



Universiteit
Leiden
The Netherlands

F*ck Endo. More than just menstrual pain.

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Citation

Geurds, W. (2022). *F*ck Endo. More than just menstrual pain.*

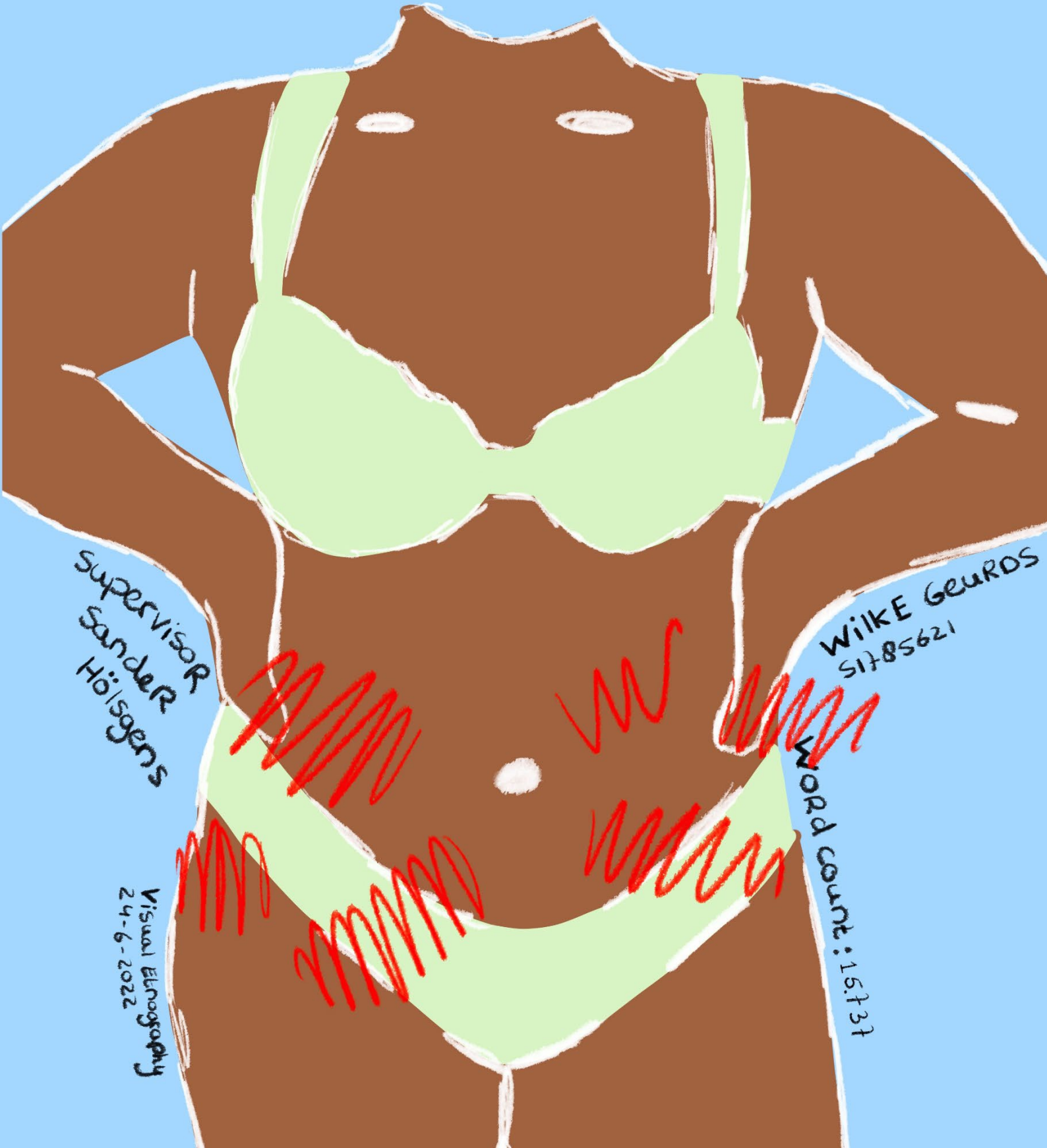
Version: Not Applicable (or Unknown)

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Downloaded from: <https://hdl.handle.net/1887/3455584>

Note: To cite this publication please use the final published version (if applicable).

F^oCK ENDO



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Visual Ethnography
24-6-2022

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S1785621

Word count: 15131



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Acknowledgements

What have I gotten myself into? I have to admit that I didn't quite realise what I was getting into by choosing this subject. Endometriosis, a disease that affects 1 in 10 women, but which I had never heard of before. And now, one and a half years later I have an idea of how difficult it is to have endometriosis. As the title of my research says, it is literally 'Fuck Endo'. I have built up a relationship with four fantastic women who have endometriosis. The further I got into this research, the more frustrated I became by the pain they had to endure. It made me feel powerless...

Now, this research is here for you, ready to be read and watched. I feel the power to spread this research into the world. The idea that I will hopefully soon be able to show my documentary at as many film festivals as possible and on television, displaces the feeling of powerlessness. But this would not have been possible without some very special people whom I would like to thank.

First of all, the 'Stichting Endometriose' (Endometriosis Foundation) made it possible to get in touch with women with endometriosis. I found four women who were open enough to let me into their lives. Thank you, Daphne and Dwayne, for letting me stay with you during the research, the many cups of tea, cooking inspiration, travel inspiration, good philosophical conversations about life and the joy that always reigned in your house despite everything. Even though you were sick, you always cared about me. You always sent me a WhatsApp message to ask me if I had come home safely. You have taught me to look at life in a different way. A life where you are in charge and do not have to walk with the herd. Thank you, Devina, for your openness and for daring to be so vulnerable. You have captured many vulnerable moments in your bedroom for me with your camera, which was very valuable. We are almost the same age and therefore we often had the same life struggles. I was not only asking how you were doing, but you were also curious about my life. Our voice memos via WhatsApp and good conversations on the couch were a valuable addition to this research. Thank you, Margot, for including me in your daily agenda, which was always completely full 😊. Whenever I was there, I felt completely part of the household. I went with you to school, work, tennis, physio, the city, the supermarket, spent the night and even got us some typical Belgian fries. I thought it was special how I was allowed to follow you and the children. Finally, Sanne thank you so much. I had known you for less than a week and I was already allowed to accompany you to the hospital for the endometriosis surgery. From the first moment that we spoke, you took me completely into your confidence and therefore, I want to thank you. Through all the video diaries that you have recorded for me, I have been able to look into your life. I know how difficult you found it to be open and vulnerably, but the fact that you allowed me to film even on the bad days is very special to me.

Thank you all!

I am grateful to be guided by Sander Hölsgens, my supervisor during this research. Even when we had to work hard on our research project, he always put our well-being first. There was always room for all kind of emotions. While enjoying many cups of tea, I always found the subgroup-meetings one of the most enjoyable moments of the week. With your new teaching methods, you made us look at our work in a different way. When you thought you were almost there, you still had that critical note that would lift our work to a higher level. You wanted to get the best out of us and I think you succeeded. Thank you, Sander!

I would also like to express my thanks to my sup group, Sarah, Anni, Viktor, Maarten and Janna. Thank you for your feedback and the pleasant subgroup meetings. A special thanks to Fleur and Jara. Our study sessions, study conversations and holiday break, keeps me motivated throughout the year. Thank you for the courage you gave me, the moments to let go my research, the moments of



venting, the valuable feedback, and the diners of laughter. I have met two new friends this year. Lastly, I want to thank Rein for always being there and the mental support.

It was a rollercoaster, but we did it! I am proud of this year of students of the Visual Ethnography Master! It was an amazing adventure!



Abstract

Severe menstruation pain is often normalized by society. However, this can be a sign of endometriosis. Endometriosis is a condition that affects people with a uterus¹, where endometrial tissue grows outside the uterus. Often this tissue grows in the pelvic, the ovaries, abdominal cavities. Despite the fact that one in ten people with a uterus have endometriosis, there is little attention for or understanding of this condition. Therefore, this research, consisting of a documentary and accompanying text, explores the complexity of the everyday life experiences of four women with endometriosis living in a Dutch and Belgian context. By placing this research topic in a larger anthropological discourse about illness experiences, it allowed me to approach endometriosis as a condition that is socially constructed by people women themselves and society. Three major themes play a major role in the women's everyday illness experiences. First, there is a lack of awareness for the condition in society that often results in misunderstandings and false diagnoses. Second, the ongoing process of grief and acceptance. Finally, the desire of women for a more holistic approach to endometriosis care. The aim of the research is to create more awareness for the condition and to help us think more openly about chronic pain linked to menstruation.

[Key words: Endometriosis, chronic illness, role constriction, sustainable liminality, embodiment, grieving loss, feminism.]

Link to the documentary²:

30-minute: available via SurfDrive Folder for supervisor and second-reader.

60-minute³: <https://vimeo.com/723694564/8c41195b61>

¹ For the convenience of the reader, I will use the term women in the rest of my thesis. However, I am aware that this term is debatable in feminist and gender studies. Especially with my feminist approach, I find it important to mention that I am aware of the use it. However, for the ease of reading, I will use the term 'women'.

² The 30-minute documentary had to be made to meet the requirements of my educational programme. However, the 60-minute documentary does justice to the experiences of my interlocutors. So, I recommend the reader to watch the 60-minute version. Watch the 60-minute version here.

³ The link is only accessible during the period of examination of my thesis. After this period, I will submit it to film festivals. If you still want to see it, you can contact me: wilkegeurdsphoto@gmail.com



1. Introduction

Today I have planned to visit my interlocuter Sanne.⁴ Sanne is 43 years old and has endometriosis. When I grabbed my phone, I saw a message from Sanne on WhatsApp. She said: 'Good morning, Wilke I am not fit. Not a good day for filming.... It's not the endo though. Just not feeling well. Shall we meet another time? Bye, Sanne'. I was curious what was going on and why she was unwell. Was it really not the endo? Carefully, I started the conversation and continued asking:

Wilke: No Corona, right?

Sanne: No, I have already had corona.

Wilke: Because if it's the endo that causes the pain, it might be interesting to visit you.

Sanne: Well, in terms of energy, the endo might be the cause. But it is not an endo-day like it used to be. I had a couple of busy shifts and now I have a headache and I am tired. I am feeling not fit, so it doesn't feel good to go out today.

Wilke: I fully understand. Then I think it is better to meet another time 🍀

Sanne: I find it very difficult. The more I think about it, the more I realise that this is exactly the impact of the endo. Overcharged at work, irritated, tired and not be able to deliver what I want. This has repercussions for the family and today is my only day off...

Wilke: The original plans for filming, can always be done later. But those mundane things or struggles can be good to capture as well. I could just drop by for a short while. But if I'm a bit too much with my camera, I understand. I don't want to cross your boundaries 😊

Sanne: Yes, I understand that. But it also feels double... to film today. I noticed that my family find it difficult, because I am not myself.... But the expectation is that it must be 'over' and that I am recovered from my surgery...

Wilke: Ahhh, yessss that is difficult.

Sanne: That is also the case at work, to report recovered is to be recovered...

Wilke: Isn't it also interesting to tell this?

Sanne: Yes, you are right! It's part of the story. Shall we meet again at 12 o'clock? And then not too long?

Wilke: Is good! Then I just stay max 1/1.5 hours, really short.

At 12 o'clock I was at Sanne's house. I grabbed my camera and asked if she could explain what was going on. Today, four months have passed since her endometriosis surgery and she started working again.

⁴ Some parts of this chapter are copied from my proposal.



Sanne: 'I noticed that working, getting up and having a rhythm did me very well, also mentally.' However, Sanne also explained some of her struggles after surgery. She tells how she find it hard to keep a good balance between work and family life. 'I can't motivate myself to empty the dishwasher. I don't do the laundry, because I cannot go upstairs. It doesn't feel fair, that I cannot do my part in the household. I'm so lucky... that I do have a husband who helps. But there are also irritations, when he says: How long have we been on the road? Still can't do it yourself? Yes, I can do it myself, but somehow it just doesn't work out! And of course, it's not good to give all my energy for work and do nothing at home. It has to be in balance, but sometimes that balance is not there yet'.

I am still sitting opposite Sanne with my camera while she is crying. But I keep on filming, because she says: 'If you want to make endometriosis known. If you want to let people know how much impact it has on your life. Then this is what you need to record now. Then this is what it is!' She pronounced the last sentence with a raised voice.

What is endometriosis and adenomyosis?

Sanne is one of the women whom I have been following for the past year. Sanne, like the other women, has endometriosis. Endometriosis is a medical condition where tissue similar to the tissue that normally lines the inside of the uterus (endometrial-like tissue) grows outside of it. Often it grows in the pelvic, the ovaries, abdominal cavities (Farquhar 2007). However, sometimes it also grows in the lungs, the diaphragm, bladder and even in the brain (Jackson and Telner 2006). It causes chronic inflammation with a range of symptoms. One of the interlocuters has adenomyosis, a condition caused by the ingrowth of endometrium into the wall of the uterus and a form of endometriosis. Endometriosis is a chronic condition and causes all kinds of pain. For example, low back pain, abdominal pain and painful periods. It can also influence quality of life, fertility and can lead to painful intercourse (Farquhar 2007). It is estimated that one in ten women has endometriosis (Manderson et. al 2008). Endometriosis is often not diagnosed immediately, but often between 6.7 and 11.7 years after having the first symptoms (Manderson et al. 2008). Research in the Netherlands shows that the diagnostic delay is about 7.4 years (Staal et al. 2015). These 7.4 years can be broken down into 7 months of patient delay, a 35-month delay at the general practitioner and five-month gynaecologist delay (ibid.). The delay is caused by multiple sociological, economic and healthcare factors. For example, normalization of pain by General Practitioners, suppression of the pain through using contraception, false diagnosis and also the normalization of menstrual pain (Hudelist et. al 2012). These are some of the reasons why this research is important.

Anthropological contribution

In the academic world, endometriosis is mainly studied in the medical sciences. From this point of view, the medical sciences often focus on medical treatments and issues of infertility (Huntington and Gilmour 2005: 1125). Medical anthropologists criticised the biomedical world for not paying attention to illness experiences (Rønberg 2019: 400). The biomedical world tends to 'reduce lived experience to a set of narrow professional categories serving diagnostic or bureaucratic needs' (Willen and Seeman 2012: 9). Therefore, medical anthropologists argue that this distort the way in which pain is experienced by patients and that this creates a gap between the lived experiences and the biomedical practice (Rønberg 2019).

Therefore, anthropological research can add a new perspective on clinical picture of endometriosis. There is a difference between how anthropologists studied illness and how other disciplines approach a disease or pain. In anthropology chronic pain is often considered a mode of embodiment (Jackson 1994: 211), instead of using the Western mind-body dichotomy, influenced by Descartes, this research will also look at how the body and mind are one and constantly influence each other (Honkasalo 2001: 327). To go beyond this dualism, the concept of embodiment can be used. Jackson (1994) describes that 'emotions already permeated with cultural meanings' (Jackson 1994:211).



Therefore, studying endometriosis as an embodied experience, that is formed by cultural and social structures, can be a legitimate topic for social and cultural analysis.

Finally, a feminist approach will be applied in this research. First, because medical research is mainly dominated by research about men (Lamphere 2016: 41). This research aims to highlight the voices of women in the medical discourse. Secondly, the ethnographic fieldwork and documentary making pays attention to questioning the power dynamics between the anthropologist and its subjects (ibid.). This resulted in a collaborative approach. Thirdly, this research aims to educate a larger audience, politics and doctors (ibid.). Because, change is needed in the health care systems and on the work floor. Therefore, it will also contribute to a larger feminist anthropological discourse.

Problem statement

There is a gap in knowledge about the illness experiences of people with endometriosis and the impact on social life. Besides the fact that endometriosis is physically taxing, it also has social, mental and economic consequences for society. So, endometriosis is a public health issues and is not only an individual problem (Kandimalla 2021). For example, people often cannot work during their period, which can pose problems for employers.

Understanding and creating awareness for endometriosis can help to fight against this illness and reduce the disruption in life of the patient. Therefore, the aim of this study is to better understand people's everyday illness experiences of having endometriosis. Despite the fact that these experiences are located in time and space and are person-related, recognition and awareness is needed to create more understanding. Women's illness experiences are shaped by ideas of normality. The vignette above shows how Sanne is struggling with being sick or healthy and the additional expectations. Although endometriosis is a chronic illness, people expect you to recover after surgery and to be able to participate in activities again. The expectations exist because of the cultural ideas of normality, which are not applicable to women with endometriosis (Ginsburg and Rapp 2013: 54). Normality is about the stational norm, the average (Lloyd and Moreau 2011). The norm is being healthy which resulted in the idea of 'normal' bodies. When someone becomes sick, that person deviates from that norm. This idea is reinforced by the fact that endometriosis often cannot be seen from the outside. Someone can look healthy and 'normal', but can be in a lot of pain.

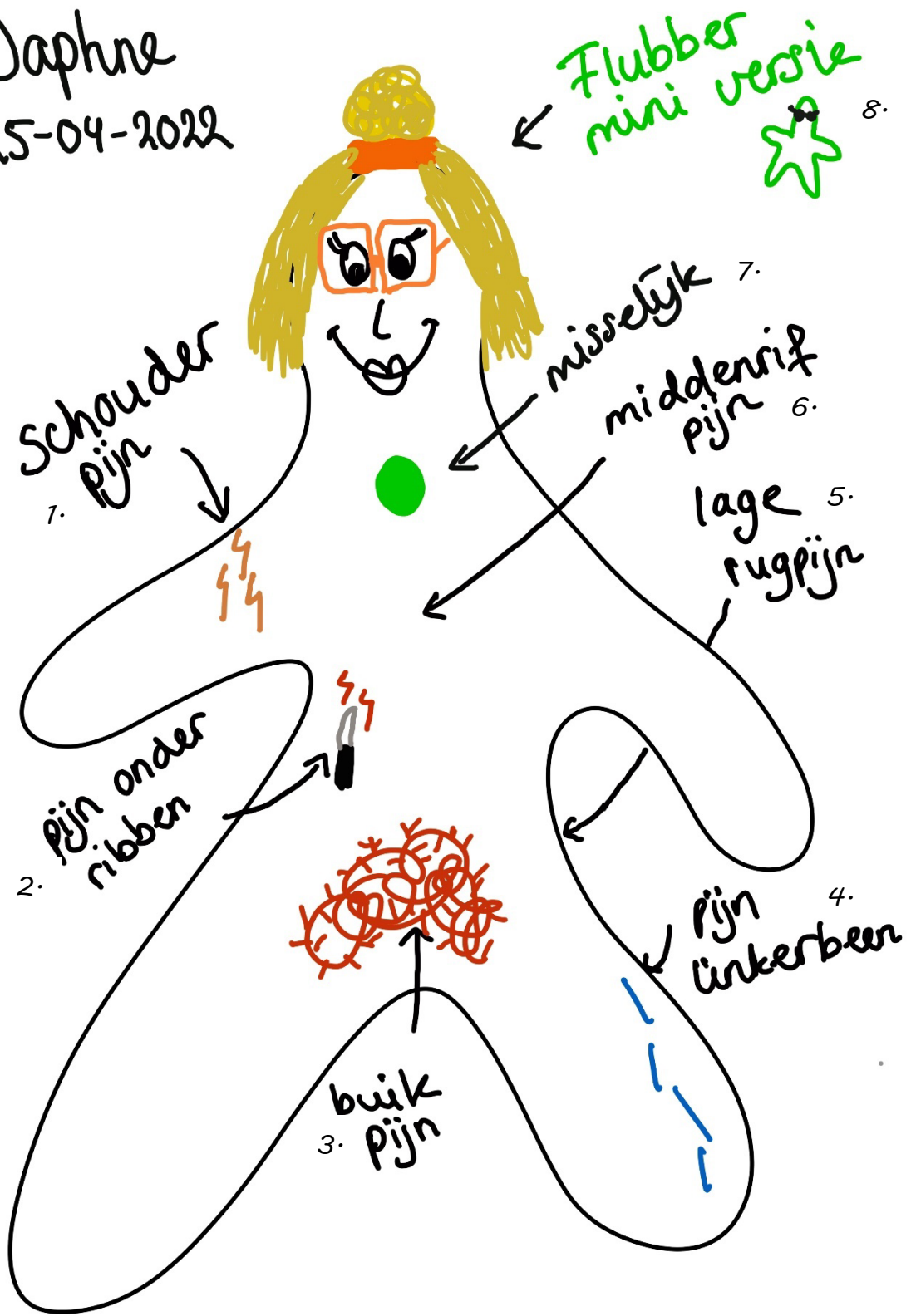
Audio-visual and qualitative research methods will be used to gain in-depth insights into their self-image, adaptation of their lives and their struggles in participating in a Dutch and Belgium society. I will focus on three themes that play a major role in the women's everyday experiences. Those themes are guided by concepts, liminality, role constriction, grieving loss, embodiment and the methodology. First, the broader awareness of the disease endometriosis in society which could lead to more acceptance of the disease. Secondly, the so-called 'grieving' and 'accepting' process that occurs when diagnosing the disease and in later stages when the body does not do what you would like it to do. Finally, the desire for a more holistic approach to endometriosis care.

The output of this research consists of two parts: 30-minute documentary (60-minute documentary) and this written text. Both outputs are based on the data that have been collected during a three-month period of fieldwork. Four interlocutors in the Netherlands and Belgium were followed, different kinds of interviews with the 'Stichting Endometriose' were held and the researcher spoke to a few other women with endometriosis and a gynaecologist and listened to all kind of podcasts, read newspaper articles and saw Instagram posts. Most information that was collected was written or spoken in Dutch. Therefore, the quotes are translated in English by the researcher.

This introduction provided an explanation of the research topic and the social and academic relevance of it. In the next chapter interlocutors will be introduced and ethics of the research will be discussed.



Daphne
25-04-2022



Translation in English:
 (1) shoulder pain, (2) pain under ribs, (3) abdominal pain, (4) left leg pain, (5) lower back pain, (6) diaphragm pain, (7) nausea, (8) Flubber mini version



2·Collaboration and ethics

Through the Endometriosis foundation, the researcher came into contact with many women who have endometriosis.⁵ The Endometriosis foundation posted a message on Instagram and asked if there was anyone who wanted to participate in a documentary. About 30 women responded. Eventually, 15 women and sent them an e-mail asking if we could have a video call. I made the selection on the basis of age, different medication and different degrees of pain. Finally, I interviewed about 10 women via a video call. From these 10 interviews, I selected four women (Margot, Sanne, Daphne and Devina) for my research.

Because the main focus point of this research is the sick body, my research is not a place-driven research project. I chose my interlocuters on the basis of their illness experiences, use of medication, age, social network and personal connection with them. This resulted in multi-sited research in different cities in the Netherlands (Zevenaar, Rosmalen, Utrecht) and Belgium (Boechout). According to Marcus (1995) multi-sited ethnography 'moves out from the single sites and local situations of conventional ethnographic research designs to examine the circulation of cultural meanings, objects, and identities in diffuse time space' (1995:96). Marcus distinguishes different modes of construction to do multi-sited ethnography. In my research I followed the life and the stories of these women. By following four different women, I tried to get insights in their lives and tried to connect their different stories to the bigger anthropological debate about illness experiences. I will explain this later in my theoretical framework. I also selected them, because I felt a good connection during the interview. This makes it easier working together for almost a year on such an intimate topic.

Because I built a personal connection with them and they played a major role in my research. I find it important to tell their stories and explain who they are. Therefore, you can read their personal stories in short.

⁵ Some parts of this chapter are copied from my proposal.



Margot

Age: 36

Country: Belgium

Relationship: Mother and has two young children, Olivia (5) and Arthur (8)

Job: She worked as a pharmacist and now she is studying to become teacher.

Her endo story:

'It took 15 years before I was diagnosed with endometriosis. For 15 years, I had symptoms such as fatigue, very painful periods, intestinal problems, etc. I regularly went to a doctor, but the diagnosis was usually irritable bowel syndrome and stress. Of course, you get stressed when you know that you experience such intense pain and you are unable to function normally. I often fell flat on the floor from the pain. With a lot of painkillers, I managed to go to school or work. However, a few months after the birth of my daughter, I developed chronic abdominal pain. The pain got worse, week after week. When she was 11 months old, I couldn't go on without taking two painkillers every day. It was extremely difficult to take care of a baby, my son, my family and to work. For the umpteenth time, I decided to see the doctor. However, she was on holiday and so I ended up with the doctor in training. I decided to tell my whole story, because she did not know me. She proposed to schedule a series of examinations. The external ultrasound revealed that I had an endometrioma on my ovary measuring about 6 cm. A subsequent laparoscopy revealed that I had grade 3 endometriosis. Or as the gynaecologist said: 'It's not cancer. But endometriosis does behave like cancer. It doesn't kill you but it can come back.'



Daphne

Age: 30

Country: The Netherlands

Relationship: Lives with her partner Dwayne and two cats: Beer and Boef.

Job: She worked at a school, but has been on sick leave for two years now. Since the beginning of this year, she has been receiving sickness benefit from the UWV, because she was declared unfit for work.

Her endo story:

'I was diagnosed with endometriosis on 24 January 2020. For the past 4 years, I have had enormous pain before and during my periods. I work in special education and had to call in sick every month. The general practitioner didn't know what it was and told me to just take a paracetamol and carry on. Two years ago, I went back to my GP and told him that I thought of endometriosis. I was immediately told that if I had endometriosis, I would have had very different complaints. She went on and said "you just have it worse than the rest" and "there is no explanation for everything". I insisted on a referral to a gynaecologist in the hospital. The gynaecologist told me that he thought it might be endometriosis, but to be 100% certain, he wanted to do keyhole surgery. I had my surgery on 12 March 2020. Dwayne told me that I had been away for over two hours, because so much endometriosis was found. It was found on my: peritoneum, uterine ligaments, left ureter and on my diaphragm and behind the liver. However, there were many complications after the operation. They had burned out the ureter and for the next few months I had to go in and out of the hospital. Complications kept arising... Finally, I was discharged from hospital on Sunday 17 April. In February 2021, I had another surgery and they removed the endometriosis on the diaphragm and placed an IUD. During this whole period, I have been guided by a medical psychologist because I have suffered some traumas because of the complications. Until this day, I am still at home and have been on sickness benefit for over 1.5 years.'



 Devina 

Age: 28

Country: The Netherlands

Relationship: Has a boyfriend and is still living with her parents.

Job: She just graduated and is searching for a job.

Her endo story:

'All the pain and misery began from the moment I started menstruating as an 11-year-old girl. No one around me recognised and acknowledged my pain for over 15 years and that started to affect me. I knew for sure that the pain I was feeling could not be normal. Yet my discomforts were trivialised every time I went to the doctor. Also, by people close to me and that really hurt. "I'm not crazy, am I?" I thought.

In 2019, a friend told me to have an endometriosis check-up. I wanted to, but I wasn't ready for the confrontation: I was afraid. My periods started to get really abnormal in the spring of 2021. I was worried and the pain was becoming increasingly unbearable. I only had 5 to 7 'good' days per month and the rest of the time I was mentally or physically completely exhausted. This was the reason why I made an appointment with the doctor, who referred me to a gynaecologist.

An ultrasound was made and soon after that I had an MRI scan. On 7 September 2021, I was told that I have adenomyosis. A month later we started the treatment plan: a hormone coil, because that could counteract the adenomyosis. And that is true, the IUD does its job. But my body is clearly not a fan of the IUD: I have been in pain 24/7 since the placement.'



 Sanne 

Age: 43

Country: The Netherlands

Relationship: I have a partner and two children (15 and 17).

Job: I work as a paediatric nurse in the hospital.

Her endo story:

'When I was 18, I was diagnosed with endometriosis after a second opinion in the Catharina Hospital in Eindhoven. The diagnosis was confirmed via an MRI and keyhole surgery. As a result, I quickly got my extreme abdominal pain under control. I am now 43 years old, so I have been living with endo for a while. I was given a light hormonal contraceptive pill as treatment and was free of pain for a long period. I was advised to think of my fertile years if I wanted to become a mother. As my relationship was stable and the desire to have children was there, I tried to get pregnant at 24. I gave birth to a premature baby at 35 weeks who was otherwise healthy. Two years later, we had another healthy son. In the years after my pregnancy, I regularly suffered from severe problems with my endo. This required keyhole surgeries. Each time, I got back on my feet. However, still with a lot of symptoms. Always tired, low libido and sometimes erratic and lifeless. I just never realised then that this has always been the endo that determined my life to a large extent. Around my 40th, the abdominal complaints started to break through again, I recognised the pain but did not know how to explain it. It turned out to be adenomyosis. My uterus was removed. Last year, the endometriosis returned. This time on my intestines. During an intestinal surgery in October, the endometriosis spots were removed.' During my fieldwork period, Sanne was recovering from the surgery.



As Crowder and Marion (2013: 4) noticed, building rapport is essential in doing anthropological research. It is not worth damaging the relationship for the sake of making beautiful images (ibid.). First of all, because endometriosis is an intimate topic. I have seen my participants at their most vulnerable moments. These were the moments when they were sick, had little energy and were often lying on the sofa or in bed. Filming these moments requires trust in me as a researcher, that is obtained by building rapport. Second, rapport is important to me, because of informed consent. Every time I passed by, I asked permission to turn on my camera. Also, I explained and showed what I was doing during and after my fieldwork period (ibid.: 7). I made a WhatsApp group to give updates about my research process and showed them fragments of the documentary. In the end, I also showed them the whole documentary so that they could give feedback. Nevertheless, I did not always find it easy to film, which I will illustrate with the following vignette.

I have known Sanne for less than a week and I am standing here at her bedside in the hospital, while she has just had an endometriosis surgery to remove the endometriosis spots on her intestines. Yesterday, I met her for the first time in person. I went to her house and asked her if I was allowed to film her before and after surgery. She agreed, because she thought it was important to give endometriosis more attention and to tell people her story. She said that after surgery, she is always drowsy from the morphine and that it might not be the most beautiful images. However, if it was important for me to film, I could take my camera there too. (...) The surgery is over. I waited in the hospital for almost 5 hours. Time was ticking away and I was nervous. Would everything go well? Shall I give her a card and flowers? How should I film her when she is lying vulnerable in the hospital bed? Can I ask her questions after surgery? All these questions were running through my head. Even though she had given her permission to film after surgery, I found it difficult to grab my camera. She had her eyes closed and was lying in bed, but she was awake and I told her I was there. We had a short conversation, so I knew that she knows that I was there. She saw me grabbing my camera and I told her I was going to film a small clip. When the nurse came and checked her belly, I found it not appropriate to film. You could see the tubes coming out of her belly and the plasters on the places where the doctors had made cuts. While I put my camera aside, Sanne asked me if I wanted to film it with her phone. She wanted it for documentation and later she also sent me the clip via WhatsApp. This indicated that Sanne did not mind me filming and that she actually appreciated it. The tense feeling slowly disappeared from my body. I really don't want to harm anyone by filming and it was nice to see that Sanne was aware of the camera and fully agreed my presence.

Thirdly, I noticed that good rapport would lead to the best research outcomes and ensured that I could avoid harm to my participants. Representation is important and endometriosis is still often misinterpreted and misunderstood. By constantly consulting with my interlocutors, the gynaecologist and the endometriosis foundation, I hope to give this nuanced view of the condition and to avoid misinterpretation.

To conclude, the kind of rapport that I build was not only about knowing when it was appropriate to film. It was also about building long-term relationships in which we collectively explored shared and non-shared experiences. I will delve deeper into this, in my methodology chapter.



3. Theoretical Framework

The concepts liminality, role constriction, grieving loss and embodiment were a starting point to analyse their illness experiences.⁶

Role constriction

Women with endometriosis often suffer from completing their social functions in society. This is because, endometriosis can cause all sorts of symptoms, making it impossible for many endometriosis patients to do what they would like to do in life. To explain this theoretically, Medical Anthropologist Sue Estroff introduced the concept of 'role constriction' (Estroff 1989: 194). This concept explains how someone with a chronic illness cannot always fully participate in social life, because there are not able to fulfil all kind of vital social roles, such as worker, parent, spouse, friend, etc (Estroff 1989; Miles 2021). In other words, there is a loss of all kind of social roles. The loss can change over the course of their illness. Sometimes the loss is temporarily and otherwise it will have an effect for a longer period of time. Estroff (1989: 194-195) noticed that identities are created through these social roles (ibid.). She revealed that the only role that often remains is the patient or the sick role if a person has schizophrenia. Therefore, people often identified themselves with the disease and thus as schizophrenic.

By using this concept, I want to contribute to the larger debate around illness experiences and show how those experiences are largely shaped by the roles they can or cannot fulfil. This concept can help me to define the position of women in social space. Because endometriosis is very unpredictable, women have to constantly negotiate what roles, spouse, friend, employee, etc., they can and cannot perform and what adjustments are needed. For example, the vignette in the introduction showed how Sanne was not able to fulfil a good role in her household and being a good partner. She is always struggling with keeping balance between the high expectations of others and taking care of herself.

Estroff (1989, 1991) noticed that the only role that will remain when someone has schizophrenia, is the patient role or as explained by Glenton (2003) the 'sick role'. Structural-functionalist Talcott Parsons is one of the major figures in the medical sociology and developed the concept 'sick role' (Parsons 1951). He considered being sick as deviating from the norm in the social system. Being healthy is functional for society, if someone deviate from this, you fall outside the system (ibid.). Therefore, he not only examined the biological condition of a disease, but also the social impact in the form of the social roles a person fulfils. Women with endometriosis experience how they often fall outside the system and fit into the sick role. Just like Ware (1999: 312), I noticed how hard it can be for women dealing with endometriosis on the work floor. Endometriosis is very unpredictable and can suddenly cause fatigue and craps in the abdomen. The moment someone get endometriosis, the rigid framework and schedule may no longer suit woman. Therefore, women ended up in the 'sick role', because they cannot behave in the same way as the healthy employees. However, I disagree with Estroff that the sick role is the only role that remain when you get endometriosis. The sick role is a new role that women obtain through the illness, but it does not replace all existing roles. My research showed that women are still capable to fulfil other social roles. However, there is loss and women often have to adjust their roles to the disease. For example, Sanne is still able to work. However, the endometriosis has prevented her from applying for a higher position. She would like to, but her body would not be able to. This feels like a loss, because she does have the mental capacity.

Parsons (1951) draws up a balance sheet, with, on the one hand, the rights and, on the other hand, the obligations you have when you end up in the sick role (ibid.). On the one hand when someone is

⁶ Some parts of this chapter are copied from my proposal.



ill, somebody is not obliged to fulfil all kind of normal role obligations. Also, a patient is not seen as being responsible for being ill. On the other side of the balance, a patient must do everything to recover and to reintegrate into society. Therefore, illness experiences are not only influenced by the disease itself, but also how society and social networks respond the disease. Glenton (2003:2244) and many other social scientists criticised this point of view and stated that this concept is focused on acute pain and does not fit when you have chronic pain. It is hard for chronic patients to recover and they always have to deal with uncertainty. I think that this is exactly the case in my research. The classical sick role does not fit when you have endometriosis. However, I noticed that the idea of the classical sick role still exists in society and especially women with endometriosis have to deal with these expectations. As showed in the vignette in the introduction, people expected that Sanne would recover within six weeks after surgery. As she had not recovered after six weeks, she experienced many problems due to people's wrong expectations. In my empirical chapters I will discuss in more detail how women have negotiated social roles and the sick role.

Grieving loss

The concept of role constriction is linked to the concept of grieving losses. Being ill often accompanies with losing social roles (Estroff 1989). However, being ill also can lead to other losses, such as physical losses, physical losses, economic losses and social losses (Charmaz 1991: 257). When somebody becomes ill, the future is uncertain. How will your body react? Is it possible to continue working? Will you lose your job? Will your friends understand the illness? As explained by Moss and Dyck (2003):

'This distress over uncertainty in other people's reactions, about negotiating one's own body in relation to "bodies in context," manifest in the women's stories as a presence of absence-identifying what a woman loses on becoming chronically ill and then dealing with those losses' (Moss and Dyck 2003: 133).

In other words, every time you talked about your illness you have to negotiate with all kind of losses that shaped the illness experiences. This feeling is reinforced by being confronted with healthy bodies and then becoming extra aware of your losses. In their research, Moss and Dyck (2003) studied women with chronic illness and one of their interlocuters identified this whole process of losses as a grieving process. A patient grief for those losses and especially they grief because of the loss of their 'self'. Charmaz (1991) defined loss of the self as 'being involuntarily dispossessed of former attributes and sentiments that comprise one's self-concept, as well as the actions and experiences upon which they are based' (Charmaz 1991: 257). This means that because of loss of former characteristics and feelings, a patient will look at themselves differently. Therefore, a patient has to reinvent the boundaries of the self-concept (ibid.). Patients often have the desire to look for renewal and find out what they can still do (Moss and Dyck 2003). Patients have to recognize that the illness is now part of their life and part of who they are.

After grieving, patients must go on. Charmaz (1991: 258) calls this process the 'transcendence of self'. Charmaz stated that the self is not only defined by the body and thus the illness, even if the illness will decide a large part of the experiences. This means that the illness will not be the only factor that determines the borders of the self (ibid.). Therefore, the process of transcendence includes a process of self-acceptance (ibid.). In other words, first a patient enters a stage of mourning the losses. Then she enters the stage of acceptance and a patient have to search again for who she is and what she can do. Charmaz (ibid.) add that a chronic illness is uncertain. You do not know beforehand if you will have a good day or a bad day. Any day could be a bad day. Therefore, people with a chronic illness have to deal the social world around them with uncertainty. This means that both losses and transcendence are embedded in time. This concept shed light on the effects of role constriction, in other words the losses that are caused by the illness and shape the illness experiences. My interlocuters stated that getting the diagnosis entail a process of grieving and



accepting. For example, Daphne had to quit working and had to accept that her body is now temporarily unable to work. She will receive benefits for a year and after that period her file will be reviewed to see if her situation remains the same or improves and she might be able to start working again for a few hours a week. In my empirical chapters, I will elaborate on the process of grieving and acceptance.

Liminality

It often takes many years before someone gets the diagnosis endometriosis. In receiving the diagnosis, a change of the self takes place (Charmaz 1991). Before a woman was diagnosed, she was someone in pain not knowing that she has a chronic illness. After the diagnosis, the label endometriosis can describe that pain and can put her identity in a box. The period between those identities can be explained with the concept of liminality. Liminality comes from the Latin word, limen, that means 'threshold' (Barnard and Spencer 2010: 616). There is a change in the process and this creates a limen, because it causes the possibility of going to a new phase or staying in the old phase.

Anthropologists Victor Turner (1969) used this concept for the first time in anthropology. He borrowed the concept from van Gennep who wrote about rites of passage (Barnard and Spencer 2010: 616). Rites of passage are rituals that describe the transition from one stage in life to another one (ibid.). For instance, a marriage, the baptism, puberty etc. Turner (1969) identifies three phases or three kinds of rites of passage: rites of separation, transition rites and rites of aggregation. The transition phase is marked as liminal phase. This means that the status is ambiguous, someone is 'neither here nor there, they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial' (Turner 1969: 81). This liminal stage places individuals outside the everyday life. For example, in my research the women are in pain, however if they are not diagnosed, they do not have endometriosis. They are in a liminal phase between a healthy person and a patient. Brown et. al (2017: 698) describes how Turner connect this concept to society. Turner states that before the ritual an individual is stripped of its status in society. During the liminal phase a transition takes place and after the liminal phase and ritual, the society will integrate the person again. In other words, Turner argues that a liminal phase is temporary and that a person will 'aggregate' in society in the end (Turner 1969).

Little et. al (1998) contests this temporality in the case of a chronic illness. They did research on cancer patients and describes that in the cancer experiences there are two phases of liminality. First, when a patient gets the diagnosis, he or she enters a liminal phase. Little et. al (1998) calls this 'acute liminality'. This means that there is an acute disruption in the lives of patients that is marked by uncertainty (ibid.) Second, Little et. al (1998) describes sustained liminality. This is the phase after acute liminality, because a patient enters a condition of chronic illness. Cancer is not a chronic illness, but a patient often still experiences body changes for the rest of his life and must visit a doctor for regular check-ups (ibid.). Therefore, a patient is constantly reminded of the disease. This is marked by sustained liminality and is different from the idea of Turner that a liminal phase is temporary. I agree with the approach of Little et. al (ibid.) and disagree the idea of Turner, because the idea of sustained liminality fits my research best. Since, women with endometriosis live their whole life in uncertainty, they are not sure if the pain will return and in what form. Using this concept can help me to put the illness experiences in time and questions what chronic means.

Out-of-Tune Embodiment

As already explained in the introduction, I want to go beyond the mind-body dualism of Descartes. This concept can help in adding new insights to already existing medical research, because medical research often ignores the illness experiences and therefore does not consider an illness as an embodied practice.



Embodiment explains that the lived body is the starting point for experiencing the world (Csordas 1990). On the one hand, people reconstruct and try to make sense of their body, their self and the world around them through their bodies (Manderson 2011: 34). Becoming ill disrupt someone's life and therefore they have to find a new way of embodiment (ibid.: 261). New ways to cope with the illness and their bodies. Frank (1995:2) argues that illness narratives are embodied, because they are created by the disease that causes a disruption from the past and the future. He states 'the body, whether still diseased or recovered, is simultaneously cause, topic, and instrument of whatever new stories are told' (Frank 1995: 2). In other words, you experience the world through your body and you recreate and tell these stories from the perspective of your body.

On the other hand, our embodied experiences are also influenced by the world around us (Rønberg 2019: 403). Rønberg (2019) introduces the term attunement and detuned. If the body, the self and the environment are aligned with each other it means that someone is attuned. In other words, as a human being we follow rhythms in the world and when the body, self and the environment knows these rhythms and can follow them, they are attuned. A detuned body occurs in a state of illness (ibid.). This is what Leder called the 'absent body' (Leder 1990). When we experience pain, we become aware of our body. A sick person experienced his body as wrong, alien or bad and that the body threatens your plans and life goals (ibid). Your body is seen as an obstacle and the body is not always able to attune to the world and others (Rønberg 2019). This concept is especially interesting to understand the need of women with endometriosis. When women are diagnosed, their bodies are categorized as a sick body. I noticed that the focus in the medical health care system is often based on finding solutions to recover the sick body. It is often forgotten here that having an illness also has a great impact on the mental health. Having an illness is an embodied experience and it is therefore important to adjust the health care system accordingly. Women indicated that they would like to see a more holistic system of health care for endometriosis patients. This includes looking at other solutions to support the women, such as psychological help, a nutritionist, a physiotherapist, an osteopath, alternative supplements and vitamins, etc. In my research I tried to examine these embodied experiences.



4. Methodology

The starting point in understanding illness experiences was using three different anthropological methods, participant observation, semi-structured interviews and audio-visual methods.⁷ Furthermore, I had numerous informal conversations, made drawings, had WhatsApp conversations, conducted in-dept interviews and one focus-group and did online observations (for example Instagram). In this chapter I will explain why I chose those methods and how what kind of knowledge those methods produced.

Understanding an illness

I texted Daphne that I was ready to video call. From my student room in Leiden, I set up my phone and we called each other on WhatsApp. Daphne appeared on the screen with a big smile on her face. She had her hair in a bun, was wearing make-up and looked fit and happy. She asked how my holiday was. Daphne loves to travel and listened attentively to all my stories. The reason I wanted to video call, was because I saw on her Instagram account that she hadn't been feeling well for a few days. The CBD oil wasn't working and the last few days she could only lie in bed or on the sofa. While we were video chatting, all I could see was a happy, attentive woman sitting in front of me. It's crazy, because I know that she is sick, but I never see this. After my holiday stories, I asked how she was doing and what her pain rating was. She told me that she had a lot of pain in her diaphragm and her lower abdomen and that she would give the pain a number 6 or 7 out of 10. This shocked me. How is this possible? You don't look sick!

Anthropologist Warin (2010) did research on anorexia and had the same struggle as I. How can I understand the illness experiences if I do not have the illness myself? How is it possible that Daphne can be so cheerful when she is in so much pain? For Warin (2010) this changed when she became pregnant. Still, she had not the exact same experience as somebody with anorexia, but she found a common ground to talk about the changes and the visibility of her body (ibid.). Just like Warin, I also position my body sometimes vis-à-vis of my interlocuters. Although, I do not have endometriosis, I was looking for interexperiences, experiences that I had in common with my interlocuters. For example, I also have an IUD to regulate my periods and knew how painful it was to insert. I slept really bad and had also a strange pain in my belly for two weeks. These kinds of experiences, could serve as a starting point for conversations. My interlocuters often told me very personal stories and after a while I knew a lot about someone. But how can I expect someone to keep sharing their personal stories with me, if I do not dare to show my vulnerability as a researcher? I noticed that if I put my insecurities on the table, such as the fact that I felt overworked, she also dared to be more open. We got to know each other better and that created a better relationship, which made my interlocuters dare to share more about their experiences. This feministic approach, is contesting the traditional way and 'male-stream' way of doing interviews. Just like Oakley (1981 in Allan 2020), I want to have a more reciprocal way of interviewing. So, finding a common ground in the relationship between me as a researcher and my interlocuter, is what Jackson (1998 in Warin 2009: 65) called analogy. Jackson explained that empathy is needed and not necessary mimicry. Therefore, going native and becoming the other is not necessarily needed to understand illness experiences and as explained, I also experienced that during my research.

Examining the invisible

I started my research with doing interviews and having informal conversations. I was curious to know what they had been through, how they were organising their lives at the moment, what kind of medication they were taking, etc. Interviewing gave me access to the idea's, thoughts and memories of women (Reinharz and Chase 2011). I soon realised that I had a different relationship with each

⁷ Some parts of this chapter are copied from my proposal.



woman. For example, Daphne and I share many of the same hobbies and she is only 6 years older than me, so we are more or less in the same age bracket. While Sanne and I have a much bigger age difference and a completely different life. Therefore, as explained by Reinharz and Chase (2011), 'interviewing women is not a "one-size-fits-all" type of activity' (Reinharz and Chase 2011: 2). This means that I have to keep in mind the difference between women in terms of age, class, race etc. Because of this approach, it can be hard to compare their stories and generalise their experiences. However, this is not my aim. Using a feminist approach, I think these stories matter, because they tell me something about their illness experiences of many women with endometriosis. Reading newspapers, Instagram posts, interviewing other women with endometriosis, taught me that there are experiences that 'speaks to a broader social experience' (Maynes et al. 2008: 128). Such as getting the diagnosis after living years in pain, that it is mentally tough, the desire for a holistic approach to care, etc. In other words, I used personal narrative analyses to make ethnographic generalization (ibid.: 129). I use their personal narratives 'to open up a culture and reveal the operation of otherwise obscured transactions, social conventions, mythologies, meanings and motivations' (ibid.: 129-130). I learned a lot about their mental problems, the influence on their relationship, their doubts, their struggles with friends and colleagues that have other expectations, etc. However, this method is limited in that I only had space for a limited number of stories. For example, endometriosis can have a major impact on your fertility. Since none of my participants had to deal with this, this automatically meant that I did not include this part in this study.

However, still it was still difficult to get a grip on their daily lives. To bridge this knowledge gap, I sometimes stayed a night. Rea-Holloway and Hagelman (2021: 216) noticed that being at someone's home can generate knowledge.

First, observing patients can reveal the routines, patterns, their daily life activities and the impact of the treatment and the disease (ibid.). Because I could stay overnight, I could see their evening and morning rituals. Often, they have to take medicines and I saw that they were tired. When I visited them for three or four hours, it was more like a 'coffee visit'. While enjoying a cup of tea, I only gained knowledge through conversation. By staying the night, I was able to access a new layer of knowledge, means knowledge I gained through observations. For example, I noticed that Daphne does not sleep well and has to take all kinds of medicines before going to bed. She also has to take two showers a day, because she sweats a lot because of the pain. When I stayed at Margot's house, I noticed how much time and space the children were taking up. In the evening, when the children were in bed, Margot was alone for the first time that day. She was very tired after the whole day doing all kind of things. She couldn't really do much more and so she went to bed at 10 o'clock.

Second, observing at home showed the material culture (ibid.). Women with endometriosis can use different medications, but also have some tools to relief the pain. For example, blankets, a warm pouch, wide trousers, etc. These objects gave my patients a feeling of control (ibid.). I also noticed that Daphne has a lot of minerals to give rest. Besides, the material objects, I noticed the importance of pets. For both Daphne and Margot, a dog or cat give a lot of support when they are in pain. They come and lie with them and then they are not alone.

Third, Rea-Holloway and Hagelman (2021: 216) state that having a medical condition changes your identity, your self-image and how someone position his or herself. For example, Daphne never leaves home without make-up even when she is in pain. She does not want to represent herself as a patient in public places. For example, one day, Dwayne (Daphne's partner) came to pick me up from the station by car, because Daphne wasn't feeling well. Dwayne told me in the car that Daphne had asked him that morning if she could keep her jogging trousers on. Even for me, Daphne wanted to put on some nice clothes, but in the end she didn't do. By visiting the women a lot at home, I ended up in their most intimate place.



Collaborative approach in filmmaking

My main method to gain insights in their experiences, was using audio-visual recordings. This resulted in a 30 and 60-minute ethnographic film⁸ that focuses on the illness experiences of my interlocuters. Within anthropological discipline, there are a lot of debates about the role of the camera in academic research. Ethnographic film-making developed as a way for documentation, instead of producing documentary films structured around a central narrative (Henley 2020: 28). The goal was to provide visual records in the most objective way possible. However, over the course of the 1970s criticism arose and reflexivity became important (ibid.: 154). Reflexivity was about subjectivity of the ethnographer and that ethnographic film-making involves having relationships of power between the ethnographer and the subjects (ibid.: 152). I also noticed that building rapport and having trust of my interlocuters, was the only way to make this film about such an intimate topic. Therefore, Margaret Mead, Jean Rouch and the MacDougalls developed some collaborative approaches and would like to give more voice to their subjects. In *Chronique d'un été* (1961) Rouch and Morin gave one of the protagonists the camera to tell her own story. However, still Morin and Rouch directed the film and edited in the story of the filmmaker. Lawrence (2020: 19) argues that even collaboration not led to a balance in power relations between the filmmaker and subjects. I agree with Lawrence and the only thing that I could do in making my film was trying to involve my interlocuters as much as possible. This whole debate is about representation. Therefore, MacDougall (1991) asked the question 'whose story is it, if we make a film?'. I think, this is an interesting question and during the whole process of making my film, I tried to have an open discussion and showed scenes and footage.

It was Wednesday evening, three weeks before the deadline, and I send the first rough cut of my film to my interlocuters. I was nervous. Would they recognise themselves in the film? Would they find it confronting? Was I able to tell their story correctly? All these questions rushed through my head. Suddenly I received a few messages!

Sanne: I saw the whole film!!! 🧐 How incredibly proud I am of us!!! Endo sisters for live and someone who filmed it so beautifully!!! 🧐 🍷

Margot: Amai Wilke! This is really a very good job!!!! Very beautiful how you have portrayed all aspects!!!!

Sanne: It feels so familiar somehow... very strange.

Daphne: I totally understand what you mean.

Sanne: For me that has to do with you Wilke.

Daphne: Yes, Wilke is very open and that is why you soon have that familiar click that makes you want to give a lot of yourself away.

I included this vignette, because my main goal in making this documentary was to give voice to women with endometriosis. I want to tell their story and I was happy that my interlocuters recognised themselves in the film. We had also a critical conversation afterwards, where my interlocuters were indicated that I had to remove a few scenes from the film because they could be misinterpreted. So just like Lawrence (2020), I tried to involve my interlocuters in the process, through viewing and criticizing the film, thinking about the script and giving the camera to my them.

⁸ The 30-minute documentary had to be made to meet the requirements of my educational programme. However, the 60-minute documentary does justice to the experiences of my interlocuters. So, I recommend the reader to watch the 60-minute version.



Spray (2020) also questions the power positions between the anthropologist and the subjects. In her film *Record* (2018) she records a conversation between herself as an anthropologist and her interlocuter. She acknowledged her present in the film and explains what she was doing. I also tried to do this with the children of Margot (scene in the 60-minute documentary). I asked if they knew why I was here and what I was filming. We talked about endometriosis and if they have to help their mother. This open conversation and presenting my own positionality, was important to me. Because, I wanted to show that my interlocuters agree with me being there to film everything in such intimate situations.

Creating awareness and representation

One of the reasons that I decided use audio-visual methods, is to reach a larger audience beyond academia. This means that within a feminist discourse, I hope that the women I followed, can tell their own stories through my documentary. It enables them 'to construct their own knowledge about women according to their criteria as a woman, and to empower themselves through knowledge making' (Kramarae and Spender 1992). I hope to give women a platform to make their voices heard through my film. They represent the stories of many women in the Dutch and Belgium society that have endometriosis. Feminist anthropologist argues that representation is not only about having one's voice heard, but also about depiction and that you can see yourself back in the popular debates (Kramer 2016: 76). Because one in ten women has endometriosis and menstrual pain is often still normalised in our society, representation is also about that you hear more women talking about these problems. That you see women 'like you' on television to show the broader spectrum of human experiences (ibid.). Trinh. T. (Chen and Trinh T. 1994: 443) added that it is important to leave space of representation open to my interlocuters. Therefore, she argues that it is better to speak nearby, rather than speak about. Because there is a gap between the researcher and the people you recorded. By doing this, I hope as a researcher not to claim a position of authority in relation to my interlocuters. I tried to do this by discussing the film, to ask if their stories are represented in the right way and not to use voice overs in the film.

Film styles

I used different styles to visualise this topic: observational, participatory and experimental styles. First, the observational techniques helped me to record events and some of their daily activities, such as going to bed and going to the hospital for surgery. Nichols (2017: 125) states that an observational film is characterised by the apparent absence of the filmmaker and little intervention by the filmmaker in the recorded events. Observational cinema let my interlocuters express and explain themselves, through showing their actions and using their own words (Carta 2015: 1). The only thing I did as a researcher was moving around with my camera during events and recording what my subjects were doing and how they did it. Inspired by the film *Doon School Chronicles* (MacDougall 2000), I tried to capture the routines and activities of the women with endometriosis. So, I followed my interlocuters to the hospital, the sport lessons, the physiotherapist and the routines at their homes. I found this approach important, because it is their illness and I want to give them the opportunity to tell their own story.

I found it difficult to record the real pain and gain insight into their daily activities when I was not there as a researcher. Because, when I was there, they felt responsible as hostesses and put on make-up. Because they knew they were going to be filmed. So, I complement observational cinema with participatory filmmaking. This helped me to show a new perspective of their illness experiences.

This participatory film style consisted of two parts. First, one of my participants kept a video diary with her own mobile phone, where she gave a short update in one minute about the process before and after surgery. Secondly, I lent each participant my camera for a week so that they could film themselves when I was not there. This last method can also be seen as a form of video diary, but this was more focused on their activities. Both ways gave me a sense of being in someone's lives and the



environments of my interlocuters (Pink et al. 2017: 375). As stated by Holliday (2000: 510) video diaries give my interlocuters agency, this means that they have greater control in choosing what to film. The diaries were full of all kind of activities, such as going to bed, waking up, reading a book, laying on the couch, cooking a vegan meal, going to work and being on work, etc. Interlocuter-created footage has great epistemological benefits (Muir and Mason 2011). Just like Holliday (ibid.), I noticed that my interlocuters perform totally different then I was there. They film their selves without wearing make-up, in their pyjamas and having pain and laying on the couch and do nothing. For example, Devina did not dare to apply for jobs yet, because of the pain. So, she was a lot at home. I found it difficult to imagine what you do at home all day and whether you get bored. By watching her video diaries, I saw that she was often in pain and had to rest a lot because of the pain. She also recorded how she cooked, sometimes went out for a short walk and how she took care of herself with care products on Sunday evenings. These clips are a valuable addition to my documentary, because they often showed the pain that I was not able to record if I was there. It is difficult for me to say to my interlocuters: 'don't pay attention to me. Because as a researcher, my presence is most conspicuous. Whereas if I am not there, there is only a camera and you are more easily tempted to record yourself for half an hour.

Music and animations

I used an experimental and poetic approach in editing my documentary. A poetic mode is characterized by using images that generates a mood or emotions (Nichols 2017). I implemented this mode especially in the opening scene, where I filmed close-ups of the skin of my interlocuters and I used voice-overs in which they explain their pain. Suhr and Willerslev (2012) argue that montage can show the invisible aspects of social life. Pain and illness experiences are often invisible; therefore, montage and this experimental approach helped me to visualise the pain. In addition, I used music and animations in my film. There is a big debate about using music in anthropological films, because as a filmmaker you can create meanings or emotions in the spectator (Henley 2007: 55). I am aware of this fact, but together with my interlocuters I decided to use the music because the music represented their feelings.

The documentary 'Waarom bleef je niet voor mij' (Gevers 2020) combined images and animations to tell a story about four children and how they lost a parent to suicide in primary school. The animations are used to depict a new phase in the grieving process. I was inspired by how she combined these two modalities to convey an argument. Because my interlocuters wanted to show how endometriosis look, I also decided to combine animations with my footage. Animations helped me to show the invisibility of the disease, i.e., experiences in the past and tried to do justice to the complexity of their experiences. For example, I used animations to explain endometriosis and to make the viewer aware that some of the moments are filmed with the mobile phone of my interlocuters.



5.1 Grieving and accepting



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...

Today was my interview at the UWV. An insurance doctor went through my file of two years of illness.

The final word, which I've been waiting for a long time, has been spoken. I will get a WIA benefit. This feels very double, I am happy, happy for the peace that I will get in the coming year in terms of work. Because unfortunately, to this day, I still can't work.

But there is also sadness. Sadness, because I have to say goodbye to my work in which I have gained so much experience and which I have enjoyed so much. Grief for the fact that my body has let me down for two years now because of this dreadful illness... Even though I know, deep down, that my body and my head need this rest. Because mentally, these past two years (and what is yet to come) have not been easy and have brought with them a rollercoaster of emotions. So it needs time to process this and I am going to get it now.

◦
◦

#wia #uwv #afgekeurd #endometriosestichting #endometriose #endometriosenederland #chronicillness #chronicillnesswarrior #feelings #time #endometriosis #endometrioseawareness #sick #rollercoaster #work

Bewerkt · 17 w.

In this chapter, I will explain how women enters constant a stage of grief and accepting. Labelling the pain and getting the right diagnosis (often after a lot of years) has an enormous mental impact. On the one hand, I noticed how women were relieved when they received the diagnosis. The right label is given to the pain they have often felt for a long time and their pain is recognised. This gave them the feeling that it is not their own fault that, for example, they are tired or cannot participate in certain activities. As Margot told me:

'After a while, I felt as if I could handle less than the average woman. Not getting a diagnosis does something to your self-image; after a while you almost start to believe that you can do less.'

On the other hand, women have to cope with the idea that they are chronically ill. The illness causes a disruption between the past and the future (Frank 1995: 2). Daphne said that you are literally going through a grieving process and that she had to negotiate all kind of losses. On her Instagram post above, shows Daphne how endometriosis causes that she cannot work and how it took her job, that she loved, away from her. She explained how this makes her feel excluded from society and how she is constricted in the roles she would like to perform (Estroff 1989: 194). Everyone around her goes on, has a fixed rhythm and a goal in life. Her life stands still. She wakes up every day and then she often sits at home all day.

Those losses are connected to work, but the women also experienced other losses, such as not able to join activities with friends, adapting your diet because some food can trigger the pain, losing your partner or close friends that do not understand the illness, not be able to get children, etc. So, the losses are not only at the beginning when you get the diagnosis. Daphne: *'There is always something new that you have to accept. When you think you've solved one problem, something new comes along that you have to grief and accept.'* I think this quote shows how the life of the patient is marked by sustained liminality (Little et. al 1998). However, when women enter the menopause,



there is a big chance that the symptoms will disappear. This is why sustainable liminality appears in the phase from the first menstruation until the menopause.

These examples above show how women with endometriosis are constricted in fulfilling the roles that they wanted to maintain, as previously explained in my theoretical framework (Estroff 1989). However, I noticed that besides the losses, the women also encounter new roles. For example, Daphne spends more time cooking and Devina sometimes does volunteer work. Charmaz (1991) states that this process of self-acceptance is part of the process of transcendence of self. I don't want to detract from the impact of the losses that the women have to endure, but I do want to show that the women I have met, look for new activities that fits with their bodies. Also, because endometriosis is still very unknown, women not always show the pain they have and often do not want to constrict in the roles they perform. Menstruation pain is normalized and talking about it, is difficult. Because of the unfamiliarity and prejudice surrounding menstrual pain, it can be difficult to set boundaries for women. Furthermore, sometimes women do not have a choice and have to continue performing certain roles despite the illness. For example, Margot has two little children. Even if Margot has a bad day, she has to pick up the children from school, have to cook for them and have to bring them to bed. Therefore, women are certainly to some extent limited in the roles they perform, but there is also not always a choice to drop a role. Margot compares this to a backpack worn by endometriosis patients. *'The backpack contains pain, some days weighing more than others. But they have to keep on walking with that backpack, even on hard days.'*

Also, every woman experience endometriosis differently and has different losses. Where Daphne can no longer work, Sanne can still work. But Sanne also has to deal with other losses at the work floor.

'A colleague offered a new, higher position after two weeks of her endometriosis surgery. I would have preferred not to know that this new position became vacant, because then I wouldn't have to miss anything. It feels like a loss. People see your potential and I feel I could do it. But because of my body I can't take this job.'

In this chapter I critically discussed the concepts' role constriction, grieving loss and sustainable liminality in relation to endometriosis. In the next chapter I will discuss the expectations of having the sick role.



5.2· Expectations about being ill

'Chronic illness, with its inherent fluctuations, undermines the expected stability of the material body. We understand the expected stability of the material body to be part of that which is taken-for-granted.'

- (Moss and Dyck 2003: 105)

What Moss and Dyck (2003: 105-106) describe is an important issue for women with endometriosis. All kind of things linked to body are often taken-for-granted, such as having to bend down in the supermarket and pick up your groceries from the bottom shelf, eating sweets, planning events, going to a party, etc. However, these activities are not always straightforward for women with endometriosis. The course of endometriosis is uncertain and therefore women cannot always rely on their bodies. You do not know beforehand if you will have a good day or a bad day (Charmaz 1991). Any day could be a bad day. Therefore, people with a chronic illness have to deal the social world around them with uncertainty (ibid.). For example, because of the pain, Daphne had to cancel her friends who were coming to visit her. Devina wanted to go on holiday with her friends, but since she did not know whether the pain would still be there in a few months' time, she did not dare to plan anything.

This is also the case at work. Women have to deal with the limits of their bodies and cannot always do what they wanted to do at any moment in time. As explained in the vignette in the introduction, Sanne gives all her energy at work, making it impossible to do the housework and take care of her family at home. It feels out of balance to her. This is what Charmaz (1991: 171) calls 'temporal incongruence'. This means that there is a disconnection between what the sick body allows to do at a given moment in time and what is expected to do in specific time structures. Because Sanne also wants to combine her job, with keeping the house, spending time with her husband and children, meeting friends and colleagues, it is hard to get enough rest. Sanne is confronted with the fact that she has to reallocate her time and energy. She finds it difficult to decide what to do next. Work less? Report sick again? She doesn't know what's good for her and cannot fully accept in this stage that her body has changed.

Therefore, in her own opinion, Sanne is not always able to fulfil the role as employer or good wife and mother. Also, the surroundings have an influence on the illness experiences of Sanne. This is what Parsons (1951) called the obligations and the rights when you end up in the sick role. I would like to nuance Parson's idea that women with endometriosis have the obligation to recover, because endometriosis is a chronic illness and full recovery is not possible. The major player in legitimising the sick role, is a doctor (ibid.). After her surgery the gynaecologist said that her recovery period would take six weeks. Sanne experienced that people (and herself) expected that she would recover within 6 weeks. During this recovery period she was relieved of her duties and obligations at work and at home, and the sick role was recognised. However, after six weeks, the wound in her abdomen had healed reasonably well, but she still noticed the effects of the medication she had been taking. She was tired because of the poor sleep and her energy level was not yet up to standard. Those people around her assumed that she was recovered, but this was not fully the case. Sanne found it difficult that she could not live up to expectations and that her body was failing her. So, I would argue that women with endometriosis have to deal with the acute sick role that society gave them, but that this role does not fit the illness course. This shows that endometriosis is a chronic illness and therefore there is the concept of sustainable liminality fits (Little et. al 1998).



In addition, my interlocutors must learn to cope with everyday expectations. For example, an endo belly, a swollen belly that can occur if you have endometriosis, is a common phenomenon. However, people do not always expect this to be due to a chronic condition.



mijn.endo.en.ik • Volgend



° Vulnerable °

It has not been going so well for two weeks now. I had a lot of pain and therefore many physical discomforts, such as the endo belly. The endo belly always becomes quite large and it is therefore impossible to hide it anymore, very uncomfortable when you have to go somewhere and I also feel more vulnerable.

This morning, I had to have my eyes measured. Dwayne was with me and he stayed in the shop waiting for me. I went with the shop assistant to the back for the meeting and Dwayne stayed in the shop with another assistant.

The woman talks to Dwayne and asks: Is your girlfriend pregnant too? Dwayne starts explaining that the belly is not because of pregnancy, but that this is due to the endometriosis. When I got home, Dwayne told me this and I thought I should write/say something about it.

I really want to tell everyone to watch out what you say.... This is such a hurtful statement to many women and I find it inappropriate, as well as hurtful. A fat / swollen belly is not always a pregnancy but can also have to do with a chronic medical condition.

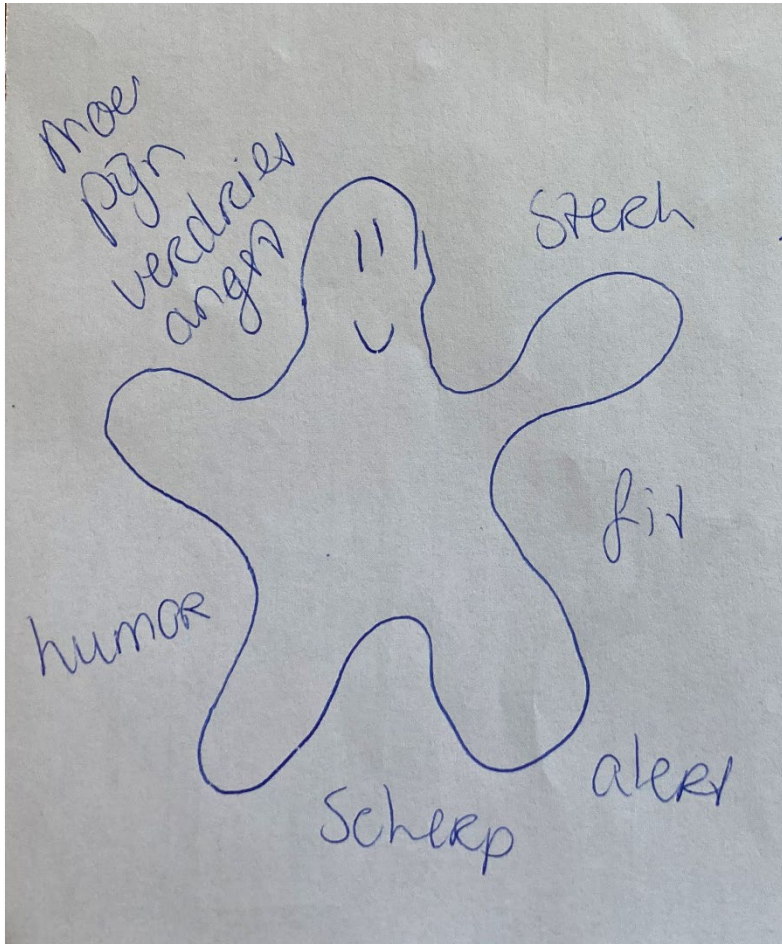
#endobelly #endometriosis #endometriosestichting #endowarrior #endometrioseawareness #endometriosenederland #chronicillness #chronicillnesswarrior #chronicpain #pijn #endometriose #ziektebeelden #projectonzichtbaar

Bewerkt - 6 w.

In this chapter I discussed the concept of the sick role in relation to the expectations of the surrounding. In the next chapter, I will delve deeper into work life of endometriosis patients.



5.3. Pain on the work floor



A drawing that Sanne made about how she looks at herself and how others look at her. The words on the top left are about how she sees herself and the other words are about how other people see her.

Translation in English:

- Tired, pain, grief, fear
- Humour
- sharp
- alert
- fit
- strong

What I noticed during my research is that it can be difficult to be vulnerable and especially on the work floor. Sanne's drawing shows that it is difficult to adopt the sick role. Despite the fact that you are sick and cannot always do everything, you do not want to show this vulnerability to everyone.

Sanne: 'With whom do you share these intimate stories? I don't show off my illness. I am out of the running for a longer period than people expected. Understanding and unsolicited support is very helpful, but often people don't know how bad it is. You have to demand attention for yourself, but that's difficult if you can't always talk about everything in detail. How many vulnerable moments, time and attention do you need to get understanding from other people? I don't always want to be sad on the work floor. It's something private and my own, but it's in my backpack and therefore I always carry the illness with me.'

Devina too, experiences problems around work. She would like to apply for a job, but she is afraid that when she gets a job, she will not be able to meet expectations of her employer. Devina indicated that she needs special treatment at work. For instance, that you are allowed to plan your own time and not working to a fixed timetable. This would allow her to rest when she is in pain and to finish her work later in the evening, for example. The corona pandemic has increased her flexibility, but she still notices that she is afraid of the advantages that people will have.



In this chapter, I wanted to show the difficulties to negotiate the sick role on the work floor for endometriosis patients and that it can be difficult to get a special treatment that would fit the needs of these women. In the next chapter, I will delve deeper into the social issue surrounding holistic care. I will argue that not only the patient, but also society and therefore employers will benefit from this.



5.4. Holistic healthcare



mijn.endo.en.ik ° Uitslag MRI °

25 januari ben ik gebeld door mijn arts over de uitslag van mijn MRI. Waar we al vanuit gingen werd gezegd, alles ziet er rustig uit. De pijn die ik nu heb en niet te verklaren is, is frustrerend. De arts denkt nu dat het mogelijk zenuwpijn is.

° Results MRI °

On 25 January I was called by my doctor about the results of my MRI. What we expected was said, everything looks calm. The pain I now have that cannot be explained is frustrating. The doctor now thinks it might be nerve pain.

This short comic showed how Daphne was struggling with the biomedical approach. Endometriosis is not always visible on an MRI or ultrasound. This sometimes makes it difficult to explain where the pain is coming from. Daphne: *'They only offer help through the medical booklet, but they do not look beyond their medical perspective.'* Daphne and the other women, are often searching for other ways to support their health:

'You often look for other solutions yourself in order to maintain control. You may think it happens to me, but you can still do something about it. Anything is better than having problems with my belly.'

Since 1980s, there has been a growing interest in holistic health care, because of the limitations of biomedicine (Nissen 2013: 75; Feldberg 2004: 181). New forms of health practices, such as alternative and complementary medicine (CAM), arose as a countermove against the Western mind-body dualism (ibid.). There was also a women's health movement (WHM), that emerged in Canada and the United States in the 1960s, which specifically stood up for the special nature of women's health (Feldberg 2004: 182). Those movements assume that illness experiences are embodied (Nissen 2013:80). We experience the world through our bodies and thus there is an embodied self (ibid.).

My research showed that this approach is also important in the health care for endometriosis patients. It is important not to treat the physical symptoms of endometriosis in isolation, but also, for example, paying attention to mental well-being, nutrition, vitamins, etc. I agree with Rønberg (2019) that getting endometriosis causes a detuned body. The body, the self and the environment are no longer aligned with each other and endometriosis patients have to search for new ways to shape their lives. This showed that illness experiences are embodied and therefore the need for a holistic health care system is essential.

During my fieldwork I noticed that women were particularly in need of the following three types of help: psychological help, advice on nutrition and help from a physiotherapist. First, having endometriosis it is mentally very heavy. Margot even ended up in burnout because she had been carrying on with her symptoms for too long. My participants also indicated that they had regular contact with a psychologist. The women must learn to cope with and accept the pain; a psychologist can help with this. Second, a special endometriosis diet, FODMAP diet, can help reduce pain.



Products such as gluten, meat, dairy, soya and sugars are often recommended to avoid. Daphne has adjusted her diet:

'I started eating completely plant-based and I really noticed that my body reacted better to this. Now I'm also going to try to get rid of gluten. Gluten are proteins that cause an inflammation of the intestinal lining and if you have endometriosis, you can be extra sensitive to this. I always noticed that my belly hurt after eating bread, yesterday we had some dip sticks to put in hummus, and yes.... there was the stomach ache again.'

Also, my interlocuters use other products such as oils, vitamins, minerals, supplements, etc. to support their health. They often search for natural medicines, because this is not rubbish for your body.



mijn.endo.en.ik ° CBD olie °

...

So, after a while of silence, I am back! And I would like to share what I have started, namely with CBD oil!

I started using this oil because I heard a lot of positive things around me. After two years, my pain is still there every day and the hospital doesn't know any more either. Also, continuously stuffing your body with medication (oxycodone, tramadol, naproxen etc) is not okay. So I thought: you can't miss a shot. My pain rating is 7 or 8 every day. After three weeks I can say that the oil does its job! After one week of use, I already noticed a reduction in my pain, but I didn't want to be too optimistic (I've had the lid on my nose too often) but, after two years of permanent misery, this is a very nice medicine from which I can reap the positive and pain-relieving benefits. My pain rating has dropped to a 3 and I am so happy with this.

How this product affects the body is of course different for everyone and you have to play a little bit with the dosage. If you are still in doubt, take a look at the website of Mediwiet or watch the documentary 'Weed the people' on Netflix.

- °
- °
- °

#cbd #cbdhealth #cbdproducts #cbdOil #endometriosis #endometriosestichting #endometrioseawareness #pain #cbdforthepeople #cbdforpain #stichtingmediwiet #mediwiet

Bewerkt · 12 w.

Finally, Margot and Sanne told me that it is important to keep their bodies fit. Sanne sports under the guidance of a coach to get her body fit before and after an endometriosis surgery.

Margot: 'I think doing sports is important when suffering from a chronic condition. Through sports, my muscles can become stronger, this reduces the risk of injury and improves my posture. Of course, when I have a lot of pain, I can't do sport. But I do try to keep up my condition.'

Both women do sport under the guidance of a coach, who helps them with the right exercise and adjusts the exercises when they have pain somewhere in their body. The only disadvantage is that you often have to pay for all this complementary care yourself. This care is not included in the standard endometriosis care package. This frustrates Sanne.

'It's shit you have to deal with and it's almost impossible to manage on your own. That's why a psychologist and other help is so important. Taking good care of yourself requires a big wallet. It makes me sad. The operation is paid for, but why not the other care? That costs even less money, with 1/20 of that amount I could also take care of myself for a year.'



The women indicate that if this care was reimbursed, there would be less drop-out at work and in other areas of society. This year, President Macron of France recognised endometriosis as a social problem. This will bring more attention to the disease and the associated costs. My clients would like to see this in the Netherlands and Belgium as well.



Translation:

Endometriosis.

It is not a women's issue; it is a societal issue. The national strategy we are launching holds out the hope of a better quality of life for millions of girls and women.

To conclude, because endometriosis is an embodied experience, it is important to adjust the health care system. A holistic approach to care, would like the women to cope better with the illness and to reduce the pain.

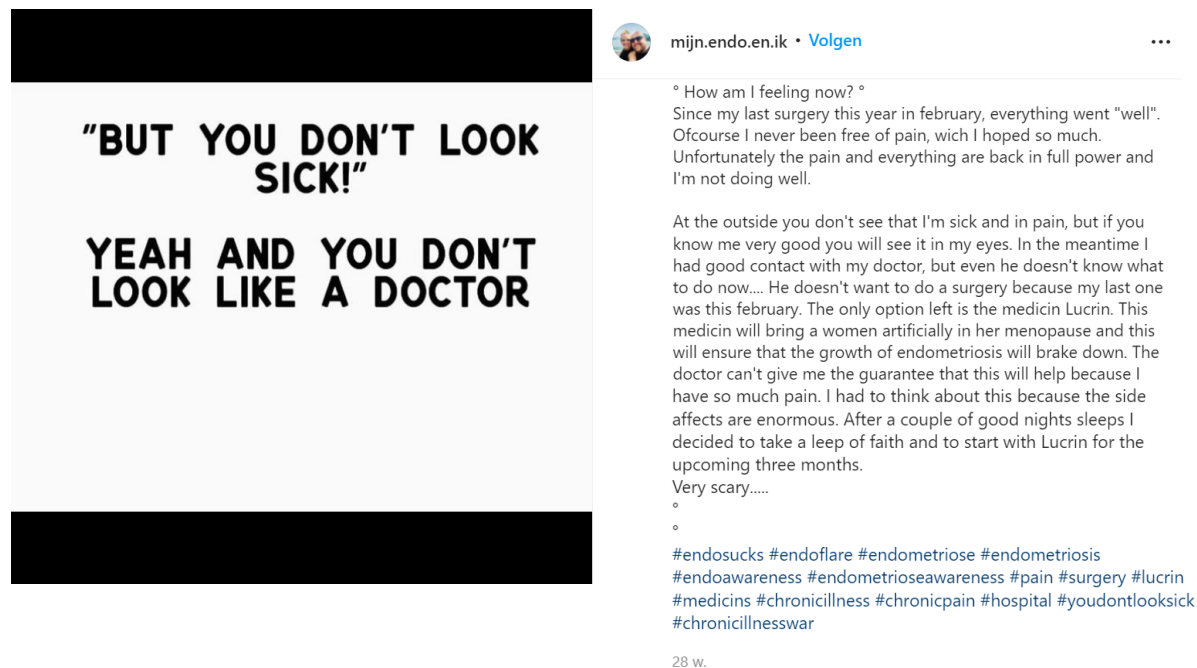


5.5. Understanding, recognition and body limits

'You just have to go on living your life. You have to deal with this disease. I do not always show it to the outside world. I can be gloomy or sad, but feeling sad does not make it easy for me either. So, I just try to live with it. This also means that you do not always see my pain. This makes it quite unbelievable for some people, because sometimes they say: You look perfect and can do everything most of the time, right? That is true. But I also have moments and days when I just cannot do what I want to do. You have to be brave enough to admit it and you have to hope that the people around you understand it.'

- Margot, April 2022, Belgium

Margot not always shows to the people around her that she is in pain. Margot explained that people are not always as understanding, honest or respectful as you might think. And when she does tell them honestly that you have endometriosis, she sometimes gets resistance. *'Often people don't quite understand what endometriosis is and this is reinforced by the fact that it doesn't show on the outside that you are ill. I don't say every five minutes that I have abdominal pain. I can go shopping with a lot of pain, but no one will notice.'* Also, Daphne posted on Instagram a post about this topic.



Having endometriosis is unpredictable and on a day-to-day basis it can change (Charmaz 1991). As already explained, women do not always know how much energy they have to do things. Therefore, they have to priorities their energy. My interlocuters told me that this is one of the reasons why they find it hard to keep up relationships with friends or family. For example, Daphne explained that having a chronic illness learns you who you real friends are. Daphne finds it difficult to set boundaries. She would rather take care of everyone around her than herself. But that is no longer possible. *'I have to put myself at the top and the rest at the bottom. After a while, people give up. They find my illness too difficult, too severe or they don't want to deal with the nagging any more. I've lost some friends because of this.'* This is what Frank (1995) explains about how illness narratives are embodied. I agree with Frank that the body is the starting point for creating and telling stories. A friendship is suddenly interrupted by the illness stories that are prominent in the foreground. So,



bodily limits can lead to a 'shrinking' of someone's social worlds, because you can lose people (Moss and Dyck 2002: 153). In this chapter I tried to show how illness narratives are embodied and have an influence on the people around you.



6. Conclusion

This research originated from the fact that I had listened to a podcast about endometriosis and wondered, how can 1 in 10 women have endometriosis, but I and most people around me do not know this illness? From my feminist and activist stance, I discovered that the norm prevailing in society does not resonate with women who have endometriosis. First, our health care system does not know how to respond to so-called heavy menstruation pain and how to meet the needs of endometriosis patients. Women have been told for far too long that abdominal pain is normal, that it is just part of menstruation. However, endometriosis is not normal, it is a chronic condition. Second, our society does not know how to deal with a chronic, invisible illness like endometriosis. It is often a taboo to talk about menstruation, to which the problem of endometriosis is associated. This is slowly changing, but it is still difficult to understand a chronic female illness that is invisible.

Therefore, the aim of my research was to understand the illness experiences of women with endometriosis in the Dutch and Belgium society. Because endometriosis is often not understood and is only studied from a biomedical point of view, I paid attention to illness experiences of women in this research. Recent, years there is more focus on chronic illness on the political and medical agendas (Fainzang et. al 2010: 18). Anthropologists respond to these changes and focus on the relationship between those agendas and the lived experiences of patients (ibid.). The aim of my research was to do justice to the complexity of everyday illness experiences of women with endometriosis, because illness experiences are not only influenced by the disease itself, but also how society and social networks respond the disease. By placing this research topic in the bigger anthropological discourse about illness experiences, it allowed me to approach endometriosis as an illness that is socially constructed by the women themselves and society.

I found out how their social roles changed and that the classical sick role does not fit when you have endometriosis (Parsons 1951; Glenton 2003). Having an endometriosis means grieving and accepting that your body changed and that entails loss of social roles. I noticed that my interlocuters still have the desire to look things and activities that they still can do. However, getting the diagnosis and dealing with all kind of obstacles, has an enormous mental impact. Therefore, I argue that it is important to consider endometriosis as an embodied experience. It not only influenced your body, but also yourself and how you look at the world. That is why endometriosis needs a holistic health care approach, which would include information about a diet, psychological help, support from a physiotherapist, information about supplements, etc.

The chosen concepts made me focus on their embodied experiences in society in certain time and space. I have particularly examined how these concepts can be applied to endometriosis; a subject that has hardly been explored in anthropology. Because of these concepts and my chosen interlocuters, my research is limited in the fact that I do not paid attention to pregnancy. Many women have difficulty getting pregnant and this could be the subject of further social scientific research. Also, in further research there could be more attention to the role of the partners and relationships that are affected by the illness. Another research could be done among younger girls. My research focuses on women over 28. I also think it could be interesting how adolescents deal with this disease in high school.

Furthermore, anthropological methods helped me to engage with the illness experienced of women. The common remark 'but you don't look sick' also went through my head. In fact, I often only met four women who don't look sick. Capturing those sick moments was extremely difficult. I discussed how handling over my camera to my interlocuters, helped me to capture those intimate pain moments that I, as a researcher, could not always attend. The footage that they made themselves, gave me a better understanding of their daily life rhythm. Also, I showed how interviews,



conversations and observing at their homes helped me to understand how endometriosis influenced their lives. I noticed how they adjusted their schedules to the disease, took medicines and what kind of objects were in their homes that were related to endometriosis. This is where I noticed how endometriosis is marked by sustainable liminality. Their whole life is affected to a greater or lesser extent by the illness.

Although these anthropological methods helped me gain insights into the experiences of these four women, ethnographic methods also have their limitations. This is mainly in terms of scale. My research is limited to the experiences of these four women. Many of these experiences are shared by other women, but in order to generalise and examine the extent of the problem in our society, research can be done on a large scale. For example, more attention could also be paid to the period before the diagnosis. Too many women suffer from menstrual pain for too long because it has become normalised. More social research on a larger scale on stigma surrounding menstrual pain is desirable.

Finally, on behalf of my interlocuters, I want to make one final remark to you, as a reader. There are many prejudices about having a chronic illness. Especially since endometriosis is an invisible illness, people are quick to judge someone as faking it or being weak. But not looking sick does not mean that you are not sick. The women I have met, try to have a life as 'normal' as possible, such as playing tennis, meeting up with friends and cooking. They are more than just their illness; they are not busy with their illness every minute of the day. Yet, finding that balance is often difficult. On Instagram, for example, you see them having a party on King's Day, but not the tiredness of the woman on the sofa the days after. That is because you don't want to make yourself vulnerable and showing that you are weak. I hope my research showed how complex it can be to have endometriosis and that my documentary will contribute to a better understanding of the illness.



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