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Umar Muhammad Shahbaz and Bett Nickson

ENDOMETRIOSIS:IMPROVEMENT OF QUALITY OF LIFE FROM A NURSING PERSPECTIVE

BACHELOR'S THESIS | ABSTRACT

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ABSTRACT

The purpose of this bachelor thesis was to explore about different effects of endometriosis on the quality of the life of the patient and to explore more about the role of the nursing to improve the quality of life in the affected patients of endometriosis.

The aim of the thesis was to improve the knowledge among the nurses about endometriosis so that they could play a more constructive role in managing and treating this disease.

The thesis was written by using the literature review methodology. The authors of the thesis did their research by using the search engines, provided by the Turku university of applied sciences web sites Finna, Cinahl Complete (EBSCO host), Google Scholar, PubMed and E-Library. For importing the different references, the authors used RefWorks. The authors reviewed 34 articles and used the content data analysis, to analyze the articles.

The results show, there is no doubt that endometriosis causes problems to the quality of life of the patients, their partners and with the society. But on the other hand, if we could equip the nurses with the enhanced and further updated knowledge of the disease, the life can be lived with more ease even with endometriosis and the treatment would be more successful.

KEYWORDS:

Pathophysiology, Symptoms, Diagnosis, Treatment and Consequences of Endometriosis

OPINNÄTETYÖ(AMK)/ TIIVISTELMÄ

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ENDOMETRIOOSI:HOITOTYÖN NÄKÖKULMA ELÄMÄNLAADUN PARANTAMISEEN

Tämän opinnäytetyön tarkoituksena oli tutkia endometrioosin vaikutuksia potilaan elämänlaatuun ja tutkia paremmin hoitotyön roolia elämänlaadun parantamisessa potilailla, joilla on endometrioosi.

Opinnäytetyön tavoitteena oli parantaa sairaanhoitajien tietämystä endometrioosista, jotta heillä voisi olla rakentavampi rooli tämän taudin hoitamisessa ja hoidossa.

Opinnäytetyö toteutettiin kirjallisuuskatsauksena avulla. Opinnäytetyön tekijät tekivät tiedonhaun hakukoneiden avulla, joita tarjosi Turun ammattikorkeakoulun Finna, Cinahl Complete Google Scholar, PubMed ja E-kirjasto. Eri viittausten tuontia varten kirjoittajat käyttivät RefWorks-ohjelmistoa. Kirjoittajat tarkastelivat 34 artikkelia ja käyttivät sisällönanalyysiä artikkeleiden analysoimiseksi.

Tulokset osoittavat, että endometrioosi aiheuttaa ongelmia potilaiden, heidän kumppaniensa ja yhteisön elämänlaadulle. Mutta toisaalta, jos pystymme varustamaan sairaanhoitajia parannetulla ja ajantasaistetulla taudin tuntemuksella, elämää voidaan elää helpommin jopa endometrioosin avulla ja hoito onnistuu paremmin.

ASIASANAT:

Patofysiologia, oireet, diagnoosi, endometrioosin hoito ja seuraukset

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LIST OF ABBREVIATIONS

HRQL-----Health Related Quality of Life (Wickström, Edelstam 2017).

APN----- Advance Practice Nursing (Mao, Anastasi 2010).

WERF-----World Endometriosis Research Foundation (Vitonis et al 2014).

EPHect----Endometriosis Phenome and Biobanking Harmonisation Project (Vitonis et al 2014).

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1 INTRODUCTION

Endometriosis was first diagnosed in 1860 by Rokitanski and it is characterized by ectopic presence with growth of functional endometrial tissue, glands outside the uterus. It majorly affects women of the ages 25 to 29 as it increases with age as well. Its occurrence is high amongst women with infertility and mostly to those having regular and severe pelvic pain. (Darvishzadeh, Shirkhoda et al. 2016; Palla, Karaolanis et al. 2017.)

Endometriosis continues to be insufficiently treated despite the numerous researches done. The major reasons could be the confusion of the symptoms with dysmenorrhea and other routine menstruation related symptoms and pain. This confusion could be relatively more pronounced in females of young age due to their lack of experience and shyness. In this way most women delay in the diagnosis of it despite having dysmenorrhea and other symptoms of endometriosis. This delay might take many years and thus the quality of life is as well affected for those many years. The delay in diagnosis causes serious negative effects on the individual life, social life, individual economy and the economy of the state as well. On the other hand, unavailability of non-invasive ways of identifying endometriosis may also cause the delays in diagnosis of it. (Ahn, Monsanto et al. 2015.)

Keeping in view the wide range drastic effects of endometriosis, it seems essential to have some more exploration and research on this topic. With a wide range of knowledge available, it will be easy to understand the disease, how to cope up with it, management and treatment of the disease and how to educate the whole population in general. (Ahn, Monsanto.)

The purpose of the thesis was basically consisted of two points, i.e, how the endometriosis effects the quality of life and how nursing care can improve the quality of life for the endometriosis patients.

2 BACKGROUND

2.1 Pathophysiology

Endometriosis is a diversified and dependant on oestrogen kind of an inflammatory disease. It occurs to women during their reproductive years and is always localized to the ovaries and the peritoneum of the pelvis. The implantation of the tissues to these areas is as a result of retrograde menstruation which was first brought up in 1927 by Sampson and is termed to be the focal point to the pathogenesis of endometriosis. (Harris, Vlass 2015.)

There are various theories that do explain the causes of endometriosis and they include; Meyer`s theory, Sampson`s theory and Halban`s theory. Moreover, it`s further narrowed down to three major types namely superficial endometriosis, deep infiltrating endometriosis and finally ovarian endometriotic cysts. Depending on how severe the endometriosis is, it can be put into either stage one, two, three and four with the former being minimal as the latter is harsh. (Harris, Vlass 2015; Ahn et al. 2015.)

2.2 Symptoms

It might be a bit difficult to diagnose endometriosis in most of the patient as the symptoms for Endometriosis are quite confusing with that of menstrual pain or Dysmenorrhea, which is quite common in females. More over the common problems like IBS (Irritable Bowel Syndrome) may also overlap the symptoms of the Endometriosis. (Surrey, Carter et al. 2017.) Never the less, there might be some common symptoms like dysmenorrhea, dyspareunia, rectal pain, cyclical and noncyclical rectal bleeding, infertility, tenesmus, and diarrhea. On the other hand some signs like “ Dysmenorrhea not responding to medical therapy with nonsteroidal anti-inflammatory drugs and/or combined oral contraceptive pills is suggestive of endometriosis among adolescents”(DiVasta, Vitonis et al. 2017). The picture below shows an example of the symptom which is peritoneal vesicular implant.



PICTURE 1. Peritoneal vesicular implant. (O'Sullivan, Overton 2018)

2.3 Diagnosis

Since the symptoms for the Endometriosis seem to be confusing/overlapping so it might not be an easy task to pin point diagnose Endometriosis in most of the patients. While discussing the diagnosis of Endometriosis, health professionals divide the diagnostic ways in to two parts, i.e, invasive and non-invasive one. Though both ways may work out in different ways in different types of endometriosis. For example “Both ultrasound and pelvic examination were 100% successful in predicting ovarian endometriosis; the other noninvasive procedures were moderately successful in predicting ovarian endometriosis but predicted nonovarian endometriosis less reliably. The presence of any symptom (dysmenorrhea, pelvic pain, dyspareunia, or infertility) correctly classified 66% of endometriosis diagnoses (ovarian and nonovarian combined), with lower positive predictive ability than a positive ultrasound”(Surrey et al. 2017). In a more simpler way, the gynecologists may make a clinical diagnosis about Endometriosis, based upon the

patient's medical history, gynecological examination and ultra sound examination. Moreover, a gynecologist can go for the option of laparoscopy, for further assurance of her diagnosis (Grundström, Kjølhede et al. 2016).

2.4 Treatment

While discussing the treatment there can be both options of treatment with medicines and surgical treatment. Of course, the first option of treatment is usually by medication, which might be consist of some NSAID (Non-steroidal anti-inflammatory drugs) and some hormones, like contraceptive pills or some other hormonal therapies. On the other hand, the surgical treatment might consist of surgical removal of the effected tissue/ out growths, removal of the part of the effected organ or removal all the organ, for example partial removal of the uterus or complete removal of the uterus, in case of uterine Endometriosis. (Grundström et al. 2016.)

2.4 Consequences

The major thing which causes the disturbance in the life a patient of endometriosis is the pain. Since it's a bit common to have pain during menstruation, so the patient is mostly confused herself and due to the consultations of the health professionals. (Grundström, Alehagen et al. 2018.)

Infertility is one of the other complications of the Endometriosis, "women with endometriosis may represent a particularly suitable group since they are at increased risk of premature ovarian exhaustion and about half of them will experience infertility"(Somigliana, Viganö et al. 2015).

Surgeries are also quite common in the treatment of the endometriosis patients, which on the other hand, somehow effects the quality of life, of the patient (Barbara, Facchin et al. 2017).

3.PURPOSE AND RESEARCH QUESTIONS

The purpose of this thesis was to clarify how nursing care can improve the quality of life of the endometriosis patients. The awareness of the disease is also very crucial keeping in mind that most ladies suffering from it hardly know how to detect it (Ahn, Monsanto et al. 2015b) . Thus, it's very important that more studies are done concurrently with educating people as well as the nurses adequately. The main aim was to point out and describe the various nursing practices that help in ensuring that the endometriosis patients have a better life.

The research questions are:

- 1.How can nursing care improve the quality of life for the endometriosis patients?
2. How is the quality of life affected by endometriosis?

4. LITERATURE REVIEW AND SYSTEMATIC APPROACH

4.1 Research Methods

The research method used was literature review with a systematic approach. Which is searching and evaluating the already available literature on a specific subject (royal literary fund 2018). With the use of literature review, many articles were reviewed and analysed and to come up with the results.

4.2 Data Collection

Data collection from the reviewed articles was done electronically. This is since it had a huge and wide base for articles and journals. It was majorly from the databases provided for by the Turku university of Applied Sciences library. The databases from which our searches were done were: CINAHL complete, FINNA, PubMed and MEDLINE(Ovid)

The search was limited to the years 2008 to 2018 with the language being English. The main search keywords were Endometriosis pathophysiology, symptoms, diagnosis, treatment, consequences, the quality of life and nursing care.

4.3 Inclusion and Exclusion criteria.

While compiling the thesis, the results were limited based on the inclusion and exclusion criteria. That was including English articles, free texts as well as articles not older than 10 years. What was excluded were the articles not in the category named above. The Table 1 below shows the summary of inclusion and exclusion criteria whereas Table 2 shows how the articles were chosen based on their relevance to the topic.

INCLUSION CRITERIA	EXCLUSION CRITERIA
<ul style="list-style-type: none"> ➤ Available articles to the search engine. ➤ Free of charge articles. ➤ PDF articles with full text. ➤ Accessible articles. ➤ Presence of the key words. ➤ Empirical studies. ➤ Articles in English language. ➤ Articles published from 2008 till to date. 	<ul style="list-style-type: none"> ➤ Other than English language articles. ➤ Articles without the key words. ➤ Articles published before 2008. ➤ Articles which were not related to endometriosis. ➤ Articles not related to the research questions.

TABLE 1. Inclusion and exclusion criterion table.

DATABASE	SEARCH TERMS	FILTERS	NUMBER OF RESULTS	CHOSEN ON GROUND OF THE TOPIC	CHOSEN AFTER APPLICATION OF FILTERS
CINAHL COMPLETE (EBSCOhost)	Endometriosis and quality of life, Endometriosis Nursing care	English language, 2008-date, Full text	571	20	89
PubMed	Endometriosis and quality of life, Endometriosis Nursing care	English Language 2008-date Free full text	120	9	105
Science Direct	Endometriosis and quality of life, Endometriosis Nursing care	English Language 2008-date Full text	6375	15	268

Google scholar	Endometriosis and quality of life, Endometriosis Nursing care	2008-date	24400	5	16800
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TABLE 2. Literature search table.

The number of articles finally chosen were 34.

4.3 Data Analysis

Data analysis is defined as the analysis of the data in some way using research methods for one to explore for the trends and patterns in the data (Clack, Houser et al. 2017). That's by knowing how up-to-date they are, on what basis and which reason was the research done. This in the long run helped us come with the most suitable articles and information for our topics and thus in turn aided us in finding cognitive results.

5.RESULTS

Endometriosis affects the quality of life of the patient from different aspect including social, physical and psychological. According to a study endometriosis is the third main reason of the hospitalization of the females in USA for gynaecological reasons. The incident of pain due to endometriosis is not limited to the menstrual period but also occurs during the non-menstrual phase, which makes endometriosis, more uncomfortable for the suffering person. The pain related to endometriosis may be felt in different areas like lower abdomen, lower back intestine bladder and legs.(Ferreira, Bessa et al. 2016a.)

5.1 Quality of life

Quality of life of the endometriosis patients is always adversely affected negatively as they try to keep up with the vast outcomes that come up because of having endometriosis. There has always been a low concern of how their quality of life are impacted but with recent developments, the need to understand and know how their lives are affected has come to the limelight. This is because the symptoms of endometriosis have a big impact on the well-being of the those affected (Ferreira, Bessa et al. 2016a).

The pelvic pain symptoms related with endometriosis, could be dysmenorrhea (usually the first and most common symptom), non-menstrual pelvic pain, deep dyspareunia, dyschezia and chronic pelvic pain. The women having chronic pelvic pain may suffer from worse health related quality of life (HRQL). It can be said that the health-related quality of life is disturbed by the same degree as the degree of pain is increased. It might affect the quality of life to that extent that the patient might feel difficult to continue her daily routine movement of walking or doing the basic personal stuff.(Wickström, Edelstam 2017.)

Keeping in view the suffering from health-related quality of life(HRQL), it seems that the younger females suffer from the symptoms more often which might be due to the observation that their mothers, elder sisters and cousins had had been suffering from such types of symptoms, so young girls think that its common to have pelvic pains or other confusing symptoms of endometriosis. This might be the reason for the delayed diagnosis (a common thing) of the endometriosis. Depending upon the case and age

group, the duration of the delay could be from three to eleven years. According to studies, as the young females suffer more from the symptoms of endometriosis, it is suggested that young females should be provided with more consultations from medical experts and psychologists.(Lökvist, Boström et al. 2016.)

If we have a look on the compromise of the health-related quality of life due to cost of treatment of endometriosis, then we shall come to know that endometriosis might be one of the expensive diseases to be treated. According to a study, it is estimated that if we include the direct health care costs, i.e. cost of medication, visit to doctors, hospitalization, monitoring tests, surgery, informal care given by family/ friends and then direct non-health care costs like support in house hold things and transportation and finally the indirect cost of productivity loss due to endometriosis and treatment, then the total average cost per patient per year will be nine thousand five hundred and seventy nine (9579 €) Euros. On the other hand, this per annum expense might be multiplied with 7 (the average number of years, during which the treatment continues). This data might vary from country to country due to number of factors.(Simoens, Dunselman et al. 2012.)

Endometriosis affects all the female population without any distinction of age and the mostly affected aspects of life are physical and physiological, sexual relationships and the other social relations. In the younger age group (sixteen to twenty-four years) the education was the main aspect which was affected. In the middle age group (twenty-five to thirty-four years) the employment and opportunities of life were more pronounced. But in the even older age group (thirty-four and above) the financial stress was the more affected aspect of life. According to the study, endometriosis effects negatively on the female population, without any age distinction. But with the better understandings, this could lead to less negative effects of endometriosis by better consultations and care. In this way the future generations could live a bit easier life with the lesser negative effects of the endometriosis.(Moradi, Parker et al. 2014.)

One quite interesting thing about Endometriosis is that, it not only affects the female population but also affect their male partners. But on this aspect not enough information is available which in turn makes the male partners of the affected female, more negatively. Adding fuel to fire, due to less available information about the issues of male partners of the affected female, there is no proper system of guidance and consultation available. In this scenario male partners are affected in different aspects, for example sex and intimacy, working life, house hold income, additional support in house hold tasks and medical care to their female partner (visits to the doctors, visits to laboratories, pre-

surgical and post-surgical care etc.). All this causes a great emotional stress, helplessness, frustration, worry and anger to the male partners of the affected females.(Culley, Law et al. 2017.)

Despite all these issues, most of the male partners try to play positive roles. Here is a point of view from a male partner in his words.

“I'd be a pretty shit husband if I was like ‘well this is rubbish isn't it’ ... you've just got to take it on the chin really ... if it's my needs or whatever, who gives a toss about that, let's, like I said, get her better. It's not about me.”

Though male partners expressed many negative effects due to endometriosis on their life, they also mentioned some positive effects. They described that due to this disease, how they support their partner and how their female partner appreciated, how they become more sympathetic person, more caring and loving. In a way, this disease brings them closer to each other and strengthen their bond of relationship.(Culley, Law et al. 2017.)

5.1.1 Sexual Life

One of the major aspect of life of the endometriosis patient is the suffering of the sexual relationship. As the dyspareunia, interpersonal relationship, sexual function and overall quality of sexual life are quite common issues in endometriosis patient. A better solution, to some extent, for these issues could be the radical laparoscopic excision of endometriosis (Fritzer, Tammaa et al. 2016).

With the rampant bleeding and pain, the sexual life of the women suffering from endometriosis is always adversely affected. Others tend to be frustrated by not having any orgasm because of frequent pain thus putting in strains in the marriage. It's not only them affected but also their partners. Majority will end up giving up their sexual life to avoid going through embarrassing situations like bleeding. This will also adversely impact on the life of their spouses and might as well lead to marriage break-ups. Infertility or the risk of being infertile because of endometriosis also is another reason that led to family breakages especially in situations where their partners aren't understanding or

have less information of what their spouses are going through.(Ferreira, Bessa et al. 2016b.)

According to another report, the effect of dyspareunia might be exacerbated by the number of factors, like biological, social, cultural psychological factors. Furthermore, it says that there is a need for further and better long-term treatment measures, including improved psychological, social and physiological out comes. In this way we shall be able to guide and counsel those affected by endometriosis, young females and their partners, to help them keep their pace of life along with Endometriosis.(Pluchino, Wenger et al. 2016.)

Not only dyspareunia but depressive symptoms are also associated with impaired sexual life of the endometriosis patient. So, it would be worthwhile to further explore the role of depressive symptoms in the related patient. This will further help to understand and improve the depressive symptoms in endometriosis patient, especially keeping in view the fact that their male partners don't have any sexual pain issue (De Graaff, Van Lankveld et al. 2016). How sexual functioning is affected by endometriosis is shown in picture 2.



PICTURE 2. Sexual function in endometriosis patients (Pluchino et al. 2016).

5.1.2 Work productivity

One of an important negative effect of the endometriosis on the patient and the society is a significant decline on work productivity either from job or study. Due to endometriosis, a patient might have to take more sick leaves. Work quality, ability to do work, efficiency at work, total time of the work and work satisfaction is affected. The major cause of the

low work ability is found due to certain symptoms of endometriosis like pain, change in mood, heavy bleeding, bladder and bowel issues. Since endometriosis is a chronic disease these effects on the work productivity are usually long lasting and socio-economically more drastic.(Hansen, Kesmodel et al. 2013.)

In another study, the young girls who study in secondary school and upper secondary school, are also affected by the endometriosis and their quality of life is also affected. Their study, co-curricular activities and extra-curricular activities are affected due to the common symptoms of endometriosis. Some of them contact the school nurse but some of them consider it related to their abnormal menstrual periods and related symptoms.(Boden, Wendel et al. 2013.)

5.1.3 Stigmatisation

Stigma is a deeply discrediting and socially undesirable attribute (Seear 2009). By being stigmatised, one is not able to feel complete, able or desirable. Depending on where somebody hails from or what his/her beliefs are, there are very numerous ways that one might be stigmatised. Culture being a way of living of certain individuals and their beliefs, is a very integral part when it comes to stigmatisation (Seear 2009).

Menstruation has for a while been termed as something not to publicize but rather kept secret. When ladies undergo this process, more than often will the second party not be aware as they term it as something not to be shared. The self-thought that menstruation period is embarrassing and secretive is how the social stigmatisation comes in. Women will tend to be reluctant to do anything or rather less outgoing as when it's on a normal day. This is moreover made worse when it comes to endometriosis. Endometriosis being characterized mainly by presence of pain (Ferreira et al. 2016b). Women tend to be socially inactive as they try to cope up with the adverse pain. The quality of the life lived by women having endometriosis is greatly impacted not only by the frequent and rampant pains but also made worse by the fact that they have to go through stigmatisation. (Seear 2009.)

Women having endometriosis always have alteration in their moods. This might come up because of one having to cope up with the fact that maybe they might not have the ability to bear children anymore. If not attended to with the urgency it deserves, most women end up being depressed. The rampant changing of moods also manifests itself as they try to cope with the pain. Others might be having pain-free spells which to them is a happy time then after a while, the painful periods come by and again the change of mood from happiness to sadness kicks in. This keeps going on for a long period and thus the frequent change of mood.(Ferreira et al. 2016d.)

With the high cost of drugs to help with endometriosis, many women end up having financial constraints. This might also come because of the high costs if someone must undergo any form of surgery to treat the disease. The working-class ladies suffering from endometriosis might be affected to the extent of working only during part time as they try to balance both working and coping with the disease. This will eventually lead to financial difficulties as one will not have enough Working time to earn enough money.(Moradi, Parker et al. 2014.)

However, despite the negative impact endometriosis has on the quality of life of the patients, other patients also tend to approach it positively. They get to learn how to live with endometriosis, how to handle it and eventually making them stronger. With the positive approach towards the disease, one slightly gets to have an easy time coping with the disease and save oneself from depressions and stresses.(Moradi et al. 2014.)

5.2 Nursing Care

Since endometriosis is a chronic inflammatory disease, which may progress with the passage of time, having usually normal physical examinations with variable clinical presentations, some overlapping symptoms with other diseases, these makes endometriosis a difficult to diagnose disease. On the other hand, there are no specific and accurate non-invasive diagnostic tests, available yet. In this scenario, the importance of advance practice nursing (APN) care for the concerned patients, increases many folds. By taking proper and timely care, guidance and providing the awareness about the management and treatment of the endometriosis, APN can play a pivotal role in endometriosis management. APN can greatly help the patient by pain management, improving the quality of life, reducing or preventing the further progress of the disease and preventing infertility case scenario. This nursing approach can make the patient realise the importance of compliance with the recommended treatment regimes, maintaining the regular visits, observing and reporting the changes in the symptoms and arranging some referrals, if needed.(Mao, Anastasi 2010.)

5.2.1 Patient-centered care

According to the institute of medicine, patient-centred care is defined as “respectful of and responsive to individual patient preferences, needs, and values guided by patient`s values.” Thus, when treating or providing care to the endometriosis patients, the care givers should be able to understand the most common wishes, needs and values. With the understanding of the core principles that surround endometriosis, one can provide care and attend to it more easily. For over a long period of time, the endometriosis health centres have always mainly focused on the physical well-being of the patients by provision of medications or surgical treatment which has always not lived the expectations of the patients as well as the health care professionals. However, as time progresses, the need to provide an all-round healthcare that is patient-centered has emerged.(Geukens, Apers et al. 2018.)

5.2.2 Patient Education

According to World Conference on Education Sciences of 2009, patient education is a combination of learning experiences that protects health and helps produce behavioural changes in individuals. It's one of the most critical roles that nurses play in any health care setting. The main aim of educating patients irrespective of their diseases or situation is to help better their quality of life, minimise cost and more importantly make people to practice preventive traits. It's through patient education that the patients can grapple with their ailment and develop the capacity to make their own decisions pertaining their health.(Demir, Bulut et al. 2009.)

Patient education is an ongoing process that always starts when one is admitted to the hospital and ends when the patient departs from the hospital. A nurse ought to know the patients as well as their next of kin for them to be able to pitch suitable education. Their families or precisely their partners should always be included in the process since as stated earlier before, endometriosis not only impacts on the patient but also their partners. Nurses too should be well informed about endometriosis fully and well for them to be able to educate a patient. It's very paramount as giving wrong information not only goes against the nursing ethics but also constitutes an offense.(Demir et al. 2009.)

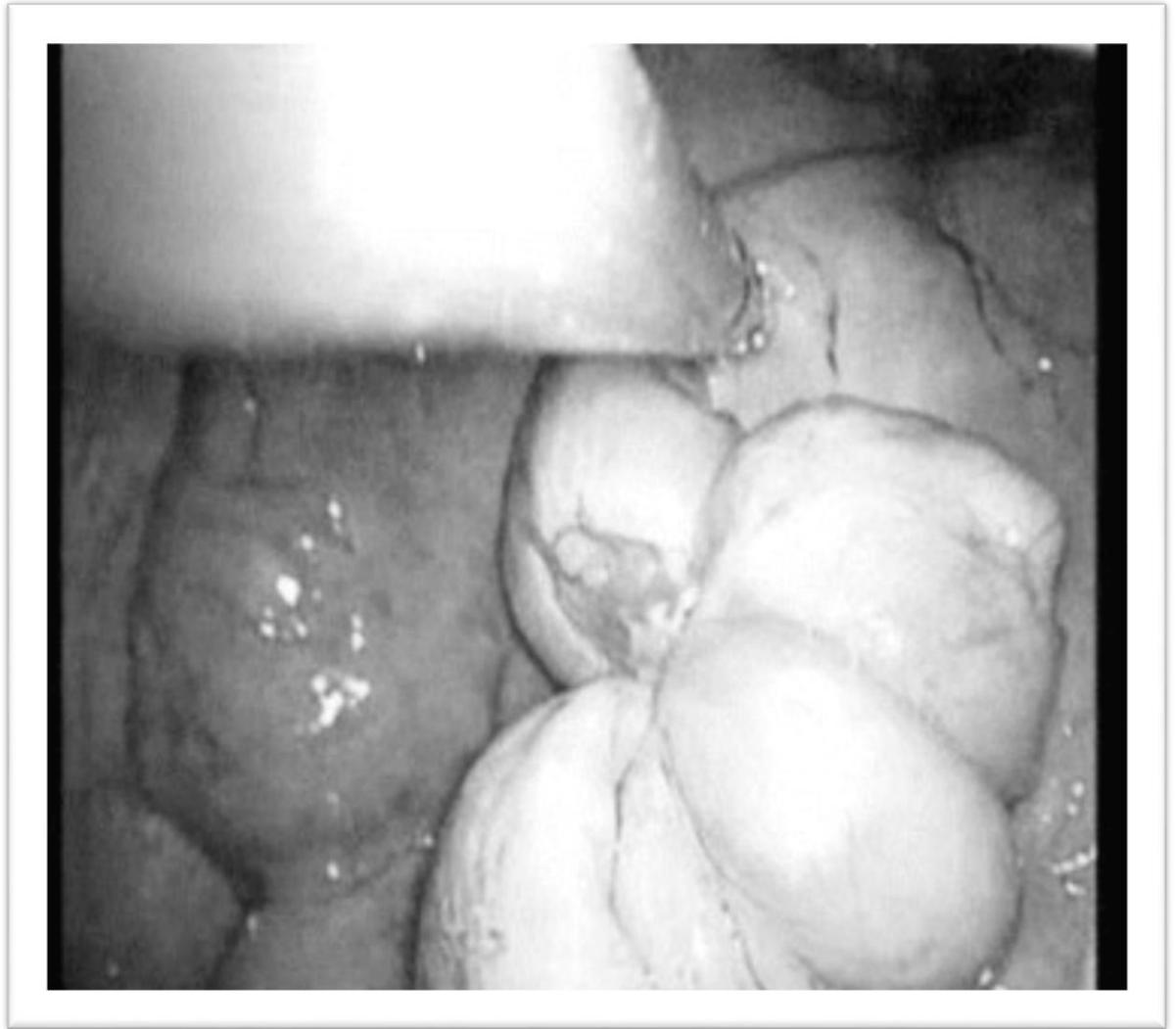
Patient education mainly focuses on the patients in the hospitals. However, the public needs to be educated as well concerning endometriosis. The emphasise when providing the education to the public should mainly be on identifying the symptoms earlier. This is because many endometriosis patients always assumed the early symptoms that could indicate the pre-existence of endometriosis for normal menstruation effects. Thus, with the public being informed of the signs and symptoms like pain during sex, heavy and irregular periods, pain before and after the periods and infertility amongst others, they will be able to prevent the disease from taking its course over the patient as this will lead to early diagnosing.(Arbique, Carter et al. 2008.)

5.2.3 Research

Since the discovery of endometriosis, there have been numerous researches done on it. Endometriosis being a heterogenous disease; that is caused and affected by many different genes and alleles, many factors contribute to its existence. This also does manifest itself with the various ways it affects a patient. For instance, depending on a certain individual, the way endometriosis affects that specific person may vary depending on the duration, when it was first diagnosed and the extent in which its symptoms affect the individual (Vitonis, Vincent et al. 2014).

With all the said factors contributing to how endometriosis manifest itself, various studies and researches have already been done to try and tackle various aspects of it. Despite the numerous findings from the researches done being successful, there has also been some information that are conflicting. This majorly has been because the information collected and studied has never been put in a way that they can be imminently compared for a more specific conclusion. For instance, a study done by P3G collaborative network from a 53-huge population-based studies of more than 10,000 people found that 47% of the variables studied were impossible to match. With such variations, it's difficult to get a more cognitive and fast scientific progress in researching about endometriosis which is the paramount goal of any researcher. (Vitonis et al. 2014.)

For a successful and meaningful research that will help in improving how nursing care can improve the quality of life of endometriosis patients to be arrived at, the data provided by researchers should be put and compared in terms of their sameness and compatibility. This will help in arriving at a more precise finding and thus avoiding conflicting information. This has been made easy with the creation of the World Endometriosis Research Foundation (WERF) Endometriosis Phenome and Biobanking Harmonisation Project (EPHect) that comes up with an outline to be followed when collecting and sampling endometriosis researched data. (Vitonis et al. 2014.) Picture 3 shows how the development of new technology with the aid of research has made it possible to attend to endometriosis.



PICTURE 3. Laparoscopic vision of an implant of Deep infiltrating endometriosis (López Carrasco, Hernández Gutiérrez et al. 2017).

6. ETHICS AND RELIABILITY

Ethics, refer to “the moral principles that guide decision-making and behaviour or how best to live a life which is moral (Ingham-Broomfield 2017). When doing the research, the work and achievements of the previous researchers was respected (tenk.fi 2012). Our topic was based upon our previous knowledge while making some assignments about endometriosis. During our research we tried to cover an overview of the disease, what type of problems it can cause and due to those problems, to what extent the quality of life is disturbed. We then tried to write something about the probable role of nursing in consultations, managing and treating the endometriosis. Since this thesis was carried out by using literature review, there were no consents, participant interviews, personal observations or questionnaires. We used the database of Turku University of Applied Sciences for our thesis and we tried to use the references appropriately. This literature review might have some limitations owing to lack of funding for the articles with some price tag. Due to this, the thesis contains only freely available articles. During research we tried to select the articles, which are ethically more appropriate and contains no personal information, no personal preference and no personal contacts of the patients.

7.DISCUSSION

The purpose of our thesis was to find out how the quality of life of the endometriosis patients was affected and what forms of nursing care can help improve the life of the endometriosis patients. This was to help the nursing fraternity understand how the effects of endometriosis or the disease itself affect the lives of those suffering from it or those close to them. It's as well important for the health care providers to comprehend what other forms of nursing care can be implemented to help improve the quality of lives of the endometriosis patients. The effects not necessarily are negative but also positive though less.(Ferreira, Bessa et al.2016.) The results did portray that endometriosis does affect the quality of life lived by the endometriosis patients in a great way. Most of the endometriosis patients live a life more drifted away from how normal people do.

From the results, the most common symptom of endometriosis(pain) is the underlying reason to as to why the endometriosis patients live an uncomfortable life. Pain because of endometriosis is way too adverse in that the way of living of the endometriosis patient is directly affected by the amount of pain one has. The pain experienced tends to be stronger that many women will end up sacrificing their jobs, sexual life as well as other social activities just to try and attend to the pain. For instance, the quality of life of the patients who are of the working class can be drastically affected when one is having too much pain to the extent that one decides to just boycott working, take sick leaves and do part time work. This in turn means that the work productivity of that individual will as well drastically drop together with one's job satisfaction.(Hansen, Kesmodel et al.2013.)

The trend might as well get to be worse when one gets to know that she can no longer be productive at work. One might end up being depressed as its been from the results that most endometriosis patients if not attended to well always end up being depressed (Ferreira,Bessa et al.2016a). From the results, the extent to which the quality of life is affected is not only to the ones suffering from endometriosis but also to those close to them like their partners and family members when it comes to the cost of attending to endometriosis. Thus, it is very necessary for the nurses to know the impact endometriosis has on the lives of their patients and provided help according to their needs.

Another integral part of how the quality of life of the endometriosis patients is affected is with the stigmatisation they encounter. For as much as we are living in a more developed world and well-informed society, endometriosis patients sadly still encounter

stigmatisation. This greatly depends with where somebody is from with some societies terming menstruation as private matter not to be mentioned openly. This situation is always made worse with the fact that with endometriosis patients, bleeding is often in excess than when it's on a normal menstruation period. However, this has been on a decline as many societies are nowadays well-informed.(Seear 2009.)

From the results, for as much as most endometriosis patients are affected greatly negatively, there are some instances where others have some positives too. Other patients tend to embrace how to live with the condition and try to live a normal lifestyle despite the adverse effects endometriosis has. More so, some couples come out of it stronger in situations where their partners are more understanding of the disease and the situation in which both are in (Culley, Law et al.2017).

With the quality of life of the endometriosis patients affected in various ways, it is essential for the health care professionals to know how attend to them and come up with more nursing care practices that can help the patients have a better quality of live. From the previous researches done, treatment has always been the major aspects of nursing care that has been focused on. This has sadly not been sufficient to help the endometriosis patients live a better quality of life. More needs to be done other than just the treatment being offered as endometriosis needs a continuing management outline unlike the short-term plan in place currently.(Clemenza, Sorbi et al. 2018.)

From the results, it's very essential for nurses to establish a patient-centred care when dealing with endometriosis patients. It`s the kind of care that is respectful of and responsive to individual patient preferences, needs and values guided by the patient`s values. A nurse ought to be able to understand that when dealing with a specific patient, she should be attended to as an individual and not being attended to having a basis of other individuals. Patient-centeredness implies that a nurse should primarily focus on the patient keeping in mind her history, surrounding, beliefs as well as the goal of that specific patient.(Geukens, Apers et al.2018.)

Another important part from the results that needs to be attended to when providing nursing care to the endometriosis patients is the education of the patients and the population at large. It is an ongoing process that should entail everybody within the healthcare set up as well as those without. With patient education, the partners of the endometriosis patients will be able to understand the situation within which their partners are in. This will go a long way in making sure that issues like family break-ups are dealt

away with since most parties will be well informed. In as much as the patients will be educated, the community too at large needs to be educated to help reduce the diagnosis time that is always a major hindering to the early detection of endometriosis.(Arbique, Carter et al.2008.)

With the ever-changing life we are living as humans, frequent and up-to-date researches need to be done. This will in turn help healthcare practitioners be able to identify new ways that will help in improving the quality of life lived by the endometriosis patients. It is with this ideology that the WERF decided to come up with a specific framework that will be used to when collecting and sampling endometriosis researched data. More research will finally lead to a better and well improved quality of life for the endometriosis patients (Vitonis et al.2014).

8.CONCLUSION

Since the effects of endometriosis are not only limited to the related patient but also the partner of the patient and the society in number of ways, So it seems that this disease should be tackled with more vigilance and attention.

As the affected span of the endometriosis is quite long so are the drastic effects of it. Which ranges from the early youth of the females to the later ages and effects the females directly and their partners and society indirectly. It causes disturbances in quality of life of the concerned patient in different ways for example unpredictable pelvic pain, out of routine bleeding, weakness, dyspareunia, sudden mood swings, different type of disturbances in their partner's life, productivity losses to the economy, different types of social issues including stigmatization.

- 1) Creating proper awareness about endometriosis, its symptoms, management and treatment. These goals can be best achieved by the proper emphasize on the training and the knowledge of nurses which in turn could counsel the related persons including females and their partners to recognize its symptoms, manage and treat it properly.
- 2) There should be a proper system for the counseling of the partners as well. Where they should be given proper guidance and counseling to understand the condition of their female partners so that they could understand the mood swings, sexual relations avoidance, chronic pain and other conditions owing to this disease.
- 3) More research should be done that majorly focuses on how the quality of life of the endometriosis patients is affected and how healthcare professionals can help in making sure that the endometriosis patients live a better life.

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ENDOMETRIOSIS:IMPROVEMENT OF QUALITY OF LIFE FROM A NURSING PERSPECTIVE

Literature review with systematic approach

PURPOSE

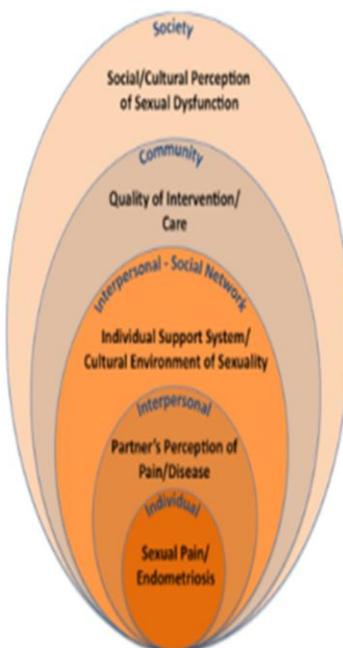
How nursing care can improve the quality of life of the endometriosis patients.

RESEARCH QUESTIONS

- 1.How can nursing care improve the quality of life for endometriosis patients?
- 2.How is the quality of life affected by endometriosis

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SEXUAL FUNCTION IN
ENDOMETRIOSIS
PATIENTS(Pluchino et al.2016)

RESULTS

The results were divided into quality of life and nursing care

Nursing care PATIENT-CENTERED CARE

-Focusing on the patient
PATIENT EDUCATION
-Educating the patient and the community at large

RESEARCH

-Working on getting new information on endometriosis

Quality of life

SEXUAL LIFE

-Most affected aspect of life

WORK PRODUCTIVITY

-Reduces productivity

STIGMATISATION

-Some patients get stigmatized

CONCLUSION

-The quality of life has been negatively affected due to lack of researches and awareness

-Nurses should strive to create awareness and educate the public
-More researches need to be done

CONTACT

Umar Muhammad Shahbaz(Shahbaz.umar@edu.turkuamk.fi)

Bett Nickson Kiptoo(nickson.bett@edu.turkuamk.fi)

PNURSS15