



Endometriosis and Pain Management at Home: The Nurses Role in Providing Effective Information to Patients

Oskar Lönnqvist &
Mikko Erkkilä

Degree Thesis
Nursing 2013

2017

DEGREE THESIS	
Arcada	
Degree Programme:	Nursing 2013
Identification number:	
Authors:	Oskar Lönnqvist & Mikko Erkkilä
Title:	Endometriosis and Pain Management at Home: The Nurses Role in Providing Effective Information to Patients
Supervisor (Arcada):	Sh Satu Vahderpää
Commissioned by:	Endometriosisyhdistys, Chairman Dana Paredes & Thesis Coordinator Henna Hassinen
<p>Abstract:</p> <p>The aim of this study is to collect information regarding the methods that women suffering from endometriosis use to alleviate pain in the home surrounding that can be used on top of pain medication. This does not include dietary, long term or methods that cannot be performed at home. This thesis is a mixed methods study involving 50 women who suffer from endometriosis. The participants are from a Facebook endometriosis support group called Endometriosisittaret. Through an 11-question anonymous online questionnaire data was collected using Google Forms. The questionnaire dealt with the three research questions which are the following: What kind of pain do persons suffering from endometriosis experience? What methods do persons suffering from endometriosis pain use for alleviating pain in the home surrounding on top of the use of medication and where do they find this information from? What type of information regarding medication free pain-management and care do patients receive from healthcare institutions, and what kind of information regarding medication free pain-management would the patient want from healthcare when given an endometriosis diagnosis? Background research was found from peer-reviewed material from 2008 onward. Previous theses that have touched our subject were found from the Endometriosisyhdistys. This study's theoretical framework is Dorothea Orem's Self-Care Deficit. The results were analyzed using content analysis. Prevalence of words and themes were collected as well as quotes that represent patients' experiences. From the results, it is seen that patients receive none or insufficient information about non-medication pain alleviation methods from health care staff and that they would like patients to receive such information when they are diagnosed in the future. Heat methods were a favorite method of the participants. The results also give a valuable insight into what type of pain endometriosis patients experience and this type of information should widen a nurse's understanding and respect for the patients' subjective description and experience of pain which participants feel is easily belittled and underrated.</p>	
Keywords:	endometriosis, pain alleviation, pain management, chronic pain, home surrounding, self-care deficit, nursing system, Endometriosisyhdistys
Number of pages:	93
Language:	English
Date of acceptance:	

OPINNÄYTE	
Arcada	
Koulutus:	Nursing 2013
Tunnistenumero:	
Tekijät:	Oskar Lönnqvist & Mikko Erkkilä
Työn nimi:	Endometriosis and Pain Management at Home: The Nurses Role in Providing Effective Information to Patients
Työn ohjaaja(Arcada):	Sh Satu Vahderpää
Toimeksiantaja:	Endometriosisyhdistys, Chariman Dana Paredes & Thesis Coordinator Henna Hassinen
<p>Tiivistelmä:</p> <p>Lopputyön tarkoituksena oli kerätä tietoa siitä, miten endometriosisia sairastavat naiset käyttävät lääkkeettömiä keinoja kivun lievitykseen kotiolosuhteissa kipulääkityksen lisäksi. Tutkimuksessa ei huomioitu ruokavaliota tai menetelmiä joita ei voi suorittaa kotona. Opinnäytetyö toteutettiin kyselynä jonka kohderyhmä oli endometriosisi diagnoosin saaneet naiset. Kysely toteutettiin Facebookissa Endometriosisittaretutkir ryhmässä. 50 osallistujaa vastasi nimettömästi Google Forms -verkkokyselyyn. Kyselyssä käsiteltiin seuraavia kolmea tutkimuskysymystä: Millaista endometriosisi kipu on? Millaisilla lääkkeettömillä menetelmillä kipua hoidetaan kotiympäristössä ja mistä he löytävät tämän tiedon? Minkälaisia tietoja lääkkeettömästä kivunlievityksestä on saatavilla terveydenhuollossa ja millaisia tietoja lääkkeettömästä kivunhallinnasta haluttaisiin terveydenhuollosta diagnoosin yhteydessä? Taustatietoa löytyi vuodesta 2008 alkaen. Aiemmat lopputyöt jotka koskevat aiheitamme löytyvät Endometriosisi-yhdistyksen kotisivujen kautta. Tutkimuksen teoreettinen viitekehys perustuu Dorothea Oremin teoriaan ” Self-Care Deficit”. Kyselytutkimuksen tulokset analysoitiin sisällönanalyysimenetelmällä. Datasta tutkittiin sanojen ja teemojen esiintyvyyttä sekä kerättiin vastanneiden kokemuksia edustavia lainauksia. Tutkimustiedon pohjalta oli selvää että potilaat eivät saa joko mitään tai hyvin riittämättömiä tietoja lääkkeettömistä hoitomenetelmistä sairaanhoitajilta ja että he toivoisivat tulevaisuudessa potilaiden saavan myös tietoja sairauden lääkkeettömistä kotihoitomenetelmistä diagnoosin yhteydessä. Suosituin kivunlievityskeino kyselyn mukaan oli lämpö. Tulokset antoivat arvokkaan käsityksen sairaanhoitajille millaisia kipuja endometriosisipotilaat kokevat. Työn aikana saadun tiedon tarkoitus oli laajentaa sairaanhoitajien tietoja lääkkeettömistä itsehoitomenetelmistä että lisätä ymmärrystä potilaan kokemasta kivusta sekä muistuttaa kunnioittamaan potilaan subjektiivista kokemusta kivusta ilman vähättelyä ja aliarviointia.</p>	
Avainsanat:	endometriosisi, kivunlievitys, kivun hallinta, krooninen kipu, kotiolosuhteissa, self-care deficit, nursing system, Endometriosisiyhdistys
Sivumäärä:	93
Kieli:	Englanti
Hyväksymispäivämäärä:	

Table of Contents

1 INTRODUCTION	7
2 BACKGROUND	9
2.1 BACKGROUND RESEARCH	9
2.1.1 <i>What is Endometriosis</i>	9
2.1.2 <i>Causes of Endometriosis</i>	9
2.1.3 <i>Symptoms</i>	10
2.1.4 <i>Types of Endometriosis</i>	12
2.1.5 <i>Diagnostics</i>	12
2.1.6 <i>Treatment</i>	13
2.1.7 <i>The expert patient</i>	15
2.2 PREVIOUS THESES	17
2.2.2 <i>Women’s experiences on pain caused by endometriosis</i>	19
2.2.3 <i>Endometriosis treatment – A guide for professionals</i>	20
3 THEORETICAL FRAMEWORK	22
3.1 THE 3 PARTS OF OREM’S SELF-CARE DEFICIT THEORY	22
3.1.1 <i>Theory of self-care deficit or Dependent-care deficit</i>	22
3.1.2. <i>Theory of self-care</i>	23
3.1.3. <i>Theory of nursing systems</i>	24
4 AIM AND RESEARCH QUESTIONS	25
5 METHODOLOGY	26
5.1. RELEVANCE IN WORKING LIFE	26
5.2. METHODOLOGY RESEARCH PROCESS	26
5.2.1. <i>Platform</i>	26
5.2.2. <i>Evolution of Questionnaire</i>	27
5.2.3. <i>Analysis of Data</i>	28
5.2.4. <i>Time Frame</i>	30
5.3 ETHICS	31
5.3.1 <i>Consent</i>	31
5.3.2 <i>Privacy and confidentiality</i>	31
5.3.3 <i>Ownership and authorship</i>	32
5.3.4 <i>Governance and custodianship</i>	32
5.3.5 <i>Data sharing</i>	33
6 FINDINGS	34
6.1 RESEARCH QUESTION 1: QUESTIONNAIRE QUESTIONS 1, 2, 3, 4	34
6.1.1 <i>Background information results</i>	34
6.1.2 <i>Question 1</i>	37
6.1.3 <i>Question 2</i>	38
6.1.4 <i>Question 3</i>	39
6.1.5 <i>Question 4</i>	41
6.2 RESEARCH QUESTION 2: QUESTIONNAIRE QUESTIONS 5, 6, 9	43
6.2.1 <i>Question 5</i>	44
6.2.2 <i>Question 6</i>	44
6.2.3 <i>Question 9</i>	44
6.3 RESEARCH QUESTION 3: QUESTIONNAIRE QUESTIONS 7, 8, 10, 11	45
6.3.1 <i>Question 7</i>	45
6.3.2 <i>Question 8</i>	46
6.3.3 <i>Question 10</i>	46

6.3.4 Question 11	48
7 DISCUSSION	50
7.1 BACKGROUND	50
7.2 ENDOMETRIOSIS PAIN.....	50
7.3 NON-MEDICATION METHODS OF PAIN ALLEVIATION.....	52
7.4 INFORMATION FROM HEALTH CARE PROFESSIONALS	55
8 CONCLUSION.....	57
9 REFERENCES	59
APPENDIX 1 LITERATURE RESEARCH	61
APPENDIX 2 QUESTIONNAIRE.....	65
APPENDIX 3 TABLES OF DATA	69

Figures

<i>Figure 1. Schedule.</i>	29
<i>Figure 2. Research Question 1.</i>	33
<i>Figure 3. Age of participants.</i>	34
<i>Figure 4. Age during diagnosis.</i>	34
<i>Figure 5.</i>	<i>Mankoski pain scale 1-5. 36</i>
<i>Figure 6.</i>	<i>Mankoski pain scale 6-10. 37</i>
<i>Figure 7. Research question 2.</i>	42
<i>Figure 8. Research Question 3.</i>	44
<i>Figure 9. Non-medication methods of pain alleviation complete.</i>	53

Tables

<i>Table 1. Background search process 1.</i>	60
<i>Table 2. Articles found from search process 1.</i>	60
<i>Table 3. Search process 2.</i>	61
<i>Table 4. Articles found from search process 2.</i>	61
<i>Table 5. Research found from</i>	<i>Endometriosisyhdistys website. 61</i>
<i>Table 6. Previous Theses.</i>	62
<i>Table 7. Theoretical Framework search process.</i>	62
<i>Table 8. Methodology search process.</i>	62
<i>Table 9. Declaration of Helsinki document source.</i>	63
<i>Table 10. Age of participants.</i>	68
<i>Table 11. Age during diagnosis.</i>	68
<i>Table 12. Year of endometriosis diagnosis</i>	68
<i>Table 13. Experience of pain on the</i>	<i>Mankoski pain scale 1-5 69</i>
<i>Table 14. Experience of pain on the</i>	<i>Mankoski pain scale 6-10 69</i>
<i>Table 15. Descriptive terminology of acute endometriosis pain</i>	70
<i>Table 16. Words not from provided terminology for describing acute endometriosis pain</i>	71
<i>Table 17. Types of experiences of acute endometriosis pain</i>	71
<i>Table 18. Descriptive terminology of endometriosis pain</i>	72
<i>Table 19. Words not from pain terminology.</i>	73
<i>Table 20. Specific locations of pain or actions that cause pain</i>	74
<i>Table 21. Different types of experience of pain</i>	75
<i>Table 22. Different themes related medication used for pain alleviation</i>	75
<i>Table 23. Experiences and methods concerning non-medication pain alleviation in the home environment</i>	76
<i>Table 24. Methods involving heat</i>	79
<i>Table 25. Methods that involve cold</i>	80
<i>Table 26. Methods involving touch</i>	80
<i>Table 27. Methods involving distraction</i>	80
<i>Table 28. Methods involving positions and rest</i>	81
<i>Table 29. Methods involving moving your body</i>	82
<i>Table 30. Have received or haven't received information regarding non-medication pain alleviation</i>	82
<i>Table 31. Source of information</i>	83
<i>Table 32. Whom has given information</i>	83

<i>Table 33. What type of information was given</i>	83
<i>Table 34. Long term methods</i>	84
<i>Table 35. Themes regarding non-medication pain alleviation given at the hospital</i>	85
<i>Table 36. Pain alleviation alternative to medication</i>	85
<i>Table 37. Non-medication pain alleviation methods that are long term</i>	86
<i>Table 38. Themes regarding sources for non-medication pain alleviation information</i>	86
<i>Table 39. Abundance of non-medication pain alleviation information from healthcare professionals during diagnosis</i>	87
<i>Table 40. Themes regarding reasons for why healthcare professionals have/give, no or very limited amount of information regarding non-medication pain alleviation</i>	88
<i>Table 41. Themes regarding what information should be told in conjunction with diagnosis</i>	89
<i>Table 42. Specific methods mentioned</i>	90
<i>Table 43. Expert consultation</i>	91

1 INTRODUCTION

This study was conducted in a hope to deepen and gain knowledge for nurses about endometriosis pain and how it is alleviated in the home surrounding on top of medication use. Endometriosis is a condition in which the tissue of the endometrium is found outside of the uterus where it causes an inflamed state that can lead to chronic pain. This type of pain requires the frequent use of pain medication and when the pain becomes too much patients are limited to surgical options. Its symptoms can be treated but it is an incurable disease. Endometriosis can be debilitating due to the pain and affects many patients' lives in a restrictive manner. Through this study nurses can deepen their understanding of patients' experiences of pain and what methods work for them, and what information they would like future patients to get. The nurse's role as an educator and provider of information that will allow an endometriosis patient to perform self-care is what this study focuses on.

This is an inductive mixed methods study focused more on the qualitative aspect. This study used an 11-question online questionnaire through Google forms that provides anonymity for participants. 50 participants were required. This work was commissioned by Endometriosisyhdistys. The two researchers of this study worked in collaboration with the head and student correspondent of the Endometriosisyhdistys. The link to the questionnaire was posted onto the Facebook group 'Endometriosisittaret' which is an online Facebook support group for women who suffer from endometriosis set up by Endometriosisyhdistys. A confirmed endometriosis diagnosis was required to be able to participate.

By looking at previous research and theses the student researchers have gained some insight of this subject. Because there isn't much research specifically on non-medication pain alleviation methods for endometriosis patients that can be used in the home environment, there will be much that is uncovered through the data collected in this study. The previous research that was used were peer-reviewed and from 2008 onwards.

The theoretical framework is based on Dorothea Orem's Self-Care Deficit Theory. The nurse's role and knowledge in providing patients' with the necessary tools for caring of their pain and themselves in the home surrounding when they leave the medical facility is an essential part of what this study is trying to improve.

This study is interested in methods of pain alleviation that can be conducted at home through methods or equipment and is non-medication based. Life-style changes or long term methods are not methods that we are looking for. By doing this study it is a goal to retrieve information that will allow nurses to guide endometriosis patients in pain management in the home environment that can be used on top of the use of pain medication.

2 BACKGROUND

2.1 Background Research

Background research was collected for the purpose of describing the epistemology of endometriosis and information gained from previous theses so as to deepen the reader's knowledge of the subject at hand. Specific search methods for sources can be found in Appendix 1.

2.1.1 What is Endometriosis

Endometriosis is a chronic gynaecological disease that involves the growth and placement of endometrial tissue outside of the uterine cavity. (Barrow et al, 2015:2541) This displaced endometrial tissue does not shed or bleed in accordance with the menstrual cycle. This tissue can bleed and swell in a noncyclical fashion or in a cyclical one. Lesions and cysts can also develop. This is because the endometrium or endometrial cells/tissue is found outside of the uterus and thus try to perform their duty in the wrong place. These types of behaviour from the displaced tissue can cause severe cramping, bleeding and pain. (Seear, 2009b:195) This causes a "chronic, inflammatory process and a tendency for adhesion formation". (Mao & Anastasi, 2010:109) In the US endometriosis affects approximately 10% of the female population. The disease affects about 6.3 million people around the world. In a new source of information there are 10-15% of reproductive females in Finland that have endometriosis. This is the equivalent of up to 200 000 women. There exists no 'Käypähoito' designed for endometriosis which shows how little information is available for healthcare professionals including nurses. (Sarkomaa, 2017)

2.1.2 Causes of Endometriosis

The origin and cause of endometriosis is unsure even though there exist several possible theories. One of the most known and accepted theory is that of Retrograde Menstrual Flow. This involves the backwards flow of menstrual fluid through the fallopian tubes so that it ends up in the peritoneal cavity. This theory suggests that not all of the menstrual blood during menstruation exits through the cervix as it should but instead flows up the fallopian tubes and exits from there into the cavity. Thus, there are endometrial cells finding themselves outside of the uterus.

Another theory is that of Celomic Metaplasia. In this theory, the mesothelial and peritoneal cells along the ovaries evolve into endometrial tissue. It is thought that various triggers would cause this unwanted change. These triggers have been thought to be due to menses, toxins or immune factors. (Mao & Anastasi, 2010:110) There have been correlations between prevalence of endometriosis and exposure to the toxin dioxin and biphenyl pollutants which exist naturally but are also by-products of industrial manufacturing. These specific toxins contain Xeno-estrogen which mimics the hormone estrogen. So, the body is technically having too much estrogen and this can possibly affect and in theory cause the formation of endometriosis in female foetuses in women who are exposed to these toxins during pregnancy. These toxins are found in food and a very wide range of normal household products. There is a correlation but the relationship is still unclear and unproven. (Sear, 2009a:371)

One theory called the Embryonic Rest Theory suggests that Mullerian cells in the rectovaginal area are triggered by some sort of stimuli to then turn into endometrial cells. Some other theories involve the haematological or lymphatic system. (Mao & Anastasi, 2010:110)

There are many theories for the cause of endometriosis and none have been proven so far. In the future, there might be more insight upon this which might be useful in trying to hinder the formation of endometriosis in people. As the disease is incurable the focus is on managing the symptoms.

2.1.3 Symptoms

The classic symptoms of endometriosis are dyspareunia (pain during intercourse), dysmenorrhea (painful menstruation), chronic pelvic/back pain and rectal dysfunction such as dyschezia (constipation, difficulty or pain in defecating), and infertility. (Mao & Anastasi, 2010:109) Adhesions caused by endometriosis can distort pelvic anatomy and thus cause impaired ovulation. Patients can suffer from menorrhagia (heavy menstrual bleeding), metrorrhagia (irregular/noncyclic bleeding). (Mao & Anastasi, 2010:110) Symptoms are

typically cyclical but chronic pain for example occurs up to a third of endometriosis patients in the UK. (Barrow et al, 2015:2541) Chronic pelvic pain is the leading motivator for endometriosis patients to seek help and care. Those who suffer from pain usually have chronic pelvic pain. Pelvic pain in the cyclical form tends to increase in severity leading up to menstruation and then subsides when menstruation ends. (Mao & Anastasi, 2010:110) Even though pain is a major concern for endometriosis patients there are also patients who do not experience pain. In the UK in a study it has been seen that up to 20% of patients are asymptomatic. (Barrow et al, 2015:2541)

Endometriosis-associated pelvic pain can be cyclic or noncyclic and are very individual in relation to onset and duration. Some systemic symptoms of endometriosis is that of diarrhoea, nausea, vomiting, fatigue, headache, light-headedness, fever, or malaise. (Mao & Anastasi, 2010:111) The symptoms that patients have are very individual and depend on the type of endometriosis they have and where it is situated. The type of pain though that patients experience does not necessarily correlate with the type of endometriosis they have. There exists a 4-stage ranking classification system for severity of endometriosis. It is a ranking system used for example in the USA, and is useful for infertility prognosis but is in no way an indicator for the patient's experience and level of pain. (Mao & Anastasi, 2010:110) Fertility difficulties are a very unfortunate problem that many individuals suffering from endometriosis have to deal with but it needs to be remembered that a patient as a whole and as a woman is not only a reproductive being but has many other concerns that have to be taken into account in the process of treating individuals holistically. One of the largest concerns is helping the patient manage their pain as much as possible.

Nurse Jo Johnson who worked in the UK who has endometriosis gives her own account of her experiences with the disease in the article 'Reluctant Role Reversal'. The nurse explains how debilitating her condition was as she for example was in so much pain at times that she could hardly walk, she had to clutch to a bottle of hot water to herself to ease pain while sitting in meetings, and she eventually collapsed from pain at work. It was after this collapse that she had to have multiple emergency surgeries to remove endometriosis tissue that had spread in the body. These surgeries have been able to lessen her pain for at least a while. (Knight, 2010:25) This shows from a personal account the type of pain a person can have and how much it affects their daily life and quality of life. It comes up in the article as well how the nurse felt that her experience of pain was not taken seriously by her own GP who only

prescribed and advised the use of ibuprofen, a not very strong pain medication. This made this nurse in the role as a patient to feel that she was exaggerating her pain due to the doctor's and others reactions. This has to remind us of how as a nurse we must take the patient's account of pain seriously and as real even if we question the pain due to clinical presentation. It is a very unfortunate thing that she didn't feel empowered as a patient.

2.1.4 Types of Endometriosis

There is endometriosis that exists outside of the uterus and then there is endometriosis that is also found inside of the uterus. The endometriosis that is found inside of the uterus is called adenomyosis (endometriosis interna). There are three main types of endometriosis. The first type is that of superficial implants which are nicknamed 'powder burns'. Second is 'endometriomas' which are also called 'chocolate cysts'. Endometriomas are thick-walled cysts that contain blood products of no function. The third type is 'deep infiltrative endometriosis. DIE (deep, infiltrative, endometriosis) is when the endometrial tissue finds itself outside of the abdominal lining/cavity or found in the pelvic gastrointestinal and urological areas for example. (Barrow et al, 2015:2542) There are even cases where deep infiltrative endometriosis has been found in the lungs and brain. (Mao & Anastasi, 2010:109) Especially with deep infiltrative endometriosis the disease resembles cancer and can be life-threatening. For most of the time though endometriosis is not a fatal disease but is associated with chronic pain that can be a very debilitating factor and affect drastically upon the quality of life for patients.

2.1.5 Diagnostics

For a confirmed diagnosis of endometriosis, a visual confirmation is needed which is usually done through a laparoscopy. There are some forms of endometriosis where cysts or masses can be detected through the use of ultrasound, magnetic resonance or physical examination but this will only reveal deep infiltrative endometriosis. (Barrow et al, 2015:2542) If misdiagnosed and left untreated, endometriosis can evolve from small lesions on normal pelvic organs to large ovarian endometriomas and extensive fibrosis with adhesions.

The laparoscopy is considered the ‘gold standard’ for giving a full diagnosis. Before a full diagnosis, a patient can be treated based on their symptoms and endometriosis can be a perceived state. Due to this method of diagnosis there is usually a delay of up to 12 years before a confirmed diagnosis. (Mao & Anastasi, 2010:113) This can be a frustrating experience for the patient, not knowing for sure for all that time. The only way to get a confirmed diagnosis is through an invasive procedure which allows visual confirmation. As doctors will want to avoid surgery as much as possible this procedure is usually only done when the pain that the patient is experiencing is unbearable. In conjunction with making the visual confirmation endometriosis is removed surgically usually in these procedures. From the point of view of the doctor they are doing two useful things in a single procedure. From the patients point of view it is frustrating to have to wait for so long to be diagnosed. It is understandable that surgery is avoided for as long as possible due to the associated complications and the prevalence of endometriosis growth that easily forms to the adhesions that come from surgery.

2.1.6 Treatment

The primary goals of treatment for endometriosis involves the relief of pain and restoring or maintaining fertility. First line of treatment is the use of NSAIDs (nonsteroidal anti-inflammatory drugs) and low-dose COCPs (combined oral contraceptive pill). (Mao & Anastasi, 2010:113) For many painful cramps as well as the spread of endometriosis is linked to menstrual flow. Through using COCPs menstruation is hindered for longer periods of time to manage the pain. The use of combination OCs can result in decidual changes in the endometrial glands and thus has had the positive effect of decreasing dysmenorrhea and even slowing the progression of endometriosis. (Stoelting-Gettelfinger, 2010:519) This is of course not an option for patients who are trying to get pregnant. The NSAIDs are used for the management of pain. There are though risks and negative side effects that occur from regular use of NSAIDs which is especially the case for those who have chronic pain.

The second line of non-invasive treatment from the medication standpoint involves the use of progestins, androgenic agents, gonadotropin-releasing hormone (GnRH) agonist analogs, and antiprogestins. If through medication symptoms cannot be managed effectively or pain becomes high enough and acute there are surgical options available. These procedures are

used for removal of endometriosis. Laparoscopic surgery with removal of endometrial lesions has been associated with a decrease of pain in mild-to-moderate endometriosis and increases likelihood of pregnancy rates in patients with endometriosis-associated infertility. When it comes to the use of laparoscopic surgery to remove endometriosis it needs to be known that in 40% - 60% of cases endometriosis does re occur within 2 years afterwards. (Mao & Anastasi, 2010:114) When laparoscopic surgery is not enough and patients still have high pain that is intolerable definitive surgery becomes an option. In these cases, a hysterectomy can be performed where parts of the uterus or the whole uterus is removed. This can also involve salpingectomy or oophorectomy which is where the ovaries or/also the fallopian tubes are removed from one or both sides. (Seear, 2009b:195) This definitive surgery will indefinitely make the person infertile. It is also a big procedure that involves more risks. The problem with using definitive procedures is that there is more and more research which indicates that it can relieve pain but is not a cure and may not always have the effect desired. Even after definitive surgery, endometriosis may re occur in 5% to 15% of cases. (Mao & Anastasi, 2010:114) So surgery may not be able to reach all the endometrial growths and will not stop new ones from being developed. Hysterectomy may not make endometriosis disappear, and the condition can re occur even after menopause. (Knight, 2010:25) This emphasises on the fact that endometriosis is a lifelong, chronic, ever changing disease that requires a strong constant relationship between patient and the medical staff especially because pain can re occur despite different types of treatment.

Because treatment is limited to medication and surgery patients are very interested in alternative methods for treating pain. This includes alternative therapies such as acupuncture, changes to diet and lifestyle. (Seear, 2009b:195) Many patients take on advice from others regarding these methods and is the reason why there are many self-help guides that have to do with diet, exercise and homeopathy. There needs to be more research specifically to endometriosis and the effect of such methods and lifestyle changes so as to have the medical scientific proof of their effectiveness. Into the category of assisting in treating pain in the home surrounding are the methods that this thesis will be analysing from patients' own experiences. While trying to find sources regarding specifically of the subject of endometriosis pain management at home that is not medication, diet change, exercise or alternative therapy there wasn't any such research found from peer reviewed research. There was more information regarding these aspects in thesis work from Finnish universities.

Information about this research is taken into account in the 'Previous Theses' section of the background chapter.

2.1.7 The expert patient

These alternative methods mentioned above and lifestyle changes brings us to the next section of the background. The burden that patients take on due to their disease can be overwhelming. Kate Seear in her article 'The third shift: Health, work and expertise among women with endometriosis' analyses through a qualitative semi-structured interview study involving 20 Australian patients who suffer from endometriosis their experience of living with the disease and their journeys in becoming experts in their own disease in an effort to manage their pain and heighten the quality of their lives. In another article that Seear's has written called 'Nobody really knows what it is or how to treat it': Why women with endometriosis do not comply with healthcare advice.' which discusses through another 20-participant qualitative study the reasons for why patients can start to question and disregard advice from healthcare professionals.

Seear explains how women diagnosed with endometriosis may experience 'concern, worry, anxiety, self-blame, financial and relationship difficulties and a reduced quality of life'. (Seear, 2009b:196) There is a consensus among the participants of their feelings of powerlessness, fear, anger and depression partly due to the attitudes expressed by their GP's that made the patients feel that they were not being taken seriously. Patients realize after diagnosis that their condition is incurable, with an unclear cause, unpredictable development and with limited courses of treatment that have uncertain outcomes of effectiveness. This gives more reason for patients to feel that they have to take more responsibility themselves regarding the management of their disease outside of what the medical professionals and facilities can provide. This can be empowering but also an overwhelming burden. Nurses would be able to lessen some of this burden by providing information about non-medication methods of pain alleviation already at the medical facility.

Through the use of support groups patients gain and share knowledge in an effort to support each other's self-management of the disease. They seek advice and methods that can work for

them. The problem that many face though is how cumbersome, contradictive and unreliable the knowledge that they receive is. It is also true that as individuals we will react differently to different methods and some methods will not be suitable for a person even though it is effective to someone else. Many of the suggested methods and alternative ways to manage the disease can be strict, complicated and require a great deal of change and restructuring in an individual's life. This is what the term 'the third shift' relates to. It is that on top of normal work, and responsibilities in life patients feel that the management of their disease becomes a third job for them that interferes with the first two aspects of their life. 'Health self-management was physically and emotionally demanding' (Seear, 2009b:202) explains one of the patients in the article. It becomes a dilemma when one is trying to manage one's disease which takes up so much time and effort to the extent that in the process of acquiring better quality of life the quality of life actually suffers. This is especially a problem when patients try to follow a difficult dietary, exercise or alternative therapy regime that becomes impossible or very difficult to achieve due to financial and time consuming reasons. Then the patient can suffer from a 'moral failure' which makes them feel responsible, shame and guilt for not being able to continue with something that possibly can lighten their pain. This aspect is important for nurses to be aware of when they are suggesting methods. Patients are individuals for whom certain methods work while others don't and it is extremely important to take into account their individual capabilities to perform those methods. The creation of blame and guilt without understanding adds only to creating an unfair feeling of 'moral failure'. This should be avoided by nurses as much as possible.

Another aspect brought up that was mentioned briefly already was the attitudes and manner in which medical professionals take on the subject of patients managing themselves. Some doctors focused so much about the infertility aspect that they continuously suggested and pushed the treatment option of pregnancy as it should alleviate pain. The manner in which this is brought up though seems to the patient as if the health care professional is disregarding totally the patient's desire, circumstances, and possibility to want to have children. Having a child is a very private and life changing subject which becomes a lifelong responsibility that cannot be taken lightly. (Seear, 2009a:377) It also has to be taken into account that the pain relief due to pregnancy when suffering from endometriosis is most likely only temporary for the duration of pregnancy but will come back once menses starts again. Advertising pregnancy as a 'cure' is misleading.

Some women had experiences of the medical professional wondering why a patient has not for example exercised more or done more yoga and it needs to be reminded that patients are restricted by time, finance, availability, etc. The doctor might think that the patient isn't taking seriously their advice or being lazy. Patients are individuals who are in charge of their lives and ultimately make their own decisions regarding the management of their disease. It also has to be taken into account that however much a patient would like to adopt some of these methods the disease itself due to the chronic pain and debilitating effect can be a hindering factor.

The patient must be regarded as a whole, a unique individual for whom the choices they make impact greatly on their lives. From this article, it is important to take away how medical professionals regard their patients is just as important as the treatment itself. One cannot judge a patient's decisions so harshly without understanding better their point of view and situation. As Seear puts it in her own words in the article; 'This study reminds us of the importance of paying attention to the experiences of patients suffering from a debilitating chronic illness and raises questions about what can be done to assist them in managing their illness. There appears to be a need for strategies and support mechanisms to be implemented to assist women in the management of their health problems, especially given the findings in this study, which suggest the processes of becoming an expert patient and of self-management can be a burden to some patients.' (Seear, 2009b:204)

2.2 Previous Theses

It became clear from the beginning that previous research answering the set research question has not been made. Many articles that were read were either too internal medicine oriented or not experience based. The material that couldn't be used focused on external problems related to endometriosis or they did not include the nursing aspect related to endometriosis. Peer researched theses were picked. All of them are commissioned by Endometriosisyhdistys, the Finnish endometriosis patient association. These theses incorporate some of the same aspects in their work as what the research questions are for this thesis.

2.2.1 Endometriosis related pain alleviation

In this study by Hemminki and Karaslahti, the researchers used a themed interview to find out what women suffering from endometriosis pain use to alleviate the pain. The research questions reveal that the study leans toward dietary and exercise related ways to alleviate pain and only the follow up question suggests that there can be other methods to alleviate pain too. For the interview, they wanted to find out the median age of the interviewees and how many days in a month they suffer from endometriosis related pains. Only endometriosis patients that are diagnosed by a doctor were picked for this qualitative study to bring out the experiences of the participants as subjectively as possible.

The interviews were conducted through the Endometriosisyhdistys website and their closed Facebook group. The material was analysed using inductive material analysis and it was chosen because the analysis answered the research question through the unification of concepts from the collected background materials. 19 answers were received in the span of 2 months. Median age of the interviewees is 28, 2 years, from ages 21-51. The average time from being diagnosed is 6 years. In a month, the answers say, there are on average 10 days of endometriosis related pain. According to the answers the researchers concluded that most of the participants did not find dietary change to help them with endometriosis related pains. On the second part, they concluded that eating habits (size of the meal and eating schedule) did not bring alleviation to pain. Only one answer said how much you eat has an effect on pain in a positive manner. The third question asked if exercise helped with pains. The conclusion is that exercise helps with pains with 7 of the participants. 3 answered no effect and the rest answered that the pains take away the ability to exercise. The follow up question on what other means endometriosis patients have found out to be useful were 1. Heat 2. Relaxation 3. Positioning 4. Cold 5. Rest 6. Mind control. The results of the study are meant for women suffering from endometriosis as well as professionals who might encounter these patients in their profession.

This thesis by Hemminki and Karaslahti the collection of data and materials are done in a similar fashion as this study, through an open questioned survey. The survey like in this thesis was put up in Endometriosisyhdistys's closed Facebook group by the student correspondent of Endometriosisyhdistys. Hemminki and Karaslahti focused in their study on how endometriosis patients experience of dietary change and exercise affect their pains. They

also had a follow up question on what other non-medical ways these patients have found out to be helpful. This study focuses on the latter question of non-medical ways to alleviate pain in the home setting. It is expected to have similar replies on the question but in more detail.

2.2.2 Women's experiences on pain caused by endometriosis

The study by Kuntola and Lähdesmäki focuses on how women suffering from endometriosis perceive pain and how the public care nurses and nurses as well as the patients' family members can support, help, guide and teach patients. The researchers' concern was the lack of experience based descriptions of pain. The study reflects through theory on what endometriosis pain is and what is needed for comprehensive guiding and teaching especially in the areas where public care nurses operate.

The study was conducted as a qualitative study by following the Endometriosisyhdistys website's message board in the span of 6 months. 3 texts were picked with the permission from the writers, 35 pages altogether. The texts were written by women aged 20, 25 and 29. They all had gotten their diagnosis within the previous year but had been suffering from pains years before that. The pains experienced by these women were over 7 on the VAS-scale (1-10) which is commonly used in health care to describe pain.

The analysis is divided under 4 types of pain: physical, social, mental and spiritual. The results suggest that physical pain was experienced in lower back, lower abdomen, genitals, legs and while urinating/defecating. The strength of the pain perceived varied depending on the time of the month. Pain was described as continuously aching, inexplicable, squishing and worsening. Social pain in the study includes sick leaves from work, human relationships, hobbies and sexual intercourse. All three of the text mention suffering in their lives which reduces the options to live life regularly. Mental pain is according to the study fear for the future and childlessness, anxiety, despair, worries and bitterness. Mental pain is highlighted in the texts as much as physical pain. Spiritual pain is suffered less but the results show that they suffer from fear and hopelessness.

All of the pains perceived by these women makes them feel like their quality of life is reduced due to the illness. From the texts researchers also concluded that doctors belittled the women's experiences and questions. No other medical professionals are mentioned. The researchers bring up the fact that endometriosis treatment is doctor lead and that nurses and public care nurses should be brought to the equation. Supporting and educating can give the patients a better feeling that their problems are heard.

The thesis by Kuntola and Lähdesmäki has an interest in the personal experiences of women who suffer from pains and how it affects their lives and how public care nurses and nurses can help guide and teach these patients. The information was gathered through Endometriosisyhdistys. In this study, it is important to find out how pain is perceived and where people get information on their disease, or if they have gotten any information at all. This study includes more participants through a survey so it is expected to have more variety in the answers on how pain is experienced and a broader view on how bad it can be.

2.2.3 Endometriosis treatment – A guide for professionals

The aim for the research conducted by Korhonen and Valtanen was to create a clear and functional guide for endometriosis treatment for the medical professionals which can also be used as a tool to evaluate and develop better means of guiding patients. The study was carried out from the perspective of patient counselling including a comprehensive literary review on the disease itself, symptoms, treatment and pain alleviation. An endometriosis treatment guide was developed based on the research. It is meant for health care professionals to help guide patients suffering from endometriosis. The study included an impressive amount of literary sources which according to the text gives a very good overall picture of the disease. Ethically the study can be classified as reliable with so many resources.

The study resulted in a comprehensive guide for medical professionals to use in their line of work when encountering patients with endometriosis symptoms. General part consists of aetiology and forms of endometriosis. It is followed by what symptoms may appear and how and when it is diagnosed. Treatment of endometriosis is divided into surgical treatment, medication related treatment and non-medical treatment parts. The guide talks about childlessness within endometriosis patients and the means to survive with endometriosis. The

important parts of patient counselling and the role of the family and friends as well as the importance of peer support are included in the guide.

The thesis by Korhonen and Valtanen combined a useful guide for medical professionals based on a comprehensive literary review. Endometriosisyhdistys commissioned the work and published it on their web page including an idea that the guide can also be used in a larger entity of guides related to endometriosis. This study is interested in knowing about the experiences of women and what information they, after having the diagnosis, think would have been important to be given when diagnosed.

3 THEORETICAL FRAMEWORK

Dorothea E. Orem's self-care deficit theory in nursing practice is the theoretical framework of this thesis. Known also as 'SCDNT'. Through her life's work around the concept of self-care it is now recognized as a timeless nursing theory for health care sciences. The model consists of three parts which were formulated through her own research and discussions with her colleagues. It was later developed further to be used in practice by the Nursing Development Conference Group. (Alligood 2013: 222-223) Meaning of re-occurring words: Self-Care: "The production of actions directed to oneself or to the environment in order to regulate one's functioning in the interests of one's life, integrated functioning, and well-being". Therapeutic Self-Care Demand: "The measures of care required at moments in time in order to meet existent requisites for regulatory action to maintain life and to maintain or promote health and development and general well-being". Self-Care Agency: The abilities of persons in performing Self-Care. "The complex capability for action that is activated in the performance of the actions or operations of self-care". Self-Care Deficit: "A relationship between self-care agency and the therapeutic self-care is not adequate to meet the known therapeutic self-care demand". (Orem 1985: 31)

3.1 The 3 parts of Orem's Self-Care Deficit theory

3.1.1 Theory of self-care deficit or Dependent-care deficit

"Nursing is required because of the inability to perform self-care as the result of limitations." Nursing is needed when they are subject to health-related or health-derived limitations in which the patient is unable to perform continuous self-care or dependent-care resulting in ineffective or incomplete care. (Orem 1985:34)

The 5 methods of helping used by nurses in the theory

1. Acting and doing for another
2. Guiding and directing
3. Providing physical and/or psychological support
4. Providing and maintaining a supportive environment for personal development
5. Teaching

The presuppositions lay on these propositions and link Self-Care deficit and theory of Self-Care together. They consist of 2 things: personal and societal platforms. Personal aspect suggests that Self-Care requires self-management. As a form of self-regulation, Self-Care is necessary for life itself, for health, for development as a human and for general well-being. Self-Care and dependent-care rest on the individual members' educability and their attainments of social groups. On the other end, societies provide ways and means to aid persons according to their individual needs. If a person is institutionalized the people for example at the hospital become the means for aiding persons who are dependent on others to meet their needs. (Orem 1985:35-36)

3.1.2. Theory of self-care

“Maturing or mature adults deliberately learn and perform actions to direct their survival, quality of life and well-being.” The actions or activities which are performed by individuals or the people maintaining life, health and well-being on their behalf. These actions keep patients functioning and maintain their structural integrity while contributing to human development. Self-Care –“Practice of activities that individual initiates and perform on their own behalf in maintaining life, health and well-being”. Self-Care Agency “the ability for engaging in self-care – conditioned by age, developmental state, life experience, sociocultural orientation, health and available resources”. Therapeutic Self-care demand is “Totality of self-care actions to be performed for some duration in order to meet self-care requisites by using valid methods and related sets of operations and actions”. Self-care requisites is “action directed toward provision of self-care”. This part is divided into 3 parts: Universal, Developmental and Health deviation Self-Care requisites. (Orem 1985:36-37) Universal requisites are the basic needs to maintaining life: Sufficient intake of air, water and food. Elimination of waste from one's body, balance between solitude and social interaction, hazard prevention and promoting human functioning. Developmental self-care requisites are associated with developmental processes for example adjusting to body change or even a new job. Health deviation self-care is needed when a person has an illness or injury. Understanding their current situation through getting medical assistance, being aware of the effects and results of these conditions. Following given medical instructions and being able to learn to live with their condition and understanding the effects. (Alligood 2013:227)

3.1.3. Theory of nursing systems

“The product of nursing is nursing system(s) by which nurses use the nursing process to help individuals meet their self-care requisites and build their self-care or dependent-care capabilities.” (Alligood 2013: 223) Theory of nursing systems is the key element in Self-Care Deficit Theory. It establishes the nurse – patient relationship and the type of nursing needed in the current situation. As the theory is focused on person it gives a description of the roles between a nurse and a patient and their own responsibilities. Nursing systems are the action or series of actions that nurses undertake in aiding to meet a person’s self-care demands. Organizing nursing care to provide adequate means for self-care are divided in to 3 stages. According to the following stages the role of the patient and nurse is determined. The patient’s needs may vary so they can be switched between the stages at any time. Wholly compensatory system is when the patient is not active in performing self-care. At this stage, the patient is dependent on others due to the limits of their self-care agency. The nurse is the only active member and fulfils the recognized self-care demands while supporting and protecting the patient. Partly compensatory system is when the patient and nurse work together in fulfilling the self-care demands of the patient. The patient is active in meeting their Self-Care needs as much as they can but the nurse takes care of the self-care limitations of the patients. Supportive – Educative system. The patient is active in meeting their Self-Care demands and the nurse’s role is reduced to overseeing that the actions are taken care of within the limits of the needs of the patient. The nurse also uses resources and other tools to educate the person and their family to perform Self-Care. A patient can have adequate skills and knowledge to meet their Self-Care needs but requires help in making decisions, controlling behaviour or acquiring knowledge. (Orem 1985: 33-34)

Dorothea Orem’s Theory of Self-Care deficit is a timeless conceptualization of what nursing is. As nurses, we are required to give knowledge onwards and understand the dynamics of patient education and guiding. “Lack of knowledge can lead to adverse patient outcomes, and for that ignorance is no excuse but rather our responsibility.” (Gokenbach 2012) This aspect is especially useful for this study. This emphasis on the nurse’s role as an educator and provider of necessary knowledge to the patient is central. The nurse has a duty to ensure that this occurs and it is just as vital when it comes to providing information about non medication methods of pain alleviation in the home environment for patients with endometriosis.

4 AIM AND RESEARCH QUESTIONS

The aim of this study is to find information from patients about medication free pain-management in the home environment for endometriosis pain. The information gained will be important for widening the knowledge about endometriosis pain and its management from patients themselves so that nurses can more effectively be able to guide endometriosis patients in alleviating pain at home in the future.

Our research questions are as follows:

1. What kind of pain do persons suffering from endometriosis experience?
2. What methods do persons suffering from endometriosis pain use for alleviating pain in the home surrounding on top of the use of medication and where do they find this information from?
3. What type of information regarding medication free pain-management and care do patients receive from healthcare institutions, and what kind of information regarding medication free pain-management would the patient want from healthcare when given an endometriosis diagnosis?

5 METHODOLOGY

5.1. Relevance in Working Life

The practical implications of this research are that the information we collect will be used to deepen the knowledge for nurses about the methods that are preferred by endometriosis patients at home to alleviate pain in tandem with the use of pain medication. In the healthcare and hospital environment staff are quite knowledgeable about pain relief from the medication perspective but might not have knowledge about methods on top of that that can be used and executed at home. Therefore, they can't guide patients about methods on top of medication for pain-relief. From Dorothea Orem's Self-Care Deficit, it is the nurse's role to ensure that the patient can continue rehabilitation and self-care outside the hospital environment as effectively as possible. This study will hopefully fill in a gap of knowledge on this issue for the nurse.

This information can be used to possibly construct a detailed pamphlet about preferred methods of not medication based pain relief that patients who are diagnosed with endometriosis can be given. This same information will also teach and make nurses aware of effective methods from the persons' themselves who suffer from the disease.

5.2. Methodology Research Process

5.2.1. Platform

This study is an inductive mixed method study that weighs on the qualitative aspect. This study has been commissioned by the Finnish Endometriosis Society. The chairwoman of Endometriosis Society Dana Paredes has given us permission and support for this study. We used an 11-question questionnaire that exists online on a website to which participants can answer anonymously. The survey program we used is 'Google forms'. The questionnaire can only be filled by persons who are given the website address and can answer without giving any personal information. This makes it impossible to trace the answered questionnaire back to the participant. The study is primarily a qualitative study.

The aim is to have data from at least 20 candidates and maximum 50 candidates. The reason for this type of restriction is the amount of work that qualitative data can take to be analysed in regard with the fact that it is two university students conducting the analyses and that they have a limited amount of time to do this; it is a question of limited resources. The study can be conducted in larger scale by other individuals if they see it useful in the future. The questionnaire's website was posted onto a Finnish Facebook endometriosis support group called 'Endometriosisittaret' (contains 2524 members: checked 14.03.2017). This support group is owned and run by Endometriosisyhdistys and through their cooperation they gave us permission to use this group for acquiring participants for our survey.

5.2.2. Evolution of Questionnaire

The questions are a mix of quantitative and qualitative questions. There are 4 quantitative multiple choice closed questions, two of which are in the background information section and two through which we should be able to gain data regarding our research questions. There is one short answer question and 7 long answer open ended qualitative questions that are based on a participants' experience and views about different issues concerning our three research questions. Because the participants are Finnish the questionnaire was in Finnish and not in any other language. There was a risk that we would not get enough participants to answer but as the subject of pain is quite a big issue for endometriosis patients there was hope that the interest of this subject will be a motivator for acquiring the necessary number of participants. There was also a risk that for questions which are qualitative and have the opportunity for the participants to answer at length that there is no way of foreshadowing the kind of answers we will receive, the length of answers and the quality and usefulness of the answers. The questionnaire does require for every question to be filled for it to register which hindered participants from giving half answered questionnaires which would make the data received insufficient. The questionnaire does deal with the sensitive subject of the person's disease and pain. The participant has no obligation to complete the questionnaire and can withdraw and stop answering the questionnaire. If a participant already has pressed the submit button we will unfortunately not be able to retrieve the information as we have no way of knowing who the sender has been. The fact that the questionnaire does not require personal information that

can directly link the person to the information it should make it easier for participants to share their experiences.

The questionnaire was tested initially with four acquaintances of the researchers, then after changes based on that feedback the questionnaire was modified and then tested by four participants again that were provided through Endometriosisyhdistys whom are commissioning this work. Through feedback from the testers, by those who we have been in contact with us from Endometriosisyhdistys and our supervisors was the final version of the questionnaire was constructed. The questionnaire can be found from the appendix. (Appendix 2)

5.2.3. Analysis of Data

Google Forms puts the quantitative data automatically into percentages to make it easy to analyse results in the form of descriptive statistics. If it was needed correlations between quantitative data would have been analysed using statistics software programs. The qualitative data was analysed through Content Analysis (White & Marsh 2006; p.16) which was through a manual and labour intensive method. We looked at words and themes and different categories that are prevalent in the data that relate to issues from our research questions.

There were some assumptions that could be made about what kind of results we would get based on prior research but there was no way of knowing what type of answers we get which makes it inductive. The data was only analysed by the two students conducting the study. The answers only exist in our Google Forms account to which only the two student researchers have access to through a password. In the beginning of the questionnaire we stated what the study was being used for and that by answering the questionnaire the participant was giving us the right to use the data acquired for the study. As it was mentioned earlier we wanted data from 50 participants. 50 participants won't be able to represent fully the 2524 members of the support group and neither the up to 200 000 sufferers of endometriosis in Finland. This is primarily a qualitative study the, data based on participants experiences will give useful data and insight into the mind of a person suffering from this disease.

5.2.4. Time Frame

The plan was that when we are able to post the website for the questionnaire with a short statement of what the study is the peer support group will be given a maximum of two weeks (14 days) to answer. There would be a reminder posted after one week and another one two days before the deadline. Then we would have enough time to categorise and analyse the data (kuvio 2).



Figure 1. Schedule.

We received the proposed 50 participants after a few days but if that would not have happened we would have had to remind the group more often and possibly even extend the time limit. These are risks that are possible to happen when conducting this type of research.

5.3 Ethics

Ethical conduct of online digital data needs to be governed by the 5 rules for ethical use of digital data: (Clark K & Co: 7)

“In any research on human beings, each potential subject must be adequately informed of the aims, methods, sources of funding, any possible conflicts of interest--“ (Declaration of Helsinki 1964)

5.3.1 Consent

By answering the questionnaire subjects gave consent to use their answers in this study. It was made clear in the introduction to the questionnaire.

5.3.2 Privacy and confidentiality

Research was done anonymously as the subject is a very private matter. The questionnaire was available online on Google Forms where the participants got to by following a link in a closed group, Endometriosisittaret, on Facebook. After filling the questionnaire and submitting it, the answers appeared for us to read in real time. There is no way possible to trace individual responders from the data. The questionnaire had no questions that could be used for identifying participants. The only collected data from participants were the answers provided to us through the questionnaire. The answers were discarded in a safe manner after the study was finished. The information collected was only used for the purpose stated above. Participants were free to choose to not submit or complete the questionnaire. Only the two

researchers had access to the answers which could not be traced back to the survey participants.

5.3.3 Ownership and authorship

Participants were made aware that the researchers only used the data collected and that the researchers had the right to use the data only for the purpose of the study after the participants submitted their questionnaire.

5.3.4 Governance and custodianship

Only the two researchers had access to the data which was only used for the time of the study until analysis was complete. No other information was collected. Data collected existed in Google Forms to which only through a username and password security system can be accessed. The data was used for the purpose of our thesis which will be made available to be read by others in the future. The data has been deleted after it was analyzed.

The initial responses and data has been discarded after analysis. Only conclusions drawn from the data will be shown in the thesis. The data was not shared with others, but the analysis in this thesis is available to others and may be referenced to in other works.

“Medical research is subject to ethical standards that promote respect for all human beings and protect their health and rights.” (Declaration of Helsinki 1964) We ensured that participants were protected from any harm; physical or psychological through their involvement in the study. The questionnaire dealt with the sensitive subject of pain and endometriosis but it was the assumption that the motivations of researchers had for using the data for the purpose of improving care for endometriosis patients was also motivating the participants. “The research protocol should always contain a statement of the ethical considerations involved--“. “The subjects must be volunteers and informed participants in the research project.” (Declaration of Helsinki 1964) The introduction to the questionnaire made it clear what the information was used for and the right for participants not to submit their responses or participate at all. “The right of research subjects to safeguard their integrity must always be respected. Every precaution should be taken to respect the privacy of the subject,

the confidentiality of the patient's information and to minimize the impact of the study on the subject's physical and mental integrity and on the personality of the subject." (Declaration of Helsinki 1964) The anonymity in the survey was the basis when planning it and it affected the forming of questions in it. The study strongly considers the ethical rights of participants and adheres by methods which have secured that.

5.3.5 Data sharing

The data received from this study will not be used in the future. Like mentioned before, the survey answers will be deleted right after the study has been concluded and all the necessary information for it is collected. Therefore, there is no risk in data used in this study to be used for a different, unintended, purpose.

6 FINDINGS

The information gained from the survey was analyzed and put into tables that can be viewed in Appendix 3.

6.1 Research question 1: Questionnaire questions 1, 2, 3, 4

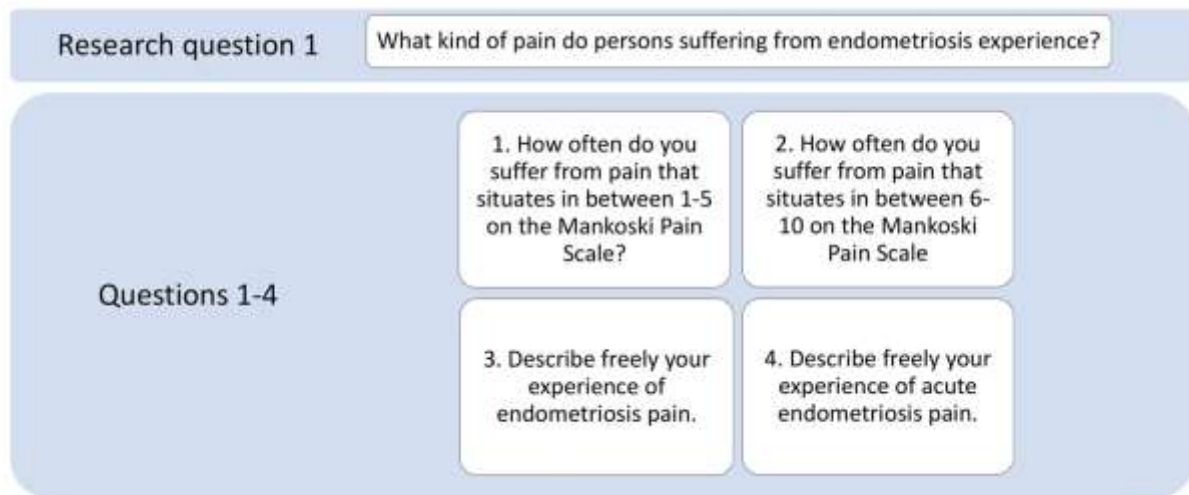


Figure 2. Research Question 1.

6.1.1 Background information results

Most of the participants of the study are between the ages 20-39, which is 80% of all participants (see *Table 10*). One person was over 50 years of age and another person was under 20 years of age. As the study responses are from a Facebook group, one possible reason for this age group being the largest is that the generation they have been born into are used to using the internet and web based groups. This idea would suggest that there would be much more participants of an even younger age but to this affects the fact that there is often a delay of receiving a confirmed diagnosis, which is another most likely reason for why this is the largest age group (see *Figure 3*).

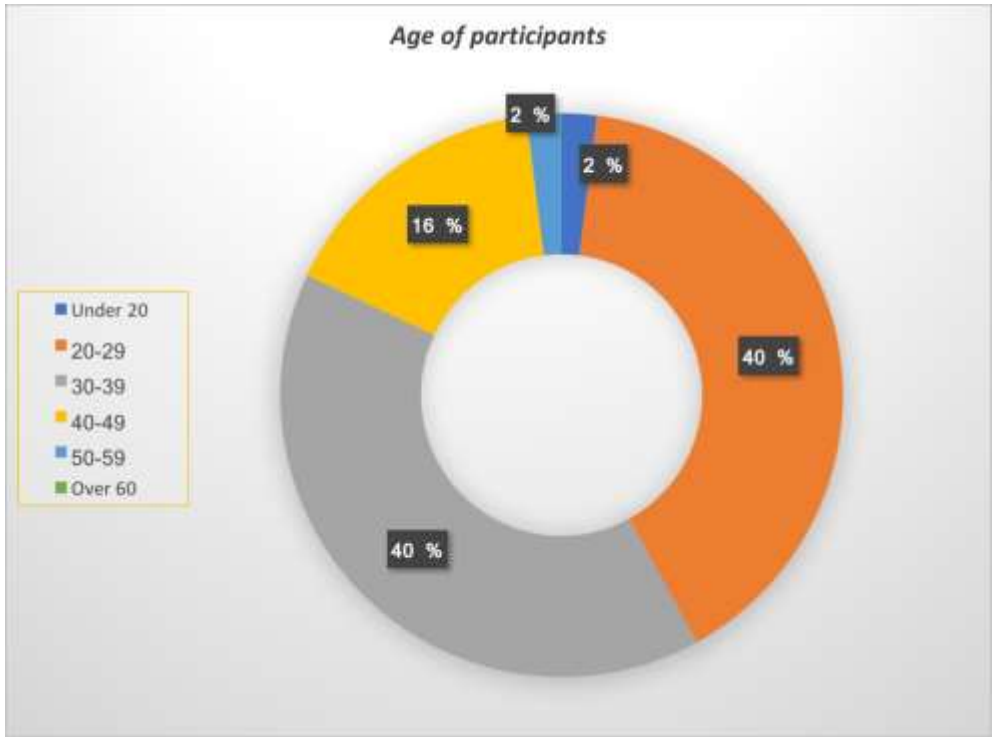


Figure 3. Age of participants.

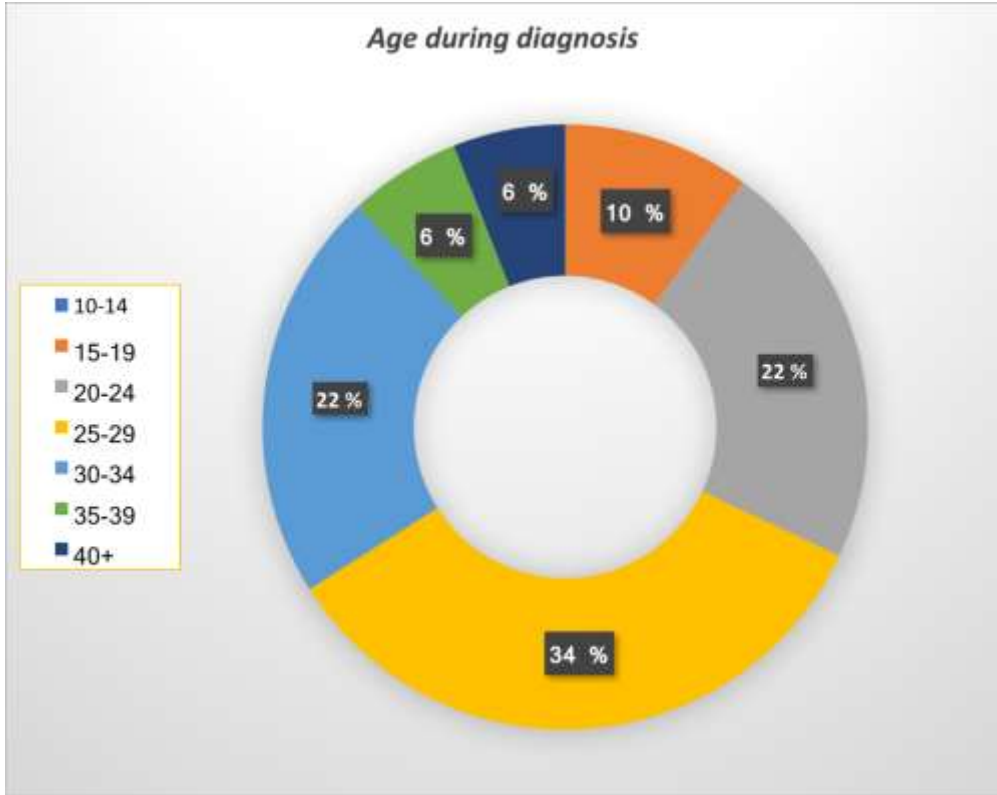


Figure 4. Age during diagnosis.

74% of participants were given the diagnosis between the ages of 20-34. 10% of participants had their diagnosis before the age of 20. 6% combined were of the age 35-39 years or over 40 years. The age of getting diagnosis between 20-34 years is related to the delay in confirmed diagnosis (see *Table 11*). In the background it was mentioned from Mao & Anastasi's article that there can be up to a 12 year diagnosis delay. If symptoms start at puberty in the age of 11-15 years when menstruation starts the full 12 years delay would put the age of confirmed diagnosis to ages 23-27 which situates in the largest diagnosed age group (see *Figure 4*).

54% of the participants have gotten their diagnosis between the years of 2012-2016. Prior to this, from 1998 to 2011, 30% were given the diagnosis. 4% were diagnosed in 2017 and one participant answered the age she was diagnosed instead of the year. From these results, it can be concluded that from our study population most people suffering from endometriosis symptoms got their diagnosis within the last 5 years (see *Table 12*). This can correlate with participants most likely having pains and symptoms of severity that has led to surgery during those years thus confirmed diagnosis. The higher results during this time period might also suggest more knowledge upon the disease and its symptoms which has led to more prevalence of diagnosis. This theory can also be the reason why there are much fewer diagnosis being confirmed from 1998 to 2011. Patients' age must be taken into account as well when looking at these results as there is a much higher possibility that the older the patient the earlier the year of diagnosis. The largest age group for getting a confirmed diagnosis was 20-34 year olds which would possibly correlate with diagnosis during the years 2012-2016 when taking into account the diagnosis delay factor.

6.1.2 Question 1

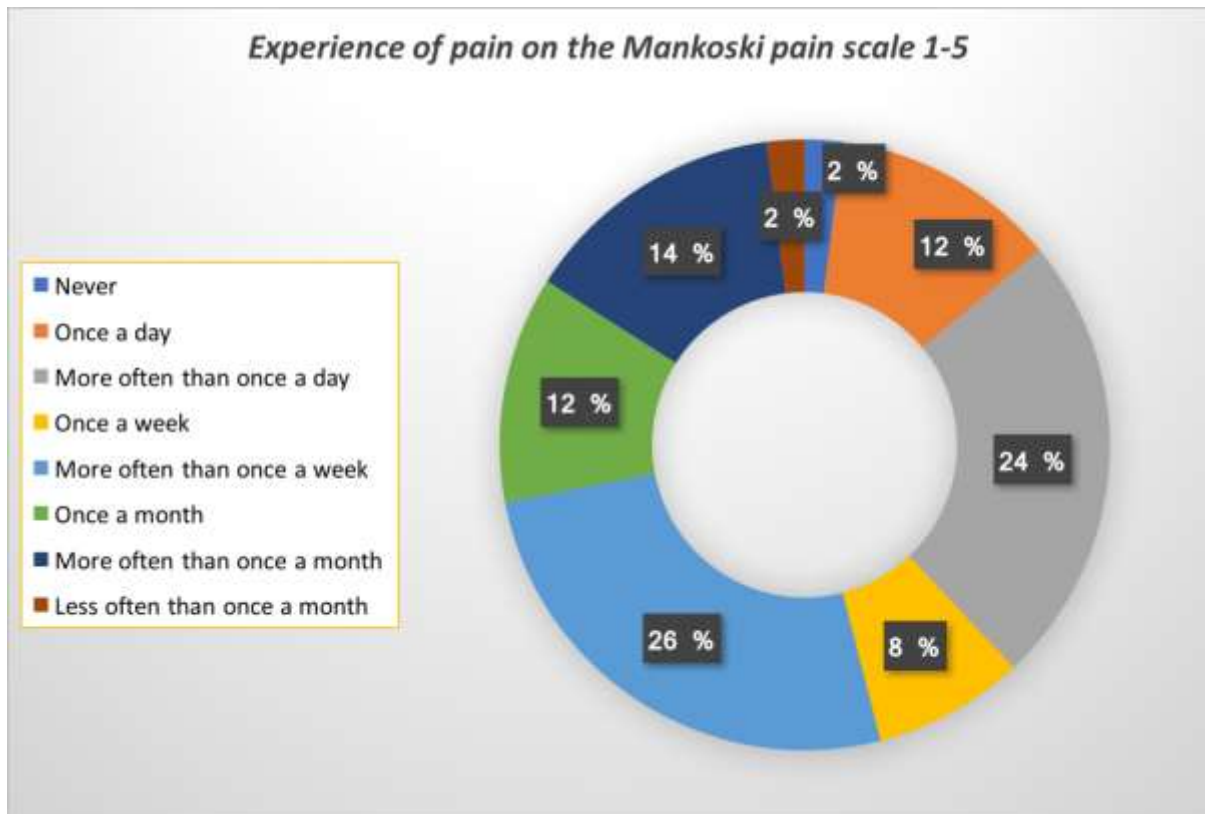


Figure 5. Mankoski pain scale 1-5.

When asked how often participants feel milder endometriosis related pain (1-5 on the Mankoski pain scale), one participant stated not having any kinds of pain. 36% feel pains daily or more than once a day. 34% answered having these pains once a week or more than once a week. 26% suffer monthly or more often than that. 2% feel the pains less than once a month (see *Table 13*). There is more endometriosis pain that is felt daily and weekly in comparison with monthly felt pains that occur less often. Daily pain suggests that patients have chronic pain as suggested from research upon the pain experienced by patients in the background section. The participants who had pain monthly would suggest to a cyclical type of pain but of a sort that doesn't reach into the stronger acute pain that is found in the next question (see *Figure 5*).

6.1.3 Question 2

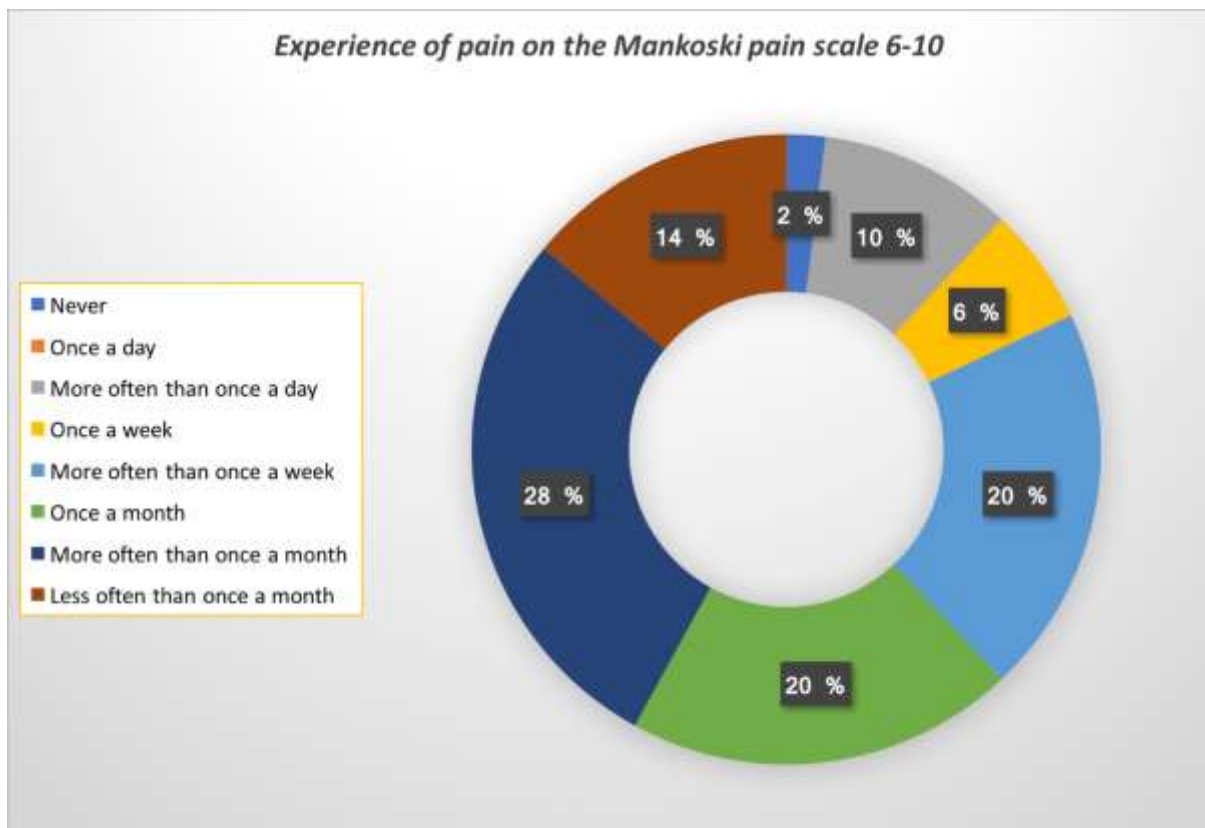


Figure 6. Mankoski pain scale 6-10.

Higher pains (6-10 on the Mankoski pain scale) were experienced as follows: one participant does not feel pain. 10% feel these higher pains more than once a day. 26% suffer from them weekly and 48% monthly. 14% of the participants feel these pains less than once a month (see *Table 14*). Here is a clear indication of a monthly type of stronger acute pain experienced by a large number of participants (almost half). This can relate to the cyclical form of pain which correlates with menses. In this type of pain the pain increases in severity the days leading up to menstruation and subsides after menstruation has occurred. (Mao & Anastasi, 2010:110) It is also noticed that 26% suffering from this type of pain weekly is also quite high and could correlate with a chronic experience of even stronger acute endometriosis pain. Pain of these levels are of a standard that affects daily living and functioning, it can be quite debilitating. If a person is having such pains weekly it must affect greatly upon their life and functioning (see *Figure 6*).

From research done in the UK there are 20% of endometriosis patients who are asymptomatic and do not feel pain. (Barrow et al, 2015:2541) In this case though the participant who experienced no pains at the moment has experienced pains before but has now for a few years been without pain, so this individual has not been asymptomatic since the start.

6.1.4 Question 3

In question 3 and 4 to assist participants in describing their pain the following terminology list was provided:

Terävä, tylppä, jomottava, polttava, tykyttävä, raastava, kiskova/vetävä, kirvelevä, oksettava, väsyttävä, leikkaava, kouristava, puristava, pyörryttävä, voimistuva, repivä, kylmäävä, aaltomainen, pistävä, sietämätön.

This question was first analyzed by counting the prevalence of words that come from the pain terminology provided. 32% used the words Jomottava/Aching, pulsating, pounding. 24% used Pistävä/Prickling. 20% used Polttava/Burning. 18% used Kouristava/Convulsive. 16% used Repivä/Ripping. 12% used Raastava/Grating. 12% used Aaltomainen/In waves. 10% used Oksettava/Nauseating. 10% used Väsyttävä/Tiring. (see *Table 15*) Here are only included those words that were used by 10% or more of the participants to get a better understating of what terms are most commonly used by the whole group. 'Jomottava', 'Pistävä' and 'Polttava' words were used by more than 20% of the participants. This shows that endometriosis pain is experienced by many in the group as an aching/pulsating, prickling and burning type of pain when looking at words from the pain terminology.

Other words that were not from the pain terminology provided which were commonly used to describe pain were Viiltävä, Vihlova/Cutting, Aching 28%. Kramppaava/cramping 14%. Lamaanuttava/cripling 10% (see *Table 16*). All of the words above were mentioned 5 or more participants in the responses. All in all 'Jomottava' is the most commonly used word to describe a type of pain while 'Pistävä' and 'Viiltävä' are followed by it. 'Viiltävä' which was a cutting type of pain was second with 28%.

After having looked at the prevalence of words to describe pain themes that came up from the answers was that of specific locations and actions that cause pain. Locations where pain is felt by a large number of participants are in the lower back and lower abdomen, 20%. There is a large range of locations on the body where people feel pain. One person replied the pains to radiating all over the body. Defecating and intestinal pains were experienced by 8%. Other locations of pain are vaginal and ovarian pain, 4%. Pains in legs, hips, sides and sciatica pain are also mentioned (see *Table 17*). The lower back and lower abdomen pain is the most common. This type of pain correlates with chronic pelvic pain which is experienced by many who have endometriosis. (Barrow et al, 2015:2541)

An example of a very graphic metaphor for the pain they experience is revealed in the following quote.

”Kuin joku työntäisi rajusti punaisena hehkuvaa metallitankoa alakautta kohtuun, polttavaa, väkivaltaisen rajua kipua, painetta, kouristuksia. Tässä "tangossa" teräviä ja tylppiä piikkejä, jotka "repivät ja raastavat". Kipu säteilee kokonaisvaltaisesti koko keholle, erityisesti vatsan alue, alaselkä, reidet, nivuset tuskaisen kipeät.”

Translation:

”Like someone is sticking harshly a red hot metal bar downstairs into the womb, burning, violently hard pain, pressure and convulsions. This ‘bar’ is sharp and full of dull spikes, which ‘rip and grate’. The pain radiates throughout the whole body, especially in the lower abdomen area, lower-back, thighs and groin are agonizingly painful.”

For a person to use such a descriptive and strong vocabulary shows how painful this disease can be.

Three phenomena of experiences of pain were that of a debilitating effect, pain coming in waves and coming and going as well as pain being manageable by using medication preventatively. Pain experiences described as debilitating, 24% of participants felt this. Phenomenon of 'pain coming in waves, appearing unpredictably', was experienced by 22% of participants. 6% mentioned 'pains being manageable through the use of medication taken in time' (see *Table 18*). Here is a quote from one of the patients regarding the unpredictability of the pain.

”Aaltomainen hetkellisesti hyvin voimakas kipu, joka sitten lientyy hetkeksi. Mielestäni hyvin verrattavissa esimerkiksi hyttyseen samassa huoneessa, kun yrittää nukahtaa, hetkellisesti koko aivokapasiteetin täyttää se ininä/kipu ja sitten toisena hetkenä se on siedettävämpää.”

Translation:

”Pain comes in waves for instances very painful, which then subsides for a while. In my mind a good comparison is that of a mosquito in the same room when you’re trying to fall asleep. For an instance the whining/pain of the mosquito fills up the whole capacity of your brain and suddenly it’s manageable again.”

This mosquito metaphor is quite an interesting description of this phenomenon but easily allows the reader to imagine it. Another good quote for a description of the debilitating effect can be seen in the next quote.

”Silloin, kun oli kovat kivut sanoisin, että asteikolla 8/9. En yrittänyt kipua lievittää särkylääkkeillä. Vaikka mitä asentoa kokeilin, niin kipu ei hellittänyt. En pystynyt tekemään mitään, vaan olin sängyssä. Jatkuvasti viilsi alavatsaa.”

Translation:

”When I had bad pains they were at the level of 8/9 (Mankoski Pain Scale). I did not try to alleviate pain using pain medication. Whatever position I tried I could not alleviate the pain. I couldn’t do anything, only be in bed. I had a sensation of a continuous feeling of a cutting pain in my stomach/lower abdomen. ”

In this participants description one can see that the person was restricted to being in bed due to her pain. This shows how functioning hindering the disease can be.

6.1.5 Question 4

First was collected data upon prevalence of words from the pain terminology. Acute endometriosis pain (6-10 on the Mankoski pain scale) is described as oksettava/nauseating by 16%. Kouristava/Convulsive by another 16%. Polttava/Burning by 14%. Aaltomainen/In

waves by 14%. Sietämätön/Excruciating, unbearable by 12% (see *Table 19*). Words which were of interest that were not from the provided pain terminology were Lamaanuttava/Crippling by 22% and Tuskainen/Agonizing by 12%. Puukon isku/Stabbing, sensation of being stabbed with a knife by 12% (see *Table 20*). This stabbing sensation was not mentioned at all in the previous section, which shows a unique characteristic of acute endometriosis pain shared by a few of the participants. The prevalence of these words were 5 or more responses. Sietämätön/Excruciating, unbearable was only mentioned one time in the previous question (pain on the Mankoski Pain Scale from 1-5) but by 12% in the acute endometriosis pain section. This shows the severity of the pain experienced in acute endometriosis pain compared to the normal lower level of endometriosis pain. The word Crippling has the highest percentage from the provided pain terminology.

The experience of acute endometriosis related pain is described as crippling, one cannot walk as it is either impossible due to pain or that it makes the pain worse, which is a phenomenon experienced by 24% of participants. Another phenomenon is that of 'the pain is overwhelming, makes one use all their concentration and energy, having to just wait it out' experienced by 20%. Intestinal and defecating problems are experienced by 16%. 4% do not get the sensation of acute pains which are at the higher end of the pain scale used (see *Table 21*). The survey participants' answers were almost shocking to read. It shows the physical and psychological pains as well as social pain which is shown through the debilitating effect of pains that are higher on the Mankoski pain scale.

These next quotes show how much the pain when it comes on is overwhelming and only thing they can focus on.

”Ajatus fokusoituu seuraavan sekuntiin, yhteen hengenvetoon, että kestäisi vielä hetken. Ajatuksella, jos se kohta helpottaa....”

Translation:

”My thoughts focus on the next second, one breath, that I'll bear a moment more. The thought, if it(the pain) would end soon....”

”Kipuun ei auttanut mikään muu kuin ajatus, en kuole tähän.”

Translation:

”Nothing else helped with the pain, except for the thought that I won’t die to this.”

”Todella raju ja äkillinen kipu, en tällöin tiedosta mitään muun kuin sen kivun”

Translation:

”A very violent and sudden pain, at these moments I register nothing else than the pain.”

6.2 Research question 2: Questionnaire questions 5, 6, 9

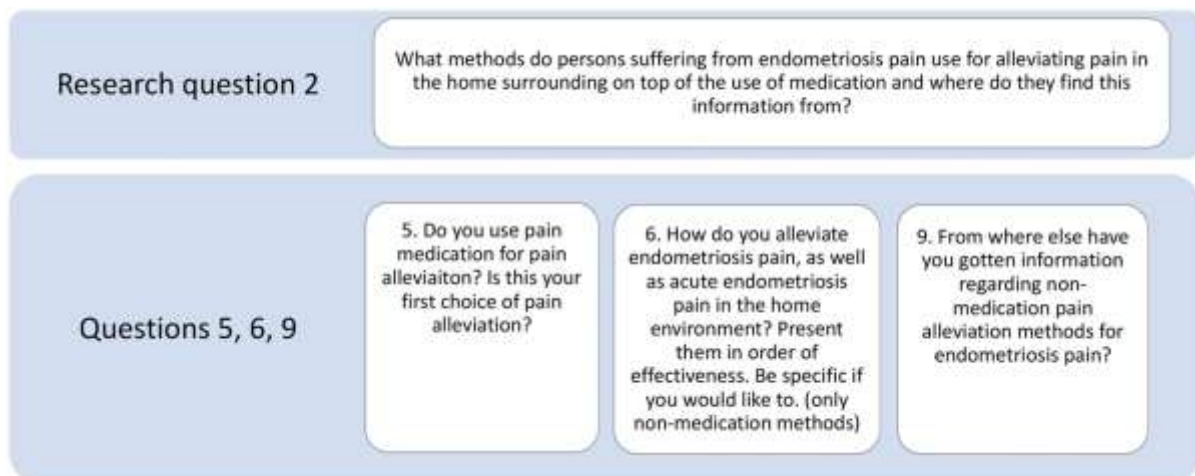


Figure 7. Research question 2.

6.2.1 Question 5

96% of the participants use pain medication in alleviating endometriosis related pain. It can be concluded that it is the most common and important way of reducing pain. 30% of women using pain medication say that it is not their primary way of pain alleviation. Another 30% do not want to use pain medication but they have to because other methods do not help the same way. 4% do not use any types of medication for endometriosis pain. 28% use pain medication pre-emptively (see *Table 22*). It can be seen that almost all of the participants use pain medication but there are many who would prefer to not have it as their only and primary choice and would like to cut down on the use of pain medication which can possibly be done by finding effective non medication pain management methods to compliment and reduce pain medication use. As the use of pain medication is so high it cannot be ignored that it is an effective way to manage pain for endometriosis patients.

6.2.2 Question 6

Besides using pain medication, the participants were asked to list ways to reduce pain in the order of experienced effectiveness. The results show that heat is the primary non-medication way of pain alleviation, 70%. Different methods involving heat are microwavable heat packs with 34% prevalence, use of larger heat blanket or pillow by 14% of participants, the use of a hot shower or bath was mentioned by 28%. Heat as a general method was answered in 7 occasions, 14% (see *Table 24*). After heat, the results show that being still, not moving is the next effective way, 54% of participants answered this. Resting is mentioned by 12, 24%. 20% found exercise or light exercise, including yoga to be helpful. Methods above each had 10 or more participants mention it (see *Table 23*).

6.2.3 Question 9

The participants found information on pain relief methods from the Facebook group Endometriosisittaret where the survey for this study was posted, 44% of participants mentioned. Other peer support groups were answered by 26%. 14% have found methods on

the Endometriosisyhdistys web page and 22% found information elsewhere on the internet. Another 14% experimented on different methods on their own and 14% have not searched or gotten information elsewhere (see *Table 37*). Most information has come through the Facebook group, peer support groups, Endometriosisyhdistys website and the internet.

6.3 Research Question 3: Questionnaire questions 7, 8, 10, 11

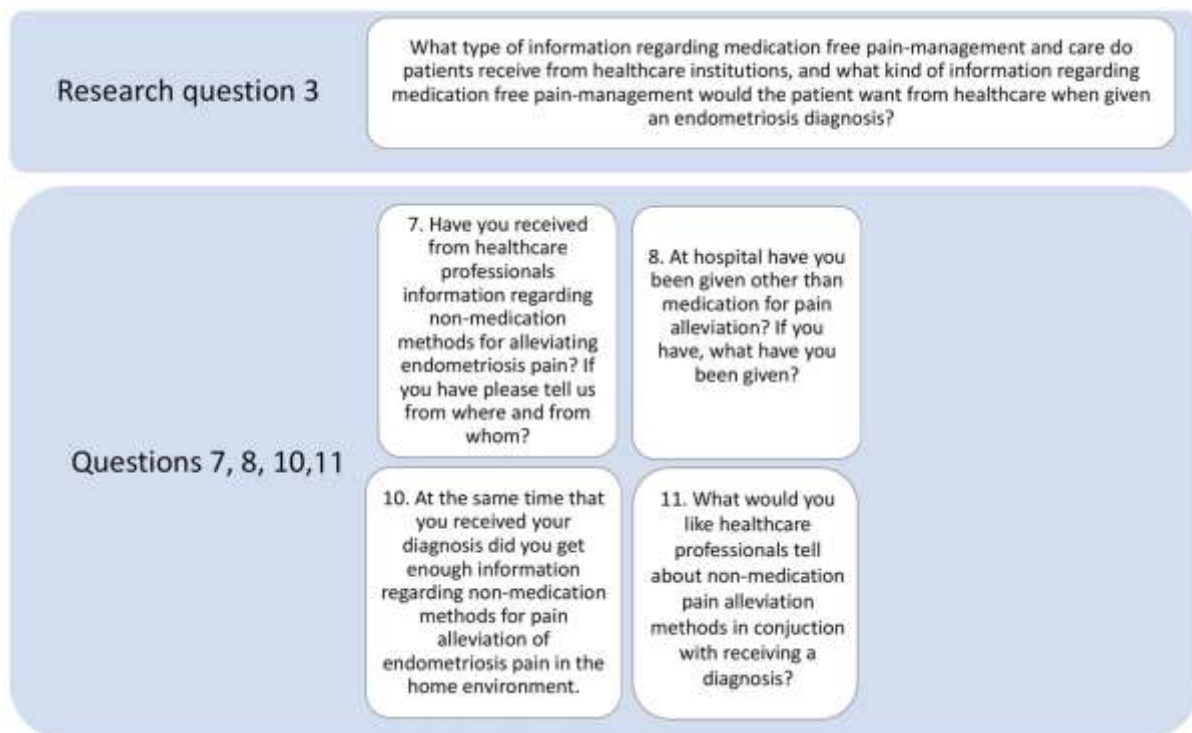


Figure 8. Research Question 3.

6.3.1 Question 7

78% of the participants have not been given information on medication free pain alleviation methods in the home setting from health care units they have visited. 22%, in their opinion have gotten some information from health care on self-care regarding medication free methods to reduce pain (see *Table 29*).

Mentioned places where information has been given are outpatient clinics for pain management, 6% have gotten information from there. From gynecological outpatient clinics

4% have received information and from health care centers another 4%. Doctors or gynecologists are the most common ones to give out this information but nurses, midwives and physiotherapists are also mentioned (see *Tables 31*). From these results can be concluded that women suffering from endometriosis pain have commonly not received guidance on pain alleviation that can be performed at home besides medication intake. The information received on medication free methods include physiotherapy, 8% and heat, 8% (see *Table 32*).

6.3.2 Question 8

72% of the participants have not received any other pain relief at a hospital besides medication. 4% have never been in a hospital due to endometriosis related pains (see *Table 34*). 20% of participants have received some form of pain alleviation other than pain medication. Heat was the most common method received with 16% mentioning heat methods. Also, TENS-electrostimulation device is mentioned as a pain alleviating method in the hospital by 4% of the participants (see *Table 35*). It can be concluded that in the hospital surroundings mostly medication is used to relieve pain and other methods are rarely used but they exist. By knowing ways to relieve one's pain in the hospital environment the patient can also be active and ask for them, for example heat packs. These methods exist in the hospital setting thus should be accepted methods of non-medication pain alleviation from the medical stand point.

6.3.3 Question 10

94% of the answers say that they did not receive enough or at all information on medication free pain alleviation methods while getting their diagnosis. One person felt she received enough information (see *Table 38*). The survey included a question towards reasons why patients think medical professionals do not give any or give a very limited amount of information on pain non medication alleviation methods. 66% think it is because of the complete lack of knowledge partial knowledge that health care professionals have on the subject. 20% are in the opinion that doctors are too medication oriented when it comes to pain alleviation. 10% of the participants think medication free methods do not work. 10% do

not feel like their pain is taken seriously and that the doctors have a bad attitude towards endometriosis patients. 8% mention they feel guilty for not being active and asking questions when they received diagnosis (see *Table 39*). It is unfair to expect for patients to have the right type of questions when receiving the diagnosis for the first time. This is another reason why it would be useful for patients to receive a pamphlet upon the subject and also where to find more information, for example through the Endometriosisyhdistys. Patients experience strongly that there is a clear knowledge gap of the subject in the health care setting. This experience of lack of knowledge as well as that the health care professional has a bad attitude and do not take the patient seriously is what was brought up in Kate Seear's 'The third shift' article. (Seear, 2009b:196) Here are some quotes from participants that emphasize on this point.

"Koko diagnoosia vähätellään. Jopa gynekologi kertoi minulle, ettei minulla voi olla kipuja, vaikka kipu onkin kokemuksena aina subjektiivinen."

Translation:

"The whole diagnosis is underplayed. Even the gynecologist told me, that I can't have pains, even though pain is a subjective experience."

"Asenne vamma on jo lääkäreillä... en koe että tätä (sairautta) oikein otetaan tosissaan."

Translation:

"The doctors already have an attitude problem... I don't feel that this disease is taken seriously."

"Luulen sen johtuvan siitä ettei tietoa ole"

Translation:

"I think it's due to there not being any research/knowledge."

"Minulle jopa leikkauksen jälkeen kirjoitettiin, että kun laparaskopia on tehty, endometriosisini on parannettu."

Translation:

”After my surgery it was written that because a laparoscopy had been performed the endometriosis is cured.”

These remarks show how hurt these patients are because of the felt lack of knowledge combined with an unsuitable attitude and approach practiced by the health care professional. With the last quote it is quite irresponsible to write blatantly that after surgery the disease is cured as the disease is incurable and there is statistical proof of a high chance of the endometriosis pain returning after a few years following surgery. (Mao & Anastasi, 2010:114)

6.3.4 Question 11

In the last question of the survey it was interesting to see what information patients themselves wish to have gotten when diagnosed. 44% think that newly diagnosed patients should get information on different or all possible methods through for example a pamphlet. 22% want to be aware that there are other methods in general and would like to hear about any such method. 16% hoped they had been told about these methods and would like to know that these methods can be used alongside medication. 16% feel that health care professionals need to be more caring, understanding, taking the pain and diagnosis seriously. Another 16% wanted to know about these methods so that they can try them and possibly found some useful as pain is a personal experience and endometriosis is found in different locations on different people. 12% mentioned separately that pain is subjective and therefore needs to be taken seriously and not make the patients feel belittled. Through knowing about possible methods, 10% of the participants feel like they could use less medication (see *Table 40*). Based on their personal experience, 10% wish the health care professional would make an individual plan for medication free pain alleviation. 8% wish these possible methods would be shown personally with guidance by the medical professional. Another 6% hope they would receive facts that back up the methods and where to get more information. Two participants hope they would get experience based facts. Emphasizing the importance of support from family, friends, peer support groups and from health care professionals was mentioned by two participants. Another two participant’s hope the psychological aspect is taken into consideration when informing a diagnosed patient. This includes telling patients

not to fear the pain, relaxation and breathing exercises. Lastly two answers suggested informing patients on pain alleviation methods that are suitable for particular locations/types of pain (see *Table 40*). Specific methods that participants wanted to inform future patients were heat, 14%, exercise or movement, 8% and dietary counselling, 8%. One quite interesting suggestion by a participant was for future patients to try similar pain alleviation methods that are used in childbirth (see *Table 41*). This patient had noticed that most methods that worked for her are similar to methods that have been used in childbirth. The doctors can refer patients towards other professional health care workers such as physiotherapists, suggested by two people. Nutritional specialist, suggested by one person. Outpatient clinic pain management for chronic pains, suggested by one person.

7 DISCUSSION

7.1 Background

From the background section from the questionnaire it can be seen that our largest age group of participants were of 20-39 and the largest age group for receiving a diagnosis was the age of 20-34. Majority of patients were diagnosed between 2012 and 2016. Over half were diagnosed in 2016. This means that experiences of what type of information patients have received from health care from many of the participants reflects greatly upon that year and gives a strong insight of the situation of the recent year. The age groups also correlates with research that suggests that there is quite a delay in gaining a confirmed diagnosis. (Mao & Anastasi, 2010:113) Otherwise participants would have a diagnosis age that would most likely correlate with the onset of menses and puberty which would be teenagers.

7.2 Endometriosis Pain

Patients' type of pain, level of pain, frequency and free worded description of endometriosis pain are analyzed in questions 1, 2, 3, and 4. From question 1 in the questionnaire it was seen that most candidates felt milder endometriosis pain in accordance with 1-5 on the Mankoski pain scale daily or weekly. Such a frequency shows that pain of a milder sort affects patients on a quite frequent basis. This kind of finding strengthens the fact that endometriosis patients can suffer from chronic pain for example chronic pelvic pain. This shows that pain for endometriosis is something that affects them constantly. Milder forms of endometriosis pain was experienced monthly by only few which could correlate with having milder endometriosis pain with menstruation (a cyclical pain) or just having milder endometriosis pain on a less frequent pace.

Question 3 of the questionnaire further analyses the experience of endometriosis pain by allowing participants to freely write about endometriosis pain with assistance from the pain terminology provided. The words aching, cutting, prickling and burning were words that were the most commonly used each having been used by almost 20% of participants or more. It has to be observed though how individual and different the experience of endometriosis

pain was which reminds us of how subjective pain is and the most important thing is to understand the pain felt by the individual.

With question 3 other information of interest was of the location of felt pain for patients. Most commonly was expressed pain that was located or radiated to the lower abdomen and lower back. This type of pain correlates with chronic pelvic pain as seen in the previous research. (Barrow et al, 2015:2541) Pain was also experienced as debilitating and unpredictable by more than 20% of participants. The descriptions and metaphors that participants used for describing their experienced pain showed how horrible these pains can be and gave a valuable insight. One patient described the unpredictability of the pain by comparing it to a mosquito harassing you in your bedroom. One patient described their pain as a burning hot spiky metal bar that is ripping your insides downstairs. These are powerful descriptions of one's pain. These personal accounts are extremely useful in bringing insight into the world of pain that endometriosis patients can experience.

From question 2 of the questionnaire information was gained about frequency of stronger acute endometriosis pain that situates from 6-10 on the Mankoski pain scale. Almost half of the participants experienced this type of pain on a monthly basis. This could correlate with the cyclical type of pain as described in previous research where the toughest pains grow stronger leading up to menses and then subsides once menses starts. (Mao & Anastasi, 2010:110) A fourth of participants suffered from stronger pains weekly and 5 participants feel these pains almost daily. When one looks at the severity of the pain on the Mankoski scale from 6-10 it is also noticeable how debilitating it is as the scale goes higher. The pains from 6-10 start to drastically affect the functionality and quality of life for the patient. It must be a struggle to keep to a regular life if pain of that scale is felt that often. At level 6 on the Mankoski pain scale pain is already something that cannot be ignored, where a person can still perform tasks outside of the house but it requires constant use of stronger pain medication. One can see how pains of this level and higher can easily hinder social and work associated functioning, and as the scale goes higher the person is confined to their home or bed. These results show that the disease can be debilitating and drastically affect a person's ability to function.

When looking at question 4 where participants freely described their acute endometriosis pain it is noticed that the most common word used was 'crippling' which shows how debilitating

the stronger pain can be and this is further emphasized by the felt phenomenon of being as one cannot walk or move due to the pain. The second most common phenomenon experienced was that of the pain becoming their only thought and a patient's only hope is the fact that the pain will go away at some point. This shows the intensity and severity of the pain that patients can feel and it is further emphasized by the descriptions that patients gave upon this subject. This creates a certain type of fear in patients when a pain starts due to the fact that they do not know when it will stop or occur again or how severe the pain will be. It is important from the nurse's perspective to understand what kind of pain endometriosis patients suffer from ranging from milder endometriosis pain to acute pain episodes that make patients' debilitating and greatly affect their daily functioning. The most important issue from the health care professional's view is to be aware that the pain experienced is real for the patient and that it is subjective. Do not belittle their pain or underestimate it. It is evident from the ways that patients' describe their pain that it can be excruciating. Pain is closely linked to the identity of the disease. To be able to educate a patient in pain management effectively the nurse needs to understand their pain.

The pain described does correlate with information from previous research but shows it in a personal and insightful manner as patients get to freely describe it.

7.3 Non-medication methods of pain alleviation

Questions 5, 6, 8 and 9 give us information on how many participants use pain medication, what non-medication methods are used at home, what non-medication methods have been given at hospital and where participants get information about these methods outside of health care facilities.

Question 5 shows us that almost every single participant uses pain medication to alleviate endometriosis pain. It comes up here that patients want to lessen the use of pain medication and hope that by finding effective non-medication methods this can be achieved. Many participants use pain medication pre-emptively and find this to be essential. It has to be noticed that pain medication is the first choice of pain alleviation. Thus these medication free pain alleviation methods are complimenting the primary choice of pain alleviation.

Question 6 is essential for this study and it is from the data provided here that a list of non-medication pain alleviation methods can be created. On the next page is a full list all the methods that adhere to our specifications (see *Figure 7*). The list is in order of popularity expressed by the participants. All possible methods were included as there were participants who wished for an extensive list so that they have as many choices as possible to test from.

Heat methods were the most common and that's why most of them are at the top of the list.

This list is the type of information patients would like at the time of diagnosis.

From question 8 it becomes clear that patients for the most part do not receive any other type of pain alleviation than pain medication. The ones who did receive something else, heat methods had been used as well as the use of the TENS electrostimulation device. If these are methods that are used in hospital they should be considered as accepted methods from the perspective of medical professionals.

From question 9 it was found that sources from where participants found information upon non-medication pain alleviation was most commonly from this Facebook group that participants were from, then it was support groups the internet and the Endometriosisyhdistys website. If a pamphlet were to be made there could be a mention to the Facebook group and the Endometriosisyhdistys website for patients as sources for more information and support.

**Pain alleviation methods starting from the most common/
Kivunlievityskeinot yleisimmästä alkaen**

Kaurapussi, lämpöpussi, vehnätyyny/Heatpack, Heatpad
Kuuma, lämmin suihku tai kylpy/Warm, hot shower or bath
Lepo/Rest
Makaaminen/Lying down
Sikiöasento, sykkyrässä, kippurassa/Foetal position, curled up
silittäminen jonkun toisen tekemänä/Massage, stroking, touch from someone else
Hengitys, hengitystekniikat/Breathing, breathing techniques
Lämpöpeitto, lämpötyyny/Heating blanket, heating pillow
Yleisesti lämpö/Heat in general
Keskittyä johonkin muuhun/Distraction, taking attention to something else
Itsensä heijaaminen/Rocking yourself
Asentohoito/Changing positions, positional therapy
Sively, silittely/Stroking
Hieronta/Massage in general
Kävely/Walking
TENS laite/TENS machine, electricity
Venyttely/Stretching
Piikkimatto/Spikemat
Läheisyys, tuki/Intimacy, support
Nukkuminen/Sleeping
Kylmä/Methods that involve cold
Sauna/Sauna
Kylmäpussi, kylmäkääre, kylmävoide, kylmäpakkaus/Cold pack, cream, gel
Itsensä sively, silittely/Stroking by yourself
Hieronta itsesuoritettu/Massage by yourself
TV:n katsominen/Watching TV
Istuminen/Sitting
Liikunta, kevyt liikunta/Exercise, light exercise
Liikkumattomuus /Not moving
Tiikeribalsami, kuumageeli/Tiger balm, Heat gel
Lämpö/kuumavesipullo/Heat, hot water bottle
Sively, silittely jonkun muun tekemänä/Stroking by someone else
Hieronta jonkun toisen tekemänä/Massage by someone else
Rentoutuminen/Relaxation
Puhuminen puolisolalle/By speaking to my partner
Jooga/Yoga
Vessassa istuminen/Sitting on the toilet
Lantionpohjan fysioterapia, liikunta/Pelvic floor physiotherapy, exercises
Selkätukivyö/Back support belt
Halaus/A hug

Figure 9. Non-medication methods of pain alleviation complete.

7.4 Information from health care professionals

In questions 7, 10 and 11 the issue of information about non-medication pain alleviation from health care facilities and staff.

In question 7 it becomes clear that most participants (78%) have not been told any information about non-medication methods of pain alleviation from health care professionals. Those who did get information got it mostly from gynecologists and doctors in general. Only one participant mentioned that a nurse had given her such information. This shows again that nurses have not been forerunners in providing this information. Here heat methods have been the only method told about that adhere to the specifications this study has for non-medication methods of pain alleviation that can be performed at home. In the role as an educator nurses can fill this role of being a supplier and explainer of such pain alleviation methods. When patients go home without this knowledge they are not fully equipped to perform self-care effectively.

In question 10 the data gives information about what information patients were given during diagnosis regarding these non-medication methods. In this section it became clear that pretty much all participants (94%) were not given enough or any information about non-medication pain alleviation methods together with receiving a diagnosis. The most common reasons why patients think this happens was because of lack of knowledge (66%), and some thought it was because treatment is so medication oriented (20%). Other reasons that were mentioned were because they feel that it is linked with their disease and pain not being taken seriously, that the doctor doesn't have enough time and there was even a few participants who blamed themselves because they feel that the reason was that they themselves didn't ask. It cannot be expected from patients to have all the right questions especially when getting informed about a newly diagnosed disease. That is why a pamphlet and an educated nurse in the subject would be a way to relay this information. Usually nurses would also have more time to educate the patient in such things.

In question 11 participants showed that they would like all information possible about non-medication methods and feel that a pamphlet would be very helpful. In this section also came up how participants would like the way health care professionals approach and communicate with patients. Many felt that their disease and pain should be taken seriously as well as

subjectively came up. As a nurse your role is to treat the patient holistically and respect them. This seems to be missing when looking at experiences that patients have had. Nurses are the bridge between doctors and the patient. Doctors might not be able to always give as much of their time as nurses do, so it would seem logical for nurses to be able to relay this information that will help the patient be able to take care of themselves at home. By there being available more knowledge about the type of pain endometriosis patients have, it can deepen nurses understanding of endometriosis patients' pain and thus create sufficient empathy from the nurse's perspective. When there isn't an understanding of this pain their pain is questioned and belittled, or even suggested that the pain is psychosomatic.

8 CONCLUSION

Through this study involving 50 participants whom have been diagnosed with endometriosis was it possible to gain data that can be used to make a list or even a pamphlet with non-medication pain alleviation methods that can be performed in the home environment. One of the main goals for this study was to collect this data and that was achieved. It was clear from the data and background research that there is a lack of knowledge about such methods in the medical scene and thus it is a gap that can be closed by having more of similar types of research conducted like this study to accumulate scientifically produced data. There is for example no Käypähoito recommendation which means there is no direct well-structured knowledge available for nurses in the health care setting for the disease and is another reason for the knowledge gap.

The list of methods presented in the discussions section could be put into a pamphlet that can be given with diagnosis or if possible even earlier based on symptoms that the patient has. If these types of pamphlets were to be available at gynecologists there would be more tools for self-care for the patient to use at home. This is important when taking into consideration the role of the nurse building up a patients self-care capabilities as described in Dorothea Orem's concept of Nursing Systems. This pamphlet would be information for the nurse as well. Furthermore the data we gathered allowed a unique look into the type of pain that endometriosis patients feel. This allows more understanding which should also make the pain described by patients when in the health care setting more credible. Through this research a nurse should be able to widen their own knowledge about the disease, its pain mechanisms and methods of pain alleviation, in this case of the non-medication sort that can be performed at home.

The data collected answered the three research questions that were set for this study. This research produced qualitative and unique information about the experienced pain that endometriosis patients have, what methods of non-medication pain alleviation they use, what information regarding these methods they receive from the health care setting and from whom and where, as well as where else they get such information and what information they would like future patients to receive. These are central aspects of this subject through which one can gain the information necessary to improve the knowledge base for nurses and staff

and to produce a list of experience based methods of pain alleviation. Pain is an important part of the endometriosis disease and an issue of grave concern for endometriosis patients that needs to be taken into account when working with them.

In organizing and planning how to make the questionnaire as anonymous as possible the use of Google Forms made that aspect very effective. The study adhered to ethical conduct and made sure not to be taking advantage of the participants' rights as human beings. Participants who were interested answered through a website to our questionnaire with no chance of identifying the sender. The questionnaire used in this study can be improved though. It was noticed from the answers that were given that there is room for improvement in wording the questions so as to guide the participant better. It was also noticed that the inclusion of pain terminology reduced quite a few participants' answers to a string of words thus hindering a more qualitative and unique view of their experience. In the future the terminology might be removed if this study was conducted again. Through repetition of this study and possibly in a larger scale the population of patients who have endometriosis in Finland will be represented better. This study was small scale because it was limited by the number of researchers being involved and time. If Endometriosisyhdistys wants to use the questionnaire for future research the researchers are willing to give them the rights to the methodology and questionnaire. From suggestions from participants there is room for research on more specific aspects of endometriosis pain and pain alleviation. For example a few participants would like to have experience based research on pain alleviation that works for specific locations and types of endometriosis pain. This can be a subject for future research.

9 REFERENCES

Background Research

Barrow, T.A., Liong, S.Y., Sukumar, Sathi Anandan. Oct 2015, Complex abdominopelvic endometriosis: the radiologist's perspective. *Abdominal Imaging*. Vol. 40, Issue 7, p2541-2556.

Knight, J. 2010, Reluctant Role Reversal. *Nursing Standard*. Vol. 24 Issue 43, p25-25.

Mao, A.J., Anastasi, J.K. Feb 2010, Diagnosis and management of endometriosis: The role of the advanced practice nurse in primary care. *Journal of the American Academy of Nurse Practitioners*, Vol. 22, Issue 2, p109-116.

Sarkomaa, S. 15.2.2017, Plea to the parliament: Kirjallinen kysymys endometriosisin hoidon yhdenvertaisesta saatavuudesta. eduskunta.fi Available from: https://www.eduskunta.fi/FI/vaski/Kysymys/Sivut/KK_30+2017.aspx Accessed 12.3.2017

Seear, K. Aug2009a, 'Nobody really knows what it is or how to treat it': Why women with endometriosis do not comply with healthcare advice., *Health, Risk & Society*, Vol. 11, Issue 4, p367-385.

Seear, K. Aug2009b, The third shift: Health, work and expertise among women with endometriosis. *Health Sociology Review*, Vol. 18, Issue 2, p194-206.

Stoelting-Gettelfinger, W. Oct 2010, A case study and comprehensive differential diagnosis and care plan for the three Ds of women's health: Primary dysmenorrhea, secondary dysmenorrhea, and dyspareunia. *Journal of the American Academy of Nurse Practitioners*, Vol. 22, Issue 10, p513-522.

Previous Theses

Hemminki, K. & Karaslahti, J. 2013. Endometriosisia sairastavien kokemuksia kipua. Available from: lievittävästä itsehoitomenetelmästä. <http://urn.fi/URN:NBN:fi:amk-2013110716696> Accessed 15.4.2017

Korhonen, A., & Valtanen, R. 2015. Endometriosisin hoito: opas henkilökunnalle. Available from: <https://www.theseus.fi/handle/10024/102366> <http://urn.fi/URN:NBN:fi:amk-2015113018502> Accessed 15.4.2017

Lähdesmäki K. & Kuntola U. 2010. Naisten kokemuksia endometriosisin aiheuttamista kivuista. Seinäjoen ammattikorkeakoulu. Available from: <http://urn.fi/URN:NBN:fi:amk-201102072090> Accessed 15.4.2017

Theoretical Framework

Orem, D., 1985. *Nursing*. 3rd Ed. New York: McGraw-Hill.

Alligood, M. 2013. *Nursing theory*. 5th ed. St. Louis: Mosby p.222-244. Available from: <http://www.nursetogether.com/5-things-that-make-a-good-nurse-great> Accessed 12.4.2017

Methodology

White, MD & Marsh, EE. 2006, Content Analysis: A Flexible Methodology. *LIBRARYTRENDS*, Vol. 55, No 1., 2006 p.22-45.

Clark, K. Duckham, M. Guillemin, M. Hunter, A. McVernon, J. O'Keefe, C. Pitkin, C. Praver, S. Sinnott, R. Warr, D. Waycott, J. 2015, Guidelines for the Ethical use of Digital Data in Human Research, The University of Melbourne, Melbourne.

APPENDIX 1 LITERATURE RESEARCH

The literature used in this Background Research chapter were peer reviewed and searched for in the following manner:

Table 1. Background search process 1

Search Engine	Search Process	Hits
EBSCO Academic Search Elite	endometriosis AND pain AND management, boolean phrase, full text, English, peer reviewed, starting year 2008	34 hits 4 sources used

Table 2. Articles found from search process 1

Article	Author/s	Year	Journal
Diagnosis and management of endometriosis: The role of the advanced practice nurse in primary care.	Mao, A.J., Anastasi, J.K.	2010	<i>Journal of the American Academy of Nurse Practitioners</i> Vol. 22 Issue 2, p109-116.
Complex abdominopelvic endometriosis: the radiologist's perspective.	Barrow, T.A., Liong, S.Y., Sukumar, S.A.	2015	<i>Abdominal Imaging</i> . Vol. 40 Issue 7 p2541-2556.
Reluctant Role Reversal.	Knight, J.	2010	<i>Nursing Standard</i> . Vol. 24 Issue 43, p25-25
A case study and comprehensive differential diagnosis and care plan for the three Ds of women's health: Primary dysmenorrhea, secondary dysmenorrhea, and dyspareunia.	Stoelting-Gettelfinger, W.	2010	<i>Journal of the American Academy of Nurse Practitioners</i> . Vol. 22 Issue 10, p513-522.

Table 3. Search process 2.

Search Engine	Search Process	Hits
EBSCO Academic Search Elite	endometriosis AND self AND care, full text, English, peer reviewed, starting year 2008	10 hits, 3 sources used (1 source exists from the search above)

Table 4. Articles found from search process 2.

Article	Author/s	Year	Journal
The third shift: Health, work and expertise among women with endometriosis.	Seear, Kate.	2009	<i>Health Sociology Review. Vol. 11 Issue 4, p367-385. 19p.</i>
'Nobody really knows what it is or how to treat it': Why women with endometriosis do not comply with healthcare advice.	Seear, Kate.	2009	<i>Health, Risk & Society. Vol. 18 Issue 2, p194-206.</i>

Table 5. Research found from Endometriosisyhdistys website.

Material	Author/s	Year	Website
Plea to the parliament: Kirjallinen kysymys endometriosisin hoidon yhdenvertaisesta saatavuudesta	Sarkomaa, Sari	15.2.2017	eduskunta.fi https://www.eduskunta.fi/FI/vaski/Kysymys/Sivut/KK_30+2017.aspx

Here is the research process for the Previous Thesis part of the background:

Information about where to find previous theses sources was obtained from a meeting with the student correspondent of Endometriosisyhdistys. The previous theses were found on Endometriosisyhdistys website from 'Valmistuneet opinnäytetyöt' section.

(endometriosisyhdistys.fi)

Table 6. Previous Theses.

Thesis	Author/s	Year	School
Naisten kokemuksia endometriosisin aiheuttamista kivuista	Kuntola, Ulla. Lahdesmäki, Kaisa.	2010	Seinäjoen AMK
Endometriosisin hoito-Opas hoitohenkilökunnalle	Korhonen, Anna. Valtanen, Roosa.	2015	Jyväskylän AMK
Endometriosisia sairastavien kokemuksia kipua lievittävästä itsehoitomenetelmästä	Hemminki, Katja. Karaslahti, Johanna.	2013	Diakonia AMK

Table 7. Theoretical Framework search process.

Search Engine	Search Process	Hits
Arcada Finna	Orem, Dorothea: words searched	17 hits, 1 source used
Arcada Finna	Nursing, theorists: words searched	6 hits, 1 source used

Book	Author/s	Year	Library
Nursing. Concepts of Practice	Orem, D.	1985	Arcada library
Nursing Theory	Alligood, M.	2013	Arcada library

Table 8. Methodology search process.

Literature	Author/s	Year	Format
Guidelines for the Ethical use of Digital Data in Human Research	Clark, K & Co	2015	Online PDF
Content Analysis: A Flexible Methodology	White, MD & Marsh, EE	2006	LI-BRARYTRENDS, Vol. 55. No 1. Summer 2006 (pp.22-45)

Table 9. Declaration of Helsinki document source.

Document	Assembly	Year	Journal
Declaration of Helsinki	World Medical Association Assembly	2001	<i>Bulletin of the World Health Organization, Vol 79, Number 4 pg. 278-380</i>

APPENDIX 2 QUESTIONNAIRE

Endometriosiskipu ja lääkkeetön kivunlievitys

Tämä kysely on sairaanhoitajatutkimuksen opinnäytetyötä varten. Tämä on anonyyminen kysely. Kysely on tarkoitettu henkilöille joilla on endometriosisdiagnoosi. Tarkoituksena on tuottaa lisätietoa sairaanhoitajille endometriosisin lääkkeettömästä kivunlievityksestä ja sen tehosta sekä kotona että eri terveydenhuollon yksiköissä. Lääkkeetön kivunlievitys on kaikki eri kotiolosuhteissa käytettävät kipua lievittävät keinot. (pois lukien: ruokavalio, lääkkeet, hoitoa joka voi toteuttaa pelkästään kodin ulkopuolella) Tavoitteenamme on kehittää sairaanhoitajien tietopohjaa ja tehokkaampaa ohjaamista endometriosispotilaan lääkkeettömästä kivunlievityksestä kotiolosuhteissa.

Tavoitteena olisi saada maksimissaan 50 osallistujaa. Ensimmäiset 50 osallistujan vastauksia käytetään, loput hylätään. Vastaamalla kyselyyn annat luvan käyttää vastauksiasi tutkimuksessa. Kysely on vapaaehtoinen ja sen voi keskeyttää milloin tahansa. Toivomme kuitenkin vastaamista kaikkiin kysymyksiin, jotta vastaukset rekisteröityvät. Vastaukset annetaan anonyymisti ja niitä käsittelevät vain allekirjoittaneet, eikä niitä voida yhdistää vastaajaan. Data jonka keräämme on käytettävissä pelkästään sen ajan joka on tarpeellista analyysia varten, sen jälkeen kerätty tieto tuhotaan. Pelkästään alla mainituilla opiskelijoilla on pääsy kerättyyn aineistoon.

Tutkijoina toimivat 4. vuoden sairaanhoitajaopiskelijat Oskar Lönnqvist ja Mikko Erkkilä Arcada AMK:sta. Lyhyesti: Valitsimme aihepiiriksi endometriosisiin liittyvän kivun lieivityksen vähäisen tutkimustiedon ja lähipiirissä olevien ihmisten kokemusten perusteella.

Suuri kiitos kaikille jo etukäteen!

Kyselyssä käytetyt termit:

Endometriosiskipu = Voimakas, useamman päivän kestävä kuukautiskipu

Kipukohtaus = Endometriosisista johtuva kova äkillinen kipu

Lääkkeetön kivunlievitys = Kivunlievitys, johon ei liity lääkeaineiden käyttöä eikä kirurgista hoitoa

Avustava sanastoa kivun kuvailua varten:

Terävä, tylppä, jomottava, polttava, tykyttävä, raastava, kiskova/vetävä, kirvelevä, oksettava, väsyttävä, leikkaava, kouristava, puristava, pyörryttävä, voimistuva, repivä, kylmäävä, aaltomainen, pistävä, sietämätön.

Kyselyssä käytössä oleva kipumittari ensimmäistä kahta kysymystä varten. Mankoskin Kipuasteikko: 1-10

0=Kivuton

1= Heikosti epämiellyttävä tunne, ajoittaisia lieviä vihlaisuja. Ei tarvetta lääkitykselle.

2=Epämiellyttävä tunne, ajoittaisia voimakkaampia vihlaisuja. Ei tarvetta lääkitykselle.

3=Häiritsevästi epämiellyttävä tunne. Miedot särkylääkkeet tehoavat.

4=Häiritsevää kipua, josta huolimatta keskittyminen esim. työntekoon onnistuu. Miedot särkylääkkeet tehoavat 3-4 tunnin ajan.

5=Kipua ei voi jättää huomiotta puolta tuntia pidemmäksi ajaksi. Miedot särkylääkkeet lieventävät kipua 3-4 tunnin ajan.

6=Kipua ei voi jättää huomiotta hetkeksikään, mutta siitä huolimatta töihin meno ja muut sosiaaliset aktiviteetit onnistuvat. Vahvemmat kipulääkkeet tehoavat 3-4 tunnin ajan.

7=Kipu alentaa keskittymiskykyä ja häiritsee unta. Normaalit toiminnot onnistuvat, mutta vaativat ponnistelua. Vahvemmat kipulääkkeet tehoavat vain osittain.

8=Kipu rajoittaa selvästi normaaleja fyysisiä toimintoja. Lukeminen ja keskustelu vaativat erityistä ponnistelua. Pahoinvointia ja huimausta esiintyy kivun takia.

9=Puhuminen mahdotonta. Kipu saa huutamaan tai voihkimaan. Olo lähellä houretilaa.

10=Tajuttomuus. Tajunnan menetys voimakkaan kivun vuoksi.

Taustatiedot:

Ikä (valitse yksi)

- Alle 20
- 20-29
- 30-39
- 40-49
- 50-59
- 60 vuotta tai yli

Minkä ikäisenä sait endometrioosidiagnoosin? (valitse yksi)

- 10-14 –vuotiaana
- 15-19
- 20-24
- 25-29
- 30-34
- 35-39
- 40+ vuotiaana?

Minä vuonna sait endometrioosidiagnoosin?

Kysymykset

1. Kuinka usein koet kipua joka sijoittuu Mankoskin kipuasteikolla välille 1-5? (valitse yksi)

- Ei koskaan
- Kerran päivässä
- Useammin kuin kerran päivässä
- Kerran viikossa

- Useammin kuin kerran viikossa
- Kerran kuukaudessa
- Useammin kuin kerran kuukaudessa
- Harvemmin kuin kerran kuukaudessa

2. Kuinka usein koet kipua joka sijoittuu Mankoskin kipuasteikolla välille 6-10? (valitse yksi)

- Ei koskaan
- Kerran päivässä
- Useammin kuin kerran päivässä
- Kerran viikossa
- Useammin kuin kerran viikossa
- Kerran kuukaudessa
- Useammin kuin kerran kuukaudessa
- Harvemmin kuin kerran kuukaudessa

3. Kuvaile endometriosikipua vapaamuotoisesti.

4. Kuvaile kipukohtausta vapaamuotoisesti.

5. Käytätkö kipulääkettä kivunlievitystä varten? Onko tämä ensisijainen valinta kivunlievitykseen? Vastatkaa vapaamuotoisesti.

6. Miten lievität kipukohtausta kotiolosuhteissa? Luettele tavat tehokkuusjärjestyksessä. Voit halutessasi tarkentaa yksittäisiä keinoja. (vain lääkkeettömät keinot)

7. Oletko saanut terveydenhuollosta tietoa endometriosikipivun lääkkeettömästä lievityksestä? Jos olet, niin mistä ja keneltä?

8. Oletko sairaalassa saanut muuta kuin lääkkeellistä kivunlievitystä? Jos olet, niin mitä?

9. Mistä muualta olet saanut tietoa liittyen endometriosikipivun lääkkeettömään lievitykseen?

10. Saitko diagnoosin yhteydessä tarpeeksi tietoa endometriosin lääkkeettömästä kivunlievityksestä kotiolosuhteisaa? Jos et, niin mistä luulet sen johtuvan?

11. Mitä toivoisit, että hoitohenkilökunta kertoisi lääkkeettömästä kivunlievityksestä kotiolosuhteissa juuri diagnoosin saaneelle?

Appendix 3 Tables of data

Table 10. Age of participants.

Age (years old)	Number of participants	Percentage of participants
Under 20	1	2%
20-29	20	40%
30-39	20	40%
40-49	8	16%
50-59	1	2%
Over 60	0	0%

Table 11. Age during diagnosis.

At what age did you get your endometriosis diagnosis? (years old)	Number of participants	Percentage of participants
10-14	0	0%
15-19	5	10%
20-24	11	22%
25-29	17	34%
30-34	11	22%
35-39	3	6%
40+	3	6%

Table 12. Year of endometriosis diagnosis.

What year did you get your endometriosis diagnosis?	Number of participants	Percentage of participants
1998	1	2%
1999	1	2%
~2000	1	2%
2004	2	4%
2005	1	2%
2006	1	2%
2008	2	4%
2009	3	6%
2011	3	6%
2012	5	10%
2014	6	12%
2015	9	18%
2016	12	24%
2017	2	4%

*1 participant answered wrong: 42	1	2%
-----------------------------------	---	----

Question 1

How often do you suffer from pain that situates in between 1-5 on the Mankoski Pain Scale? (Appendix 1)

Table 13. Experience of pain on the Mankoski pain scale 1-5.

As often as:	Number of participants	Percentage of participants
Never	1	2%
Once a day	6	12%
More often than once a day	12	24%
Once a week	4	8%
More often than once a week	13	26%
Once a month	6	12%
More often than once a month	7	14%
Less often than once a month	1	2%

Question 2

How often do you suffer from pain that situates in between 6-10 on the Mankoski Pain Scale? (Appendix 1)

Table 14. Experience of pain on the Mankoski pain scale 6-10.

As often as:	Number of participants	Percentage of participants
Never	1	2%
Once a day	0	0%
More often than once a day	5	10%
Once a week	3	6%
More often than once a week	10	20%
Once a month	10	20%
More often than once a month	14	28%
Less often than once a month	7	14%

Question 4

Kuvaile kipukohtausta vapaamuotoisesti/Describe freely your experience of acute endometriosis pain.

Table 15. Descriptive terminology of acute endometriosis pain.

Word	Participants who used word	Count	Percentage of participants
Terävä/Sharp	4, 6, 7, 11, 19	5	10%
Tylppä/Blunt	11, 15, 45	3	6%
Jomottava/Aching, pulsating, pounding	6, 11, 15, 45	4	8%
Polttava/Burning	4, 9, 27, 41, 45, 46, 47	7	14%
Tykyttävä/Ticking, pulsating	2, 45	2	4%
Raastava/Grating	-	0	0%
Kiskova, vetävä/Tugging	45	1	2%
Kirvelevä/Stinging:	45	1	2%
Oksettava/Nauseating	2, 6, 14, 28, 29, 30, 41, 45	9, one participant mentioned twice	16%
Väsyttävä/Tiring, exhausting	19, 41, 45	3	6%
Leikkaava/Cutting	-	0	0%
Kouristava/Convulsive	6, 7, 23, 39, 43, 44, 45, 46	9, one participant mentioned twice	16%
Puristava/Tightening	6, 2, 17, 45	5, one participant mentioned twice	8%
Pyörryttävä/Dizziness, feeling of fainting	41, 45	2	4%
Voimistuva/A growing	9, 15, 44, 45	4	8%
Repivä/Ripping	27, 44, 45	3	6%
Kylmäävä/Cold	-	0	0%
Aaltomainen/In waves	3, 22, 31, 33, 35, 43, 45	7	14%
Pistävä/Prickling	9, 11, 40, 41	4	8%

Sietämätön/Excruciating, unbearable	2, 12, 17, 21, 26, 41	6	12%
-------------------------------------	-----------------------	---	-----

Table 16. Words not from provided terminology for describing acute endometriosis pain.

Word	Participants who used word	Count	Percentage of participants
Kramppaava/Cramping	28, 31, 39, 47	4	8%
Tuskainen/Agonizing	23, 27, 41, 44, 46	6	12%
Lamauttava/Crippling	1, 8, 15, 16, 26, 27, 28, 35, 40, 43, 47	11	22%
Tuikkivaa/Pulsating	4, 6	2	4%
Puukon isku/Stabbing, like a knife stabbing sensation	32, 34, 35, 40, 48, 49	6	12%
Ahdistava/Distressing	35, 46	2	4%
Yllättävä/Surprising, sudden	5, 33, 41, 50	4	8%

Prevalence of themes that came up in the answers

Table 17. Types of experiences of acute endometriosis pain.

Experience	Participants who experienced this	Count	Percentage of participants
Suolisto-oireita, ulostamisen vaikeuksia, kipuja/Intestinal problems, defecating problems, pain	6, 8, 14, 20, 23, 43, 45, 49	8	16%
Kipu ottaa vallan ajatuksista kun se on	1, 5, 8, 13, 15, 29, 30, 31, 34, 40	10	20%

yllä, pitää sinnitellä kunnes se on ohi/pain takes all my concentration, just have to wait it out			
Ei pysty kävellä kivun takia, tai kävely lisää kipuja/Can't walk due to pain or walking increases pain	1, 9, 10, 13, 15, 17, 29, 30, 35, 36, 43, 47	12	24%
Joka liike sattuu, pitää olla liikkumatta/Any movement hurts, must stay immobile	10, 29, 34	3	6%
Kipu on yhteydessä kuukautisiin/Pain correlates with menstruation	8	1	2%
Jalat menevät alta/Sweeps my feet underneath me	9, 43, 47	3	6%
En koe kipukohtauksia/I do not suffer from acute pain	24, 37	2	4%

Question 3

Kuvaile endometriosiskipua vapaamuotoisesti./Describe freely your experience of endometriosis pain.

Table 18. Descriptive terminology of endometriosis pain.

Word	Participants who used word	Count	Percentage of participants
Terävä/Sharp	4, 21, 22, 33	4	8%
Tylppä/Blunt	11, 13, 41, 45	4	8%
Jomottava/Aching, pulsating, pounding	3, 4, 5, 6, 7, 10, 11(2), 13, 16, 31,	17, one mentioned twice	32%

	35, 36, 39, 41, 43, 45		
Polttava/Burning	1, 2, 4, 9, 11, 14, 30, 45, 48, 49	10	20%
Tykyttävä/Ticking, pulsating	45	1	2%
Raastava/Grating	1, 5, 22, 23, 32, 44	6	12%
Kiskova, vetävä/Tugging	45, 47	2	4%
Kirvelevä/Stinging	45	1	2%
Oksettava/Nauseating	6, 31, 36, 41, 45	5	10%
Väsyttävä/Tiring, exhausting	27, 36, 41, 44, 45	5	10%
Leikkaava/Cutting	-	0	0%
Kouristava/Convulsive	1, 3, 6(2), 9, 14, 21, 28, 30, 44, 45	10, one mentioned twice	18%
Puristava/Tightening	6, 45	2	4%
Pyörryttävä/Dizziness, feeling of fainting	21, 45	2	4%
Voimistuva/A growing	14, 32, 45	3	6%
Repivä/Ripping	1, 2, 3, 9, 14, 34, 44, 45	8	16%
Kylmäävä/Cold	-	0	0%
Aaltomainen/In waves	5, 12, 16, 44, 45, 47	6, one spelling mistake	12%
Pistävä/Prickling	3, 14, 26, 28, 30, 33, 35, 37, 40, 44, 49, 50	12, one spelling mistake	24%
Sietämätön/Excruciating, unbearable	11	1	2%

Table 19. Words not from pain terminology.

Word	Participants who used word	Count	Percentage
Paine/Pressure	1, 11, 37	3	6%
Tuska/Agonizing	1, 5, 25	3	6%
Hengitysvaikeus/ Breathing difficulties	6, 50	2	4%
Lamauttava/Crippling	14, 20, 23, 30, 32	5	10%
Turvottava/Bloating, swelling	27, 44	2	4%

Kramppaava/Cramping	2, 28, 31, 36, 38, 47, 48	7	14%
Viiltävä, vihlova/Cutting, aching	3, 13, 15, 22, 30, 31, 33, 35, 36, 38, 39, 47, 48, 49	14	28%
Jäytävä/Nagging, gnawing	41, 42	2	4%
Pahoinvointi/Nauseous	6, 22, 47	3	6%
Säteilevä/Radiating	1, 10, 35	3	6%
Jatkuva/Continuous	6, 40, 49	4, one mentioned twice	6%

Table 20. Specific locations of pain or actions that cause pain.

Word	Participants who used word	Count	Percentage of participants
Emätin/Vaginal	17	1	2%
Munasarja/Ovaries	9, 18	2	4%
Alaselkä, alavatsa, alavartalo/ Lower abdomen, lower back	1, 6, 8, 9, 10, 13, 18, 37, 38, 40(2), 46	11, one participant mentioned twice	20%
Virtsaaminen/Urinating	37, 48	2	4%
Ulostaminen/Defecating	6, 13, 37	3	6%
Suolisto/Intestines	17	1	2%
Kylki/Pain on the side	17	1	2%
Lonkka/Hip pain	17	1	2%
Iskias/Sciatica pain	17	1	2%
Jalka/Leg	37, 40	2	4%
Koko keho/Whole body	1	1	2%

Table 21. Different types of experience of pain.

Experience of pain	Participants who experienced this	Count	Percentage of participants
Lamaannuttava, tekee toimintokyvyttömäksi/Debilitating, hinders functioning	6, 8, 10, 14, 15, 20, 23, 24, 30, 33, 42, 43	12	24%
Aaltomaista, tulee ja menee/Phenomenon of pain coming in waves, unpredictable, comes and goes	2, 11, 12, 16, 24, 26, 30, 31, 44, 45, 47	11	22%
Hallittavissa ajoissa otetun lääkkeen avulla/Manageable through use of pain medication in time	6, 14, 24	3	6%

Question 5

Käytätkö kipulääkettä kivunlievitystä varten? Onko tämä ensisijainen valinta kivunlievitykseen?/Do you use pain medication for pain alleviation? Is this your first choice of pain alleviation?

Table 22. Different themes related medication used for pain alleviation.

Theme	Participants who experience this	Count	Percentage of participants
Käytän kipulääkkeitä/I use pain medication	1, 2, 3, 4, 5, 6, 7, 8, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 50	48	96%
Ei ole ensisijainen valintani/Not my first choice of action	4, 5, 8, 10, 11, 12, 13, 17, 18, 20, 28, 32, 37, 38, 42	15	30%
Ei käytä lääkkeitä/Don't use medication	9, 49	2	4%

En haluaisi mutta on pakko/I don't want to but I have to	5, 8, 10, 12, 13, 15, 18, 20, 23, 25, 28, 32, 37, 38, 42	15	30%
Kuukautiskipuja varten/For menstrual pain	3, 23, 38	3	6%
Tarvitsen kipulääkkeitä jotta voin mennä ulos, tehdä töitä/Need pain medication to be able to function outside of the home environment, do work	10, 13, 16, 38	4	8%
Käytän ennakoivasti kipulääkkeitä/Take pain medication as a preventative method	3, 5, 10, 12, 13, 16, 18, 19, 23, 24, 34, 38, 44, 47	14	28%

Question 6

Miten lievität endometriosiskipua entä kipukohtausta kotiolosuhteissa? Luettele tavat tehokkuusjärjestyksessä. Voit halutessasi tarkentaa yksittäisiä keinoja. (vain lääkkeettömät keinot)/How do you alleviate endometriosis pain, as well as acute endometriosis pain in the home environment? Present them in order of effectiveness. Be specific if you would like to. (only non-medication methods)

Table 23. Experiences and methods concerning non-medication pain alleviation in the home environment.

Experience or method	Participants with same experience	Count	Percentage of participants
En käytä/Lääkkeettömät vaihtoehdot eivät toimi /Who does not use or alternative methods do not work for	21, 22, 24, 25	4	8%
Kipukohtaukselle ei ole mitään lääkkeettömiä	21, 24, 25	3	6%

keinoja/For acute pain there are no medication free methods			
Rentoutus, hengitystekniikat/ Relaxation, breathing techniques, taking mind off of the pain	1, 3, 5, 6, 7, 8, 15, 19, 27, 30, 31, 35, 37, 41, 48	15	30%
Rentoutuminen/Relaxation	5, 6, 8, 15, 35, 37	6	3%
Hengitys, hengitystekniikat/Breathing, Breathing techniques	5, 7, 19, 30, 31, 35, 48	7	14%
Keskittyä johonkin muuhun /Distraction, taking attention to something else	3, 6, 7, 8, 15, 27	6	12%
Lämpö, kuuma/ Methods that involve heat, warmth	1, 2, 4, 5, 6, 7, 9, 11, 13, 15, 16, 17, 18, 19, 26, 27, 28, 29, 30, 31, 33, 34, 36, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49	35	70%
Kylmä/Methods that involve cold	30, 35, 41	3	6%
Nukkuminen/Sleep	9, 15, 37, 40, 44	3	6%
Liikkumattomuus/Not moving	18, 32	2	4%
Lepo, liikkumattomuus, istuminen, makaaminen, sikiöasento/Rest, not moving, sitting, lying still, foetal position	1, 4, 5, 7, 8, 10, 11, 12, 15, 16, 18, 19, 20, 23, 26, 27, 29, 32, 33, 34, 35, 40, 42, 44, 46, 49, 50	27	54%
Lepo/Rest	1, 10, 11, 16, 19, 20, 23, 29, 33, 35, 46, 50	12	24%
Makaaminen/Lying down	1, 31, 32, 34, 37, 42, 43, 44, 49	9	18%
Sikiöasento, sykkyrässä, kippurassa/Foetal position, curled up	5, 8, 12, 31, 34, 42, 46, 49	8	16%
Asentohoito/Changing positions, positional therapy	1, 15, 27, 35, 41	5	10%

Istuminen/Sitting	15, 17, 50	3	6%
Vessassa istuminen/Sitting on the toilet	43	1	2%
Hieronta, sively, silittäminen jonkun toisen kautta/Massage, stroking, touch from someone else	1, 2, 5, 6, 16, 19, 27, 30	8	16%
Kiropraktikolla käynti/Chiropractic treatment	8	1	2%
Lantionpohjan fysioterapia, liikunta/Pelvic floor physiotherapy, exercises	13	1	2%
Selkätukivyö/Back support belt	17	1	2%
Läheisyys, tuki/Intimacy, support	1, 16, 27	3	6%
Halaus/A hug	16	1	2%
Piikkimatto/Spike mat	9, 37, 41	3	6%
TENS laite/TENS machine, electricity	26, 28, 36, 41	4	8%
Itsensä heijaaminen/Rocking yourself	1, 30, 41, 43, 48	5	10%
Kevyt urheilu, venyttely, jooga/Exercise, easy exercise, yoga	8, 11, 12, 13, 15, 17, 23, 30, 38, 49	10	20%
Venyttely/Stretching	5, 13, 17	3	6%
Jooga/Yoga	23	1	2%
Liikunta, kevyt liikunta/Exercise, light exercise	8, 23, 49	3	6%
Kävely/Walking	11, 12, 17, 30, 38	5	10%
Erikoisruokavalio/Dietary methods have helped them	7, 8, 9, 14, 19	5	10%

Methods put into similar categories.

Table 24. Methods involving heat.

Different methods that involve heat	Participants with same experience	Count	Percentage of participants
Yleisesti lämpö/Heat in generally	5, 7, 16, 18, 19, 33, 44	7	14%
Kaurapussi, lämpöpussi, vehnätyyny/Heatpack, Heatpad	1, 2, 13, 15, 17, 26, 28, 29, 30, 31, 34, 36, 38, 42, 43, 45, 48	17	34%
Kuuma, lämmin suihku tai kylpy/Warm, hot shower or bath	1, 4, 9, 15, 18, 20, 26, 27, 30, 38, 39, 40, 41, 47	14	28%
Lämpöpeitto, lämpötyyny/Heating blanket, heating pillow	2, 4, 9, 11, 18, 30, 39	7	14%
Lämpö, kuumavesipullo/Heat, hot water bottle	6, 47	2	4%
Tiikeribalsami, kuumageeli/Tiger balm, Heat gel	38, 41	2	4%
Sauna	13, 17, 49	3	6%

Table 25. Methods that involve cold.

Methods that involve cold	Participants with same experience	Count	Percentage of participants
Kylmäpussi, kylmäkääre, kylmävoide, kylmäpakkaus/Cold pack, cream, gel	30, 35, 41	4, one participant mentioned two cold methods	6%

Table 26. Methods involving touch.

Different methods that involve touch	Participants with same experience	Count	Percentage of participants
Hieronta/Massage in general	1, 6, 17, 19, 38	5	10%
Hieronta jonkun muun tekemänä/Massage by someone else	1, 6	2	4%
Hieronta itse suoritettu/Massage by yourself	17, 19, 38	3	6%
Sively, silittely/Stroking	1, 2, 5, 16, 30	5	10%
Sively, silittely itse suoritettu/Stroking by yourself	2, 5, 30	3	6%
Sively, silittely jonkun muun tekemänä/Stroking by someone else	1, 16	2	4%

Table 27. Methods involving distraction.

Methods for distracting oneself	Participants with same experience	Count	Percentage of participants
Keskittyä, ottaa huomio muuhun/Distractio, taking attention to something else	3, 6, 7, 8, 15, 27	6	12%

TV'n katsominen/Watching TV	3, 6, 7	3	6%
Nukkuminen/sleeping	15	1	2%
Puhuminen puolisolle/By speaking to my partner	27	1	2%

Table 28. Methods involving positions and rest.

Methods involving different positions and rest	Participants with same experience	Count	Percentage of participants
Lepo, olla liikumatta, istuminen, sikiöasento/Rest, not moving, sitting, lying still, foetal position	1, 4, 5, 7, 8, 10, 11, 12, 15, 16, 18, 19, 20, 23, 26, 27, 29, 32, 33, 34, 35, 40, 42, 44, 46, 49, 50	27	54%
Lepo/Rest	1, 10, 11, 16, 19, 20, 23, 29, 33, 35, 46, 50	12	24%
Makaaminen/Lying down	1, 31, 32, 34, 37, 42, 43, 44, 49	9	18%
Sikiöasento, sykkyrässä, kippurassa/Foetal position, curled up	5, 8, 12, 31, 34, 42, 46, 49	8	16%
Asentohoito/Changing positions, positional therapy	1, 15, 27, 35, 41	5	10%
Istuminen/Sitting	15, 17, 50	3	6%
Nukkuminen/Sleeping	9, 15, 37, 40, 44	3	6%
Olla liikumatta/Not moving	18, 32	2	4%

Table 29. Methods involving moving your body.

Methods involving moving your body	Participants with same experience	Count	Percentage of participants
Liikunta, kevyt liikunta, jooga/Exercise, light exercise, yoga	8, 11, 12, 13, 15, 17, 23, 30, 38, 49	10	20%
Venyttely/Stretching	5, 13, 17	3	6%
Jooga/Yoga	23	1	2%
Liikunta, kevyt liikunta/Exercise. light exercise	8, 23, 49	3	6%
Kävely/Walking	11, 12, 17, 30, 38	5	10%
Itsensä heijaaminen/Rocking yourself	1, 30, 41, 43, 48	5	10%

Question 7

Oletko saanut terveydenhuollosta tietoa endometrioosikivun lääkkeettömistä kivunlievityksestä? Jos olet, niin mistä ja keneltä?/Have you received from healthcare professionals information regarding non-medication methods for alleviating endometriosis pain? If you have please tell us from where and from whom?

Table 30. Have received or haven't received information regarding non-medication pain alleviation.

Theme	Participants who have experienced the same theme	Count	Percentage of participants
Ei ole saanut tietoa lääkkeettömistä kotihoidosta/Have not gotten information regarding medication free pain alleviation at home	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 39, 41, 42, 44, 48, 49	39	78%
On saanut jotain tietoa lääkkeettömistä kotihoidosta/Have gotten some form of information about	34, 35, 36, 37, 38, 40, 43, 45, 46, 47, 50	11	22%

medication free pain alleviation at home			
--	--	--	--

Table 31. Source of information.

Where have you gotten information from?	Participants who have experienced the same theme	Count	Percentage of participants
Naistentautienpoliklinikka/ Gynecological outpatient clinic	34, 43	2	4%
Kipupoliklinikka/Outpatient clinic for pain management	43, 46, 50	3	6%
Terveysasema/Health Center	35, 45	2	4%

Table 32. Whom has given information.

Whom gave the information?	Participants who have experienced the same theme	Count	Percentage of participants
Lääkäri, gynekologi/Doctor, Gynecologist	36, 37, 43, 45, 46, 47, 50	7	14%
Kättilö/Midwife	34, 43	2	4%
Sairaanhoitaja/Nurse	35	1	2%
Fysioterapeutti/Physiotherapist	38, 40, 46	3	6%

Table 33. What type of information was given.

What kind of information was given?	Participants who have experienced the same theme	Count	Percentage of participants
Fysioterapia ylipäätään/Physiotherapy in general	36, 38, 40, 46	4	8%

Fysioterapian kautta lantiopohjan liikkeitä, asentoja/Through physiotherapy pelvic floor exercises, positions	36, 40	2	4%
Lämpö, lämpötyyny, lämpöpussi, kuuma suihku/Heat, electric heat pillow, heating pad, hot shower	35, 37, 39, 43	4	8%
Liikunta/Exercise, movement	39, 45	2	4%
Meditaatio/Meditation	43	1	2%

Table 34. Long term methods.

Information given of methods that are long term or cannot be done at home	Participants who have experienced the same theme	Count	Percentage of participants
Ruokavalio/Dietary advice	47	1	2%
Akupunktio/Acupuncture	43, 47	2	4%
Psykoterapia/Psychotherapy	46	1	2%

Question 8

Oletko sairaalassa saanut muuta kuin lääkkeellistä kivunlievitystä? Jos olet, niin mitä?/At hospital have you been given other than medication for pain alleviation? If you have, what have you been given?

Table 35. Themes regarding non-medication pain alleviation given at the hospital.

Theme	Participants who have experienced the same theme	Count	Percentage of participants
En ole saanut ei lääkkeellistä kivun hoitoa sairaalassa/I have not been given any other non medicative pain alleviation at the hospital	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 28, 29, 30, 31, 34, 37, 41, 42, 43, 46, 48	36	72%
En ole ollut sairaalassa/I haven't been to hospital	35, 38	2	4%
Olen saanut ei lääkkeellistä kivunlievitystä/I have received non-medication pain alleviation	26, 27, 32, 33, 36, 39, 40, 44, 45, 47, 49, 50	12	24%

Table 36. Pain alleviation alternative to medication.

Type of pain alleviation alternative to medication	Participants who have experienced the same theme	Count	Percentage of participants
Lämpötyyny, lämpöpakkaus, lämpöpussi, lämpöpeitto/Electric heat pillow, heat pack, heat pad, electric heat blanket	26, 27, 32, 33, 36, 44, 45, 49	8	16%

TENS laite/TENS electrostimulation device	39, 47	2	4%
Kylmä/Cold	47	1	2%
Lantionpohjanlihaksien jumppa/Pelvic floor exercises	40	1	2%

Table 37. Non-medication pain alleviation methods that are long term.

Pain alleviation methods alternative to pain medication that are long term	Participants who have experienced the same theme	Count	Percentage of participants
Ruokavalio/Dietary	40	1	2%

Question 9

Mistä muualta olet saanut tietoa liittyen endometrioosikivun lääkkeettömään kivunlievitykseen?/From where else have you gotten information regarding non-medication pain alleviation methods for endometriosis pain?

Table 38. Themes regarding sources for non-medication pain alleviation information.

Theme	Participants who have experienced the same theme	Count	Percentage of participants
Netti/Internet	7, 20, 17, 24, 28, 29, 39, 43, 46, 47, 48	11	22%
Facebookryhmä/ Facebook group	5, 6, 10, 11, 13, 17, 18, 19, 21, 23, 25, 31, 32, 33, 37, 38, 39, 43, 44, 45, 48, 49	22	44%

Vertaistukiryhmä/Support group	8, 10, 15, 22, 26, 28, 29, 35, 38, 42, 46, 47, 50	13	26%
Endometriosisyhdistys/ Endometriosisyhdistys(Finnish Endometriosis Association)	12, 24, 33, 38, 42, 44, 48	7	14%
Kirjallisuus/Literature	24, 25, 33	3	6%
Työpaikka, oma työ/Work, own profession	9, 42	2	4%
Läheiset ja perhe/Friends and family	24, 36, 37, 48	4	8%
Oma kokeilu /Experimenting, trial and error by own means	7, 12, 14, 23, 30, 34, 43	7	14%
Ei mistään/I haven't found from anywhere such information	1, 2, 3, 4, 27, 40, 41	7	14%

Question 10

Saitko diagnoosin yhteydessä tarpeeksi tietoa endometriosisin lääkkeettömästä kivunlievityksestä kotiolosuhteissa? Jos et, niin mistä luulet sen johtuvan?/At the same time that you received your diagnosis did you get enough information regarding non-medication methods for pain alleviation of endometriosis pain in the home environment.

Table 39. Abundance of non-medication pain alleviation information from healthcare professionals during diagnosis.

Saitko tarpeeksi tietoa endometriosisin lääkkeettömästä hoidosta saadessasi diagnoosin/ Did you get enough information about medication free pain	Participants who have experienced the same theme	Count	Percentage of participants

alleviation methods in conjunction with getting the endometriosis diagnosis?			
En saanut/No I did not	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 21, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50	47	94%
Sain tarpeeksi tietoa/I was given enough information	20	1	2%
En ole varma/I'm not sure if I did	40	1	2%
En ymmärtänyt kysymystä(?)/I did not understand the question(?)	22	1	2%

Table 40. Themes regarding reasons for why healthcare professionals have/give, no or very limited amount of information regarding non-medication pain alleviation.

Theme	Participants who have experienced the same theme	Count	Percentage of participants
Ei oteta tosissaan, vähättely koko sairaudesta ja kivusta. Huono asenne/Not taken seriously, downplaying, the whole diagnosis, pain. Bad attitude	3, 12, 30, 44	4	8%
Lääkkeellinen suhtautuminen lääkäriltä/Medication orientated doctors	4, 7, 8, 9, 14, 19, 28, 37, 38, 43	10	20%
Hoitohenkilökunnalla ei ole yhtään tai tosi vähän tietoa lääkkeettömästä kivun lievityksestä/Healthcare professionals have no or very limited knowledge about medication free methods of pain alleviation	3, 6, 11, 12, 13, 18, 19, 21, 26, 27, 29, 30, 32, 33, 34, 35, 36, 41, 42, 44, 45, 46, 47	23	66%

Lääkkeetön kivunlievitys ei ole toimivaa/Non-medication methods are not effective	25, 27, 29, 32, 41	5	10%
Tunnen olevani vastuullinen, syyllinen koska en kysynyt sitä tietoa/I feel responsible, guilty for not asking for that information	10, 17, 24, 39	4	8%
Hoitohenkilökunnalla on liian kiire, ei riittävästi aikaa kertoa/Healthcare professionals are too busy, don't have enough time to inform us	23, 36	2	4%

Table 41. Themes regarding what information should be told in conjunction with diagnosis.

Theme regarding what information should be informed to patients during diagnosis	Participants with same experience	Count	Percentage of participants
Kaipaa hoitohenkilökunnalta empatiaa, ymmärtävää, ottavat diagnoosin ja sairauden vakavasti/Feel that health care professionals need to be more caring, understanding, taking the pain, diagnosis seriously	1, 6, 10, 18, 27, 28, 30, 43	8	16%
Heidän pitäisi antaa listan kaikista mahdollisista tavoista, infolehtinen/They should give a list of all possible methods, pamphlet	2, 3, 15, 16, 21, 23, 24, 25, 26, 27, 31, 33, 36, 38, 39, 41, 42, 45, 46, 48, 49, 50	22	44%
Tekniikkoja jotka perustuvat yksilölliseen suunnitelmaan, mikä voi toimia juuri kyseiselle henkilölle/Methods based on an individual plan, what can work for them specifically	2, 10, 25, 27, 33, 46	5	10%
Potilaille pitää kertoa, että kaikki keinot eivät välttämättä auta, yritä löytää, se on yksilöllistä/Let patient be aware that methods might or might not work for you, try to find out, it is individual	2, 4, 15, 25, 31, 32, 33, 36	8	16%

Opastusta, näyttävät miten eri metodeja käytetään/Guidance, show how to use methods	1, 22, 24, 44	4	8%
Potilaan kipu otetaan vakavasti, ei vähäteltyä, kipu on subjektiivista/Patient's pain should be taken seriously, not underestimated, pain is subjective	1, 6, 18, 28, 30, 33	6	12%
Lääkkeellisiä ja lääkkeettömiä tapoja joita voi käyttää samanaikaisesti unohtamatta lääkehoitoa/ Medical and non-medical methods, what can be done alongside medication, don't forget medication	1, 5, 6, 14, 21, 23, 30, 32	8	16%
Menetelmiä jotka toimivat tiettyjä kipuja varten, tiettyihin kehon alueisiin/Methods that work for specific types, locations of pain	6, 17	2	4%
Haluan mitä vaan tietoa ja haluan olla tietoinen että lääkkeettömiä menetelmiä on olemassa/Want any information and just to become aware that there are other methods than medication	8, 12, 19, 20, 21, 31, 32, 41, 44, 45, 47	11	22%
Haluan tietää lääkkeettömiä menetelmistä koska haluan vähentää lääkkeiden käyttöä/What to know about non-medication methods for the purpose of lessening use of medication	5, 6, 23, 38, 47	5	10%
Haluavat tietoa psykologisesta näkökulmasta; estää kivun pelkoa, rauhoitellu menetelmistä, henigtystekniikoista/Want there to be information about the psychological aspect; not to fear pain, relaxation methods, breathing techniques	4, 7	2	4%
Kertokaa miten tärkeää on tuki jota voit saada perheeltä, kavereilta ja hoitohenkilökunnalta/Tell about importance of support from family, friends, peer support groups and health care professionals	27, 43	2	4%

Toivoisivat kokemukseen perustuvaa tietoa, tutkimuksia niin kuin tämä tutkimus/Wish to get information about methods based on experience, research such as this study	30, 34	2	4%
Konkreettisia menetelmiä, faktaa ja mistä lisää tietoa saa/Concrete methods, facts and where to get more information	35, 46, 47	3	6%

Question 11

Mitä toivoisit, että hoitohenkilökunta kertoisi lääkkeettömästä kivunlievityksestä kotiolosuhteissa juuri diagnoosin saaneelle?/What would you like healthcare professionals tell about non-medication pain alleviation methods in conjuncture with receiving a diagnosis?

Table 42. Specific methods mentioned.

Specific Methods Mentioned	Participants with same experience	Count	Percentage of participants
Lämpö/Heat	2, 4, 5, 11, 30, 43, 47	7	14%
Kylmä/Cold	30, 43	2	4%
Liikunta/Movement, light exercise	4, 12, 30, 44	4	8%
Venyttely/Stretching	4	1	2%
Hengitys/Breathing	4, 30	2	4%
Asennot/Positions	4, 43, 48	3	6%
TENS laite, sähköhoitoa/TENS device, electric therapy	13, 41	2	4%
Synnytyskivunlievityskeinoja/Child birth pain alleviation methods	30	1	2%
Lantionpohjan liikkeitä/Pelvic floor exercises	13, 44	2	4%
Ruokavalio, ravintoterapeutin konsultaatio/Dietary, nutrition specialist consultation	9, 14, 19, 44	4	8%

Table 43. Expert consultation.

Consultation, referral to specialists	Participants with same experience	Count	Percentage of participants
---------------------------------------	-----------------------------------	-------	----------------------------

Fysioterapia/Physiotherapy	13,19	2	4%
Ravintoterapeutti/Nutritional therapist	44	1	2%
Kipupolklinka/Outpatient clinic for pain management	19	1	2%