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DAILY LIFE EXPERIENCES AND HEALTH CARE SEEKING PRACTICES AS WELL AS ASSOCIATED BARRIERS AMONG WOMEN WITH UTERINE PROLAPSE

Gynaecology

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ABSTRACT

INTRODUCTION: Uterine prolapse (UP) has detrimental effects on a woman's physical health, sexual life, and her ability to perform daily household work and earn a living.

OBJECTIVES: To study daily life experiences of women with UP, its perceived causes, health care seeking practices and associated barriers. Also, to see if there was gender based violence.

METHOD: Semi structured and in depth interviews were conducted among 50 UP affected women.

RESULTS: Study participants were 21-80 years of age. Obstetric history given by patients which increases the risk for having UP was that of young age at first pregnancy (68%), lack of proper birth spacing (76 %), not gone for the minimum required antenatal care visits (84%), home deliveries (44%), less awareness or lack of use of contraceptives and decreased rest in postpartum period. Most patients described major physical discomforts as difficulty in walking, standing, working, lifting, along with urinary incontinence and bowel symptoms. Most of them did not seek healthcare due to neglect (60%), poverty (40%), increased workload (14%), taking care of children (8%) and some due to the lack of the husband's support (8%). Other responses included shame, fear of surgery, being refused for surgery due to other existing medical ailments and seeking of local treatment.

CONCLUSIONS: Causes of UP are multi-factorial but modifiable. Thus, keeping these in mind, health programs, awareness programs and women empowerment programs must develop interventions targeting prevention of UP.

KEYWORDS

Uterine prolapse, daily life experiences, health-seeking practice, barriers, gender based violence

Introduction

Uterine prolapse (UP) is the most common gynecological health problem contributing to maternal morbidity and mortality among women of reproductive age in developing countries.[1] In fact, exact prevalence of uterovaginal prolapse is difficult to be determined because many women are asymptomatic, and many women feel shy or do not reveal the presence of uterovaginal prolapse due to social reasons.[2]

UP occurs when weakness in normally supportive tissues cause uterus to descend, with or without the urinary bladder and bowel, into the vagina.[3] In first-degree prolapse, cervix appears at the vaginal opening only when the woman is asked to bear down. In second degree prolapse, cervix descends to the level of the vulva, and in third-degree prolapse, cervix protrudes outside the vulva. The condition where the entire uterus may protrude outside the vulva, bringing with it both the vaginal walls, is called procidentia.[4]

Weakening of musculature and ligaments even though multifactorial, the etiology comprises of large number of pre-disposing factors which are easily preventable.[5] Clinically, UP symptoms are organized into four groups according to presentation: vaginal, urinary, bowel, and sexual.[6] Although this condition is non-fatal, the pain and discomfort experienced by these patients hampers the quality of their day to day life, affecting their ability to earn a livelihood and making them socially withdrawn. However, a majority of these women seek treatment very late. By then the degree of prolapse has increased.

Only a few studies have been done to assess the quality of life and experiences and health care seeking practices of such women.[7] There is a need for closing the knowledge gaps with respect to perceptions, awareness, practices and treatment seeking behavior so that these problems could be addressed, particularly in the Government programs.[8] Thus in this study, in-depth interviews were conducted with women coming to the Outpatient Department (OPD) of a tertiary care hospital, linked with a government hospital.

Aims and Objectives

The objectives of this study were to study the prevalence of UP among women belonging to different socioeconomic classes and having different obstetric histories. This study will also help shed some light on the experiences of women with uterine prolapse and its effect on daily life, its perceived causes and health care seeking practices. This study was also done to learn about gender based violence associated after disclosure of uterine prolapse and the barriers present which unable these women to seek treatment.

Materials and methods

Type of Study – Hospital based cross sectional study

Sample Size – 50 women

Inclusion Criteria – women coming to the OPD who had already been diagnosed with UP, or those who came with gynecological complaints and as a result got diagnosed of having UP by a gynecologist.

Exclusion Criteria – women who had other gynecological problems other than UP, for example, vaginal cyst or vaginal cancer which may have been perceived as something protruding through the vagina.

This study was conducted after the approval of the Institutional Ethics Committee, using a convenience sampling method. Semi structured and in-depth interviews were conducted over a period of two months. Qualitative data was collected. Deductive approach was used for content analysis.

Confidentiality -

- Because women fear that others will know their problems, they might be reluctant to share personal information with others. They also might fear the consequences of sharing personal experiences and exposing themselves to potential harm from their spouse and other family members. [8]
- Thus, at the OPD each patient was ensured privacy and confidentiality. They were also be informed about the objectives of the study and that their participation would be useful for developing awareness programs for early diagnosis of UP and thus help improve the quality of life of many. [8]

The semi structured questionnaire included the following:

1) Socioeconomic characteristics
2) Family type
3) Obstetric history
4) Maternal health services Awareness/Accessibility
5) Duration of rest in post-partum period
6) Workload after Delivery
7) Family Decision Making for Health Care

Impact of uterine prolapse on quality of life was assessed using open ended questions as mentioned in the questionnaire under the following headings: [7,8,9]

1) Experiences of physical discomfort
2) Effect on daily household chores
3) Effect on work done to earn a living
4) Impact on sleep
5) UP related sexual discomfort
6) Emotional stress
7) Impact on social activities/relations
8) Spouse behavior after disclosure
9) Experiences of domestic violence following disclosure of UP
10) Self-perceived reasons for UP
11) Health care seeking practices

The results were obtained in terms of percentages as per the responses obtained from the women.

Observations and Results

In this study, a majority belonged to the age group of 41-50 years old (32%), followed by 31-40 years old age group (26%).(Table 2) We also encountered a UP patient of 23 years of age. A majority of these came with third degree of UP (42%) followed by second degree of UP. Women with procidentia accounted for 18%. (Table 1)

92% of the women were Hindus and 8% of the women were Muslims. More than half these women (52%) were illiterate and none of them had attained higher secondary level of education. (Table 3) More than half of these women (56%) were farmers. (Table 4) Most of these women are dependent on agriculture as their source of income. Furthermore, they were also dependent on their husband's income. Other occupations were those of fruit or vegetable sellers, garbage pickers and small scale business services like food catering services.

Half of these women (50%) belonged to nuclear family. (Table 7) 34% women reported that they could independently take decisions regarding healthcare. However, most of these women, that is about 66% of them were dependent on their husband in this matter. They depended on their spouse not only financially but also for transportation as the hospital is far off from where they live.

While more than half of these women (56%) were not aware about contraceptives, (Table 5) reasons stated for not using contraceptives by those aware about them were, that they did not feel the need to use them AT home and a few also wanted a male child. One of the women stopped using Copper-T due to infection. A few did not feel the need to use them as there was infrequent sexual activity and some did not live with their husband.

On enquiring about various aspects of safe motherhood practices, an appalling number of women (84%) were unaware about antenatal visits and only 8% women attended all the antenatal visits regularly. In 44% women, deliveries were conducted at home, in 34% women deliveries were conducted at a hospital and in 22% women initially deliveries were conducted at home and then last one or two deliveries were done at a hospital. (Table 6)

More than half of the women (62%) belonged to the age group of 15-20 years during their first pregnancy. Few of these women (26%) had birth spacing of only one year. Our results also demonstrate that parity plays role in the development of uterine prolapse. A shocking number of these women (72%) did not take any rest post-partum. Most of them had no choice but to resume both household chores as well as other outside work to earn a livelihood. (Table 8)

Table 1. Distribution of degree of uterine prolapse among the women in this study

Degree of uterine prolapse	Number	Percentages
First degree	5	10%
Second degree	15	30%
Third degree	21	42%
Procidentia	9	18%

Table 2. Distribution of age groups to which women in this study belonged

Age (years)	Number	Percentages
21-30	3	6%
31-40	13	26%
41-50	16	32%
51-60	5	10%
61-70	11	22%
71-80	2	4%

Table 3. Distribution of level of education attained by the women in this study

Education	Number	Percentages
Illiterate	26	52%
Primary education (1-5 grade)	9	18%
Secondary Education (6-10 grade)	15	30%
Higher Secondary Education	Nil	Nil

Table 4. Distribution of different occupations among the women in this study

Occupation	Number	Percentages
Farmer	28	56%
Housewife	14	28%
Wage labourers	5	10%
Others	3	6%

Table 5. Utilization of contraceptives by the women in this study

Use of contraception	Number	Percentages
Used regularly	4	8%
Used intermittently	2	4%
Did not use willingly despite being aware about it	10	20%
Did not use as she was not aware of it	28	56%
Use of contraceptives was not allowed by the husband	6	12%

Table 6. Safe motherhood practices among the women in this study

ANC visits	Number	Percentages
None	42	84%
Only a few	4	8%
All done	4	8%
Place of delivery	**Number**	**Percentages**
Home	22	44%
Hospital	17	34%
First at home, later at a hospital	11	22%

Table 7. Types of families to which the women in this study belonged

Type of family	Number	Percentages
Nuclear	25	50%
Joint	18	18%
Three generation	4	8%
Lives alone	3	6%

Table 8. Distribution of various. obstetric factors possibly contributing to uterine prolapse among the women in this study

Age at first pregnancy (years)	Number	Percentages
<15	1	2%
15-20	32	64%
21-25	13	26%
>25	4	8%
Parity	**Number**	**Percentages**
1-2	21	42%
3-4	18	36%
5-6	11	22%
Birth spacing (years)	**Number**	**Percentages**
1	13	26%
2	25	50%
2.5	6	12%
3	5	10%
>3	1	2%
Duration of rest taken post- partum	**Number**	**Percentages**
1-7 days	36	72%
7-14 days	2	4%
15-30 days	5	10%
60 days	5	10%
>60 days	2	4%

Experiences of physical discomfort and symptoms

Table 9. Various Physical discomforts and symptoms among the women in this study

Physical discomforts	Number	Percentages
Pain in the abdomen	12	24%
Pain in the lower back	3	6%
Difficulty while walking,	19	38%
sitting and standing		
Difficulty while urination	21	42%
Difficulty while defecation	7	14%
Vaginal problems	17	34%
Others	2	4%

Difficulty while walking, standing or sitting was attributed mainly due to the discomfort due to friction. Most of the women experienced incomplete voiding of bladder and bowel as well as urinary incontinence, particularly on coughing or sneezing.Various vaginal symptoms stated were itching, ulceration, bleeding, red sticky discharge or sometimes white discharge. A few complained of burning micturition and heavy menstrual flow. Two of the women also complained of decreased appetite.

Effect on daily household chores and ability to earn a livelihood

Table 10. Effect of uterine prolapse on the ability of these women to work to earn a livelihood and to do household chores

Effect on work	Number	Percentages
Continued work	34	68%
Reduced both outside and	10	20%
house hold chores		
Reduced work outside home	5	10%
Stopped all the work outside home	1	2%

Impact on sleep

Table 11. Effect of uterine prolapse on the sleeping patterns these women

Effect on sleep	Number	Percentages
No change	28	56%
Decreased hours of sleep	19	38%
Frequent waking up at night	12	24%
Excessive daytime sleepiness	17	22%
Bad dreams	2	4%

Frequent waking up at night every 1-2 hours was mainly to urinate due to incomplete evacuation of the bladder. This disturbed sleep in many cases and the reduced hours of sleep led to excessive day time sleepiness and fatigue during the day.

UP related sexual discomfort

Table 12. Effect of uterine prolapse on the sexual life of these women

Sexual pain and discomfort	Number	Percentages
None	27	54%
Present	10	20%
No sexual activity on the account of being a widow/ old age	13	26%

Emotional stress

Emotionally, most of these women were frustrated and stressed out as they were alone handling a lot of work with no one to help them. Many of them felt the shame as uterine prolapse continues to be a social stigma. One of these women also had suicidal thoughts. Her exact words were: "I used to cry daily. Cry myself to sleep. I felt it was better to just die."

Impact on social activities/relations

Table 13. Effect of uterine prolapse on the social life of these women

Effect on social life	Number	Percentages
Could go out	39	78%
Reduced going out	7	14%
Stopped going out	4	8%

Behaviour exhibited by spouse and other family members after disclosure about uterine prolapse

Table 13. Behavior of the spouse after disclosure about the uterine prolapse by the women

Spouse behavior	Number	Percentages
Did not tell spouse	4	8%
Supportive	35	70%
Non-supportive/Neglect	10	20%
Re-married	1	2%

Neglect shown by the spouse was mainly due to the financial burden and time constraints. Moreover, in a few cases husbands who were alcohol addicts added to the woes of these women and resorted to verbal and physical violence. One woman from the Banjara community who had travelled for 3 days from her village to seek treatment at our hospital revealed that the moment her husband came to know about her uterine prolapse, he abused her, had an affair with his previous wife and later remarried her. This one incident emphasizes on the need to conduct community level studies to know the exact picture at the village level.

Table 14. Behavior of other family and society members after disclosure about the uterine prolapse by the women

Behavior of other family and society members	Number	Percentages
Did not tell	7	14%
Non-supportive/abusive	4	8%
Supportive	39	78%

Self-perceived reasons for UP

Table 15. Self-perceived reasons for occurrence of prolapse by these women

Self-perceived reasons as to why prolapse occurred	Number	Percentages
Did not know/ Did not think over it	26	52%
Heavy lifting	14	28%
Many pregnancies	3	6%
Decreased spacing	2	4%
Early pregnancy	2	4%
Other	3	6%

Three surprising responses when asked about self-perceived reasons as to why uterine prolapse occurred included blood transfusion, piles operation and the belief that it was "karma".

Health care seeking practices

92% of these women were late in seeking treatment, some as late as 22 years. Only 8% of these women came for treatment within 2-3 months of noticing the bulge in the vaginal area.

Most of these women did not bother reducing the prolapse, as the prolapsed part used to spontaneously go inside on standing. Those who resorted to manual reduction of the bulge by hand, had to do so mainly during urination and defecation as the increased abdominal wall pressure used to cause protrusion making it difficult of void urine and in some cases, pass feaces. Other measures for reduction include seeking local help in the form of medications and "pushing it in" by one of the local woman.

Table 16. Measures taken to reduce the uterine prolapse by these women

Measures taken to reduce the prolapse	Number	Percentages
None	28	56%
Manual reduction by hand	20	40%
Other	2	4%

Table 17. Number of years of delay in seeking treatment after first noticing the protrusion herself

Delay in seeking treatment after first noticing the protrusion (years)	Number	Percentages
<1	12	24%
1-5	22	44%
5-10	7	14%

10-15	2	4%
15-20	3	6%
20-25	4	8%

Table 18. Responses for reasons for the delay in seeking treatment by these women

Reasons for the delay	Number	Percentages
Neglect	30	60%
Poverty	20	40%
Increased workload	7	14%
Had to take care of children	4	8%
Not allowed by husband	4	8%
Was taking some local	2	4%
treatment		
Shame	3	6%
Afraid of surgery	1	2%
Has other medical problem	4	8%

Discussion

A majority of these came for consultation at a late stage when the size of the bulge increased and the symptoms became worse. The delay associated in seeking treatment after they first "noticed a tiny pea sized bulge" led to progression to higher degrees of prolapse. Women often consider the reproductive morbidities as normal, and do not report their symptoms to health workers or seek any treatment. Mulgaonkar et al reported that women sought health care only when their gynecologic problems became severe.[10]

In this study, a majority belonged to the age group of 41-50 years old (32%), followed by 31-40 years old age group (26%) and then 61-70 years age group (22%). In a Jordanian study, 47.2 % of cases at the time of presentation were ≥50 years.[11] However, in studies done in and Egypt[11], majority of cases were of age group 20–29 and 30–39 years, respectively, at the time of onset. Thus, it can be inferred that uterine prolapse can occur in any age.[5]

Most of the women were illiterate. Also, most of the prolapse cases were of lower socio-economic status and were farmers, which is concordant with studies done in Nepal [12] and Tamil Nadu[4]. Next group affected was that of housewives. Farmers gave history of lifting heavy things, strenuous work in farm or masonry work, and housewives gave history of carrying heavy pots of water over long distances. Also, in India, most of the work is done in the squatting position. In a Nigerian study, most women were manual labourers.[14] These findings infer that women engaged in strenuous activities and occupations get exposed to raised intra-abdominal pressure over prolonged periods and thus are at risk of developing prolapse.[14]

Most women belonged to nuclear families. They complained of the burden of all the work falling on them with nobody to help them, thus, aggravating the symptoms. However, another study states that in extended family, the workload may increase due to more number of members to be taken care of. [3] Our results also demonstrate that parity plays a role in the development of uterine prolapse. This is suggestive of that effective family planning programs could prevent uterine prolapse.

In a study by Joseph et al. risk of UP was more among grand multiparous women in this study. In other studies, risk was most after second delivery [4], after third delivery [15], after fourth delivery [16], and after fifth delivery.[14,15,17] A study done in Italy also reported that risk was greater even after a single birth.[18] The process of aging causes loss of collagen and weakness of fascia and connective tissue and the risk of prolapse gets increased during subsequent child births. [18]

Knowledge about contraceptives was very poor among these women. This combined with lack of knowledge about ANC visits and importance of birth spacings, early age at pregnancy, home deliveries, inadequate rest post-partum and multiparity, could have aggravated the symptoms. Generally, after delivery the mother should rest for at least six weeks for the uterus to develop and three months for all the pelvic ligaments and organs to function normally again.[9]

In our study 44% of the women had home deliveries, which is similar to another study done in Tamil Nadu. [4]About 40 % of women with prolapse had history of home deliveries, while in a study done in Nepal 96.3 % of babies were born at home. [12] This again supports the fact that poorly supervised labor and delivery conducted by untrained personnel in home environment lead to faulty delivery practices like bearing down for a long time before full cervical dilation, not performing episiotomy when it is indicated and not stitching perineal tears.[19]

This causes damage to supporting structures of uterus.

The most common symptom in this study was urinary incontinence (42%) followed by difficulty in walking, standing and sitting (38%) and then followed by vaginal problems (34%). Other symptoms included pain in abdomen (24%), pain in the lower back (6%), problem in defecation (14%) and decrease in appetite (4%). This is similar to a study done in Jordan which reported that 34.9% cases presented with difficulty in micturition.[11] Most common associated symptom was abdominal pain (84.9 % patients) in a study done in Nepa[19], vaginal discharge in studies done in Egypt[11], lower back ache in a Nigerian study [17] and urinary incontinence in the study done by Palm.[10] On the other hand, a study done in Maryland, USA observed that 81 % UP cases had no associated symptoms.[20]

In most cases, 70% of husbands and 78% of the other family and society members were caring and supportive and in many cases encouraged the women to seek medical consultation. 20% of the husbands did not pay any heed their partner's suffering. Reasons attributable for this neglect could be lack of awareness, financial burden and lack of time. A few were alcoholics and resorted to physical and verbal abuse.

In a study done in Nepal, twenty three percent of spouses were caring and supportive, but 16% harassed their wives by threatening to remarry or separate. 24%of spouses remarried after their wives disclosed a UP diagnosis.[7]Additionally, in laws humiliated and harassed them because they could not perform the expected level of household.[7]

In our study, 10% of the women complained of pain during sexual intercourse. Severe physical symptoms result in low desire for sexual intercourse. In a study done by Shreshta et al. participants exhibited low self-esteem, which they frequently described as anxiety, aggression, frustration, and despondency. Affected women guiltily accepted any undesired sexual relationship and endured painful sexual intercourse because they depend on their spouse's income. They also found that most spouses are not interested in engaging with their wives after they disclose UP.[7]

It is possible that many women did not reveal the truth either due to fear or non-willingness to something that personal. A study done in Nepal reported something similar. The patriarchal culture as well as the lower economic and social statuses of women in Nepal reduce their ability to fight against discrimination and injustice. As a result, women suffer from domestic violence.[9]

Economic position, increasing their dependence on spouses or other family members, illiteracy and lack of awareness about this condition and the treatment options available for it, along with the social stigma and the sensitivity of issues relating to the genital region, contribute to a delay in seeking health care.

The reasons for the delay need to be carefully targeted during awareness and health programs. More than half of the woman (60%) neglected it when they first noticed the bulge due to its small size. Many revealed to us about their financial burden (40%), duty to do household work (14%) and take care of children (14%). Other reasons included no support from the husband, use of local treatment options, shame and fear of surgery. The most common surgery done in our setting was vaginal hysterectomy and pelvic floor repair.

Ring pessary and Kegel exercises were the main non-operative procedure for UP cases in a Nigerian study. [17]. Benefits of pelvic floor muscle training in improving prolapse symptoms have been mentioned in a multicenter study done in UK, New Zealand, and Australia .[21]

Pelvic floor strengthening exercises and pessary rings are suitable for local level implementation and low-income settings as they are inexpensive. Muscle training has shown beneficial effects in conditions like urinary incontinence, fecal incontinence, and lower back pain besides preventing UP.[22]

The limitation of this study is that it is a pilot study at an institutional

level conducted on a small sample size of 50. Studies at a community level are required with a larger sample. Community studies may also help get better insight into aspects of gender discrimination and domestic violence and their consequences. Husbands, who received an education, play an important role for they influence the health seeking behavior of women and are the decision makers in their households. Thus, involvement of husbands will not only give a better insight but also help generate awareness among them.

In conclusion, the causes of uterine prolapse are multi-factorial. Many of the risk factors are modifiable. Thus, keeping these in mind, health programs, awareness programs and women empowerment programs must modify their own policies or develop interventions targeting the prevention of uterine prolapse.

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