Erasmus School of Health Policy & Management

Stuck with endometriosis, moving to a better future

Improving the diagnostic process of endometriosis in the Dutch health care system

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Preface

I would like to thank everyone who has in some way contributed to this study. First, the several foundations that actively helped me to find participants. Second, a special thanks to all the patients and professionals that took the time to participate. Third, my personal surroundings, who supported me through the process. Last, but not least, my thesis supervisor Dr. Van Wijngaarden.

Because of this study I came to understand the importance of finding a diagnosis for patients even more. Therefore, I would like to mention https://www.endometriose.nl/ for people who recognize themselves in the complaints described in this paper. Here, a checklist can be found that could help during the consultation with a general practitioner.

Summary

Introduction: Multiple diseases deal with a delay in diagnosis. Finding a diagnosis has benefits for different reasons, such as systematic, mental and physical ones. Endometriosis is a disease that deals with diagnostic delay. Women with endometriosis may encounter serious consequences in their daily lives. A timely diagnosis is desired for women who suffer from endometriosis. Current research focuses mostly on reasons for delay and consequences. Thereby, practical improvement points for the Dutch health care system are lacking in the research body. As not all delay might be removed, improvement points for support during a long diagnostic trajectory are also desired. Therefore, this research aims to answer how the diagnostic process of endometriosis is experienced by patients, gynecologists and general practitioners and how it could be improved according to them.

Methodology: 12 qualitative interviews were conducted with 9 patients, 2 gynecologists, and 1 general practitioner. All had experience with the Dutch health care system. Deductive thematic analysis was applied. As the sample group was specific, a non-probable sampling method was used.

Results: Endometriosis patients deal with heterogeneous medical complaints that have consequences for many aspects of their daily lives. Several obstacles in the diagnostic trajectory were found. Those included stigmatization and gender issues, narrow anamnesis and late referral. Moreover, a tension in the meaning of a diagnosis existed between patients and professionals. Both during and directly after, patients felt they missed respectively mental support and practical support. The research resulted in three improvement areas. Those include education for society, education for professionals and patient activation. Within those areas, multiple solutions are provided.

Conclusion: Three areas of improvement were found. All of which suggested improving the diagnostic trajectory both in an accelerating and supportive manner. The first area includes better education of society on the topic of endometriosis and menstruation. The second area suggests the development of training for general practitioners, improved education, and better guidelines. The last area describes which tools can help to activate patients, who were seen as desirable. More awareness for such tools needs to be realized. While all areas include practical suggestions, there is a need to further explore how to reach optimization in some areas.

Keywords: endometriosis, diagnostic delay, improvement

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Chapter 1: Introduction

Delayed diagnosis is a problem for many chronic diseases, such as cancers, Alzheimer's and COPD (Büchner & Spijkerman, 2011). A faster diagnosis is desirable for such diseases for multiple reasons. First, the problem is systematic, meaning solving the problem could result in improvement for many (Ibid.). Thereby, many patients could experience a better diagnostic process. Diagnostic delay might furthermore come with both physical and mental implications for patients. A faster process might inhibit the further onset of the disease and prevent patients' physical and mental complaints due to delay (Büchner & Spijkerman, 2011; Pita-Fernández et al., 2013; Staal et al., 2016).

Endometriosis, a chronic and inflammatory disease, is an example of an illness with ongoing systematic diagnostic delay (Staal et al., 2016; Agarwal et al., 2019; Máxima MC, 2021). Recent research suggests an average of 6 to 10 years before a correct diagnosis (Staal et al., 2016). In the Netherlands, 2 to 10% of women are affected by endometriosis (Máxima MC, 2021; Symons et al., 2018). The disease is characterized by endometrial tissue growth outside the uterine cavity (Ibid.). Women living with this condition often deal with ongoing pain, one of the main symptoms. Next to this, frequent symptoms include dysmenorrhea, chronic abdominal pain, bowel problems, and subfertility. The symptoms are, however, heterogenic. Meaning they can vary in significant amounts from person to person (Staal et al., 2016). Resulting from these symptoms, women encounter constraints in everyday activities and reduced quality of life (Máxima MC, 2021; Symons et al., 201; Staal et al., 2016). As a result, their mental well-being is also influenced (Agarwal et al., 2019). Possible long-term consequences of endometriosis include, among others: infertility, increased risk of certain chronic diseases and cancers, severe mental health issues, and economic burden due to constraints in working (As-Sanie et al., 2019; Shafrir et al., 2018).

Currently, no cure for endometriosis exists, but patients can benefit from treating symptoms and characteristics (As-Sanie et al., 2019). For instance, treatment can inhibit growth, and surgery could remove the visible tissue (Abou-Setta et al., 2013). Thereby, further disease development can be reduced, pain can be relieved, and mental well-being increased (Abou-Setta et al., 2013; As-Sanie et al., 2019). Timely diagnosis can also reduce healthcare costs. Women experience an average of 7 visits to the primary healthcare provider before being referred to a specialist and receive a misdiagnosis 75% of the time (As-Sanie et al., 2019). Reaching the correct diagnosis faster could thus reduce the amount of care time needed and thereby reduce costs. Moreover, treatment can help women to be involved paid work better (As-Sanie et al., 2019; Shafrir et al., 2018). An improved diagnosis process would thus be beneficial for endometriosis patients and society in general.

Literature reveals several reasons that make obtaining a diagnosis harder in some cases than others (Eekhof, 2012). Some ask for further development in diagnostic tests, such as MRI scans.

Others encompass less technical reasons (Zwaan & Singh, 2015; Walter et al., 2012). Health care ystem design related problems are an example of reasons not due to diagnostic testing, thus less technical. For instance, the lack of teaching or a failing referral system (Ibid.). For endometriosis, both are of relevance. This as endometriosis is sometimes hard to detect through the available diagnostic tests. However, system design problems related to the disease are recognized too (NASEM, 2015; Zwaan & Singh, 2015; Sims et al., 2021). Understanding such less technical issues can provide insight into what is needed to improve. However, most research is limited to barriers in the process but does not touch upon practical points for improvement to lift those barriers.

Not all delay may be removed because delay is partly related to underdeveloped diagnostic testing. Therefore, the help that patients need to deal with those delays might require improvement too. Patients involved in a long diagnostic trajectory may experience issues affecting their overall well-being (Pita-Fernández et al., 2013; Staal et al., 2016). Social production function theory can help discover points of improvement for supporting patients during this trajectory (Nieboer et al., 2005; Nieboer & Cramm, 2018). This theory describes how physical and social well-being determines a person's overall well-being. Basic needs influence physical and social well-being. Examples of basic needs include physical comfort and affection. One level below, activities, resources, and health care services influence the basic needs. For instance, the activity of emotional support leads to affection. An increase in affection, in turn, positively influences the social well-being of a person (Ibid.). During a diagnosis process, specific activities, resources, and healthcare services might need optimization to improve the overall well-being. Thus, by understanding which activities, resources, and health care services are needed, patients' overall well-being might be improved upon while in a long trajectory towards diagnosis.

Concluding, there is a problem in the diagnostic process of some diseases. Endometriosis is such a disease. Current research focuses on the reasons for delay and consequences of it. However, actual improvement suggestions based on current experience are lacking for endometriosis in the Dutch health care system. This research aims to analyze how to improve this diagnostic trajectory of endometriosis according to the patient, gynecologist, and general practitioner. It does so by focusing on the non-technical side of the process, unraveling both what is needed to reach a diagnosis faster and discovering what support patients need in a delayed process. Therefore, the following research question was constructed:

How do patients, gynecologists, and general practitioners experience the diagnostic process of endometriosis, and how can this process be improved according to them?

The following sub-questions aim to provide an answer to the main research question:

1. How do patients, gynecologists, and general practitioners experience the diagnostic process of endometriosis?
2. How can the diagnostic process of endometriosis be accelerated?
3. How can patients' experience be improved during a long diagnostic process?

The theoretical lens for the research will be further explained in the next chapter through a critical analysis of the existing literature on endometriosis. This chapter is followed by the methodology, where the research method is justified and described in detail. Moreover, validity and trustworthiness are considered in this chapter. In the fourth chapter, an analysis of the results is outlined and supported by quotes. The last chapter consists of the conclusion and discussion of the results. Appendices show material used during the study, such as interview guides.

Chapter 2: Theoretical framework

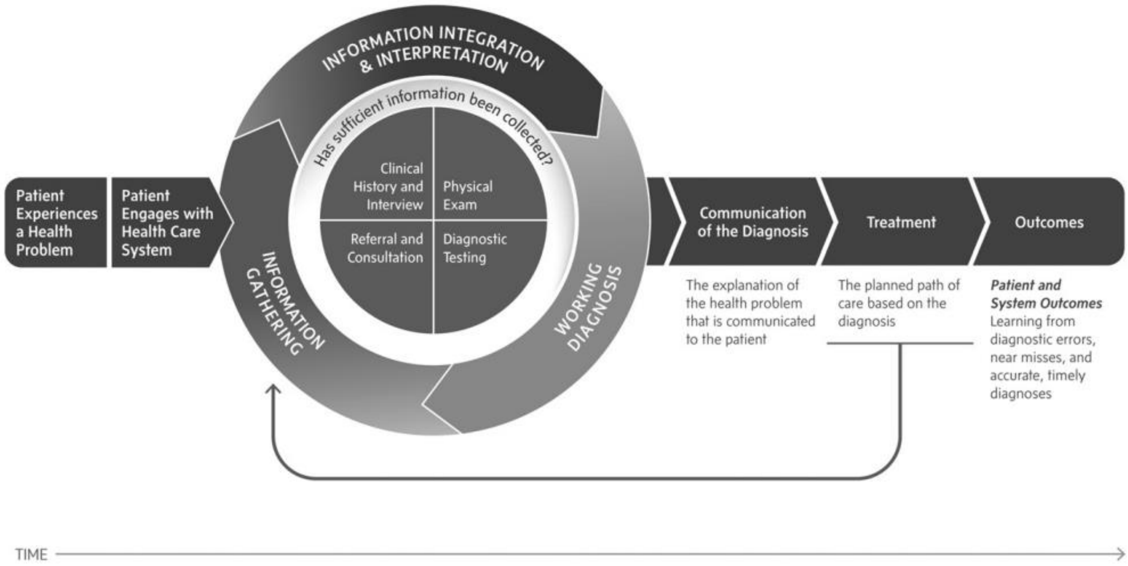
This chapter introduces the theoretical lens for the research. First, the structure of a general diagnostic process is explained. Then, it is discussed how different reasons exist that make a diagnostic process hard. Those reasons fall into four categories. Recent research shows that those generic reasons for making a diagnosis hard are also apparent in the process of endometriosis. Those concepts offer a lens to study how the process could be improved upon, as improvement research is lacking. Furthermore it is discussed how a delayed process may impact patients' quality of life. As the delay in diagnosis of endometriosis may prevail (partly), improvement of the process should also focus on support of patients dealing with the consequences of delay. Social production function theory provides a framework for researching how.

2.1 The diagnostic process

For general practitioners (GP) in the Netherlands, a specific structure is taught to follow during a consultation with patients (Timmerman et al., 2016). It consists of starting a consult, gaining information, physical examination, explanation of the diagnosis, policy and planning, and finally ending the consult. Within this process, the first four steps play a role in forming a diagnosis (Ibid.). At the start of the consult, the reason(s) for the patient to come in are identified. Next to his, there is some preparation. During this preparation, the GP checks the patient history, providing context for the doctor (Ibid.). Following is the physical examination, when necessary (Ibid.). After, a differential diagnosis arises. This is a list of potential diagnoses that arises during this process. As the process is iterative, the differential diagnosis is narrowed down, and the clinician moves to verification (NASEM, 2015). Then, the diagnosis is explained to the patient. Lastly, the policy and planning for treatment are discussed (Timmerman et al., 2016). There may be some diagnostic uncertainty when treatment is started. The goal is to reduce this as much as possible (NASEM, 2015). When treatment is not effective, the process is repeated. When a GP cannot determine a diagnosis, the patient should be referred to a specialist (Ibid.). Here, the diagnostic process is similar. A specialist's knowledge is, however, more focused. Anamnesis and physical examination are therefore more focused too. For instance, during a gynecologist visit, a general physical examination consists of bimanual pelvic examination (BPE) and speculum research. After this, it can be decided whether additional examination is necessary (van der Zanden, n.d.). This diagnostic process is summarized in the model below, which explains a desirable diagnostic process (NASEM, 2015).

Figure 2.1

The diagnostic process



Note. Model of the diagnostic process. Reprinted from *Improving Diagnosis in Health Care* (p.33), by Committee on Diagnostic Error in Health Care, 2015, The National Academies Press.

In practice, this taught structure, consisting of inductive reasoning, is not always followed. There is a gap between education and practice. In practice, a more deductive structure is typical. An early diagnosis hypothesis is formed cognitively, and confirming questions are asked based on this hypothesis (Stolper et al., 2005). Prototype theory may explain why this is the case. This theory describes that the pathologies which are most easy to recognize move to the forefront within cognition. This while, during education, illnesses are categorized in an encyclopedic manner. In practice, a diagnosis comes to mind depending on the ease of recognition, which replaces a rational differential list of diagnoses. Eekhof (2012) describes the way diagnosis is formed in reality. Namely by making it definitive directly after its cognitive development or through refinement of the cognitively present disease(s). Refining the diagnosis involves considering probability, exclusion of diseases, stepwise refinement through further research, recognizing the patterns in a disease, or using clinical decision pathways to help a doctor decide (Eekhof, 2012). Refinement is thus an important step when a diagnosis is not directly evident.

2.2 Difficulties in the diagnostic process

A (correct) diagnosis is not reached for some illnesses through a first refinement of the cognitively present disease(s). As the diagnostic process is iterative, new hypotheses are then formed, and refinement is repeated (Eekhof, 2012). Such an iterative process might lead to diagnostic delay or misdiagnosis. The reasons for a diagnostic process being hard, thus not being reached through first refinement, generally fit into four categories (Walter et al., 2012; Zwaan & Singh, 2015; Van der Zanden, n.d.; NASEM, 2015). Those categories include disease factors, the patient, the health care system and the physician.

First, there are some reasons specific to the disease. It could occur that the disease is not showing any symptoms and, therefore not clinically diagnosable (Zwaan & Singh, 2015). Moreover, some diseases are hard to recognize or invisible in diagnostic tests (Van der Zanden, n.d.). Sometimes a delay occurs because obtaining a diagnosis would not alter the treatment (Zwaan & Singh, 2015). A last example includes how diagnostic testing is seen as more harmful than watchful waiting in a certain disease. Those reasons are disease-specific and might only be improved through further development of diagnostic testing.

In the category linked to the patient, someone might not have gone to the general practitioner timely, resulting in a diagnostic delay. Moreover, the patient is the one who needs to share their story of symptoms (Zwaan & Singh, 2015; Timmerman et al., 2016). This can sometimes lead to problems as symptoms might be taboo to discuss for the patient. For instance, taboo resting on problems arising during sex or complaints in the area of the genitals (Grandey et al., 2020).

In the health care system category, there could be a lack of education for practitioners on a specific disease. Moreover, as there is a gap between what is taught and what happens in practice during consultations, the system may not be adjusted correctly to the actual processes (NASEM, 2015). Other challenges in the diagnostic process due to the system could include lack of teamwork among health care professionals, lacking involvement of patients and families, lack of systems to identify and learn from mistakes, time constraints, and lack of support through health information technologies (NASEM, 2015; Zwaan & Singh, 2015; Society to Improve Diagnosis in Medicine, 2021; Walter et al., 2012). Examples of these errors can be found in research on many diseases, such as different types of cancer. For instance, an Australian literature review focused on delays caused by system design in lung cancers (Malalasekera et al., 2018). They found many barriers due to the system in different process stages. One example was the absence of a regulated referral system (Ibid.). Singh et al. (2012) provide another example. They looked into abnormal cancer screens and found an error in the reliability of electronically communicated positive fecal blood tests. More than a third of the results were not followed-up (Ibid.). Improving such system design errors could systematically improve delay in the diagnostic process.

Lastly, some challenges in the diagnostic process can be linked to the physician. However, health care provider factors and the system design are closely interrelated (Walter et al., 2012; Zwaan & Singh, 2015; NASEM, 2015). Providers namely base their actions partly on the system.

Moreover, it is possible cognitive processes occur, which are not in line with the structure taught. As a result, delay might occur. The cognitive aspect of clinical reasoning is quite inevitable, which is why this could also be seen as a problem related to the system design.

2.3 Diagnosing endometriosis

Endometriosis is one disease frequently misdiagnosed and delayed in diagnosis. Staal et al. (2016) have identified that, in the Netherlands, the most significant part of the delay in time is between the first visit to the general practitioner and the referral to the gynecologist.

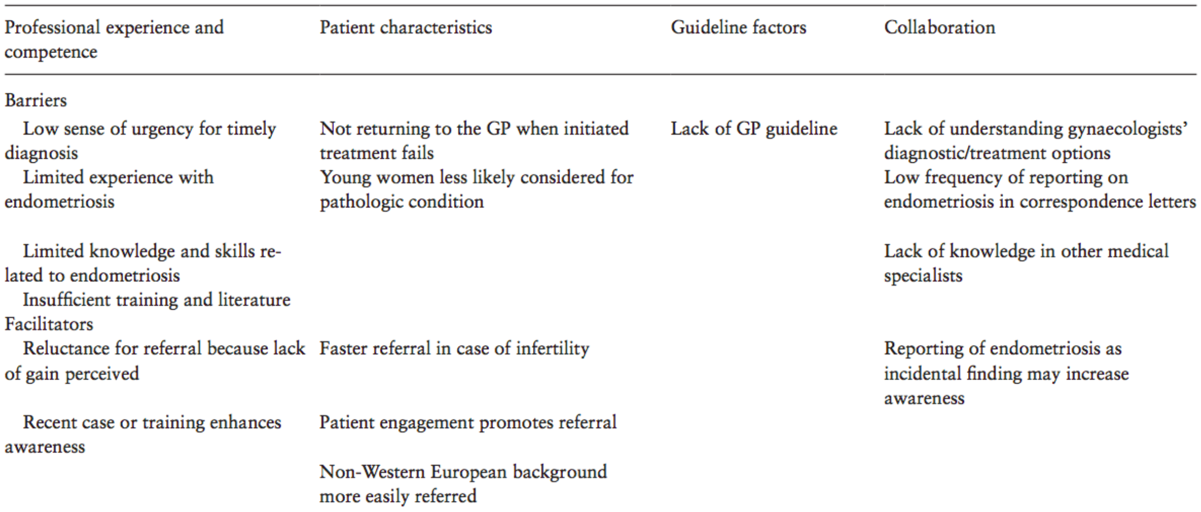
Specific to the disease, the general gynecological investigation may not lead to diagnosing endometriosis. Diagnostic test methods can, at this moment, not provide certainty about the existence of the disease (ESHRE Endometriosis Guideline Development Group, 2013). Moreover, laparoscopy is considered the gold standard for endometriosis, but this is an invasive method (Cardoso et al., 2014; Van der Zanden, n.d.). Therefore, it is often avoided (Van der Zanden, n.d.). Disease-specific reasons for diagnostic delay are thus apparent. However, for improvement on this part, development in diagnostic testing is required.

It is known that patient-related reasons also seem to play a part because stigma and taboo surrounding this topic still exist (As-Sanie et al., 2019). This could make it hard for patients to speak freely about their complaints and symptoms, which may cause an extra delay (Sims et al., 2021). Moreover, it is known that heavy abdominal pains are often stigmatized as menstrual pains and something that is part of being a woman (Sims et al., 2021). As a result, women might not go to the general practitioner timely (Ibid.).

Furthermore, reasons related to the health care system design and physician (related to the system) are recognized for endometriosis. Van der Zanden et al. (2019) have studied barriers to timely diagnosis of endometriosis in the Netherlands under GPs. Their perceived barriers are summarized in the figure below (Ibid.). Indeed many barriers in this research are linked to system design. Moreover, Staal et al. (2016) found reasons for a delay, such as considering one or more other diagnoses before endometriosis. Thus, prototype theory might play a role, as other diseases may be easier to come to mind considering the symptoms. An example of a result is blaming the pain on menstrual pains (Ibid.). Van der Zanden (n.d.) furthermore emphasizes the importance of the role the general practitioner has in the process of diagnosis, as they act as the gatekeeper to specialist care in the Netherlands. Here, another system-related issue could be the problem. For example, lacking communication between professionals or a failing referral system (NASEM, 2015).

Figure 2.2

Practitioner barriers



Professional experience and competence	Patient characteristics	Guideline factors	Collaboration
Barriers			
Low sense of urgency for timely diagnosis	Not returning to the GP when initiated treatment fails	Lack of GP guideline	Lack of understanding gynaecologists' diagnostic/treatment options
Limited experience with endometriosis	Young women less likely considered for pathologic condition		Low frequency of reporting on endometriosis in correspondence letters
Limited knowledge and skills related to endometriosis			Lack of knowledge in other medical specialists
Insufficient training and literature			
Facilitators			
Reluctance for referral because lack of gain perceived	Faster referral in case of infertility		Reporting of endometriosis as incidental finding may increase awareness
Recent case or training enhances awareness	Patient engagement promotes referral		
	Non-Western European background more easily referred		

Note. Perceived barriers by general practitioners. Reprinted from Barriers and facilitators to the timely diagnosis of endometriosis in primary care in the Netherlands, by van der Zanden et al., 2019, *Family Practice, 37*(1), p.134.

Existing research is mainly focused on the reasons for the delay. There is, however, a lack of improvement research. For instance, considering the figure above. Patient engagement was seen to promote referral, however, it remains unclear how this could be reached exactly. Further understanding of problems and needs in the mentioned categories might help to discover points for actual improvement.

2.4 Consequences of diagnostic delay

Many chronic diseases, such as COPD, Alzheimer's and cancer, deal with diagnostic delay (Büchner & Spijkerman, 2011). This delay impacts both the physical and the mental health of the patient and, thereby, their quality of life (Pita-Fernández et al., 2013).

For endometriosis, the diagnostic delay may also have a significant impact. The clinical onset of the disease is only a part of the consequences (Staal et al., 2016). Due to enduring chronic pain, quality of life and work productivity decrease (Nnoaham et al., 2011). Moreover, the delay and misdiagnoses can cause many psychological problems. A list of only some examples includes periods of uncertainty, distrust, the feeling of not being taken seriously, fear, anger, depression, and self-blame (Husby et al., 2003; Seear, 2009). Moreover, social problems such as relationship problems may be a consequence (Seear, 2009). The long process may even lead to a traumatizing experience (Staal et al., 2016).

For some cases, a diagnostic delay might be reduced by improvement in those categories. However, diagnostic delay in endometriosis may still be prevalent, even after improvements are made. Therefore, improvement of the diagnostic process for the patient should also include considering the consequences of a delay named above (Pita-Fernández et al., 2013; Staal et al., 2016; Nnoaham et al., 2011; Husby et al., 2003; Seear, 2009).

Social production function (SPF) theory can help to explain how the overall well-being of patients (in general) is influenced by both social and physical well-being (Nieboer et al., 2005; Nieboer & Cramm, 2018). Social and physical well-being are influenced by the basic needs of comfort, status, affection, stimulation, and behavioral confirmation. Comfort includes someone's psychological needs and a pleasant and safe environment. Stimulation stands for optimal level of arousal, such as through sports. The basic need of status concerns controlling scarce resources, for instance, through paid work. Behavioral confirmation is the approval for doing the right things, like having a social network. Lastly, affection is related to positive inputs from caring others (Ibid.). The relation to endometriosis patients is directly visible from these explanations of the concepts. Such as the difficulty for some patients to keep performing paid work, resulting in lower status and influencing the overall well-being. The basic needs are supported through activities, resources, and health care services. Those might be improved upon in the diagnostic process, leading to the better overall well-being of the patient. For instance, providing the health care service of emotional support could improve the basic need affection (Ibid.).

Research on factors contributing to the diagnostic delay and its consequences is present (Pita-Fernández et al., 2013; Staal et al., 2016; Nnoaham et al., 2011; Husby et al., 2003; Seear, 2009). However, again methods to improve during a delay are lacking. SPF theory can help to understand what improvement is needed to support the basic needs and, thereby, the overall well-being of endometriosis patients during a delayed process. This can be done through insight into the activities, resources, and health care services needed to support the basic needs. Focusing on improvement on this side, too, results in a more holistic improvement of the diagnostic process for patients.

Endometriosis is one disease hard to diagnose. Reasons for the diagnostic delay are previously investigated and related to four categories. Improvements might be made by understanding what is needed in those four categories, as improvement research is currently lacking. Moreover, some diagnostic delay may remain prevalent for endometriosis. Therefore, improvement of the diagnostic process also includes considering what support patients need during a long process. SPF theory can help with this.

Chapter 3: Methodology

The aim of this study included (1) understanding patients', GPs' and gynecologists' experience of the diagnostic process and (2) discovering how the process could be improved according to them. This section explains how a qualitative study design was constructed to answer the research question. Then, it is discussed how the data was collected through interviews and analyzed using deductive thematic analysis. Last, the validity and trustworthiness of the study are considered.

3.1 Study design

A qualitative design was found relevant for studying the improvement of the endometriosis diagnosis process. Qualitative studies are deemed suitable for understanding experiences (Babbie, 2008). This study focuses on the experience of the process for patients and professionals. Moreover, this paper aimed to discover ways to improve the existing diagnosis process. Therefore, gaining thorough, new insights and understanding of the current procedure are helpful. Retrieving this understanding and insight fits best into a qualitative design as it is hard to quantify (Ibid.).

The research design includes interviews with Dutch participants. Interviews helped to understand the lived experiences in a conversational manner. This allowed the researcher to gain a deep understanding of the process and feelings and opinions involved. By using this method, the researcher could also verify a correct understanding (Ibid.).

3.2 Data collection

The method deemed most suitable for creating understanding, perspectives, experiences, and interpretations is interviews (Babbie, 2008). This is of relevance for the paper, as is discussed above. Semi-structured interviewing was chosen as a suitable method, as it allows both for comparison and room for discussion and probing (Ibid.). Moreover, this type of interviewing allows for building rapport between the researcher and participant, which is helpful because the topic may be sensitive for some (Ibid.). To provide some idea of the interviews, the interview guides are included in appendix B. A different interview was created for each group of participants, thus patients, gynecologists, and general practitioners. Patients were interviewed first and were asked to provide any questions they might have for professionals. Those questions were integrated into the interviews for gynecologists and GPs. Moreover, several points of improvement that came up during interviews were discussed with the participants further in the process.

Three types of respondents were approached to participate in this study, namely patients, gynecologists, and general practitioners. All experienced the Dutch health care system. This paper solely focuses on the Dutch context as the number of participants was limited due to time constraints. As the research is focused on the current diagnosis process, the patients were all recently involved in the diagnostic process. These conditions already provided for a pretty focused group, which is why no further limitations to participate in the study were defined.

Again, because this is a focused group of participants, a non-probable sampling method was used. Thus, not every individual had a chance to be included in the research (Babbie, 2008). The researcher used social media platforms to call for participants. This call was shared by various endometriosis foundations, such as Endometriose Stichting. Through Instagram and later WhatsApp contact, interviews with ten patients were scheduled. One of those patients dropped out due to the consequences of the disease. Endometriose Stichting shared the call with gynecologists over mail. As a result, interviews with two gynecologists were planned. Lastly, an interview with a general practitioner was realized through contact with an acquaintance of the researcher.

Before each interview, a consent form was provided to the participants. This form introduced their rights, such as being able to refrain from the study at any moment. Moreover, it explained the research topic of the study. The consent form is attached in appendix C. Oral consent was provided for each interview. Interviews were held both live and online. As the topic can be sensitive, participants were asked about their preferences. Two interviews took place live in a café, one interview took place over the phone, and nine interviews took place through Skype. Skype allowed the researcher to record the interviews and save those recordings. The other interviews were recorded using a phone recording application. Interviews started on March 2, 2022, and ended on March 31, 2022. To guarantee the anonymity of participants, they were numbered in the result section.

3.3 Data analysis

A deductive method was used to analyze the data retrieved from the interviews. First, the interviews were transcribed verbatim. Then, thematic analysis was applied. The applied theoretical lens makes that the study has deductive characteristics (Braun & Clarke, 2012). The analysis consisted of three coding steps. Open coding, axial coding, and selective coding (Ibid.). These three stages of coding were performed in Atlas.ti. Codes from interviews with professionals were colored to create a clear divide between patient and professional opinions. The color of the GP was different from the color of the gynecologist codes. The last coding round resulted in overarching themes, which are discussed in chapter 4 of this paper. The coding process was iterative to ensure saturation occurred (Ibid.). A thesis supervisor provided his view and instructions for improvement throughout the process. Thick description was used by providing quotes and examples from respondents (Ibid.).

3.4 Validity and trustworthiness

This research has a small number of participants, as it is performed within a set amount of time. Therefore trustworthiness and validity of the paper are limited. However, the research has put in work to assure some trustwortiness and validity.

A clear description of the data gathering and analysis process is provided to assure some trustworthiness. Moreover, the researcher provided some reflexive statements in the conclusion. By doing this, the research can be put into perspective (Mays & Pope, 2000).

Concerning the study's validity, methodological and researcher triangulation of the data were not possible to apply. However, some triangulation did occur through interviewing three different perspectives. Including the perspectives of patients and different professionals makes results more likely to be valid (Ibid.).

Lastly, generalizability is assured by providing thick description, as was explained previously in this method section (Ibid.). However, compared to quantitative research, generalizability remains low due to a limited number of participants. A discussion of the results with empirical literature provides for some theoretical generalization (Ibid.).

Chapter 4: Results

This section includes the results of the study. First, it is discussed what endometriosis means for patients. Their medical complaints and the consequences of those are outlined. Second, the obstacles in the diagnosis process are described. Third, it is explained how a diagnosis has a different meaning for patients than for professionals, which leads to a tension in the process. Fourth, missing elements in the support of patients are outlined. Last, the key areas for improvement are presented derived from the perspective of patients, gynecologists and a general practitioner.

4.1 Disease experience

This paragraph explains how patients experience the disease endometriosis. First, medical complaints that patients deal with are outlined. Second, it is discussed how those complaints and the disease influence the lives of respondents.

4.1.1 Patient complaints

All respondents described how they experience pain during their menstruation. Some patients also experience other problems during their menstruation, for instance, extreme loss of blood, clots of blood and long or frequent periods of blood loss. Multiple times, respondents compared their menstruation to others, such as friends or family members and said that their period was heavier than those compared to. However, other patients related to aspects of their menstruation as normal. Such as one patient describing her cycle was regular: “I could set my clock to it” (R3).

Complaints were not limited to menstruation. Frequently, patients mentioned dealing with abdominal pain, pain in the legs, fatigue, lack of energy, a swollen belly, intestinal complaints, the feeling of sickness, pain in the back, pain during defecation, intolerance to foods and alcohol, and pain during or after sex. Less frequently, complaints included dizziness, vaginal complaints, headaches and nerve pain. Moreover, it was apparent that most respondents dealt with complaints for multiple years. During this time, the complaints increased in number and seriousness.

4.1.2 Daily life consequences

Dealing with the complaints and the disease (first without knowing about the existence of endometriosis) resulted in consequences for the lives of respondents. Most prevalent were consequences for school/work, social life and mental health.

During their menstruation, patients mentioned not being able to stand, walk or stretch. Some patients also experienced this during ovulation or in general. Resulting from complaints, absenteeism for school was high or even problematic: “It turned out I was absent too often [...] and had to meet with the attendance officer” (R12). Multiple patients experienced problems with regards to school results, two patients even switched study. In addition to patients’ education, absenteeism was also a problem during work. For instance, during the process of finding a job or not being able to carry out the work as a healthy person would be. For instance, one interviewee said: “I have a new job, because I could not work in home care anymore” (R6).

Moreover, patients explained the consequences for their social life. Due to their complaints respondents had less social contacts. It was mentioned multiple times how this influenced their role in society: “I feel like I am less part of society. Imagine I have a birthday on Saturday night, I would have to recover for two days. So, I rather choose not to go” (R2). The disease also influenced relations with relatives and friends: “I lost so many family members and friends […] they don’t believe it, because they can’t see it” (R7). This quote also explains how the invisibility of the disease plays a role in the understanding of people, which results in social struggles. The topic of invisibility will be further discussed later in this section.

Another key area of consequences is the mental health of patients. Several patients related their complaints and other consequences to feelings of depression or were diagnosed with a form of depression. This has a relation to the social consequences of endometriosis, as multiple respondents described the feeling of being alone, resulting in sadness. Moreover, it became visible that mental issues were not only due to the disease, but also to the long diagnostic process patients experienced: “between my 16th and 17th something was off mentally too, but I couldn’t figure out what. I cried and begged at my parents saying something is not right” (R12) or “you are left with the psychological consequences [of a long process], that is undeniable” (R3).

Apart from these key areas, many other consequences existed for patients that were mentioned less frequently. Some patients dealt with difficulties with getting pregnant or the disability to participate in sports. The seriousness of the consequences is grasped in this quote: “It is actually a very invisible disease that slowly creeps into your life and takes everything apart piece for piece” (R12). In conclusion, complaints could impact many different aspects of the respondent’s lives.

4.2 Obstacles in the diagnosis process

This paragraph describes the experienced obstacles in the diagnostic process. An ideal process includes first thorough information gathering, followed by working to a diagnosis and finally the communication of the diagnosis to the patient and treatment. However, in the diagnostic process of endometriosis, this is not the case as different obstacles were found on multiple levels. First, stigmatization, taboo and gender issues still play a role in society and influence this diagnostic process. Second, there is an obstacle in the consult and anamnesis. This is related to the organization of health care and health care professionals. As a result of this, a problem occurs in referral.

4.2.1 Stigmatization and gender issues

It became clear that there is still a stigma surrounding menstruation (Sims et al., 2021). The stigma can be explained as a prejudice remaining on pain during menstruations. Pain is described as something that is normal during someone’s period, something women have to live with and accept. Because of this prejudice, pain during menstruation is often not acknowledged as something that requires treatment or should interfere with life. This stigma results in the perception that the extreme pain which women with endometriosis endure is something normal, as it is a disease connected to menstruation. It is referred to, and minimized as, the normalized menstruation pains most women encounter or deal with (Sims et al., 2021).

Stigma was recognized by both patients and professionals. This respondent explains how a hurting menstruation was often stigmatized as something one should deal with because it is normal: “People say menstruations hurt, it’s normal. Even at high school they tell you pain is part of menstruation” (R1). Moreover, young women would not understand this due to a lack of experience with periods: “He [GP] said ‘you are young, your body still has to get used to it, it is part of it’” (R2). The problem of stigma is also visible in family and could live through generations, as a gynecologist explains: “It is possible the mother has endometriosis as well [unknowingly] […] then she thinks ‘come on, don’t complain, you get this too’” (R9). Stigmatization was enacted by multiple people in patients’ surroundings, such as teachers, family, friends and GPs according to respondents.

While less prevalent within interviews, it became clear a stigmatization and taboo remained on sex. The prevailing taboo is discussed: “I thought there was no taboo on sex here, but you can’t speak about it because it is weird” (R7). Because of this taboo sphere, it was hard to compare and to understand what is normal during sex. One respondent explained: “I think in my teenage years I did not have relaxed and nice sex, but because you grow up, you think this is it, you don’t know something else. Looking back, I realized this was not OK” (R4). The pain during sex was normalized.

Several respondents mentioned that a lack of knowledge on endometriosis is also related to a gender issue in society. In their opinion women are, in multiple ways, still unequal compared to men. Respondents told this was also still the case in health care. As one patient explains: “In the end, it is just a women’s disease, for which there is less attention” (R3). Those thoughts are confirmed by professionals. For instance, it is mentioned that knowledge about women’s biology is lacking: “In general, it lags behind [women biology] […] Ellen Laan […] took care of the anatomy of women’s genitals being placed into them [books], that’s a bit late, right?” (R9). Moreover, research on women is lagging behind and constrained due to subsidies, as a gynecologist explains: “They [women] are underrepresented in most programs the government has for subsidies” (R11). Another patient recognizes a difference in the knowledge on the disease compared to a disease apparent for men too:

> I think it is because it is only for women […] if you look at how much money is spent on diabetes […] but endometriosis is maybe even more common […] that makes it hard, that there is less money for it. (R5)

4.2.2 Narrow anamnesis

Specialized gynecologists mentioned the importance of good anamnesis. This entails a holistic approach. A holistic approach includes, for example, not only understanding symptoms but also the consequences of medical complaints for someone’s life. However, patients explained that anamnesis often remained narrow, namely too focused on menstrual cycles and pain during menstruation. Moreover, no relation was made between other issues patients dealt with, as one respondent explains: “I think it would help if doctors look a bit further than that little piece of the complaints, that they maybe consider something you already had, maybe when you were 12 for instance” (R7). They experienced this especially at the GP. Almost all patients related this to a lack of knowledge on symptoms of endometriosis. Some respondents also related this lack of knowledge to the gender issues described above. One patient explained the lagging knowledge on the woman body compared to the one of men. She described how this influenced to existing knowledge in the physician’s office as there is just less information available. Moreover, patients mentioned the lacking insight in the interrelatedness of symptoms: “The fact that my bowel movement was off AND my menstruation was extreme, those should have been indicators to send me to a gynecologist” (R12).

The view that patients have on narrow anamnesis for the disease, is confirmed by the professionals. The GP explains when she thinks about endometriosis:

> For people having a hard time getting pregnant, people who have many complaints about their menstruation, often related to their cycle. Young people with a lot of belly ache, compared to others a lot of belly ache [...] Or people who have had a pregnancy in the wrong place. (R10)

Comparing these symptoms described by the GP to the long list of medical complaints brought up by patients, it is indeed only a narrow view. Moreover, the general practitioner explained it was hard to understand if someone’s menstruation was normal through anamnesis. A gynecologist recognized that GPs think about endometriosis only very late: “The only group that forms an exception is women with a desire to have children, the rest undergoes a delay” (R11).

The anamnesis was also seen as narrow due to a lack of possibilities for dialogue between the patient and professional, especially at the GP: “It has never been a dialogue between two people, it has always been ‘nothing is wrong, we cannot do anything’, I have never had options […] I think that is very bad” (R3). Through this quote, not only a lack of knowledge on the disease is visible, but also the lack of patient involvement. A cultural factor was moreover mentioned as a reason for a lack of good conversation between doctor and patient:

> I ask specifically for people with a foreign background [...] because they [doctors] don’t listen and I think it is something in the Dutch culture. I experienced that doctors with a foreign background, even if they knew little about endo, were more humane and listened better. (R4)

In contrast, several patients had a positive experience with anamnesis at the specialized Bronovo clinic, as a patient explains: “They ask what your life looks like, they ask about a lot of facets [...] they ask about social and psychological functioning. They really go into consultation with you, really like equals” (R5). Another patient describes the positive feeling derived from the possibility of dialogue and a holistic approach:

> They said you are in the lead and we can tell you what the options are, but you decide the treatment. I thought alright, let’s go, I have never experienced this before […] The trajectory is so extensive, it’s amazing! (R3)

It became clear a more holistic approach to anamnesis was desired, including multiple aspects such as the impact on life. Moreover, a better dialogue between patient and professional was considered as something positive. Those were often experienced to lack, especially at the general practitioner.

4.2.3 Late referral

Related to the narrow anamnesis, is the late referral that was found to be an obstacle. Patients discussed how they would have liked to be referred to someone specialized in endometriosis earlier. They experienced the feeling of begging for further research and doctors without knowledge “keeping” them too long: “After coming to the GP four times with the same complaints and asking for a referral myself because something was wrong, she wrote it. But not on her own initiative” (R3). This problem of referral was especially visible at the general practitioner.

Patients furthermore described they had the feeling that there was some kind of incentive for the professionals, which kept them from referring. However, professionals describe that this is not the case. They refer when they think it is needed. Moreover, there is the possibility for discussion with other professionals and short lines between institutions to ask for advice. This way, specialists can ask for a patient to be referred when they think it is necessary. However, professionals do recognize some problems in referral of patients. As a general practitioner explains what she misses: “A guideline for when to refer or not [...] I would like to hear that from gynecologists [...] because we throw in the pill or an IUD, but when do I have to refer?” (R10). One of the gynecologists mentions that referral to the right specialist could also be improved upon: “I think that is something they [GPs] get stuck in, referrals that do not end up in a clear diagnosis” (R11). This gynecologist reasons it is the result of a lack of knowledge on the symptoms, the disease and the existing referral network. Because of this, the GP spends a lot of time looking for alternative explanations. The lack of using the right regional network was seen as a result of a new way of working, which is still in development. Patients mentioned that they indeed experienced a referral to an unspecialized gynecologist as well, which slowed down the process, confirming this finding.

4.3 The different meanings of a diagnosis

From the interviews, it became clear that patients and professionals ascribe a different meaning to getting a diagnosis. For patients, a diagnosis is important to feel acknowledgement and to receive the access to the right care. Typically, they started having problems when in their young teens and ended up being diagnosed in the young twenties. Respondents thus had been looking for a diagnosis for somewhat around 10 years. Professionals, however, do not always see the necessity for a diagnosis before starting with hormonal treatment. They do recognize the importance of a diagnosis for acknowledgement.

4.3.1 Access to care

Getting a diagnosis was important for almost all patients to receive the right physical treatment. Here, a clear tension between professionals and patients was found. Patients first want to be diagnosed, whereas a GP sees often sees no problem in treatment without a clear diagnosis.

Patients described having had the prescription of hormonal treatment by the GP before getting diagnosed. This was often done to treat the pain related to menstruations which patients dealt with. One gynecologist did not consider this problematic: “Often the GP treats patients right by putting them on the pill continuously or placing an IUD, which is a good treatment for endometriosis” (R9). The general practitioner explains further how handling without a diagnosis is not a problem to her:

> When people have problems related to their menstrual cycle, a lot of blood loss or pain surrounding the menstruation, it can be endometriosis. It can also be PMS, but for women

> treatment is the pill, an IUD: so, hormones. So, we GPs prescribe hormones […] So, there is a large group who you don't officially diagnose [...] Because you are already treating it, without thinking you're dealing with this disease. (R10)

Patients, on the other hand, did not see this treatment without diagnosis as the right way to go about. They often described the normalized use of the pill as something they did not like, especially without being diagnosed. As one patient describes: "It was like, 'oh yeah, you should just take the pill' [...] But I read things, or heard things from people, or articles, that the pill can do quite a lot of damage" (R12). Patients moreover explained they were more willing to take hormonal treatment when a diagnosis was clear. Then, they were sure it was really necessary.

Maybe even more important, the start of hormonal treatment postponed the diagnosis. This while patients were still coping with other, often inexplicable, medical complaints when under hormonal treatment without a diagnosis. Especially complaints related to the bowel, for which they continued to look for an explanation. Other complaints, such pain and fatigue remained too, continuously influencing patient's lives: "It wasn't easy, not only during menstruation, but also after and when you're taking the pill. You have complaints then too" (R6). Patients described how they needed a diagnosis to create understanding of all interrelated complaints they dealt with, as this patient also describes "I think that the delayed diagnosis made that worse, all those side effects and everything you have to do to maintain those" (R7). A diagnosis was thus needed to take care of all interrelated medical complaints. This while hormonal treatment without a diagnosis just relieved part of the pain experienced and only for some respondents. Moreover, hormonal treatment would not always stop the progression of endometriosis entirely: "it put a mask over the symptoms for a long time […] I am all for it that people take hormonal treatment against pain, however, I think it is really worrisome for the progression of the disease [without diagnosis]" (R4). Several respondents explained the onset of their endometriosis did not stop entirely by taking hormones. Professionals described to recognize such physical consequences for some patients they had seen.

It is striking that on the one hand professionals see no problem in treatment without diagnosis, while on the other hand, they say a diagnosis is relevant. For instance, the GP mentions: "The only thing with endometriosis [compared to PMS] is that you can say I really advise to use an IUD or continuously use the pill, because you won't menstruate anymore" (R10). Moreover, she relates this to prevention of later problems, which is not relevant for PMS. In the end, there is thus a difference in the treatment for patients with PMS and endometriosis. As for patients with endometriosis, it is important to menstruate as little as possible, while this is not really necessary for patients with PMS. It seems like it is thus relevant to diagnose or at least to be aware of the possibility it is the disease before starting treatment. This to be able to apply the right treatment. One gynecologist explained it is a good thing the GP can start treatment, however, there is an importance of diagnosing at the same time. Moreover, the suspicion of the disease should increase too, GPs should think about it more often according to him. Therefore, he says, GPs should be helped to understand the importance of a diagnosis and be helped to set the diagnosis themselves. Another gynecologist agreed that there should especially be more awareness of endometriosis under GPs. She described how some patients were not put on hormonal treatment and ended up with deep, infiltrating endometriosis. However, she also described that she thought GP is often treating patients without a diagnosis right by prescribing hormones continuously or an IUD. She moreover related the importance of a diagnosis more to the question of the patient that should be understood. When patients are looking for a diagnosis, doctors should help to do so. From the interviews, it was clear that patients were looking for a diagnosis. In the end, there is thus a tension where patients and some professionals included do not fully agree on the importance of a diagnosis for the right treatment.

4.3.2 Acknowledgement

Getting the actual diagnosis seemed of great importance for all participants. Patients described how getting their diagnosis was not only helping them in getting physical treatment, but also had a mental aspect of acknowledgement to it. Patients explain that they often felt like an attention seeker or a poser while in the long diagnostic process. Some respondents mentioned an experience with being called out for poser or attention seeker explicitly. Other times, the feeling of such resulted from the experience of not being taken seriously and underestimation of pain by others: “I just recognized they were not taking me seriously, she [the GP] really thought of me as a poser” (R12). A diagnosis would help patients to receive more acknowledgement in such situations according to them.

Respondents also said that both their loved ones and the medical professionals underestimated the pain they felt: “You have the pain and then even the GP does not understand you … It feels like no one has it, like you are the only one […] Sometimes you are really just so done with it all” (R1). The remaining stigma on menstruation related pain meant patients needed a diagnosis to get rid of the underestimation of pain they felt. Some patients received a misdiagnosis during the process and were told their medical complaints were related to stress or a psychological aspect. This also resulted in the experience of not being taken seriously for them.

As a result of not receiving enough acknowledgement, serious consequences were mentioned. For instance, the lack of mental support, as will be further discussed in paragraph 4.4. Next to this, self-doubt and social problems were described. Multiple women described a lack of acknowledgement resulting in moments where they even started doubting their own pain: “I got surgery at the end of January and thought what if I don’t have it? After some time, you start to doubt yourself. Am I really not exaggerating?” (R2) “I only thought my threshold of pain must be very low […] and when the GP said it was related to menstruation, I thought OK it is really me” (R8). Moreover, as explained in paragraph 4.1, patients experience many consequences in their daily lives. For instance, the loss of friends and family members as they will not believe the amount of pain. One respondent mentioned a diagnosis helped her, as surroundings took her more seriously after.

Patients described how professionals sometimes gave them the feeling of not being taken seriously. The professionals included in this research explicitly recognized that patients sometimes feel this way: “It is often discarded as heavy menstruation [...] and I think that that group might not feel acknowledged […] If you know what it is you have, it gives acknowledgement and peace” (R10). The GP outlined how there is a struggle between the pragmatic work of GPs (i.e. starting hormonal treatment without diagnosis) and the need for acknowledgement that most patients have.

4.4 Missing support

To improve the long process, it was considered what support is available and what might be missing. From the interviews, it was clear that mental support during a long diagnostic process should be improved. Moreover, there was the insight that a diagnosis after such a long process results in the feeling of falling into a black hole. This resulted in the idea that support after diagnosis could also be improved.

4.4.1 Mental support

During the process, patients especially experienced a lack of mental support. The consequences of a long diagnostic process involved periods of uncertainty, the feeling of not being taken seriously, fear, depression, self-blame and social problems. These as a result of the obstacles and an ongoing long process, discussed in the sections above. For instance, the ongoing medical complaints and effects on the daily lives of patients, but also the narrow anamnesis or lack in acknowledgement. Moreover, patients related these consequences to culture and the invisibility of the disease: “You don’t see it from the outside, and that is so hard within the Dutch society. People tend to say you’re not ill, because they cannot see you’re ill” (R7). Thus, delay and many factors in the long diagnostic process explain why patients experience negative effects. As a result, patients felt the need for mental support during the process:

> It would have been nice, when I had to wait for surgery, when so much was unclear, if they had called to ask whether I wanted to talk to someone. Just to know that the option was there, that would have been nice. (R1)

Next to this, mental support on how to go about in life with the medical complaints was experienced as something desirable. Especially because it was hard to deal with the physical constraints: “At a certain moment my life paused, because I was literally disabled, I could not function” (R4). One patient confirms those types of support helped when she had no diagnosis yet:

> But when I got to the medical psychologist […] that was the first one who acknowledged my physical pain […] he said: ‘you just can’t do that when you have so much pain […] if you want to move, go for a walk half an hour per day’ […] that is what really helped me in the end. (R5)

4.4.2 Black hole after diagnosis

Surprising was the amount of comments made on support desired after the diagnosis, leading to the realization that the process does not end with a diagnosis. As one patient explained “I got diagnosed and then it stopped […] I fell into a black hole and received no further information or tips” (R2). There is a need for holistic support after the diagnosis as patients describe to deal with a lot of haziness at that moment. Patients describe being in the process for a long time and suddenly receiving a diagnosis. However, there is a lack of information on how to proceed:

> A friend of mine tucked it away and now has a trauma [...] then you are actually too late [...] It would have been nicer if doctors have better collaborations for people who get the diagnosis. Like it sucks, but we can refer you to a psychologist who can help. I will help you with processing it, how you deal with it in daily life, how to tell your employer. (R7)

The patients included had a hard time finding their way through the medical landscape as they had to ask for everything themselves. That this is the organization of health care is confirmed by professionals. Gynecologists state most often psychological help goes through the GP. The general practitioner, in turn, described how referral to mental health is given after patients ask for it.

Multiple other patients described how the diagnosis led to an information overload as they just received the diagnosis: “Now they all tell it when you just had surgery, you are not clear minded, so you don’t store it well. It would have been better if they sent it, like in a document” (R1) or “Yeah Adenomyosis […] I thought Jeez, can you put this in an email or a flier? What are the steps and treatment plans? [...] It is just a lot of info, it was just blanc at that moment” (R12). The respondents mentioned how they would like to have information black on white, on a piece of paper or an email. While gynecologists described this was available at their hospital, most patients missed a handover of information in their experience.

Again, several patients that received treatment at Bronovo described how their experience was better than in the ‘general’ hospital. They got introduced to the existence of a patient journey app. The app provides information at each step, offers treatment possibilities and contact details:

"you have a whole app with a care path. You can find really everything in it" (R5). Thus, there is a clear differentiation between patients who did and did not receive treatment at a specialized center.

4.5 Improvement areas

For improvement of the process, different possibilities were discussed. Those possibilities are visible on three levels. First, on a societal level, where mostly education is needed. Second, on the level of professionals. On this level, education and guidelines can be improved. Third, patients could be facilitated better to have an active role in the diagnosis process.

4.5.1 Education for society

Regarding education in society as a whole, it was mentioned that this could be improved by better biology classes in school, involving more information on menstruation and what problems can occur for people that menstruate: "I think improvement can be made at school […] because it is something that is common. You cannot just say your cycle is 28 to 32 days" (R4). As a result of this education, the understanding of problems that patients experience could improve. This might result in better support by surroundings. Moreover, according to respondents, it could help to reduce taboo and thereby stigmatization of pain:

> I thought at first only for girls, but now I think it is very important to make it known to a whole group. Boys, girls and everything in between. Because it is important for men and people who do not menstruate, like what happens [...] Women menstruate every month […] You can't act like it does not happen and shove it under the carpet. So, I think that needs to be there first, education on the women's body and what complications can arise if you menstruate. (R12)

As one gynecologist explained, biology classes would be helpful: "These kinds of educational projects [in New Zealand] [...] they serve as inspiration. You see that women go to the doctor more easily and get a diagnosis faster if they have the disease" (R11). Thereby, biology classes could lead to better realization under patients that something is wrong.

To educate society on the understanding of a normal menstruation an existing app was also mentioned by a gynecologist. He explains that this app is a tool to check whether your menstruation is considered normal, for instance by entering the amount of blood lost. Both professionals and patients mentioned it was hard to understand what is a normal menstruation. This, due to the existing stigma and the difficulty to understand someone's menstruation through anamnesis. Therefore, such tools might also be helpful during the consult, as the gynecologist explained. Tools could also be helpful for patient activation during the consult, as explained below. To reach a broader public on the existence of this app and other educational websites, multiple respondents mentioned (social) media campaigns as a possible solution.

4.5.2 Education and guidelines for professionals

All patients and professionals agree that education for GPs can improve on the subject. One gynecologist mentioned: “further training is needed for GPs to point out the importance of a diagnosis” (R11). All professionals agree that GPs can start treatment themselves. However, the gynecologist and patients find that there is a need for improvement to first diagnose. All agree there should be more awareness for the possibility of endometriosis being present. One gynecologist explained “I am not sure how much education GPs receive on endometriosis. Maybe we have a task ahead of us too, we do have moments of education with GPs, but not about endometriosis yet” (R9). Another explained that training for GPs is currently in development. Thus, there is a need to teach GPs more awareness on endometriosis and the importance of a diagnosis. For this, they will also need to be taught on recognizing the disease better, through a more holistic view on symptoms and consequences. Moreover, attention could be given to when and to who to refer.

Apart from training, there is another way to help GPs in their anamnesis and understanding of the need for referral. The NHG guidelines could be improved for this (guidelines for GPs). Currently, the guidelines are not providing one clear section for this subject (Bauma et al., 2012; Bauma et al., 2015; Bauma et al., 2020). The general practitioner mentioned a better guideline for referral would be helpful. Gynecologists and patients explain that anamnesis needs to become more holistic and that alarm symptoms, such as absenteeism, need to be known better. As the GP explained the NHG guidelines predominantly help her with referral, diagnosis and treatment, improving those guidelines could help. First, a holistic overview of symptoms and consequences could be provided. Including interrelatedness of symptoms and the importance to diagnose or be aware of the disease. Second, it should be explained when and to who to refer. Third, guidelines inform on treatment. Those could be improved on providing information on support during a long process for patients with such complaints. Such as supporting patients by offering mental support. Next to this, it could include how to support patients after diagnosis in the way they desire. Thus, mainly by giving retrievable information. This last point could also be improved upon at gynecologists. However, it remained unclear how exactly. The GP described the placement of such guidelines would fit best under problems with menstruation, low stomach ache for young women or women in general.

The general practitioner moreover mentioned that training can be done in the areas of interest, which might not entail diseases like endometriosis. A professional also explained the education of gynecologists in training is dependent on the “cluster”. For instance, the gynecologists in training for the hospital in Delft, receive education in the cluster of Rotterdam and Leiden. Those clusters both have educators specialized in endometriosis. Such an organization is thus very decentralized and could result in differences of knowledge between professionals. Thus, some centralization on in education might be desired, however, this needs further exploration.

4.5.3 Patient activation

According to respondents an active patient is considered one that comes to a doctor’s visit prepared. Someone, who has done own research and is able to tell a clear story, ask questions and sometimes even proposes a disease. Such a patient was seen as one that could reduce delay by both professionals and patients. As one patient explains: “I think that’s it. Because you are the one saying, ‘I think this is it’, only then real steps are made” (R12). Multiple patients described that mentioning endometriosis themselves had helped them to speed up the process. The GP confirmed that patients sometimes come up with a diagnosis she had not thought about before. Furthermore, she mentioned how an active patient could help to align the goals of a consult: “Yes, if patients can find objective information themselves, it helps. When patients bring it up, because then you directly know what patients want and need” (R10). This could help to clarify the need of a diagnosis for patients. Next to this, multiple patients mentioned how a more active role for them would result in a feeling of being taken seriously, how it could help to paint a complete picture of medical complaints and provide for better dialogue. Again, the GP confirms: “It can help when people actively did research, because I will understand their story better. What does it fit with? Or you can think, it does not fit at all with this” (R10). In conclusion, increasing patient activation was considered relevant.

Multiple possibilities to increase patient activation were discussed. Patients mentioned how a checklist could help. One respondent compared it to the checklist for Covid-19 she had to fill out before her visit. The existing checklist on the website of Endometriose in Balans was seen as a useful tool by patients when visiting the GP. Professionals acknowledged the usefulness of a checklist before visiting. As was mentioned before, an app giving insight on one’s menstruation could also be a useful tool to discuss. Another solution was keeping a diary for a few weeks. Last, the website thuisarts.nl came up to activate patients: “I think you are pointed to the websites, on the phone with a tape. Like ‘you can check your medical complaints on thuisarts.nl’, that is a good website” (R10). On thuisarts.nl, information on endometriosis is actually quite extensive (Thuisarts.nl, 2021). The website even links to Endometriose in Balans and suggests keeping a diary (Ibid.). It seems like tools to help patients to become activated, and thereby the consult, are available but are not used enough yet. Knowledge on such tools under patients might thus need to be improved. Again, (social) media campaigns were mentioned to increase awareness of information and tools by multiple respondents.

Chapter 5: Conclusion and discussion

In this final chapter, the conclusion and discussion are presented. First, the sub-questions are answered, after which an answer to the main research question is provided. Then, the findings are reflected on through discussion. After, limitations of the current research and suggestions for further research are provided. Last, the implications of the findings are described.

5.1 Answer to the research questions

5.1.1 Sub-question 1

How do patients, gynecologists, and general practitioners experience the diagnostic process of endometriosis?

Both similarities and differences were found in the experience of patients and professionals during the diagnostic process. Patients describe different medical complaints, which have consequences for their daily lives. Those influence, for instance, their school, social life, and mental health. Moreover, several obstacles in coming to a diagnosis were experienced. First, the remaining stigmatization, taboo, and gender issues surrounding the disease. Professionals and patients agreed on the endurance of such issues. However, patients also described that professionals enacted such stigmas. Second is the narrow anamnesis, especially at the GP. Gynecologists and patients agree that holistic anamnesis is necessary but is currently lacking. A GP mentioned only limited symptoms as alarming for endometriosis, which confirmed the anamnesis is narrow. Third, patients experience a delay in referral to specialized care. A GP explained she now misses understanding of when to refer. One gynecologist described how referral to the right specialist could be improved upon too.

Next to these obstacles, the meaning of a diagnosis was not entirely the same for patients and professionals. Patients find it important to get a diagnosis first while a GP explains that hormonal treatment could also be started without a diagnosis. The consequences of hormonal treatment without a diagnosis are physical and mental for patients. Physically, patients still experience endometriosis-related complaints, for which they have no explanation. Moreover, the complaints still developed worse for some. Mentally, patients experience a lack of acknowledgment. This has serious consequences, such as self-doubt. Those mental consequences are recognized by professionals too, while physical consequences less so. Due to those consequences, patients wish to be diagnosed first. Professionals did not agree entirely on when setting a diagnosis was needed. As noted, the GP mentioned hormonal treatment could be started before diagnosing. However, this GP seems to contradict herself when explaining the similarity in treatment of different diseases related to menstruation. In the end, treatments appeared to be different. Because of this contradiction, it appears relevant to diagnose before starting treatment. One gynecologist explained how a diagnosis should be looked for if patients wish to have one. Another mentioned the need for a diagnosis. He describes that setting a diagnosis should be improved at the GP, followed by or parallel with the initial treatment. However, both described the need for more awareness of the disease. Thus, there is some discrepancy among professionals regarding when there is a need to diagnose.

Last, patients encounter a feeling of missing support. This included mental support during the process and primarily practical support directly after. Professionals describe there is availability of information and help after getting diagnosed. They agree that mental support is fragmented, as there is a need to refer back to the GP, who can then refer to a psychologist. The professionals included in this research said to provide information after diagnosis, while patient respondents described missing this in their experiences. In particular, retrievable information, such as an email or flier, was lacking for them.

5.1.2 Sub-question 2

How can the diagnostic process of endometriosis be accelerated?

Three key areas were found that could accelerate the diagnostic process. First, educating society through improving biology classes on menstruation and possible problems around it. This could lead to better understanding, reducing societal issues such as stigma and better awareness of when something is wrong by patients. The improved introduction of an app could also help to educate on what is a normal menstruation. Second, the education and guidelines for professionals can be improved. Training on endometriosis for GPs can be provided. This could include emphasizing the need for diagnosing and create more awareness for the disease. Guidelines, such as the NHG standards, can be improved by providing more holistic information on symptoms and consequences of endometriosis. Moreover, A GP explained the need for more information in when to refer to a specialist. Here, it could also be included better to what specialist should be referred. Last, it was experienced that patients could play a more active role in the process. Patient activation is seen as desirable in accelerating the process. Active patients result in a better understanding of the patient by the GP or could even help the GP to consider endometriosis. Different tools could help patients and thereby better interaction during consults. An example would be a checklist comparable to one used for Covid-19. However, more awareness for those tools is needed, for which (social) media campaigns might be a solution.

5.1.3 Sub-question 3

How can patients' experience be improved during a long diagnostic process?

Delay, obstacles, conflicts, and lack of support presented influence patients' experiences, as seen from the result section. The three key improvement areas presented in this research can help accelerate the process and improve the experience for patients. Better education for society can improve the experience, as stigmatization and taboo can be reduced in this way. In turn, that could lead to a deeper understanding of what patients go through by surroundings and thereby improved support. Education for professionals can again help to reduce stigma and thereby an increased understanding of patients. Moreover, improvement in their anamnesis through education can help patients' experience through feeling heard better and being taken more seriously. Education in guidelines, such as the NHG, on how to support patients, could improve the experience too. Especially, offering mental support is needed more often. Furthermore, a long process, with a sudden diagnosis results in the feeling of falling into a black hole after diagnosis. Guidelines could include the handover of retrievable information to patients to counter this. The NHG guidelines could include encourage GPs to do this. How to reach gynecologists on this topic, remained unclear. Last, patient activation can improve the experience as it could result in the feeling of being taken seriously, having better dialogue during the consult and being able give a more complete insight in medical complaints.

5.1.4 Main research question

How do patients, gynecologists, and general practitioners experience the diagnostic process of endometriosis and how can this process be improved according to them?

A qualitative study was performed on patients, gynecologists, and a general practitioner to answer the main question. All had experience with the Dutch health care system. Through the results, it was understood that patients experience various medical complaints, which influence their daily lives. Patients and professionals agree on the experience of some obstacles in the diagnostic process. Those obstacles include stigmatization and gender issues, narrow anamnesis, and late referral. Moreover, a tension appeared in the need of a diagnosis before starting hormonal treatment. Last, a lack of support was described by patients. This included both mental and practical support that provided room for improvement. According to patients, gynecologists, and a GP, the diagnostic process can be improved in three key areas. Those areas are the improvement of education for society, education for professionals and assisting the activation of patients.

5.2 Discussion of the results

This study considered how the diagnostic process of endometriosis could be improved. Previous studies show that reasons for delay generally fall into four categories; the category of the disease, the patient, the system, and the physician (Walter et al., 2012; Zwaan & Singh, 2015; Van der Zanden, n.d.; NASEM, 2015). Those suggestions are only partially supported by the current study's findings. Some obstacles in the process fall within those four categories. However, this paper highlighted how the stigmatization of menstruation and gender issues play a pivotal role. Therefore, the existing categories are not broad enough. More comprehensive would be to add 'societal context' as another overarching category that influences the other four. This category could include processes such as stigmatization and gender issues.

Stigma on menstruation means that the pain patients experience is normalized by different people involved in working towards a diagnosis (Sims et al., 2021). This results not only in a diagnostic delay but also in severe issues for patients. They experience a feeling of being a poser or attention seeker. For some, this even results in such vulnerability that respondents start doubting themselves and the pain they experience. Self-doubt occurs while medical complaints severely influence their daily lives to a point some explain the feeling of a pause in their lives or not feeling part of society any longer. Stigmatization was not only the cause of such feelings but was also continuously confirming them. For instance, through conversations with professionals who told patients they were posing. Or friends who compared their menstruation to the ones of patients, downplaying the complaints patients deal with. Imagine the feeling when a doctor, a person with expertise, tells you that your pain cannot be so bad. The stigma is even passed on through generations, as mothers might experience the pain without knowing they have endometriosis. They unknowingly normalize living in pain for their children. Stigmatization therefore also affected how supported patients felt during the process, influencing their overall well-being. This suggests that societal context factors, such as this stigma, also play a role in SPF theory. As the current stigma influences how much of the resource 'empathy' patients receive, for example (Nieboer et al., 2005; Nieboer & Cramm, 2018). Therefore, it could be concluded that societal context would not only be a useful addition to the four categories influencing patient delay but also to the SPF model, as it is currently lacking here too (Ibid.).

In addition, research on female anatomy is lagging behind, which was also highlighted by respondents (ZonMW, 2016; ZonMW, 2022; Alcalde-Rubio et al., 2020; Tulp, 2021). Women and men are not the same and their diseases or reaction to treatment is neither. However, knowledge and research based on women is lacking compared to research and knowledge based on men (Ibid.). Moreover, the knowledge acquired about women lacks implementation in, for instance, school modules (ZonMW, 2016). Those issues are due to, among other things, the stigmas surrounding women-specific diseases, blind spots for lacking research, the late movement towards research, and education including gender-specificity and gender issues in society (ZonMW, 2016; ZonMW, 2022; Alcalde-Rubio et al., 2020; Tulp, 2021). Gender issues remain in society and are recognized by respondents too. The Netherlands currently ranks 31st out of 156 countries on the gender gap index (World Economic Forum, 2021). With a score of 0.762, there is still a long way (0.238) to close the gap. Gender issues may thus be a reason for a current lack of research, it is also something that is still visible today. It is suggested that the lack of embedding of women-specific subjects in ZonMW programs is why only two research papers funded by this organization currently focus on endometriosis. ZonMW is an organization that provides subsidies for research and works in collaboration with the Dutch government (ZonMW, 2016; ZonMW, 2022; Alcalde-Rubio et al., 2020; Tulp, 202).

Stigma, the lack of focus on women in research, and pertaining gender issues make endometriosis an almost invisible disease. This ‘societal context category’ has an overarching influence on the issues in the four categories leading to a diagnostic delay and influences the well-being of patients through resources, activities, and health care services (Sims et al., 2021; Walter et al., 2012; Zwaan & Singh, 2015; Van der Zanden, n.d.; NASEM, 2015; Nieboer et al., 2005; Nieboer & Cramm, 2018). The following examples explain further how the societal context is relevant; for instance, the insufficient attention for women in research influences GPs’ education, a health care system design, and could thereby lead to a lack of awareness of endometriosis and narrow anamnesis (Ibid.). Another example in the patient category could be a patient disclosing information when visiting the GP (Ibid.). However, those existing societal context issues influence how patients are educated, how taboo is apparent, and how stigma influences them. As shown here, societal context is not limited to influencing patients and health care providers but also influences the system and the disease category. Thus, the reasons for a delay in the diagnostic process of endometriosis go beyond four categories. There are larger issues at play, fitting in a ‘societal context’ category, which influence how things are organized and pertained in all four of the other categories. The same can be recognized in support of patients when related to SPF theory, as was exemplified above (Nieboer et al., 2005; Nieboer & Cramm, 2018). More complex interrelations are apparent, in which society has a pivotal role. As a result, points for improvement go beyond the resources, activities, and health care services as well (Ibid.). Thus, improvements cannot be limited to fit within the four existing categories, resources, activities, and health care services, they should also exist on a societal level. For instance, education should not be limited to patients or professionals but should address society as a whole.

It is also because of these societal issues that women experience during their process that getting a diagnosis is just so crucial for them. Not only does getting a diagnosis help to understand their bodies again, by being able to link all interrelated medical complaints. Receiving a diagnosis also helps patients to feel acknowledged. Moving to a moment where it is realized they are not posers or attention seekers. A moment where they can stop to doubt the pain they experience. They can explain to themselves and their surroundings that something is actually wrong. It is a maybe even paradoxical situation, where getting diagnosed with a disease leads to the feeling of relief and a positive turning point in patients' lives. This clarifies why hormonal treatment is not seen as a good solution for undiagnosed patients, as it delays their diagnosis. It highlights yet again the importance of reducing delay for patients (Pita-Fernández et al., 2013; Staal et al., 2016; Nnoaham et al., 2011; Husby et al., 2003; Seear, 2009). Improving constraints in the societal context might reduce delay. However, reducing delay is also important for patients to deal with issues resulting from the societal context they currently deal with (Ibid.).

5.3 Limitations, further research and practical implications

5.3.1 Limitations

This research has several limitations that should be taken into account. The research was constructed in a limited amount of time. Therefore, several methodological limitations exist, influencing the validity and trustworthiness of the paper (Mays & Pope, 2000). For instance, the small number of participants included and limited triangulation that occurred. Moreover, generalizability is low due to, again, the small number of participants and the qualitative nature of the research. The respondents were gathered through social media, which excluded part of the representative sample group (Babbie, 2008). This, as not all patients might have social media accounts or might have been reached on the channels and pages used. Moreover, some researcher reflexivity reveals possible limitations. The researcher is part of a family where endometriosis is common. While the researcher has tried to keep an objective perspective, it should be mentioned that personal knowledge could have led to some bias. On the other hand, this knowledge also resulted in a deep understanding of the patient's experiences. Last, the research was limited to the Dutch health care system. Therefore, the findings might not be applicable in an international context as not each health care and societal context is similar. Therefore, differences in obstacles resulting in delay and points for improvement may exist.

5.3.2 Recommendations for further research

Several recommendations for future research arose during the study. As can be concluded from the limitations, methodological improvements in future research might lead to more valid and trustworthy results. Therefore, studies with, for instance, more participants would be beneficial. Next to this, it was found that the education of professionals was decentralized. Future studies could explore this in further depth to indicate whether the centralization of education would be a valuable addition to improving the diagnostic process of endometriosis and other diseases. Second, multiple comments were made on patients relating to 'the Dutch culture' and 'ability to listen' influencing the diagnostic process. This topic as societal context factor was touched upon only lightly in the current paper. Therefore, it would be insightful to understand this in further depth. Cross-cultural studies could also be interesting for some comparison and possible improvement. Third, it can be explored whether stigmatization, prejudice, or gender issues play a role in other diseases that deal with the delay. Endometriosis is one example of a disease for which diagnostic delay is an issue. A future investigation could reveal whether other diseases encountering delay due to such issues can profit from similar improvement points. Last, but importantly, there is a need to explore further how to counter stigmatization and gender issues in society. As a result, not only delay may be countered, but patients might experience better support.

5.3.3 Practical implications

Currently, the development of training for GPs on the topic of endometriosis is in development. This research might contribute to a better understanding of what is needed in such trainings. For example, these could include better information on (the interrelation of) different symptoms, the importance of diagnosing, and improving the understanding of how and when to refer for GPs.

Moreover, the knowledge provided could form the basis for forming a new guideline. A guideline was mostly used for diagnosis, treatment and referral. On those parts, the guideline could be improved as described in the result section. For instance, it could be outlined clearly when GPs need to refer to a specialist what kind of specialist specifically.

Next, this paper could induce change in biology classes that include women's anatomy in a better way. For instance, by explaining for extensively what menstruation entails and what complications could be related to it. This could be a step to counter the stigmatization of menstruation and gender issues. Moreover, it could help women to better understand what is normal.

Furthermore, a (social) media campaign might help to reach people on the different tools that exist. This can help patients during their consult and their consideration to visit the general practitioner. A (social) media campaign on different tools could thus be constructed.

Last, this paper highlighted the importance of more equality for women in research (and in general). More research could help to close the gap in knowledge about women's anatomy. However, better embedding women-specific diseases in the context of research programs is needed, which requires relevant organizations to act on this problem (ZonMW, 2016; ZonMW, 2022).

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Appendices

Appendix A: Interview guide

A.1 Patient interview

Introductie
Zelf voorstellen en vertellen over het doel van het interview en het onderzoek. Vertellen dat het wordt opgenomen. Vragen of ze anoniem wil blijven.

Introductie patiënt
- Kun je iets over jezelf vertellen?
- Hoe lang geleden heb je de diagnose gekregen?

Beleving van het diagnose proces
De eerste vragen gaan vooral over jouw ervaring in het diagnose proces

- Zou je mij misschien iets meer kunnen vertellen over jouw ervaring in het diagnose proces van endometriose? Hoe begon het allemaal?
    - Wanneer de eerste klachten?
    - Wat heb je toen gedaan?
    - Direct actie ondernomen?
    - Waarom wel of niet
    - Wanneer ben je naar een huisarts gegaan
    - Hoe ging het daar? Alles verteld?
    - Wat heeft de huisarts verteld?
    - Wat voor onderzoeken hebben plaatsgevonden?
    - Feedback tussen huisarts en gynaecoloog?
- Was dit anders dan andere ervaringen die je had met naar de huisarts gaan? Op welke manier?
- Hoe bekend was je met endometriose voordat je de diagnose kreeg?
    - Hoe heeft dit het proces beïnvloed?
- Hoe voel je je over deze ervaring?
    - Negatief/Positief
- Waarom denk je dat het zo lang/kort duurde voordat de diagnose er was?
    - Waar hebben deze problemen mee te maken?
- Hoe vind je dat endometriose vertegenwoordigd is in de gezondheidszorg?

Verbeteren van het proces
De volgende vragen gaan over het verbeteren van het proces.

- Wat zou jij willen voorstellen om het proces te kunnen verbeteren?
    - Systeem
    - Taboe
- Hoe denk je dat professionals zoals huisartsen geholpen kunnen worden om de diagnose sneller te stellen?
- Zouden patiënten ook iets kunnen verbeteren om een snellere diagnose te realiseren?
    - Zo ja, wat denk je?
- Waarom denk je dat deze verbeteringen nog niet zijn doorgevoerd?
- Wat vind je van de internationale aandacht die er laatst is geweest voor het onderwerp?
    - Denk je dat wij daar iets van kunnen leren?

Ondersteuning

De volgende vragen gaan over ondersteuning van de patiënt tijdens het diagnose proces.

- Welke consequenties/gevolgen heeft endometriose voor jou?
- Wat zijn de consequenties van dit langer proces? Welke zijn ontstaan door dit lange proces?
    - Fysiek/mentaal
    - Sociaal
- Heb je ondersteuning gehad in het proces?
- Had je graag ondersteuning gehad gedurende het diagnose proces?
    - Zo ja, welke?
- Wat zou je tegen andere vrouwen zeggen die nu in dit proces zitten?

Afronding

Nog wat laatste vragen.

- Welke veranderingen hoop je in de nabije toekomst te zien rondom endometriose?
- Zijn er vragen die je professionals zou willen stellen?
- Zijn volgens jou alle relevante dingen besproken?
- Zou ik je nog mogen benaderen als ik nog verdere vragen heb?

A.2 Gynecologist interview

Introductie
Zelf voorstellen en vertellen over het doel van het interview en het onderzoek. Vertellen dat het wordt opgenomen. Vragen of ze anoniem wil blijven.

Introductie professional

- Kunt u iets over uzelf vertellen?
- Hoeveel patiënten per jaar ziet u met endometriose?
    - Overeenkomst met 10%

Beleving van het proces
De volgende vragen gaan over het proces van de diagnose van endometriose.

- Hoe ziet een proces van diagnose eruit voor endometriose?
    - Een voorbeeld van een moeilijk of makkelijk proces uit de praktijk?
    - Wat is er moeilijk aan het stellen van deze diagnose?
- Wat voor ervaringen heeft u vooral met de diagnose processen van endometriose patiënten?
    - Negatief/positief
    - Waarom

Het systeem
De volgende vragen gaan over de opzet van de gezondheidszorg in Nederland.

- Wat heeft u geleerd over endometriose tijdens uw opleiding?
    - Verhouding tot andere ziektebeelden
    - Bijscholing
    - Wanneer denkt u aan endometriose bij een patiënt?
- Wat vindt u van de huidige plaatsing van endometriose in het zorglandschap?
    - Genoeg aandacht
    - Genoeg kennis
    - Scholing
- Wat doet u wanneer het lastig is om een diagnose te stellen in het algemeen?
    - NHG
    - Contact met anderen
    - Wat is de rol van een patiënt in het stellen van een diagnose
- Kunt u iets vertellen over het contact tussen u en andere artsen?
    - Huisarts
    - Doorverwijzen
    - Welke manier is er contact
    - Wat vindt u hiervan
- Hoe is feedback geïntegreerd in de huidige gezondheidszorg?
    - Tussen professionals
    - Vanuit Patiënten
    - Patient related outcome measurements
- Wat gebeurt er zodra iemand de diagnose krijg?
    - Ondersteuning
    - Tips
    - Relaties met andere instellingen
- Wat is de rol van het ziekenhuis/de overheid in het bepalen van een behandelplan of doorsturen van een patiënt?
    - Geld
    - Kunnen artsen ergens feedback geven over het zorgsysteem?

- Wat is de rol van een patiënt in het stellen van een diagnose?
    - Wat vindt u hiervan?

Verbeteren van het proces

De volgende vragen gaan over hoe het proces verbeterd zou kunnen worden en hoe artsen hierbij geholpen zouden kunnen worden.

- Waarom denkt u dat de diagnose voor patiënten vaak zo lang duurt?
    - Waar zijn deze problemen aan gerelateerd?
    - Systeem
    - Taboe/stigma
    - Rol patiënt
- Wat denkt u dat zou helpen om het proces te kunnen verbeteren of versnellen?
    - Wat zou u helpen?
    - Samenwerking
    - Patiënten betrekken
    - Feedback
    - Mogelijkheden om te leren
    - Technologie voor informatie etc.
    - Heeft u een ideaalbeeld over een diagnose of consult?
- Waarom/Hoe zouden deze suggesties helpen?
- Wat denkt u dat de reden is dat deze suggesties nog niet zijn doorgevoerd?
    - Waarom denkt u dat er zo weinig bekend is over endometriose?
- Hoe denkt u over de internationale aandacht voor het onderwerp?
    - Kunnen wij daar iets van leren?
    - Zelfde of andere aanpak nodig?

Gevolgen voor patiënten

- Merkt u gevolgen bij patiënten die de diagnose krijgen?
    - Mentaal
    - Sociaal
    - Fysiek
- Wat denkt u dat hen zou kunnen helpen tijdens of na de diagnose?

Afronding

Nog wat laatste vragen.

- Welke veranderingen hoopt u in de nabije toekomst te zien rondom endometriose?
- Zijn volgens u alle relevante dingen besproken?
- Zou ik u nog mogen benaderen als ik nog verdere vragen heb?

A.3 General practitioner interview

Introductie

Zelf voorstellen en vertellen over het doel van het interview en het onderzoek. Vertellen dat het wordt opgenomen. Vragen of ze anoniem wil blijven.

Introductie professional

- Kunt u iets over uzelf vertellen?
- Hoeveel patiënten per jaar ziet u met (een verdenking van) endometriose?

Beleving van het proces

De volgende vragen gaan over het proces van de diagnose van endometriose.

- Wanneer denkt u aan de diagnose endometriose?
    - Wat is er moeilijk aan het stellen van deze diagnose?
- Hoe ziet een diagnoseproces rondom endometriose eruit?
    - Wat wordt verteld aan de patiënt?
- Wat voor ervaringen heeft u vooral met de diagnose processen van endometriose patiënten?
    - Negatief/positief
    - Waarom

Het systeem

De volgende vragen gaan over de opzet van de gezondheidszorg in Nederland.

- Wat heeft u geleerd over endometriose tijdens uw opleiding?
    - Verhouding tot andere ziektebeelden
    - Bijscholing
- Wat doet u wanneer het lastig is om een diagnose te stellen in het algemeen?
    - NHG
    - Contact met anderen
- Kunt u iets vertellen over het contact tussen u en andere artsen?
    - Huisarts
    - Wanneer wordt een patiënt doorverwezen?
    - Welke manier is er contact
    - Wat vindt u hiervan
- Wat is de rol van het ziekenhuis/de overheid in het bepalen van een behandelplan of doorsturen van een patiënt?
    - Geld
    - Kunnen artsen ergens feedback geven over het zorgsysteem?
    - Voorschrijven van de pil
- Wat is de rol van een patiënt in het stellen van een diagnose?
    - Wat vindt u hiervan?
- Hoe is feedback geïntegreerd in de huidige gezondheidszorg?
    - Tussen professionals
    - Vanuit Patiënten
    - Patient related outcome measurements
- Wat gebeurt er zodra iemand de diagnose krijg?
    - Ondersteuning
    - Tips
    - Relaties met andere instellingen
- Wat vindt u van de huidige plaatsing van endometriose in het zorglandschap?
    - Genoeg aandacht
    - Genoeg kennis

    - Scholing

Verbeteren van het proces

De volgende vragen gaan over hoe het proces verbeterd zou kunnen worden en hoe artsen hierbij geholpen zouden kunnen worden.

- Waarom denkt u dat het proces vaak zo lang is?
    - Waar zijn deze problemen aan gerelateerd?
    - Systeem
    - Taboe/stigma
    - Rol patiënt
- Wat denkt u dat zou helpen om het proces te kunnen verbeteren of versnellen?
    - Wat zou u helpen?
    - Samenwerking
    - Patiënten betrekken
    - Feedback
    - Mogelijkheden om te leren
    - Technologie voor informatie etc.
    - Heeft u een ideaalbeeld over een consult?
- Waarom/Hoe zouden deze suggesties helpen?
- Wat denkt u dat de reden is dat deze suggesties nog niet zijn doorgevoerd?
    - Waarom denkt u dat er zo weinig bekend is over endometriose?
- Hoe denkt u over de internationale aandacht voor het onderwerp?
    - Kunnen wij daar iets van leren?
    - Zelfde of andere aanpak nodig?

Gevolgen voor patiënten

- Merkt u gevolgen bij patiënten die de diagnose krijgen?
    - Mentaal
    - Sociaal
    - Fysiek
- Wat denkt u dat hen zou kunnen helpen tijdens of na de diagnose?

Afronding

Nog wat laatste vragen.

- Welke veranderingen hoopt u in de nabije toekomst te zien rondom endometriose?
- Zijn volgens u alle relevante dingen besproken?
- Zou ik u nog mogen benaderen als ik nog verdere vragen heb?

Appendix B: Consent form

CONSENT REQUEST FOR PARTICIPATING IN RESEARCH

FOR QUESTIONS ABOUT THE STUDY, CONTACT:
Charlotte Arentsen
Schieweg 249A
467235ca@student.eur.nl
0646542297

DESCRIPTION

You[1] are invited to participate in a research about endometriosis. The purpose of the study is to find improvement points for the current process of diagnosis.

Your acceptance to participate in this study means that you accept to be interviewed. In general terms, the questions of the interview will be related to endometriosis, experiences and the diagnostic process.

Unless you prefer that no recordings are made, I will use a tape recording of the interview. You are always free not to answer any particular question, and/or stop participating at any point.

RISKS AND BENEFITS

As far as I can tell, there are no risks associated with participating in this research. Yet, you are free to decide whether I should use your name or other identifying information such as gender or not in the study. If you prefer, I will make sure that you cannot be identified, by using a pseudonym.

I will use the material from the interviews and my observation exclusively for academic work, namely my master's thesis.

TIME INVOLVEMENT

Your participation in this study will take approximately 60-90 minutes. You may interrupt your participation at any time.

PAYMENTS

There will be no monetary compensation for your participation.

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[1] In the case of minors, informed consent must be obtained from the parents or other official carers. They will have to sign this form. Please make sure to adjust this form accordingly. Even if/when consent has been provided, children should never be forced to participate or to continue participating.

PARTICIPANTS’ RIGHTS

If you have decided to accept participation in this project, please understand your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time without penalty. You have the right to refuse to answer particular questions. If you prefer, your identity will be made known in all written data resulting from the study. Otherwise, your individual privacy will be maintained in all published and written data resulting from the study.

CONTACTS AND QUESTIONS

If you have questions about your rights as a study participant, or are dissatisfied at any time with any aspect of this study, you may contact –anonymously, if you wish— Dr. J. van Wijngaarden

SIGNING THE CONSENT FORM

If you sign this consent form, your signature will be the only documentation of your identity. Thus, you DO NOT NEED to sign this form. In order to minimize risks and protect your identity, you may prefer to consent orally. Your oral consent is sufficient.

I give consent to be audiotaped during this study:

Name	Signature	Date

I prefer my identity to be revealed in all written data resulting from this study

Name	Signature	Date

This copy of the consent form is for you to keep. [2]

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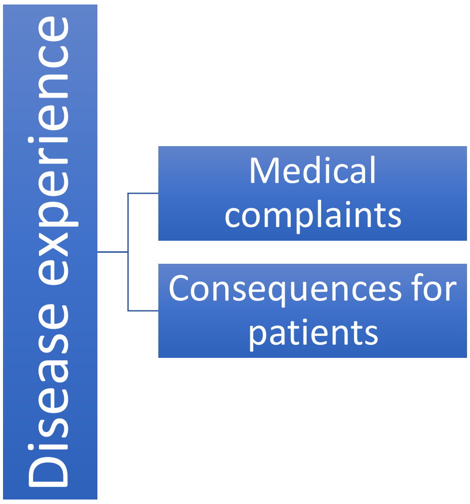
[2] Two copies should be made for each subject: one for the subject to keep and one for the student’s records.

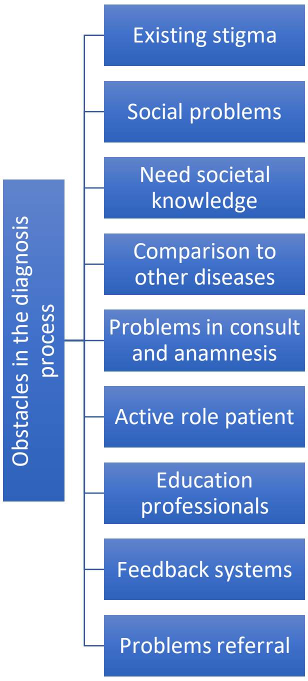
Appendix C: Coding trees

This appendix shows which axial codes were used in each theme. Some axial codes are visible in multiple themes. Whereas a clear division is made here, it should be mentioned the themes are interrelated. Especially the fifth theme, which was also constructed with knowledge acquired in the first four themes. For a clear understanding of the interrelations, please refer to the result section in chapter 4.

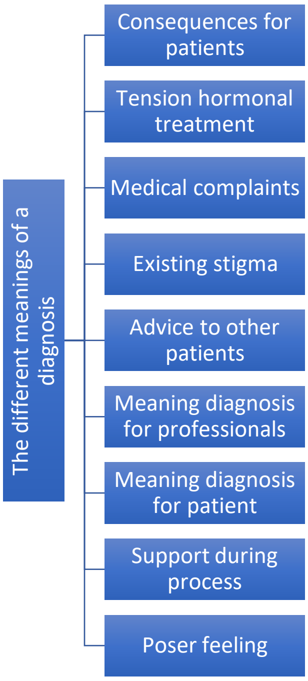
C.1 Theme one: Disease experience



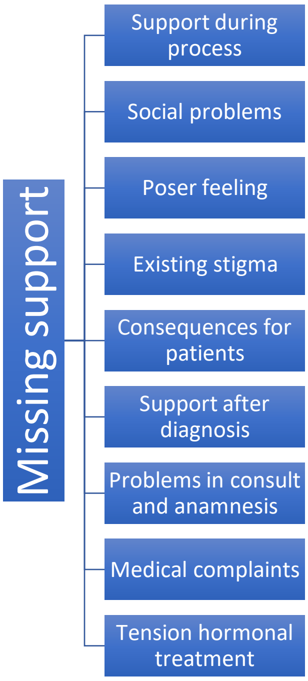
C.2 Theme two: Obstacles in the diagnosis process



C.3 Theme three: The different meanings of a diagnosis



C.4 Theme four: Missing support



C.5 Theme five: Improvement areas