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Knowledge Regarding Endometriosis and Wellbeing Among Women Diagnosed with Endometriosis.

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ABSTRACT

Background: Endometriosis is a major problem and it affects millions of women worldwide. Its prevalence is comparable to that of diabetes and hypertension. 10% of the reproductive age gets affected by Endometriosis i.e 176 million women are being affected with Endometriosis. It affects the age group between 26 to 35 years.

Objectives: To assess the knowledge regarding endometriosis and wellbeing among women diagnosed with endometriosis.

Methods: A descriptive study was conducted from January 2019 to April 2019, among 85 women aged between 21-49 years who were diagnosed with endometriosis and were on treatment in infertility center from Udupi taluk, Karnataka. Proportionate sampling technique was used to select the participants. A pretested knowledge questionnaire was used to collect the data after obtaining informed consent from the participants. After collecting the information, a leaflet, which contains brief information about endometriosis and lifestyle modifications strategies was given to all the participants.

Results: 50 (58.8%) of women had good knowledge regarding endometriosis and 81(95.3%) of women diagnosed with endometriosis had average wellbeing. The study found no statistical significant relationship between scores of knowledge and wellbeing ($p>0.05$).

Conclusion: The women diagnosed with endometriosis, is psychologically affected and thus counselling is very important to lead a normal day to day life.

KEYWORDS: Endometriosis, women, knowledge, wellbeing.

INTRODUCTION:

Endometriosis is a gynaecological disorder, as the ectopic endometrial tissue grows outside the uterus. Endometriosis affects 8%–10% of women of reproductive age; in 30% of the women, the condition is associated with primary or secondary infertility. Endometriosis is a condition which is not curable, however there are certain treatment which improves the symptoms like Analgesics, hormonal treatment,

surgical removal of endometriosis and complementary therapies like yoga, meditation and deep breathing exercises.

Some women experience no symptoms. If symptoms occur they may include:
Pelvic or back pain before or during the menstrual period, very painful menstrual cramps, pain during sex, abnormal or heavy menstrual flow, painful bowel movements, diarrhea, constipation or other intestinal problem during menstrual periods, painful urination or feeling the need to urinate often during menstrual periods, difficulty in conceiving.

According to extrapolated statistics, out of 1, 065, 070, 6072 people 53,253,530 are suffering from endometriosis in India. The incidence is about 10-15% in all infertile women[1] .

According to a study conducted by Dept. Of General surgery, Fr. Muller's medical college, Mangalore, Karnataka, the incidence of endometriosis in Karnataka has been reported to be as high as 44% in asymptomatic women undergoing laparoscopy for non-gynecological symptoms,while the incidence of umbilical endometriosis is estimated to be only 0.5% to 1% of all womenwith extra gonadal endometriosis[2].

Prevalence of endometriosis may be as high as 25% to 35%among infertile women. Infertility occurs in about 30-40 % of women with endometriosis.A woman with a mother or sister with endometriosis is six times more likely to develop endometriosis than women without this familial history [3].

A case report was done in Bagalkot, Karnataka of a 23 year old female being diagnosed with Endometriosis when she had an emergency caesarean section. The patient had no symptoms of Endometriosis. Endometriosis symptoms can be either symptomatic or asymptomatic but its rare to see this condition asymptomatic. The patient was counselled to complete her family early so that it does not lead to infertility or further progress of her condition [4].

A qualitative study was conducted to explore the experiences of women who are being diagnosed with Endometriosis. Out of 297 articles, 22 articles were included based on the inclusion criteria and were analyzed. The study result showed that women diagnosed with Endometriosis had negative experiences as it affected their social life, intimate relationship and their mental health wellbeing. The study concluded that the professional healthcare givers should support the women in all dimensions of wellbeing and to improve the quality of life of women diagnosed with Endometriosis [5].

A study was conducted in Harvard medical school to find the relationship between endometriosis and risk for infertility. 58,427 married premenopausal female nurses less than 40 years of age were included in the study. The result showed that there is a relationship between Endometriosis and risk of infertility [6] .

A meta-analysis study was conducted in Europe to see the association between coffee and caffeine intake and risk of Endometriosis. The method of data collection was by meta-analysis of epidemiological studies published up to January 2013. A total of eight studies, six case-control and two cohort studies were

identified. The study concluded that there is no evidence of association between coffee/caffeine consumption and the risk of Endometriosis [7].

A retrospective study was conducted at graduate school of medicine, Tokyo to assess the efficacy of assisted reproductive techniques (ART) and non-ART on women diagnosed with Endometriosis. A total of 1864 sample records were taken from the year January 2000 to December 2015. Data were collected by evaluating the outcomes of the treatment. Majority of women 49.4% conceived through ART and 21.9% conceived by non-ART. The study concluded that non ART had limited role in patient with advanced Endometriosis, thus ART helps to achieve conception [8].

A review was conducted with an aim to assess the social and psychological impact of Endometriosis on women's lives. Out of 3141 articles, 42 articles were retervied based on the inclusion and exclusion criteria which included 1110 women diagnosed with Endometriosis. The data was collected by using quality of life questionnaire which included their everyday activities, their intimate relationship, planning of having children, mental health and wellbeing. The study concluded that Endometriosis had a significant social and psychological impact on women living with Endometriosis [9].

MATERIALS AND METHODS:

This was a exploratory correlational study design carried out to determine the knowledge regarding endometriosis and wellbeing of women diagnosed with endometriosis, for a period of four months from January 2019 to April 2019 at infertility centre in Udupi taluk, Karnataka. After obtaining administrative, institutional ethical committee permission (IEC 679/2018) and informed written consent the women who were diagnosed with endometriosis and are on treatment were recruited for the study.

A total of 85 women who were diagnosed with endometriosis and are taking treatment were taken for the study using proportionate sampling technique. The sample size was based on pilot study. The age of the participants ranged from 29 to 49 years. Participants were taken from infertility centres, Udupi District, Karnataka. The participants were selected using the proportionate sampling technique and informed consent was taken from the participants before collecting the data.

The Inclusion criteria for the following study were women diagnosed to have Endometriosis and who:

- are willing to participate in the study
- can read and write either Kannada or English.
- are undergoing treatment at Kasturba Hospital, Manipal or Kamath Nursing Home, Udupi.

The sampling technique used in this study was non-probability, purposive sampling technique.

The knowledge questionnaire and the wellbeing tool was developed by the investigator. The knowledge questionnaire (r = 0.80) consists of 30 items regarding anatomy and physiology of female reproductive system, Endometriosis definition, risk factor, etiology, symptoms, diagnosis, treatment, prevention, complication. Each correct answer carries one mark. Higher the knowledge scores reflected higher the knowledge among women diagnosed with Endometriosis. The scores varied from 1 – 30. The scores are Good knowledge which ranges from 21-30, average knowledge ranges from 11-20, poor knowledge ranges from 0-10.

The tool consists of 32 items (r = 0.81) (physical wellbeing 8 items, psychological wellbeing 8 items, social wellbeing 8 items, spiritual wellbeing 8 items). It is a five point Likert scale. The higher the score reflects higher the wellbeing among women diagnosed with Endometriosis. The scoring for each positive item was 1 for never, 2 for seldom, 3 for quite often, 4 for very often, 5 for always. The negative questions are negatively scored. The scoring for each negative item was 1 for always, 2 for very often, 3 for quite often, 4 for seldom, 5 for never. The extent of wellbeing was arbitrary classified as low to high. The scores varied from 32-160. The scores are high wellbeing 118-160, average wellbeing 75-117 and low wellbeing 32-74.

RESULTS:

Sample characteristics

Most of the women 33 (38.8%) in age group of 21-30 were high risk age group and majority 60 (70.6%) of the women were housewife, majority of the women 59 (69.4%) did not have children, most 45 (52.9%) of the women were not diagnosed with infertility, in the last one year. 51 (60%) of the women were diagnosed with endometriosis, the women experiencing lower abdominal pain were 43 (50.6%) and it was not during menstruation, majority of them 48 (56.5%) had the pain score of 4-7, 35 (41.2%) of the women did not experience dyspareunia, women had menstruation every month were 79 (92.9%), most of the women 39 (45.9%) changes 4-5 pads per day during first 2-3 days of menstruation, majority of the women 56 (65.9%) underwent gynaecological surgery and the surgery performed was cystectomy 28 (33%).

Frequency and percentage of knowledge regarding endometriosis

Knowledge differs from person to person majority 50 (58.8%) women have good knowledge, 35 (41.2%) women have average knowledge and there is no poor knowledge regarding endometriosis among women diagnosed with endometriosis. Maximum knowledge score of women diagnosed with endometriosis was 30 and minimum score was 12 and mean and standard deviation was 21.02 and 4.66. Women diagnosed with endometriosis had more knowledge in anatomy and physiology of female reproductive system.

Frequency and percentage of wellbeing regarding endometriosis

Majority 81 (95.3%) women have average wellbeing, 4 (4.7%) women have high wellbeing and there was no low wellbeing among women diagnosed with endometriosis. Maximum wellbeing score of women diagnosed with endometriosis 129 and minimum score 91 and mean and standard deviation was 101.93 and 7.95. Women diagnosed with Endometriosis had high wellbeing in psychological domain of wellbeing.

Spearman's rho correlation (r) test on scores of Knowledge and Wellbeing

It shows that there was no significant statistical relationship between scores of knowledge and wellbeing since p valve was more than 0.05, hence the null hypothesis with respect to scores of knowledge and wellbeing was accepted and research hypothesis is rejected. The data infers that there was no significant statistical relationship between scores of knowledge and wellbeing.

Table 1 *Frequency and percentage distribution of socio-demographic data*

	N=85	
Demographic data	**f**	**%**
Age (in years)		
21-30	33	38.8
31-40	31	36.5
41-49	21	24.7
Work status		
Employed	25	29.4
Housewife	60	70.6
Education		
Primary school	5	5.9
High school	15	17.6
PUC	18	21.2
Degree or postgraduate	47	55.3
Marital status		
Married	85	100
Single	0	0
Divorced	0	0
BMI		
Underweight <18.5	1	1.2
Normal 18.5-24.9	53	62.4
Overweight 25-29.	31	36.5

N = Total number no samples, f = frequency, % = percentage

Table 2 *Frequency and percentage distribution of Endometriosis history*

	N=85	
Demographic data	**f**	**%**
Age of menarche (in years)		
12	6	7.1
13	30	35.3
14	36	42.4
15	13	15.3
Having children		
Yes	26	30.6
No	59	69.4
Diagnosed with infertility		
Yes	40	47.1
No	45	52.9
Diagnosed with Endometriosis		
Less than 1 year	51	60
1-2 years	9	10.6
More than 2 years	25	29.4

Family history of Endometriosis		
No	85	100
Yes	0	0
Experiencing lower abdominal pain		
Yes	43	50.6
No	42	49.4
If yes, during menstruation		
Yes	43	50.6
No	42	49.4
Pain score		
0	17	20
1-3	31	36.5
4-7	35	41.2
8-10	2	2.4
Dyspareunia		
Yes	27	31.8
No	58	68.2
Days of menstrual cycle		
3-5	77	90.6
6-8	8	9.4
Get menstruation every month		
Yes	79	92.9
No	6	7.1
Number of pads changed per day (first 2-3 days)		
2-3	31	36.5
4-5	39	45.9
6-7	15	17.6
Gynaecological surgery		
Yes	56	65.9
No	29	34.1
Name of the surgery		
Cystectomy	28	33
Myomectomy	21	24.8
Laparoscopy	10	11.8
Nil	26	30.6
Experiencing pain other than menstrual pain		
Yes	8	9.4
No	77	90.6
Diagnosed to have Diabetes mellitus		
Yes	0	0
No	85	100
Diagnosed to have Hypertension		

Yes	0	0
No	85	100

N = Total number no samples, f = frequency, % = percentage

Table 3 *Domain wise analysis for knowledge scores*

N=85

Area	Total score	Maximum obtained score	Minimum obtained score	Mean	SD
Anatomy and physiology	11	11	4	10.02	1.47
Definition	3	3	0	1.95	0.75
Etiology and symptoms	5	5	0	2.55	1.32
Diagnosis	5	5	1	3.49	1.38
Treatment and management	5	5	0	2.54	1.30
Complication	1	1	0	0.51	0.50
Total score of knowledge	30	30	12	21.02	.66

SD = Standard Deviation

Table 4 *Domain wise analysis of wellbeing scores of women diagnosed with Endometriosis*

N=85

Area	Total score	Maximum obtained score	Minimum obtained score	Mean	SD
Physical wellbeing	35	35	22	27.03	3.79
Psychological wellbeing	28	28	18	23.81	2.31
Social wellbeing	39	39	19	25.90	4.34
Spiritual wellbeing	32	32	20	25.12	3.14
Total scores of wellbeing	129	129	91	101.93	7.95

SD = Standard Deviation

Table 5 *Spearman's rho correlation (r) test on scores of Knowledge and Wellbeing*

N=85

Variable	Knowledge	Wellbeing	p value

Knowledge	-	.058	.598
Wellbeing	.058	-	

p > .05, not significant

Discussion:

In the present study majority 33 (38.8%) of the women in age group of 21-30 years were diagnosed with Endometriosis, the women experiencing lower abdominal pain during menstruation were 43 (50.6%), 27 (31.8%) of women were having dyspareunia.

These findings of the literature which was supported by Adamson. D.et.al.(2010) was found that affects women of age group between 26 – 35 years 100 (10%). The prevalence of Endometriosis is higher in women with dysmenorrhea 600 (60%), dyspareunia 440 (44%), pelvic pain 800 (80%).).

In the present study majority of the women 36 (42.4%) had attained menarche at the age of 14 years, 6 (7.1%) of women attained their menarche at the age of 12 years. 30 (35.3%) women had attained menarche at the age of 13 years and 13 (15.3%) women had attained menarche at the age of 15 years.

These findings of the study are contradicted by Nnoaham, k.E., Webster,P., et.al (2012) found that there are probability of 55% of women with Endometriosis had an early menarche (below 12 years of age) and the study concludes that there is a small increased risk of Endometriosis and early menarche [10].

In the present study majority 85 (100%) of the women did not have any family history of Endometriosis.

These findings of the study are contradicted by Moen, M.H., & Magnus, P (2009) was found that the relative risk of Endometriosis in first degree relative was 7.2% (95% CI). Severe manifestation was found among patient with family history 107 (26%) than among women without family history 18 (12%) $p < 0.01$. Thus the study concluded that there was seven fold increase risk of Endometriosis with family history [11].

In the present study 45 (52.9%) of the women were not diagnosed to have infertility and 40 (47.1%) of the women were diagnosed to have infertility.

These findings of the study was supported by J. Prescott, L.V Farland (2016) identified that 83% of the women who were diagnosed with Endometriosis were infertile and showed two fold increase risk of infertility of women who were diagnosed with Endometriosis with Hazard ratio of 2.12(95% CI) [6].

Knowledge regarding Endometriosis

In the present study shows that 50 (58.8%) women have good knowledge, 35 (41.2%) women have average knowledge and there is no poor knowledge regarding Endometriosis among women diagnosed with Endometriosis.

The findings of the study are contradicted by Shah, D. K., Moravek, M. B., Vahratian, A., Dalton, V. K., & Lebovic, D. I. (2010). results showed that the knowledge of Endometriosis was 91% and their increase in knowledge was associated with their education level, regular health care, and their exposure to individuals with the disease [12].

Wellbeing of women diagnosed with Endometriosis

In the present study majority 81 (95.3%) of women have average wellbeing, 4 (4.7%) women have high wellbeing and there was no low wellbeing among women diagnosed with Endometriosis.

The findings of the study contradicted by De Graaff, A.A., et.al (2013) showed that Endometriosis affected the work in 51% of women and affected relationship in 50% of women, dysmenorrhea was reported among 59% of women and dyspareunia by 56% of women and thus the study result showed that the quality of life of the women with Endometriosis were impaired [13].

A study conducted by Culley, L., et.al (2013) reveled that Endometriosis had significant impact on social and psychological impact on women living with Endometriosis among the 42 papers that were reviewed [9].

The limitations of the study were that even though women who were diagnosed with endometriosis for a longer time didn't have much knowledge regarding their health condition. Due to limited sample size it restricted the generalization of the study findings. The strength of the study was, women visited the infertility clinic it was eaiser to collect the information from them.

Conclusion:

Endometriosis is a gynaecological disorder, as the ectopic endometrial tissue grows outside the uterus. Endometriosis affects 8%–10% of women of reproductive age; in 30% of the women, the condition is associated with primary or secondary infertility. The present study revealed that the knowledge of women diagnosed with Endometriosis was good and the wellbeing of women diagnosed with Endometriosis was high. The study concludes that the psychological wellbeing of the women with endometriosis is affected and thus counselling, and the leaflet includes lifestyle modifications which includes diet and complementary therapies like yoga, meditation and deep breathing exercises must be taught to the women so it helps in their day to day life.

The nurses must encourage women of reproductive age group regarding endometriosis and how to ajust with symptoms and life style modifications which includes diet and complementary therapies like yoga and deep breathing exercises. The study concluded that there is a need to spread awarness regarding Endometriosis to improve the wellbeing of women diagnosed with Endometriosis.

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