Assessment of Pain for Women with Endometriosis

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Abstract

Background: Endometriosis is a common benign gynecological condition classically defined as the presence of endometrial glands and stoma in ectopic sites outside the uterus. **Aim of the study is to** assess pain of women with endometriosis. **Design**: A descriptive study design was used**. Setting**: The study was conducted at Benha University Hospital, in IVF unit, Obstetrics & Gynecology Department divided to 2 subunits, these units concerned with Obstetrics &Gynecological diseases and operations and outpatient clinic. **Sample Size**: The study was conducted for 100 women had endometriosis pain. **Sample type**: Convenient sample technique was used to select the sample for the study. **Tools**: Two tools of data collections were used; a structured interview questionnaire and Andrea Mankosk's Pain Scale. **Results**: The results pointed out that the percentage distribution of women according to their Andrea Mankoski Pain Scale showed that 29% of the studied women had a mild level of Andrea Mankoski Pain Scale, 36% of them had moderate and 35% of them had a severe. According to site of pain, It showed that down the pelvis (81%), lower back (56%), legs (22%), the ovaries (50%) and continuous headache (31%) of where is the pain, and according to type of pain, It showed that the burning (22%), stab (6%), nibbling (8%), sharp (9%), painful (89%) and pressure (59%) of types of pain. **Conclusion**: The present study findings concluded that the majority of women had negative knowledge regarding endometriosis pain. **Recommendations**: Activating the role of maternity health nurse, providing educational program for women to improve their knowledge about endometriosis pain and pain relieve measures.

Key words: Assessment, Pain, Women, Endometriosis.

Introduction

Endometriosis is a common benign gynecological condition classically defined as the presence of endometrial glands and stroma in ectopic sites outside the uterus. Endometriosis affects approximately 10% of child bearing women. Endometriosis is therefore of considerable importance both directly in terms of its potentially negativeimpact on women affected by the condition and indirectly on health care system and society **(Ferreira et al. 2016).**

Women with endometriosis appear to have higher pelvic pain, particularly dyspareunia, dysmenorrhea, dyschezia and pain in the vaginal and abdomino-pelvic area than women with other gynecologic disorders or a normal pelvis, pelvic pain is commonly reported among women undergoing laparoscopy, even among women with no identified gynecologic pathology. Future research should explore causes of pelvic pain among women who seek out gynecologic care but with no apparent gynecologic pathology (**Schliep et al., 2015).**

The pathogenesis of endometriosis is still unknown, and various theories have been proposed to explain it. Endometriosis has multifactorial etiology which includes: genetic predisposition, immune system abnormalities, anatomical and environmental factors **(Lagana et al.,2015).**Endometriosis can be staged I-IV (I-minimal, II- mild, III- moderate, and IV-sever) according to the American Society of Reproductive Medicine, based on; the location, extent, and depth of endometrial implants, a presence and severity of adhesions and size of ovarian endometrium **(Gupta,2015).**

Endometriosis is a chronic disease that causes a significant burden on women's, their families, healthcare systems and economies. It impacts negatively women's physical, mental and social wellbeing and significantly decreases the HRQoL (Health-Related Quality-of-Life), pain is the main reason for the impaired quality of life, even appropriate treatments cannot fully erase the negative consequences of endometriosis **(Soliman et al., 2016).**

The early signs of the negative impact preceding later diagnosis can possibly be foreseen already among adolescents with symptoms suggestive of endometriosis. One-third to half of teenage girls with severe primary dysmenorrhea report absenteeism from school, and severe menstrual pain interferes negatively with social activities, sports, sexuality, relationships and completing schoolwork **(Suvitie, 2018).**

The economic impact consists of direct costs due to surgical, medical, psychological and infertility treatments and indirect costs due to the loss of working days, impaired working ability or even unemployment **(Soliman et al., 2016).**

Treatment options for women with endometriosis are diverse and consist of analgesics, hormonal therapy. conservative or radial surgery, assisted reproduction, or a combination of these **(Dunselman ,2014).** The aim of medical treatment is to suppress the growth activity of endometriosis lesions, all have similar clinical efficacy in terms of reduction of pain- related symptoms and duration of relief. The aim of the surgical approach is the excision all visible lesions to obtain a maximum effect regarding pain relief and increase fertility.

Nurse have crucial role in improve pain for women with endometriosis to regain her life without complications and provide a solid knowledge base of care for women with endometriosis. The desired outcome is that the endometriosis women feels confident about seeking advice and taking care through increasing knowledge that lead to improving pain of endometriosis, the role of nurse is very

complex as it includes role as educator, leader or member of the profession, care giver, empowering agent, researcher user and health promoter, role model and as a counselor **(Lowdermilk, 2014).**

Significance of the study:

Endometriosis is a complex gynecologic disease that impacts nearly 176 million women of reproductive age worldwide, or approximately 5-10% of all ethnicities and socioeconomic back grounds **(sayed,2018).** In Egypt, prevalence rates are unknown, because a definitive diagnosis is established only at laparoscopy.

Endometriosis is a disabling condition noticeably affects different aspects of women's daily lives, social relation and sexual function. Therefore, there was a significant need to improve women's health-related quality of life by increasing awareness and continuous education about management of endometriosis. To improve our knowledge, no available previous research study providing educational intervention beneficial for women with endometriosis pain. Thus, this study is conducted to assess pain for women with endometriosis.

Aim of the study

The aim of this study is to assess pain for women with endometriosis through assessing of women's knowledge regarding reducing pain for women with endometriosis.

Research Question:

- What type of pain do women with endometriosis experience suffer from?

- What are non-pharmacological pain relieve measures women used?

- What are the expected information that women with endometrioses must receive from health care providers?

Subject and methods

Research Design:

The current research is descriptive design was used to achieve the aim of the study.

Setting:

The current study is conducted at Benha University Hospital, in IVF unit, Obstetrics & Gynecology Department which is divided to 2 subunits. These units concerned with Obstetrics &Gynecological diseases and operations and outpatient clinic.

Sampling:

Type: A convenient sample is used.

Sample Size:

The current study includes all women attended to the hospital for six months.

Inclusion criteria:

All women diagnosed with endometriosis regardless of their age, educational level, socio demographic status, parity and stage of disease and women with different stages of endometriosis. These are after diagnostic laparoscopy for endometriosis, under management of endometriosis related pain, during her reproductive years, married or single, free from any chronic disorder.

Tools of the study:

Two tools were used and filled by researcher to collect the required data for current study.

Tool I: Structured interviewing questionnaire tool; will be designed by the researcher based on review of literature. It is divided into three parts.

Part I: It assesses the socio-demographic data characteristics of women such as age, marital status, level of education, duration of occupation and job.

Part II:

It is designed to assess obstetric history such as gravity, parity, length of pregnancy, menstrual history (past & present), family history and surgical history.

Part III:

It includes assessment of pain for women with endometriosis including definition, risk factors, causes and symptoms, and the impact of endometriosis on life.

Scoring system:

The total score for severity of pain was 10 score. The women responses are given on a scale ranging from one to ten and the total scores are categorized into three levels as follow:

- Mild pain =1 – 3,

- Moderate pain = 4 – 6 and

- Sever pain = > 7 score.

Andrea Mankosk's pain scale (*Andrea Mankosk's Pain Scale, 2012).*

Tool II: Standard consultation questionnaire for endometriosis in UK*, (Van der Zandern, 2019)* that content general question about general health, obstetric history, family history and specific question about endometriosis pain as degree of pain with menses, dysmenorrhea, pain with intercourse, pain with bowel movement, excessive bleeding, and infertility.

Validity and Reliability of the tool:

The developed tool was reviewed by Jewry committee from maternal staff of faculty of nursing, Ain Shams University to confirm its content validity, and will be done by 2 expertise in obstetrics - gynecology specialty to measure validity and reliability of tools. This will be done using Cornbrach's Alpha coefficient test. Modifications are carried out according to the

judgment on clarity of sentences and appropriateness of content.

Ethical aspects;

A primary approval is granted from the Ethical Research Committee in Faculty of Nursing at Ain Shams University to undergo the current study at June, 2018. The researcher will clarify the objectives and aims of the study to the women who are included in the study. The researcher will assure maintaining anonymity and confidentiality of the subject data. Women will be informed that they are allowed to participate or not in the study and that they have the right to with draw from the study at any time. At the same time, women are informed that the study has no risks or hazards on their health. Final approval is granted from the Ethical Research Committee to undergo the current study at January, 2019.

2- Administrative design

Faculty of Nursing of Ain shams university administrators should approve on title and protocol. Then, ethical committee approves on protocol then an official written approval letter clarifying the purpose of the study will be obtained from the director of Banha University Hospital as an approval for data collection to conduct this study.

3- Operational Design:

The Operational design includes preparatory phase, content validity and reliability, pilot study and fieldwork.

A. The Preparatory Phase:

It includes reviewing of related literature and theoretical knowledge of various aspects of the study using books, articles, internet periodicals and magazines which are acquainted with research problem and used to develop study tools.

B. Pilot Study:

A pilot study includes 10% of women according to inclusion of the sample size to test study process to evaluate the efficiency, clarity of tools that will be used in the study the necessary modification will be made according to the result of the pilot study. Women who participate in the pilot study are excluded from the sample due to modification of certain question.

Field Work:

Data was collected after obtaining the official approval for data collection within about 6 months from October 2018 until March 2019 in Benha University Maternity Hospital.

The researcher attended on the gynecology units 3 days per week from 9 am to 2 pm. At the beginning of the interview, the researcher starts to introduce herself, briefly explaining the objectives and aim of the study to endometriosis women to gain confidence and trust and finally oral consent from endometriosis women is obtained.

Each endometriosis woman fulfills sample criteria is interviewed by the researcher in a private room to fill tools of data collection. The duration for each interview is 15-20 minutes. The researcher repeats the previous steps until finishing the predetermined number (100 endometriosis women).

4- Statistical Design:

Recorded data are analyzed using the statistical package for social sciences, version 20.0 (SPSS Inc., Chicago, Illinois, USA). Quantitative data are expressed as mean± standard deviation (SD). Qualitative data are expressed as frequency and percentage.

The following tests are done:

- Chi-square (x^2) test of significance is used in order to compare proportions between qualitative parameters.

- Spearman's rank correlation coefficient (rs) is used to assess the degree of association between two sets of variables if one or both of them are skewed.

- The confidence interval is set to 95% and the margin of error accepted is set to 5%. So, the p-value is considered significant as the following:

- Probability (P-value)

– P-value <0.05 is considered significant.

– P-value <0.001 is considered as highly significant.

– P-value >0.05 is considered insignificant.

Statistical analysis:

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Results

Table (1) shows that, the mean age of the studied women was 33.14±7.95, as 1% of them were less than 19 years, 38% of them were 20-29 years, 40% of them were 30-39,21% of them were less than 40 years. However, 20% of the studied women had school education, 26% of them had diploma, 39% of them were university education and 15% of them were post graduate.

Concerning the marital status, 19% of them were single, 68% of them were married, 4% of them were divorced and 9% of them were widowed. Regarding occupation, 46% of them were house wives, 20% of them were working in office, 24% of them were worked in a muscular jobs and 10% of them had no work..

Table (2) shows that, 65% of the studied women had no pregnancies and 11% of them had about 2 or more pregnancies. Regarding number of births, 14.3% of them had no parity, 54.3% had nillpara and 31.4% of them had 2 or more births. However, 70% of them had one single child each pregnancy and 30% of them had twins, concerning single or multi.

Regarding complications of pregnancy, 71.4% of them had no complications and 28.6% of them had complications. As for delivery and miscarriage, 57.1%of them delivered 28.6% of them delivered and miscarriage and 14.3% of them miscarriage.

Table (3)presents that 52% of the studied women know endometriosis concept, 37% of them know risks of endometriosis, 44% of them know causes of endometriosis, 44% of them know signs and symptoms of endometriosis, 45% of them know age of endometriosis and 41% of them know complication of endometriosis.

As regards information about management of endometriosis, 40% of the studied women know pharmacological management, 40% of them know non-pharmacological management and 62% of them know surgical management. However, 57% were the expected total knowledge and

information about endometriosis from health care providers.

Table (4)shows that 38% of the studied women did not use any non-pharmacological pain relief, 7% of them used warm compresses, 46% of them used warm liquids, 9% of them mixed between warm compresses and drinking warm liquids, 15% had massage, 11% of them preferred relaxation, 20% of them used counter pressure. **Table (5)** clarifies distribution of the studied women according to their types of pains as 22% of them had burning, 6% of them had

stab, 8%of them had nippling, 9% of them had sharp, 89% of them had painful and 59% of them had pressure.

Table (6) shows that 29% of the studied women's had a mild level of Andrea Mankoski Pain Scale, 36% of them had moderate and 35% of them had a severe.

Table (7) This table presents that, there were negative correlation and significant between women's knowledge and Andrea Mankoski Pain scale.

Table (1): Number and percentage distribution of women's according to their socio-demographic data (N=100).

Socio-demographic data	No.	%
Age (years)		
<19 years	1	1
20<29 years	38	38
30<39 years	40	40
>40 years	21	21
Mean±SD	33.14±7.95	
Level of education		
School education	20	20
Diploma	26	26
University education	39	39
Post graduate	15	15
Marital Status		
Single	19	19
Married	68	68
Divorced	4	4
Widowed	9	9
Occupation		
House wife	46	46
Work office	20	20
Work needs to muscular	24	24
No work	10	10

Table (2): Number and percentage distribution of the studied women according to their pregnancy history(N=100).

Items	No.	%
Number of pregnancies		
No pregnancy	65	65
1 to 2	24	24
>2	11	11
Number of births (n=35)		
No parity	5	14.3
Nillpara	19	54.3
>2	11	31.4
Single or Multi (n=30)		
Single	21	70.0
Twins	9	30.0
Complications of pregnancy (n=35)		
No	25	71.4
Yes	10	28.6
Delivery & Mischarge(n=35)		
Delivered	20	57.1
Delivered & Miscarriage	10	28.6
Miscarriage	5	14.3

Table (3): Number and percentage distribution regarding expected information about endometriosis from health care providers(N=100).

Items	Know		Unknown	
	No.	%	No.	%
Endometriosis concept	52	52	48	48
Risks of endometriosis	37	37	63	63
Causes of endometriosis	44	44	56	56
Signs & symptoms of endometriosis	44	44	56	56
Age of endometriosis	45	45	55	55
Complications of endometriosis	41	41	59	59
Management of endometriosis				
Pharmacological	40	40	60	60
Non pharmacological	40	40	60	60
surgical	62	62	38	38
Total knowledge	57	57	43	43

Table (4): Number and percentage distribution of the studied women according to non-pharmacological pain relived measures (N=100).

Items	No.	%
There is no using	38	38
Warm compresses	7	7
Drink warm liquids	46	46
Mixed	9	9
Massage	15	15
Relaxation	11	11
Counter pressure	20	20

Table (5): Number and percentage distribution of the studied women according to their types of pain (N=100).

Types of pain	No.	%
Burning	22	22
Stab	6	6
Nibbling	8	8
Sharp	9	9
Painful	89	89
Pressure	59	59

Table (6): Number and percentage distribution of women's according to their Andrea Mankoski Pain Scale (N=100).

Andrea Mankoski Pain Scale	No.	%
1-3 Mild	29	29
4-6 Moderate	36	36
7-10 Severe	35	35
Total	100	100

Table (7): Correlation between women's knowledge and Andrea Mankoski Pain scale (N=100).

	Knowledge	
	Rs	p-value
Andrea Mankoski Pain Scale	-0.672	<0.001**

*p-value <0.05

Discussion

The current study aimed to assess pain in women with endometriosis.

Regarding demographic characteristics of the studied women, the current study reported that the mean age of the studied women was 33.14±7.95.This finding is in agreement with **Facchinet al., (2015),** who conducted a study entitled "Impact of endometriosis on quality of life and mental health" and fond that the studied patients aged from 20 to 40 years old (31.05± 5.45), had a high school diploma, and majority of them had a regular job and were in a stable relationship. Moreover, in agreement with **Taylor et al., (2017),** who conducted a study entitled "Treatment of endometriosis-associated pain with elagolix, an oral GnRH antagonist" found that the majority of the participants were married and their ages ranged from 35 to 50years.

Regarding data of birth for the studies women, the current study reported that nearly two thirds of the women did not give pregnancy, more than half of them were nillpara and more than two thirds of the participants had single babies. Also, the study reported that, nearly three quarters of the study sample with endometriosis had no complications during pregnancy, more than half of them completed pregnancy till delivery. This result may be due to most of women had suitable age for pregnancy period.

In the same line **Gaichies et al.,(2019),** who conducted a study entitled "Non-traumatic diaphragmatic rupture with liver herniation due to endometriosis: a rare evolution of the disease requiring multidisciplinary management" found that more than half of women had one live birth without any complications.

On the other hand, **As-Sanie et al.,(2019),** who conducted a study entitled "Functional connectivity is associated with altered brain chemistry in women with endometriosis-associated chronic pelvic pain" stated that spontaneous abortions were more common in women with endometriosis, incidence of endometriosis was found in multi parous fertile women and high frequency of gynecologic complains, specifically: menorrhagia, dysmenorrhea, and dyspareunia.

Regarding distribution of the studied women according to expected information women should receive from health care providers endometriosis, the current study indicated that more than half of the participants had total knowledge about endometriosis, also, more than half of them knew concept of endometriosis, more than two fifths of them knew causes of endometriosis, risk of endometriosis, signs and symptoms of endometriosis, age ,and how to treat endometriosis pharmacological, non-pharmacological and surgical. This result might be due to women need to more information about endometriosis to cope with their pain and how to manage it.

More over **Vercellini et al., (2018),** that agree with the present study who conducted a study entitled "Medical treatment of endometriosis-related pain" and found that more than two thirds of the participants had enough knowledge about their disease and symptoms, complications, and management.

Regarding percentage distribution of the studied women according to site of pain, the current study revealed that the majority of the studied women suffered from down pelvis pain, more than half of them suffered from lower back pain, and half of them suffered from site of ovaries pain, and nearly one third of them had continuous headache. This result might be due to increase localization or lesion of endometriosis sites of pain for women and also women had inadequate information how to relieve pain and more comfortable methods used to relive this pain.

This result was in agreement with **Nunes et al., (2015),** who conducted a study entitled "Pain threshold and sleep quality in women with endometriosis" and stated that the majority of the participants suffering from generalized pain during menstruation period that distributed in legs, low back area, and other body bones that affect the quality of sleep for those women.

More over **Bourlev et al.,(2018),** who conducted a study entitled "Vasoactive intestinal peptide is unregulated in women with endometriosis and chronic pelvic pain" and reported that consistent patterns emerged regarding pain characteristics and endometriosis staging or anatomic location Interpretation of the present findings required caution given that were limited in assessment of pain characteristics by endometriosis staging and anatomic location.

In the other hand **Grundström et al.,(2018),** who conducted a study entitled "The double-edged experience of healthcare encounters among women with endometriosis: A qualitative study" found that nearly half of the participants had additional symptoms accompanied by endometriosis as low back pain, nausea, and legs pain and were not able to complete their normal activity daily livings.

Regarding percentage distribution of the studied women according to their types of pain, the majority of the studied women in current study had painful sensation, more than half of them suffered from pressure pain type, while minority of them suffered stab, nibbling, and sharp pain. This result may be due to effect of pain and types of pain that affect negatively on women according to stages of endometriosis as some women felt multiple type of pain with some painful, stabbing and sharp.

This result was in congruent with **Whitaker et al., (2016),** who conducted a study

entitled "An exploratory study into objective and reported characteristics of neuropathic pain in women with endometriosis " and stated that more than half of the participants suffered from pressure pain while less than one quarter of them suffered from stab and sharp pain. Similarly **Surrey et al.,(2018),** who conducted a study entitled "Long-term outcomes of elagolix in women with endometriosis: results from two extension studies" reported the same result.

Regarding percentage distribution of the studied women according to their Andrea Mankoski Pain Scale in the present study, more than one third of the participants had moderate and severe level of Andrea Mankoski Pain Scale, while less than one third had mild level of Andrea Mankoski Pain Scale. The study result might be due to effect of Andrea Mankoski Pain Scale as it was positively to describe pain of the women that assess pain associated with endometriosis.

This result was in agreement with **Ragab et al., (2015),** who conducted a study entitled "Prevalence of endometriosis among adolescent school girls with severe endometriosis dysmenorrhea" and found that the majority of the participants had moderate and sever level of Andrea Mankoski Pain Scale, while the minority of them had mild level of Andrea Mankoski Pain Scale.

Regarding percentage distribution of the studied women according to non-pharmacological pain relived measures, the current study revealed that nearly half of the participants reported that their pain relieved by drinking warm liquids while the minority of them reported that pain relieved by warm compresses and some women used massage, relaxation and counter pressure.

From the researchers point of view, this result might be due to that endometriosis pain not localized pain so it could not relieve by using warm compresses and women could be treat this by acupuncture, massage, cognitive behavior therapy. Massage was also effective to handle endometriosis pain, minimize menstrual and leg pain symptoms, being them considered

related to and coexisting with endometriosis, respectively.

In the same line, this result is in agreement with **Taylor et al., (2018),** who conducted a study entitled "Decreased Rescue Analgesic Use with Elagolix Treatment in Women with Endometriosis Associated Pain" and indicated the importance of using such options should be incorporated to conventional approaches offered to endometriosis women for having low cost, few side-effects and satisfactory results for pain relief.

In the present study, there was negative correlation and significant between women's knowledge and Andrea Mankoski Pain scale($p < 0.001$).

Recently in 2018 **Lukas et al., (2018)**, searched for predictors for women satisfaction with medical support Perceived Stress scale-Mind Garden (PSwMS) in women with endometriosis. Their found adequate information to be the most distinctive indicator for PSwMS. Further, acknowledging psychological distress and supporting women in handling their symptoms rather than to alleviate them, positively affected PSwMS. To achieve PSwMS, healthcare providers had to give adequate information on endometriosis and its management. And this made a positive relation between women's knowledge and pain sensation of endometriosis and this disagreement with our study.

On the other hand, **Denny E in 2008** found diverse experience within the primary care setting over half of the women's had negative experience which contributed to diverse impact on their quality of life.

Lack of knowledge seemed to be an aggregating factor toward pain threshold inadequacy, where a general lack of knowledge, acceptance and support for women with endometriosis through three key themes, control, changes in identity and impact of medical care. Women revealed the condition controlled their lives however, they endeavored to regain control.

Future work will focus on prospective studies examining the relationship of early diagnosis and treatment with pain on a larger scale of women is recommended

Conclusion

• The present study   concluded that there were statistical significant relation between studied women's level of knowledge and their Andrea Mankoski pain scale and also there were statistical significant relation between women's level of Andrea Mankoski pain scale and their age, level of education and occupation.

• The current study also supported research questions and aim of study.

Recommendations

Based on the results of this study, the following recommendations were suggested:

➢   Activating the role of maternity health nursing.

➢   Providing educational program for women to improve their knowledge about endometriosis pain and pain relieve measures.

➢   Further studies are needed in this field to assess women's coping mechanism regarding endometriosis impact on their quality of life.

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