The Need for a Non-Invasive Technology for Endometriosis Detection and Care

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Abstract. Endometriosis is a complex, poorly understood, female health condition that can markedly reduce a woman's quality of life. The gold-standard diagnostic method for Endometriosis is invasive laparoscopic surgery, which is costly, not timely, and comes with risks to the patient. We argue that the need for a non-invasive diagnosis procedure, higher quality of patient care and reduced diagnosis delay, can be fulfilled by advances and research to devise innovative computational solutions. To leverage computational and algorithmic techniques, enhanced data recording and sharing are vital. We discuss the potential benefits of using personalised computational healthcare on both the clinician and patient side, reducing the lengthy average diagnosis time (currently around 8 years).

Keywords. Female reproductive health, Endometriosis, Artificial Intelligence, Predictions models, Diagnosis time, Menstrual health

1. Introduction

Female menstrual health conditions like Endometriosis are common and, in many respects, can severely affect a woman's quality of life (QoL) [1]. The main symptoms of Endometriosis involve severe pain and fertility issues, affecting not only the reproductive organs but also frequently the bowel and bladder. For some sufferers endometriosis manifests with minor or no symptoms, which consequentially makes diagnosis using reported symptoms and clinical questionnaires even more difficult. There is a need to improve the computational detection of gynaecological conditions like Endometriosis, especially as they can be challenging to identify without invasive methods such as Laparoscopic surgery which carries physical risks and high monetary costs [2]. It is understandable that imaging modalities and physical exams are prioritised over the surgical approach due to the reduced risks and lower costs, however, this contributes to an increased diagnostic delay, disease progression, and ultimately a prolonged lower QoL for affected individuals [3]. Current research shows challenges in developing a computational-based diagnostic tool for such a complex multi-factorial condition, with non-specific symptoms that overlap with other gynaecological health conditions and different comorbidities [4]. The biggest technological barrier stems from the lack of

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understanding of Endometriosis leading to the insufficiency of available, usable, and accurate data on its aetiology and pathogenesis, that could be used to construct an algorithmic solution.
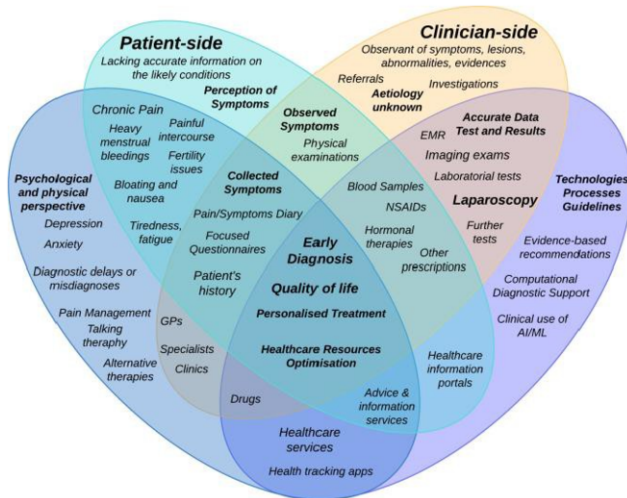

Figure 1. The context of Endometriosis diagnosis: from symptoms to improved QoL and early identification

This paper focuses on Endometriosis, one of the most poorly understood female gynaecological conditions [3]. We discuss the opportunities that the sharing of patient data can bring, regarding the diagnosis, treatment, quality of care received, and the positive implications on patient QoL. Figure 1 illustrates the context for early Endometriosis diagnosis considering the different perspectives, perceptions, and current practices on both patient and clinician sides. Section 2 describes Endometriosis as a condition, symptoms, and diagnostic delay. Section 3 presents the diagnostic techniques, implications, where technological solutions may improve the diagnosis pipeline, and where existing technologies (e.g., for recording menstrual symptoms), can improve their potential to aid in patient care. Section 4 points out how future work using data sharing can be beneficial to both clinicians and patients.

2. Endometriosis and Diagnostic Delay

Endometriosis is a common, chronic, inflammatory health condition that affects an estimated 10% of biological females of at least reproductive age. In some cases, the condition can present in an asymptomatic form, which may suggest that the rate of occurrence is greater than the predicted 1 in 10 [1]. In other cases, the condition can be life-altering, with major symptoms that have a significant potential to disrupt well-being and QoL. Clinical diagnosis (by the method of ruling out differential conditions) is being adopted more commonly in recent years due to the drawbacks of invasive surgical diagnosis, particularly the diagnostic delay incurred. On average, diagnosis takes around 8 years, with some sufferers waiting significantly longer than this [2]. Due to the progressive nature of Endometriosis, earlier diagnosis is a research priority, not only to optimise healthcare resources but also to provide better care and more personalised treatments [5]. The cause of such lengthy delays is likely due to the lack of awareness of

Endometriosis from both patient and clinician, minimal understanding of the aetiology of the condition, and typical somatisation and normalisation of its symptoms [6].

The ideal diagnostic procedure would use patient symptoms as input, but the considerably heterogeneous manifestations make this challenging, since one symptomatic presentation of Endometriosis may differ wildly from another [5]. In addition, symptoms appear to be unrelated to the disease stage, though newer research suggests that they are not necessarily unrelated to Endometriosis location and/or type [7]. The main symptoms of the condition are (but are not limited to): painful periods (dysmenorrhea), heavy bleeding during menstruation (menorrhagia), chronic/non-menstrual related pelvic pain, pain during and/or after sexual intercourse (dyspareunia), painful bowel movements (dyschezia), painful urination and loss of bladder control (dysuria), fatigue, depression or anxiety, infertility or sub-fertility, abdominal bloating and nausea, among other symptoms [1]. The variety of symptoms, and overlap with differential conditions, makes Endometriosis a challenge to identify algorithmically especially using AI techniques [8]. Despite this, we believe it is feasible, and that technological diagnosis with personalised healthcare solutions can improve the QoL for women suffering from Endometriosis.

3. Endometriosis Diagnostic Techniques & Discussion on Computational Solutions

Though clinical diagnoses are being utilised more, the gold standard diagnostic technique is still invasive surgery by means of Laparoscopy [1]. These surgeries are not only costly and risky, but their diagnostic success is highly influenced by the surgeon's experience [9]. Due to human experience and error, differences in outcome are expected, though a more uniform approach may be possible via computational input. This applies not only at the tertiary care level but also at primary care. It is also worth noting that there is a disparity between how General Practitioners (GPs) and other healthcare professionals treat menstrual symptoms, resulting in a lack of trust in the healthcare system from patients [6]. While non-invasive technologies may not be the complete solution to the long-standing issue of Endometriosis diagnosis, we believe that they provide several positive opportunities benefiting both patients and clinicians:

- Helping the general population identify irregularities in menstrual symptoms by the development of more sophisticated period tracking applications whilst reducing the diagnostic delay caused by the normalisation of gynaecological symptoms;
- Sharing of self-tracked menstrual data (with consent, in a secure manner), with medical professionals, allowing them to build a more accurate picture of a patient's symptom history. This minimises the impact of flawed human recollection of historical information that primary care doctors would receive at initial consultation;
- A clinical decision model informed by expert knowledge may assist primary care practitioners in understanding the signs and symptoms of Endometriosis and result in an earlier referral;
- Algorithmic models can be used to prioritise patients for laparoscopic surgery, considering the severity of their symptoms, QoL, and disease stage (if known). These solutions may also be used to suggest alternative solutions on an individual basis, if Laparoscopy is not appropriate for the patient;

- Prediction of endometriosis location and type in advance of Laparoscopy would be a beneficial insight for the surgical team to ensure that the correct operative experience is provisioned on a case-to-case basis to ensure the most satisfactory outcome for each patient and reduce the likelihood of the condition recurrence.

The introduction of computation into clinical care is, of course, not without intricacy. Data privacy, the sensitivity and specificity parameters used to tune algorithms, data features employed in prediction models, and acceptance of technology by clinicians are important discussion points. Any algorithmic solution can only ever be as high quality as the underlying data it makes use of. Data sharing and collaborative work within this under-researched area is crucial to successfully building innovative and accurate solutions that medical professionals will trust, accept, and incorporate into daily clinical practice.

There are several existing technologies that have the goal of improving females' menstrual well-being. In the last decade, period tracking applications have improved in functionality, and are increasingly assisting women in predicting their menstrual cycles. Though these applications aid understanding of cycles and symptoms, this self-reported data does not seem to be thorough or advanced enough for signposting to medical professionals. For example, a tracking application that notifies of menstrual irregularities generally does not have a sophisticated enough symptom-tracking interface to record the wide range of symptoms that a patient with Endometriosis may experience. Improvements in the type of data these applications collect, as well as in the sharing of this data with medical professionals, may mean that general menstrual health applications can be adapted to assist in the identification of gynaecological issues.

While research on Endometriosis has improved in the last decade, and there is a better understanding of the condition itself, we believe that there remains a lack of use of Computer Science for reducing the existing large diagnostic delay. There is a particular shortage of exploration using Artificial Intelligence (AI) including Machine Learning (ML) solutions. There is great potential to integrate ML applications into the lives of patients and/or clinicians to continue working towards a reduced time to diagnosis. Assuming this, we predict that there is an opportunity to use computation, likely an ML approach, in combination with a set of time-series patient symptoms to predict the existence of Endometriosis along with more advanced predictions such as Endometriosis type [1]. Estimating the condition stage is a more complex task due to the lack of correlation with symptoms [5]. Prediction of Endometriosis location and type in advance of Laparoscopy would be beneficial for the surgical team to ensure that the correct operative experience is provisioned on a case-to-case basis. Although having a diverse surgical team may not always be the case in every clinic, knowing that there is a high chance of a specific type of Endometriosis would be beneficial nonetheless; potentially for further referrals.

4. Conclusion

We envision that through a synergistic approach involving patient and clinician perspectives, together with technological developments, sufferers can be provided with tools and data collection interfaces to help manage their health and hence improve QoL. Not only to record a timeline of symptoms, but also to share this data so it can be examined and supplemented by clinicians for surgical triage and earlier diagnosis. The past and present recorded manifestations of the condition can be used by algorithmic

models to infer for new patients their likelihood of a gynaecological condition such as Endometriosis.

To reach this point, sharing of data and knowledge of the condition is crucial. A data collection method with notable potential is the integration of questionnaires at all levels of care, particularly at tertiary care where operative procedures are likely. The richer a picture that we can build on the symptomatic presentations (or lack thereof), and surgical characteristics (e.g., location, lesion type and size, colour), the more advanced and accurate the resulting prediction models. With enhanced quality and volume of data should come improved accuracy and trustworthiness of computational predictions; over time. Integration of these predictions into patient and clinician-side applications (e.g., clinical decision-making systems) could assist in flagging associated signs earlier, lessening the time to diagnosis. By using individual patient accounts from self-reported questionnaire data or menstrual tracking applications, together with clinician-reported medical records, cohort studies, and shared knowledge on the condition, we can expand our understanding of Endometriosis. The more data is shared over time, the more accurate and insightful will be the solutions to this poorly managed condition.

We are currently exploring ways in which we can bring data together and compare the experiences of women with Endometriosis in differing income countries and regions (within the EU and beyond), and from primary care to tertiary care. We are not dismissing the importance of clinicians and surgeons in the diagnostic and treatment pathway. We are instead suggesting that there is an opportunity to optimise the current procedures via diagnosis and care assisted by computation, providing a more personalised management plan. We envision a symbiotic solution: our ability and technology's ability to complement each other, allowing us to achieve results that neither could achieve alone. Collaborative efforts between research institutions, medical professionals, data analytics, AI and software developers will be vital in taking steps towards making this a possibility.

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