due to its abstract nature makes it difficult to explain using concrete and literal language. In pain communication, not only the subjectivity of pain experience poses a potential obstacle, but also the interpretation of the message by doctors because "codes and contextual and socio-interactional elements regulate, and constrain the interaction, hence potentially confounding successful

communication" (Jacobson, 1960, in Bullo, 2020, p.480). A study further highlights the discrepancies concerning the sensorial and narrative description of the pain, as these descriptions by clinicians were incomplete compared to descriptions by patients. In this survey, many women noted that they use *illustrative language* to describe pain; however, *illustrative language* often results in *dismissal*. Participants wrote:

"I felt as though I had to be extremely careful describing my pain as it often seemed they dismissed me as drug seeking."

"Tried so many ways to describe not just pain, but the wider symptoms. Doctors were very unwilling to listen to the range. Told multiple times that fatigue and nausea had nothing to do with gynaecological issues, that period pain was normal. Especially upsetting was the persistent questions about my partner and suggestion that he was abusive because they assumed my varied symptoms were in my head."

In addition to dismissal, stereotypical biases come to the foreground. While the first quote recalls two thematic categories of medical knowledge of diagnostic barriers, the second example represents the paradox of DBN and DPA discourse. Doctors normalise the participant's pain and, at the same time, totally disqualifies the suffering. As if endometriosis does not cause enough suffering on its own, patients typically have to go from doctor to doctor for many years, undergo unpleasant consultations and sometimes painful examinations to find out the cause of their constant pain.

While additional studies are needed to confirm the dimensionality and optimal scoring, Deal et al. (2010) demonstrate the reliability and validity of the potential use of electronic Endometriosis Pain and Bleeding Diary (EPBD). Participants also identified different diaries (e.g. daily pain or physical therapy), the description of factual characteristics, the comparison of prior pain experiences and the explanation of the loss of quality of life as essential tools of pain communication. While according to Dr Ward, "taking a full pain history would be part of the routine initial consultation", many women noted the lack of assessment of their quality of life (69%) and experienced disbelief (42%) over the severity of their pain. Similarly to previous findings, the survey results indicate the prerequisite of "a fully-comprehensive description of the painful symptoms of endometriosis as a whole in a subjective, phenomenological perspective" and suggests "the expansion of the

common concept of severe dysmenorrhoea based on clinical input" (Fauconnier et al., 2013, p. 2691).

Interestingly, an unusual theme also emerged as a *physical or audio-visual representation of pain*:

"I've recorded myself at times of high pain events. And tried to show doctors."

"List of symptoms with descriptions in metaphors and if they would allow it, show them by pressing their body"

The fact itself that women have such "radical" ideas to make doctor believe what they are going through demonstrates the "epistemological purgatory" of endometriosis defined by Barker (2002 in Whelan, 2007).

According to Dr Ward, "most doctors use a scale of 1 to 10 to assess severity when asking patients about pain as well as the effect on daily life and activities". Likewise, in a systematic review, Bourdel et al. (2014) analysed and identified the most accurate pain scales used in endometriosis pain treatment. Visual analogue scale (VAS) & Numerical rating scale (NRS) are most widely used in a general measure of endometriosis-related pain. At the same time, the authors also highlight the importance of evaluating Quality of Life (QOL) as the inclusion of patients' point of view.

However, considering patients' perspective, there is no fully validated instrument currently available to assess pain (Deal et al., 2010) which is well-presented in the responses since the *rating scale* was mentioned only by one participant. However, even in this case, the rating scale was connected to her *quality of life*. This correlates with the quantitative findings. Furthermore, while rating scale was used by 50% of the participants, metaphors, figurative language and cause-effect sensation was applied by 75% of the participants. Thus the combination of different tools may result in a faster diagnosis.

Table V. Pain communication tools		
Quantitative results Q12		
N=262	N	%
Metaphors, figurative language, cause-effect sensation	196	75%
Daily pain diary	130	50%
Rating scale	34	13%
Skipped	24	9%

Studies suggest the reliance on assessment tools using the wording and phrases of pain or metaphor identification (figurative language, metonymy and cause-effect sensation) like an integrated toolbox where different types of metaphors are mapped for different types of pain and endometriosis pain mechanism. For instance, Ballard et al. (2010) showed that although women with endometriosis commonly used pain descriptors such as "dull ache", "sharp", or "stabbing", these terms are also frequently used by women with apparently normal pelvis. Only three pain descriptors, "gnawing", "dragging pain to the legs" and "throbbing" were reported more frequently by women with endometriosis. Thus, patients could use illustrate narratives of pain that otherwise would be difficult to describe. Of course, these dimensions of pain on their own are not solid indicators of endometriosis, but they could be helpful to contribute towards the diagnosis or at least further necessary medical interventions. Without a doubt, further research needs to be done considering other clinical data involving the knowledge of experts and practising gynaecologists.

The pain description as the second thematic category revealed the lack of consensus of ideal pain assessment. The results also showed women's demand for a more patient-centred endometriosis care that adjusts pain assessment to the patient's values, circumstances and communication practices. Both indicate steps to be taken at the medical level. In the next section, I discuss the absence of such care and the desired communication support defined by the participants.

5.1.3 DESIRED COMMUNICATION SUPPORT

Concerning the necessity to improve gynaecologists' communication competencies, according to Dr Ward, there is plenty of communication training already in place for doctors (in the United Kingdom), such as training on communication

skills across every curriculum, both in medical and postgraduate schools. In addition, junior doctors at all levels are constantly assessed on their communication skills within the workplace-based assessments. "For example, it is mandatory for me to have passed an intensive three-day training course on communication skills in order to look after patients with cancer". Even though probably not all medical intuitions have comprehensive communication training similar to RCOG's, it is essential to note that medical fields include communication training. However, the situation is more complicated when it comes to communication.

N=33	N	%	Sample answers
Acknowledgement (trust, respect, empathy, acceptance of patients' knowledge, consideration of mental health)	8	24%	<i>"If doctors understood the pain and effect this has on our life maybe we could get some urgency."</i>
Patients' perspective	3	9%	<i>"Seek active feedback from patients, possibly in an anonymous survey or similar beyond the consultation."</i>
Language barriers (medical jargon, foreign language)	2	6%	<i>"Offer other ways of explaining in case the patient doesn't understand what the professional is saying or vice versa."</i>
Time	2	6%	<i>"Longer consult times."</i>
Recurring thematic categories			
Medical education	11	33%	
Dismissal	3	9%	
Inadequate care	2	6%	
Prejudice	2	6%	

Many women claimed that the improvement of medical knowledge and awareness would be the most significant help to overcome communication challenges, which is displayed in both qualitative (24% and 33%) and quantitative results (83%).

Table VII. Desired communication support		
Quantitative results Q14		
N=262	N	%
Improve medical knowledge and awareness	217	83%
Listen and empathize	175	67%
Guide the patient through questions or ask more specific questions	170	65%
Provide tools for symptoms and pain description	153	58%
Skipped	24	9%

Women believe that doctors "should be willing to refer you to another doctor if they lack knowledge of endometriosis", "should considering endometriosis as a primary disease rather than all other diseases as the primary" and "should be more aware that endometriosis has a variety of presentations and type of symptoms". Thus, *inadequate care* was also recurring topics concerning (lack of) communication support. One participant perfectly concludes the women's point of view:

"I think the medical professionals must change first. For too long it has been the patient's responsibility to communicate their disease because not enough doctors understand endo, we really need to better educate the medical profession so that they can diagnose us and provide us with proper treatment information."

Women would like medical professionals to realise that patients are not the only participants of diagnostic processes. They believe that doctors should also engage in discursive sense-making practices (Antonio et al. 2010) to improve the diagnostic delay.

Some women flagged useful questionnaires that are designed to take patient-based perception of symptoms into account. Women's experiential knowledge can help develop such questionnaires, and there are actually great efforts in this direction. Dr Ward highlighted that at the RCOG [Women's Network], they have extensive involvement in their endeavours from a group of women who participate in every aspect of their work, including committees and examinations. "We firmly believe in the value of public engagement". Unfortunately, this is not always the case. The data presented shows that nearly half of women experienced the lack of inclusion of their experiential knowledge (75%) during pre-diagnosis consultation.

Acknowledging patient by the simple act of believing and listening to them was defined as significant support. 67% of the participants chose "listen and empathise" as desired communication support in quantitative results. The qualitative findings showed the same results: women with endometriosis have diverse needs and symptoms, they require a high level of responsiveness and understanding of the broader situation. They need their symptoms to be acknowledged and being listened to through supportive consultations based on trust. For instance, one participant highlighted the absence of this *acknowledgement* with regards to mental health:

"I fully accept that mental health and physical health are intertwined. However, I find doctors are too keen to put any symptoms reported down to mental health rather than run any physical tests or investigations. Mental health issues will often be a symptom rather than a cause and physical symptoms should not be ignored".

Here, the participant acknowledges that psychological dysfunctions can arise from endometriosis but simultaneously emphasise that psychological dysfunctions are the results rather than the roots of the problem. Hence, according to some participants, endometriosis presents "not merely physical but also mental exhaustion". It takes years to rush from doctor to doctor, women along with their family members and loved ones, sometimes question themselves whether there is really an organic cause behind their symptoms which can be stressful.

Although only a few women experienced *language* barriers due to medical jargon, it is worth highlighting. The language used by health care providers constructs power structures within Medicine and has significant implications for women with endometriosis regardless of whether these constructions endorse or challenge historical dis-courses (Young et al., 2019). For example:

"Don't cut me off or tell me I can't use medical terms."

"Nobody seems to listen and if you get too technical you get reprimanded for using medical terms".

These examples reveal how Medicine maintains the authoritative knowledge, as Lupton defines "the voice of scientific expertise over a deferential patient"

(Lupton, 1994) and how this authoritative ideology elucidates the relationship between patients and providers. Reisiigl (2013) argues that representation of pain has been established from a medical point of view, and it can be difficult for patients to stick to these medical categories that lack basic pain expressions. Sociolinguistics studies showed that women tend to employ semantically rich components when referring to pain which corresponds less to doctors' expectations (Menz, 2010).

Along with the concluding results of the previous section, the thematic analysis once again determined requirements at the medical level focusing on the communication competencies. The exchange of medical information between doctors and patients is mainly carried out through question-response sequences. Openings of the conversation and specific standard phrases and expressions in pre-diagnosis consultations could define and delimit a frame for patients' responses, thus potentially restricting "their room for manoeuvring" (Menz, 2010).

5.1.4 EXPERIENTIAL SUPPORT

With the advances of digital technologies, the field of development has been altered and presented a fundamental shift in the public consciousness. Today digital communication is a vital component of health communication bringing new opportunities for social media. The technological developments in how we communicate about health and illness have provided women living with endometriosis new opportunities to seek support that may benefit them. Countless social media groups are providing emotional and informational support for women with endometriosis. However, negative aspects need to be addressed to maximise the potential benefit of online support groups, such as clearer privacy policies or moderation of content by health professionals. As one participant highlighted:

"Online support groups can be helpful or detrimental. I think it may be difficult for patients without a scientific or research background to recognise reliable sources. There is a lot of misinformation available online as well as companies seeking to exploit the desperation of people who have been failed by the system. Educational materials on how to evaluate a source is an important inclusion on any online forum that seeks to provide support".

For this specific reason, I chose Nancy's Nook Endometriosis Education Facebook group to share the survey as the platform provides verified resources and

moderates posts by professionals to avoid the spread of misinformation. Accordingly, the thematic analysis of responses concerning the benefit of such an online support group contributes to understanding how digital platforms may correct incomplete and inaccurate public and medical knowledge.

Table VIII. Experiential support			
Thematic categorization of responses Q16			
N=30	N	%	Sample answer
Validation	9	30%	"True stories and experiences that vary... indicating the often diverse symptoms of the disease."
Education (menstrual health, disease management, evaluation of resources, reviews on doctors)	9	30%	"Educational materials on how to evaluate a source is an important inclusion on any online forum that seeks to provide support."
Togetherness	8	27%	"Find others who understand from experience."
Mental health support	4	13%	"Others believe and understand the pain you are in. And do not make you feel like it's all in your head. "

Validation from other women is deemed important as there is an absence of such validation in medical encounters. In addition, the uncertainty of medical information, the socially established authority of medical professionals and the profiting of pharma companies further increase women's desire for validation "to convince others that their suffering is real and their assumption of the sick role is valid" (Whelan, 2007, p. 967). For example:

"It helped to be validated to say "I'm experiencing this, could this be a symptom of my endo?" And have others say yes they experience similar symptoms helps make you feel less crazy and less alone."

"Others believe and understand the pain you are in. And do not make you feel like it's all in your head."

To this extent, what does make stories shared by other women so valuable? Digital media can offer unparalleled opportunities to connect with others, sharing experiences, telling illness narratives which enables one to attain a feeling of normalcy that has been questioned (Melander, 2019). Validation serves women's

critique over the authoritative medical knowledge and establishes the experience of endometriosis as valuable knowledge.

The importance of validation highlights *togetherness*, which is an equally significant benefit according to the participating women. One participant noted: “To know I’m not crazy since there are so many other women suffering through and describing what I am going through”. Thanks to the social support of the platform, women can share and compare their everyday experiences without biased medical prejudice, and ultimately, provide them with the emotional support which is often absent in medical consultations. The quote demonstrates how validation and togetherness recall a third thematic category, mental health support. This category can be seen as a counter-narrative against the scientific framing of women as naturally irrational and hysterical.

Many women also highlighted their desire for *education*. The provided education can be further divided into two main categories: self-learning and self-advocacy, giving insight into how these resources are put in use. Self-learning gives information support regarding menstruation health, disease management and treatment options. Thus, self-education is an integral part of this platform to justify unexplained symptoms (by medical professionals) and evaluates previous medical statements. One participant wrote: “Nancy’s Nook is a wealth of information and helped me realize the extent to which endo can affect your body.” Self-learning has the potential to break social expectation about knowledge. Education does not only challenges the historical positioning of patient-provider roles in medical encounters, but it also arms women with knowledge; thus, they become capable of fighting their health and reproductive rights. The educational aspect of this social media group an excellent example of the DRE discourse as it empowers marginalised voices via (often web-based) endo-related activism (Krebs et al., 2020).

On the other hand, self-advocacy materials empower women to learn about the condition and present themselves as knowledgeable during interactions with medical professionals (Wilson, 2020). As one participant noted: “online patient advocacy groups have been a valuable source of information allowing me to advocate for myself”. While this particular platform does not allow doctors’ review,

it does provide a list of endometriosis surgeons, which also serves self-advocacy purposes. All doctors listed on [iCareBetter](#) have gone through a rigorous peer to peer review process (Nancynookendo, n.d.), enabling patients to use according to specific skills and needs.

The quantitative findings correspond with the qualitative findings outlined above. For example, medical sources are rather consulted than used, online published medical research, online learning platforms and support groups were found more reliable than doctors.

Table IX. Experiential support		
Quantitative results Q16		
N=262	N	%
Present self-advocacy and self-learning opportunities	199	76%
Indicate a better understanding of the reality behind the disease	179	68%
Provide mental support	151	58%
Correct incomplete and inaccurate public and medical knowledge	135	52%
Skipped	26	10%

Table X. Sources of education		
Quantitative results Q15		
N=262	N	%
Medical consultations	66	25%
Online learning platforms	222	85%
Online support groups	190	73%
Skipped	24	9%

Through the analysis, it becomes evident that the incorporation of both experiential and medical knowledge is the main advantage of social media support groups. The strength of these groups lies behind the importance of mutual understanding. While women can have a different endometriosis experience, there is no communication challenge over language and interpretation.

However, as several participants have flagged it, it is worth noting that regardless of women taking over epistemological standards, their knowledge is regularly excluded in medical consultations due to constraints of the biomedical system.

“Using the standards of the medical establishment against the members of that establishment may be a clever strategic move, but the irony is obvious: endometriosis patients’ experiential accounts have been judged invalid in biomedicine because they are not scientific, but these patients deem clinicians’ experiential accounts invalid because they are not scientific” (Whelan, 2007, p.969).

Therefore, if it is not scientifically proved, why women’s experiential knowledge should be included in the diagnostic processes?

5.2 DISCUSSION OF THE RESULTS

The fact that there are not enough specialists who have the necessary surgical skills remains the main reason behind the diagnostic delay. However, the communication perspective demonstrated that the special surgical skill is not the sole defining factor. Through the feminist framework, the analysis of diagnostic processes and challenges of pain communication built on the consideration of gender as social determinants of health (Sen et al., 2008). By placing a special focus on gender, the implications of language came to the foreground: responses revealed that language used by medical professional defines the length of diagnosis by limiting women’s opportunity to learn about endometriosis and seek further medical care. This correlates with earlier findings of Young’s studies (2019, 2020), suggesting that due to the authoritative ideology of Medicine, the power structures constructed by health care providers endorse historical discourses (i.e. hysteria, DBN and DPA discourses).

At the same time, women are gaining embodied knowledge and encouraging each other through their experiences and online platforms. This act of empowerment calls upon the emerging DRE discourse (Krebs et al., 2020), which presents the potential to challenge the historical discourses. Regardless these historical discourses are endorsed or challenged; the feminist theoretical framework explored that endometriosis narratives have a hegemonic ideological origin at the societal level (Mills, 2011): gendered assumptions are shared through language (Bullo, 2020), and the lack of informational and emotional support is often outlined by biased gendered labelling, dismissal and normalisation of pain (at the medical and personal level). Similarly to earlier studies (Krebs, 2020; Lupton, 2012;

Whelan, 2009; Carsten, 2017), these findings underline the role of ideology as a communication barrier of timely diagnosis.

The survey demonstrated that the presence of traditional medical, hysteria, DPA and DBN discourses are apparent and, accordingly, suggested communicative reasons behind the diagnostic delay: Medical education, dismissal and normalisation, prejudice and inadequate care were recurring themes throughout all four thematic categories, which gives a deeper understanding of how patriarchal ideologies impact interactions between women and medical professionals, and consequently pain communication.

When I asked women how they describe and discuss pain in medical consultations, the responses showed a lack of consensus of ideal pain assessment. In terms of communication of tools, illustrative language was by far mostly used. However, it often results in dismissal or miscommunication. While most doctors use a scale of 1 to 10 to assess severity, most women (75%) use figurative language, metaphors and cause-effect sensation to describe pain. Such discrepancy in pain communication proves the necessity of the optimization of pain description in medical consultations. Previous studies already showed the significance of communication between patient and provider (Geist et al., 1993; Krebs et al., 2020; Foucault, 2003). Similarly, 70% of participating women found communicating pain challenging and 79% believed that tools for pain description (e.g. descriptive terminology, charts, anatomy images) would have been of help in early consultations.

The responses also showed that women demand more patient-centred endometriosis care. Considering the enigmatic nature of endometriosis, the assessment of pain, which is not observable, is only possible through discursive sense-making practices that reinforce the importance of interaction and negotiation defined as a critical factor of best practice by Whelan (2009). The main symptom of endometriosis is extreme pain, which occurs most (but not only) during menstruation. For this reason, pain assessment is key to achieve the turning point, which is the diagnosis. Effective pain assessment of endometriosis builds on the acknowledgement of women's account. Such effective pain assessment can speed up the diagnostic processes. At the same time, many women face that

their pain is trivialised by others, even by medical professionals. This delays the recognition of the real problem and women are forced to listen that menstruation “hurts everyone a bit”, “it is such a thing”, “to pull themselves together”, “not to over-dramatize the situation”, “not to stand out”.

As the emerging DRE discourse or a counter-narrative of authoritative medical knowledge, the analysis demonstrates the valuable knowledge created thanks to women’s experiences and the usefulness of online support groups in empowering women. Aligned with Melander’s claim that social media can increase the understanding of the reality behind the disease (2019), the responses provided evidence that social media could amplify marginalised voices in the public domain, correct incomplete and inaccurate public knowledge and guide more inclusive policy-making practices. Nancy Nook endometriosis Facebook support is an excellent example of epistemological communities (Nelson, 1993). It challenges medical ideology and develops patient-centred knowledge claims, ultimately creating opportunities to change endometriosis care by empowering women. The study of this particular support group confirmed Krebs’ account of social media (2020): it contributed to determining communication barriers of timely diagnosis, emphasised the power of social activism through empowerment and offered a unique entry point for endometriosis advocacy efforts.

In addition, the examination of online support groups through a feminist communication lens illuminated the potential of collaborative work between women, medical and communication professionals. The already overloaded medical professional could gain advantage of communication research that incorporates the study of online endometriosis activism – as part of contemporary health communication – and women’s perspective – as the key factor of patient-centred care.

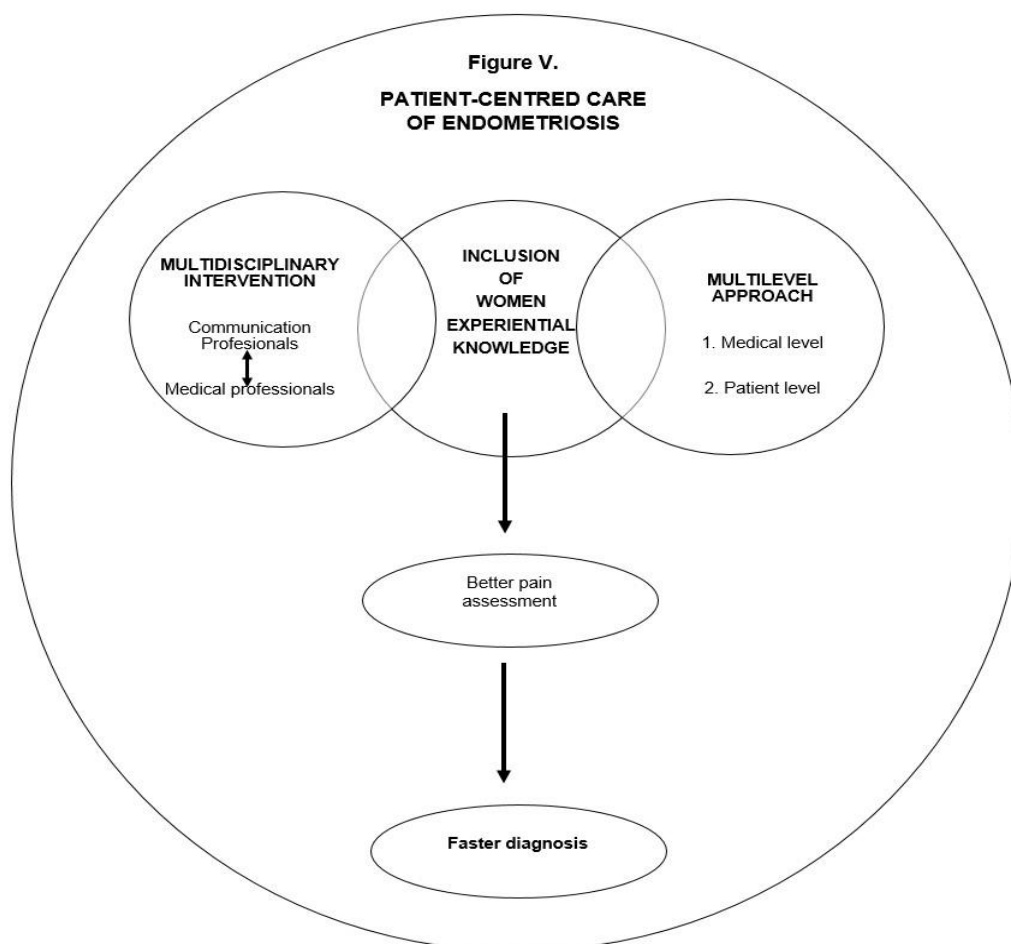
The survey results demonstrated that the relationship of knowledge and power between health care providers and women influence the length of diagnosis due to the pain communication challenges in medical consultations. While the physical and audio-visual representation of pain was used only by a few participants, the account of “allow us to show them the pain by squeezing their hand” perfectly demonstrates the “impossibility” of pain communication due to the “epistemological purgatory” of endometriosis (Baker, 2002). Although language has the power

to facilitate understanding and the empathy of the listener as well as to ease the challenges of pain communication of the patients (Bullo and Hearn, 2021), women claim that health care is not fully prepared for reproductive health's complexities, covering all of its aspects. The quality of treatment and the level of funding is not in line with the proportion of patients. It is partly because several countries lack a uniform treatment protocol and there are no reliable statistics on the global scale. Yet a patient-centred approach to treating the disease can increase patients' and providers' willingness to cooperate, reduce the number of complaints, prevent the excessive use of health resources and contribute towards timely diagnosis.

Regarding how pain communication could be optimised to achieve a better diagnosis, the results indicated the inclusion of women's experiential knowledge as the basis of the solution. The inclusion would provide medical professionals with the necessary skillset based on appropriate philosophy to address women's diverse needs, even if they are not qualified or comfortable enough to do the diagnostic surgery. In this case, incorporating women's knowledge could lead to better collaboration between different medical fields and shift the profession's attention from women's reproductive bodies to their experiences. Such incorporation includes taking into consideration physical and mental aspects of pain as well as the impact on quality of life during frequent medical consultations. This would be the key for patient-centred care, based on the legitimization of women's experiences.

VI. CONCLUSION

The Degree Project demonstrated the need for a multilevel approach to improving the diagnostic delay of endometriosis that starts with establishing appropriate menstrual health education from a young age at the patient level and based on the inclusion of women's experiential knowledge at the medical level. Moreover, the findings draw attention to the necessity of multidisciplinary interventions through collaborative work between communication professionals, social linguistics, medical professionals and women (Figure IV.).



The discrepancy of pain communication between women and health care providers revealed the potential benefit of adding a communication perspective to the study of diagnostic processes. Through this lens, the Degree Project highlighted biased communication practices and communicative barriers to effective, timely and respectful medical care and concurrently put the emphasis on societal aspects in addressing the diagnostic delay. Furthermore, it illuminated the need to

develop a pain communication tools box, a shared codebook by women and medical professionals, including figurative language, metaphors and cause-effect sensations, which could be used along with the rating scale and the assessment of the quality of life during pre-diagnosis consultations.

While a practical pain communication toolbox is necessary, how would its implementation be possible if the contact is not established in the first place? For this reason, the Degree Project suggests that pain assessment should start with the legitimization of a woman's pain through listening and guided questioning. As the results showed, within desired communication support, the acknowledgement was outstandingly the most accentuated. Consequently, this study indicates that medical professionals could help women overcome pain communication challenges by acknowledging women's symptoms and pain instead of biased labeling due to gender, age or lifestyle choices.

Change does not happen from one day to another, especially if the societal construction of gender is in the equation. "Medicine has gained the social currency of knowing the 'truth' about the body; patients' knowledge of their own bodies has historically been valued in medical encounter, being viewed as subjective and inferior. [...] Female patients are further devaluated because women's embodied knowledge is secondary to the androcentric Western medical canon" (Young et al., 2020, p.). Therefore, the Degree Project advocates for the applications of a second pillar of the multilevel intervention, women's empowerment by the agency of education and awareness-raising as building blocks of communication of development.

As findings showed, most women did not receive menstrual health education that includes the abnormal parameters of period and have experienced symptoms over eight years before achieving diagnosis, if they achieved. This result demonstrates that the normalisation of pain often occurs also at the individual level, and women lack both informational and emotional support since puberty. Unfortunately, menstruation remains repeatedly a stigmatized social experience impaired with psychological and emotional misery. Hence, instead of normalising pain, menstruation should be normalised as a common experience by initiating supportive communication practices. Appropriate menstrual health education at

school should be prioritized, and young women should be encouraged to talk about period and seek medical advice when it is necessary. The analysis revealed that stigmatization and health-related taboos result from lack of presentation, misinformation, and indoctrinated beliefs. Thus, educational strategies and raising awareness that target not only adolescents are indispensable to achieve better health outcomes.

Along with the strategies mentioned above, the thematic analysis affirmed the valuable role of popular informational sources, such as social media support groups. Women defined validation, togetherness and mental health support as crucial advantages. Most of them also expressed desire for self-learning on what constitutes as normal menstrual pain, endometriosis symptoms, treatment options and their implications, along with their desire for self-advocacy to be better equipped in medical consultation. The Degree Project showed that this knowledge enables women to fight against patriarchal influences of biomedical care and to fight for the care they well deserve.

VII. FURTHER RESEARCH

The survey methodology allowed reaching a relatively large number of participants who have endometriosis or suffer from endometriosis-related symptoms; follow-up questions were not possible at this stage. Further studies on communication barriers could provide more extent to themes revealed in this study.

As the study does not analyse country-based specificities and racial inequalities, future research should present the significance of such factors within the diagnostic delay. In addition, the study of social and economic determinants of health and the impact of the Covid-19 pandemic on gynaecological services could also highlight further implications.

In the case of online support groups' potential to empower women with knowledge, the limitations of computer-mediated communications such as the digital divide, the responsibility of posting any health-related content, and the algorithms and governance of online platforms should be addressed to inquiry the whole picture.

Lastly, although this study justifies the necessity of combining women's experiential knowledge, medical and communication studies, a special focus should be placed on how exactly such collaboration may be possible to address the diagnostic delay.

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APPENDICES

APPENDIX I. – SURVEY QUESTIONS

1. What is your age?
2. Have you been diagnosed with endometriosis?
3. How long did it take to get the diagnosis?
4. How long have you been experiencing symptoms or suspecting endometriosis?
5. In your view, why does it take so long to diagnose endometriosis?
6. Did you receive sexual health education that included mensural health in secondary education (high-school)?
7. Did menstrual health education include information about endometriosis or abnormal menstrual parameters (e.g. painful menstruation)?
8. Did you feel disbelieved about the severity of your pain in early consultations with a general practitioner (family doctor)?
9. Did your gynaecologist take into consideration your quality of life impacted by endometriosis (e.g. loss of work productivity, social life, etc.) during pre-diagnosis consultations?
10. Did your gynaecologist take into consideration your experience and knowledge of the disease during pre-diagnosis consultations?
11. Did your gynaecologist take into consideration your experience and knowledge of the disease during pre-diagnosis consultations?
12. Did you find it challenging to communicate (describe) pain?
13. How do you describe and discuss pain in medical consultations?
14. Do you think tools for pain description (e.g. descriptive terminology, charts, anatomy images) would have been of help in early consultations?
15. In your view, how could medical professionals help to overcome the challenges of communication?
16. How do you educate yourself about endometriosis?
17. In your view, what are the advantages of online support groups?
18. Do you think the inclusion of endometriosis patients' experiential knowledge could improve the diagnostic delay?

APPENDIX II. – CONCLUSION OF THEMATIC CATEGORIES ACROSS ALL SURVEY QUESTIONS

Thematic responses	N	%
Medical knowledge	31	49%
Dismissal and normalization	15	34%
Prejudice	13	30%
Inadequate care	12	27%
Illustrative language	9	24%
Validation	9	23%
Education	9	21%
Acknowledgement	8	18%
Togetherness	8	15%
Factual characteristics of pain	6	12%
Quality of life	4	10%
Mental support	4	9%
Experience comparison	3	8%
Diary (pain or other diaries)	3	8%
Physical representation	3	7%
Patients' perspective	3	6%
Language barriers	2	3%
Consultation time	2	2%
Rating scale	1	1%

APPENDIX III. – CONCLUSION OF QUANTITATIVE DATA

Question	Survey questions	Answer choices	N	%
1	What is your age?	13 to 17	5	2%
		18 to 24	30	11%
		25 to 34	100	38%
		35 to 44	96	37%
		45 to 54	27	10%
		55 to older	4	2%
2	Have you been diagnosed with endometriosis?	Yes	222	85%
		No	40	15%
3	How long did it take to get the diagnosis	1	21	8%
		1 to 2	20	8%
		3 to 5	36	14%
		6 to 8	34	13%
		8 to more	106	40%
		Skipped	45	17%
4	How long have you been experiencing symptom(s) or suspecting endometriosis?	1	8	3%
		1 to 2	13	5%
		3 to 5	35	13%
		6 to 8	30	11%
		8 to more	168	64%
		Skipped	8	3%
5	In your view, why does it take so long to diagnose endometriosis?	Dismissal of symptoms and/or normalization of pain	232	89%
		Insufficient medical knowledge of the disease and its mechanism	197	75%
		Lack of awareness among medical professionals	193	74%
		Insufficient menstrual health education and lack of public awareness	125	48%
		Exclusion of patients' experiential knowledge	103	39%
		Limited consultation time	45	17%
		Skipped	10	4%
		6		Yes
No	120			46%

	Did you receive sexual health education that included menstrual health in secondary school (high school)?	Skipped	7	3%
7	Did menstrual health education include information about endometriosis or abnormal menstrual parameters (e.g. painful menstruation)?	Yes	5	2%
		No	119	45%
		Skipped	138	53%
8	Did you ever feel disbelieved about the severity of your pain in early consultations with a general practitioner (family doctor)?	Yes	109	42%
		No	15	6%
		Skipped	138	53%
9	Did your gynaecologist take into consideration your quality of life impacted by endometriosis (e.g. loss of work productivity, social life, etc.) during pre-diagnosis consultations?	Yes	59	23%
		No	180	69%
		Skipped	23	9%
10	Did your gynaecologist take into consideration your experience and knowledge of the disease during pre-diagnosis consultations?	Yes	41	16%
		No	196	75%
		Skipped	25	10%
11	Did you find it challenging to communicate (describe) pain?	Yes	184	70%
		No	55	21%
		Skipped	23	9%
12	How do you describe and discuss pain in medical consultations?	Illustrative language	196	75%
		Rating scale	130	50%
		Daily pain diary	56	21%
		Skipped	24	9%
13	Do you think tools for pain description (e.g. descriptive terminology, charts, anatomy images) would have been of help in early consultations?	Yes	208	79%
		No	28	11%
		Skipped	26	10%
14	In your view, how could medical professionals help to overcome the challenges of communication?	Improve medical knowledge and awareness	217	83%
		Listen and emphasise	175	67%
		Guide patient through questions or ask a more specific question	170	65%
		Provide tools for symptoms and pain description	153	58%
		Skipped	24	9%
15	In your view, how could medical professionals help to overcome the challenges of communication?	Online learning platforms	222	85%
		Online support groups	190	73%
		Medical consultations	66	25%
		Skipped	24	9%

16	In your view, how could medical professionals help to overcome the challenges of communication?	Present self-advocacy and self-learning opportunities	199	76%
		Indicate a better understanding of the reality behind the disease	179	68%
		Provide mental support	151	58%
		Correct incomplete and inaccurate medical and public knowledge	135	52%
		Skipped	26	10%
17	Do you think the inclusion of endometriosis patients' experiential knowledge could improve the diagnostic delay?	Yes	219	84%
		No	14	5%
		Skipped	29	11%

APPENDIX IV. – INCORPORATED REVISIONS SUGGESTED BY THE EXAMINER

According to the examiner's feedback, I incorporated the following changes:

- Put more visible emphasis on pain communication;
- Changed the title;
- Reconstructed the introduction;
- Made the three research questions more connected throughout the whole Degree Project;
- Replaced some chapters of the literature review to the introduction (Endometriosis: key facts and implications and Diagnosis);
- Renamed the title of the chapter "Discourses to Communication" between healthcare providers and patients, so the research questions are better related to each other, putting a particular focus on the power dimensions and the effectiveness of pain communication;
- Added figures, so the relationship between discourses, normalization, pain communication and diagnostic processes are more evident to the reader. I also added a figure that concludes the multidisciplinary and multilevel approach;
- Revised the research methodology section: I removed the chapters discussing NA and CDA. However, I included a short section discussing these methods in the introduction part of research methodology as part

of the qualitative research design. Considering that historical medical biases, pain communication and diagnostic processes are deeply interconnected, while discourses are part of diagnostic processes, I believe that excluding these sections entirely would be problematic.

- Reconstructed and renamed the chapter “Analysis”;
- Added a subchapter, “Discussion of the results”, where I discuss the results reflecting on the theoretical framework and literature review and discuss the answers to the three research question;
- Moved limitations and ethical consideration into the methods section
- Added a subchapter, “Further research”, which was part of the limitations.