Original Article

Women's experiences and perception of symptomatic pelvis organ prolapse: A Cross sectional study from Uttarakhand, India

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Abstract

Background: Pelvic Organ Prolapse (POP) negatively affects the health of a woman in terms of physical, social and emotional wellbeing. **Objective:** The aim of this study was to elucidate the experience of living with prolapse and its impact on daily life. **Methods:** Women undergoing surgery for pelvic organ prolapse were interviewed to evaluate their sociodemographic profile with subsequent impact on their daily life. **Results:** Among the 45 cases with POP, 80% belonged to rural areas. Mean age of study group was 53.68 years. Young age at marriage (mean age 17.31), early first child birth (mean age being 20.5 years) and increased parity (86.66% had parity 3 and above) with majority of children born at home under supervision of untrained dais (77.78%) could probably attribute to their prolapse. Approximately 51% thought that prolapse occurs as a result of hard manual work and 64% cases considered it non treatable. POP was associated with poor quality of life in terms of physical, social and sexual life. Decreased sexual frequency was seen in 86.67% cases. 50% cases reported bladder problems. Sense of incomplete evacuation was seen in nearly 35% and constipation was reported by 37%. **Conclusion:** Though there exists a social stigma associated with pelvic organ prolapse, this study showed that in majority, it was the woman herself who delayed medical help. Health care providers should take initiative in educating women regarding prolapse and to make them aware that it is a treatable condition which can improve their quality of life.

Keywords: Pelvic organ prolapse, quality of life, sexual function

Introduction

Symptomatic pelvic organ prolapse (POP) involve many aspects of a woman's life including social, sexual, domestic, psychosocial and occupational.[1,2] It occurs due to weakened muscles and ligaments of pelvic floor. The causes are multifactorial. Pregnancy and childbirth constitute important risk factors for prolapse, risk increasing with increased number of vaginal deliveries.[3,4] The incidence may be higher in limited resource settings owing to high fertility rates, young age at deliveries, limited access to health care, and hard manual work.[5,6] Clinical presentation varies with many women being asymptomatic. Woman often report their complaints as something coming out per vaginum, sensation of bulge or heaviness in perineum, pelvic pressure, difficulty in urination or defecation, urinary or faecal incontinence and sexual dysfunction.[7] Treatment often depends on stage and severity of condition. Simple lifestyle measures like weight loss and use of pelvic floor muscle training is useful in some whereas many require surgery. Pelvic organ prolapse has negative impact on a woman's sense of body image and sexual function.[8] Despite being symptomatic for long duration, women are often reluctant to seek help for this known disease probably attributed to their

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Received: 29-08-2020 **Revised:** 27-10-2020
Accepted: 01-12-2020 **Published:** 30-01-2021

Access this article online

Quick Response Code:

Website: www.jfmpc.com

DOI: 10.4103/jfmpc.jfmpc_1763_20

How to cite this article: Prateek S, Mundhra R, Bahadur A, Kunwar K, Jha P, Chawla L. Women's experiences and perception of symptomatic pelvis organ prolapse: A Cross sectional study from Uttarakhand, India. J Family Med Prim Care 2021;10:449-53.

misinformation, potential embarrassment, cultural and personal silence concerning this condition.[9] Unlike other diseases, pelvic organ prolapse is one disease which has little public promotion. There exists a gap between how women understand their problem and how they cope up with its consequences. The rationale of our study was lack of good data on POP from this region. Women in rural areas often get neglected in terms of health care facilities. Being a hidden disease, women often tend to neglect their symptoms and seek help only when symptom worsens. With this study, we planned to identify the possible causes for delayed medical help and impact of POP on their quality of life which would help us in formulating strategies in providing appropriate services for treatment.

The present study aimed to evaluate how women with symptomatic pelvic organ prolapse experience and its subsequent impact on their day to day life.

Materials and Methods

Setting and study design

This was a hospital based cross sectional study carried out in Gynaecology outpatient department of a tertiary care centre from Uttarakhand, India between June 2019 to November 2019. The study was approved by Institutional Ethics Committee.

Subjects

Women presenting with complaints of something coming out per vaginum or a bulge in the vaginal area and those who demonstrated prolapse of stage more than or equal to II according to pelvic organ prolapse quantification system at their first visit were asked to participate in the study. Once they agreed to participate in the study, they were asked to answer a set of self-made questionnaires.

Study variables

Socio-demographic profile of women (age, religion, marital status, educational status, occupation), age at marriage, age at first child birth, number of children, duration of symptoms, distance from health facility and reasons for delay in seeking health care assistance were noted. In addition, the questionnaire included the impact of prolapse on lifestyle (physical limitations like unable to perform daily chores like cleaning, going out; emotional disturbances like feeling bad about oneself, feeling alone and depressed, being ignored by family due to bad smell, interference with sexual functions and disturbed relationship with husband, impact on bladder and bowel habits)

Results

In-depth interviews were conducted on forty-five women with symptomatic prolapse >=stageII.

Table 1 shows the demographic profile of pelvic organ prolapse cases. The Mean age of the study group was 53.68 years. Majority belonged to hilly, rural areas and had limited access to health services. Young age at marriage (mean age 17.31) with early first child birth (mean age being 20.5 years) and increased parity (86.66% had parity 3 and above) with majority of children born at home under supervision of untrained dais (77.78%) could probably attribute to their prolapse. Uttarakhand comprises both hilly and plain areas and as we have seen that most cases were from hilly areas, women were used to hard manual labour. They were the ones carrying heavy weights like buckets of water, bundles of grass and wood for household purposes. These were part of their daily activities. Almost all of our subjects were involved in hard labour.

The mean length of delay in seeking medical help was variable with a range of 1-40 years. Descriptively, the main reason for delay in seeking help was embarrassment and loss of social value in front of family (56%); lack of transportation and distant health

Table 1: Sociodemographic profile

Variable	Total (%)
Mean age	53.68
Resident of	
Urban	9 (20)
Rural	36 (80)
Mean age at marriage	17.31
Age at first delivery	Mean age at first child-20.5 years
<18 years	0
18 years and above	45
Education	
Unable to read and write	39 (86.66)
Class 1-5	2 (4.44)
Class 6-10	-
High school	2 (4.44)
Graduate	2 (4.44)
Post graduate	-
Parity	
No child	2 (4.44)
1-2	4 (8.88)
3-5	33 (73.33)
6-8	6 (13.33)
9-10	0
Abortions	
None	35 (77.78)
1-2	5 (11.11)
2-4	5 (11.11)
4-6	0
Home deliveries	
Yes	35 (77.78)
No	10 (22.22)
Principal care giver	
Husband	36 (80)
Children	4 (8.89)
Grand children	5 (11.11)
None	0
Occupation	
Working	4 (8.88)
Homemaker	41 (91.11)
Involved in hard manual labour	
Yes	45
No	0

facility (24%); financial constraints (15%) ; and lack of family support (5%). In spite of long history of prolapse, around 33% had not even informed their family members (except husband). Regarding awareness of the causes of prolapse, approximately 51% thought that prolapse occurs as a result of hard manual work, 44% attributed it to their increased number of children and 5% considered it as a curse of God. Only 36% were aware of the fact that prolapse is treatable and rest considered it to be non-treatable [Table 2].

Table 3 depicts the impact of prolapse on daily activities. Bladder function and sexual function were the most affected ones.

As evident from Table 4, it is clear that prolapse also affects sexual life. Frequency was decreased in nearly 86.67% cases. Approximately 88% cases reported pain during intercourse.

Table 2: Reasons for delay in seeking medical help and awareness of causes of prolapse

Variable	Total (%)
Delay in seeking help due to	
Embarrassment	25 (56)
Lack of transportation	11 (24)
Financial constraints	7 (15)
Lack of family support	2 (5)
Informed family members other than husband	
Yes	30 (66.66)
No	15 (33.33)
Awareness of prolapse	
Caused by hard labour	23 (51)
Caused by increased number of deliveries	20 (44)
Considered it as curse	2 (5)
Prolapse is treatable	
Yes	16 (36)
No	29 (64)

Table 3: Impact of prolapse on daily life

Variable	Total (%)
Bladder function	
Urgency	23 (51.11)
Urge incontinence	23 (51.11)
Stress incontinence	17 (37.77)
Poor urinary stream	24 (53.33)
Straining to empty bladder	24 (53.33)
Bowel complaints	
Sense of incomplete evacuation	16 (35.55)
Needs to reduce it prior to defecation	14 (31.11)
Constipation	17 (37.77)
Physical limitations	
Unable to perform daily chores like cleaning	29 (64.44)
Unable to travel	14 (31.11)
Needed tampon while travelling	5 (11.11)
Emotional disturbances	
Feel depressed	35 (77.77)
Feel bad about oneself	38 (84.44)
Personal limitations	
Disturbed Relation with husband	24 (53.33)
Disturbed sexual life	39 (86.67)

Table 4: Impact on sexual function

Variable	Total (%)
Frequency decreased	39 (86.67)
Husband shows less interest in sex	39 (86.67)
Prolapse needs to be reduced prior to intercourse	35 (77.77)
Presence of pain during intercourse	40 (88.88)

Discussion

POP affects several aspects of a women's life. Despite being a common and treatable condition, a significant proportion of women still lack a clear understanding of this condition. In low resource settings, women are still dependent on their husband for financial and emotional help. In this study, women were mostly from hilly areas. 80% of the study group belonged to rural areas and approximately 87% were illiterate. They were the ones who were solely responsible for all household chores including childcare and even working in fields and lifting heavy weights on their back. All these works are an integral part of their life. Many of them continued all their work as long as they could. In fact, one of the study subjects continued with her prolapse for nearly 40 years and attended health facility only when her prolapse stated bleeding with a foul-smelling decubitus ulcer. Women usually informed their children only when their condition got worsened in terms of bleeding decubitus ulcer, foul smelling discharge, urinary complaints or difficulty in defecation.

Adefris *et al.* reported that the mean length of delay for POP was 85.8 months with financial constraints and fear of disclosure as the main reasons for delayed medical help.[10] There exists a social stigma with pelvic organ prolapse making women feel embarrassed. As a result, they tend to hide their problems from family and friends which further aggravates their problem. In this study, the length of delay in attending health facility ranged from 1-40 years which was very wide. In around 56% cases, it was the women herself who didn't seek early treatment, main concern being embarrassment. In a recent population-based study from rural Pakistan, it was noted that despite 50% women reporting that prolapse greatly affected their everyday routine activities, only 21.3% women consulted a doctor for their condition. Nearly 50% of their study cohort had a duration of POP for more than 5 years.[11]

Illiteracy and lack of awareness about prolapse is also a major concern as nearly 64% women in this study considered prolapse as non-treatable disease.

In terms of bowel function, previous studies have demonstrated that constipation, difficult defecation, and faecal incontinence occur commonly in women with Lower urinary tract syndromes.[12] In our study nearly 50% cases reported bladder problems. Sense of incomplete evacuation was seen in nearly 35% and constipation was reported by 37%.

Prolapse affected some patient's self-esteem negatively. Women perceptions about her own body changes with prolapse. Lowder

et al. reported that women with prolapse of stage 2 and above feels isolated and less attractive, often changed sexual intimacy practices or starts avoiding sexual intimacy altogether.[2] In fact, in this study, 84.44% revealed that they had started to feel bad about their body as a result of prolapse. This even resulted in their depressive and irritable mood. In fact, prolapse greatly affected women's personal activities like cleaning floor or doing other household chores resulting in loss of interest and distraction in daily activities and thereby making them self- conscious. Prolapse resulted in limitation of women to travel outside their house in nearly 30% cases and around 11% used tampons while travelling to avoid embarrassments.

Sexuality depends on several factors like body image, sexual perception, partner's desire and competency and quality of relationship with partner.[13] Pelvic organ prolapse is known to affect issues of sexuality in terms of desire, orgasm ability and arousal.[14,15] This study also focussed on sexual life of women with POP. Despite prolapse, women continued with their sexual function as long as they managed. This implies that prolapse per se was not responsible for sexual inactivity. Answers like – I used to push my uterus inside to have sex was quite common (77.77%). Reasons for stopping sexual activity were mainly- pain during intercourse (88%). Novi *et al.* reported that women with pelvic organ prolapse have a significant negative impact on sexual function as compared to those without prolapse uterus.[15]

Abhyankar *et al.*[16] in their qualitative study of women's experiences of receiving care for pelvic organ prolapse reported that prolapse treatment services need to be more person centric. Being a hidden disease, women usually ignore early symptoms and hence to break this barrier of embarrassment and stigma, there is a need for increasing education and awareness among general public and also health professionals regarding symptomatology and various treatment options (including conservative modes and pelvic floor muscle training). The goal of treatment for evaluating a woman with pelvic organ prolapse need to focus on her daily life for better understanding her concerns.

This study was limited by its small sample size and lack of any control group. A major strength of this study was that it included only symptomatic women with POP. Information regarding reasons for delayed medical consultation remains scare for women with prolapse and with this study, we also focussed on this aspect.

Conclusion-Fear of disclosure due to embarrassment and lack of transportation with distant health facility remains an important factor contributing to delay in seeking treatment for POP. Being a hidden disease, women often tend to ignore its symptoms. Prolapse is associated with varying degrees of bladder, bowel and sexual problems. There is high prevalence of problems related to bladder function and emotional disturbances in women with POP. Health care providers should take initiatives in educating women regarding prolapse and to make them aware that it is a treatable condition which can improve their quality of life. We suggest incorporating assessment of quality of life and sexual functioning as an integral part in treating women with advanced stage prolapse.

Key points

1. Symptomatic pelvic organ prolapse remains a common genitourinary condition affecting elderly females
2. Being a hidden disease and also due to lack of awareness and embarrassment, women often neglect their symptoms and seek help only when situation worsens
3. Prolapse affects her quality of life involving bladder, bowel and sexual function
4. We suggest a multidisciplinary team involvement in assessing QoL and sexual function be incorporated as an essential component of POP treatment.

Financial support and sponsorship

No funding was required for this study.

Conflicts of interest

There are no conflicts of interest.

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