Research Article

A qualitative study on the perceptions of patients with vesicovaginal fistula

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ABSTRACT

Background: Vesicovaginal fistula (VVF) is a grave complication of gynecological surgeries and vaginal deliveries, leading to physical, psychological, and social implications. In India, due to the high patient turnover, it is not uncommon to find such patients in every region. While various works elaborate the surgical aspect of VVF, there is a dearth of literature on qualitative research. **Objective:** This study was done to better understand the impact of physical, psychological, and social factors on the lives of patient with VVF. **Materials and Methods:** This study was conducted in the department of urology at a tertiary care hospital. It was a descriptive qualitative study that involved audio recorded in-depth interviews of 18 such patients followed by their transcription and qualitative data analysis. **Results:** We identified five major categories from the transcripts, namely, understanding of the disease, initial reaction of the patient, reaction of the husband and family, personal and physical discomfort, and social implications. While majority of the perceptions were also reported in the previous studies, we found some unique perceptions in the form of false perception of urine leak from urethra in spite of vagina and blaming, the birth of female child for bad luck was found in our study. Another favorable unique response not noted in other studies was excellent family support in half of the patients. **Conclusion:** Our study supports the idea that VVF has far deeper implications other than physical discomfort. This study promotes wholesome management of patients, family, and society using a multidisciplinary approach.

KEY WORDS: Vesicovaginal Fistula; Psychological; Perceptions; Qualitative Study

INTRODUCTION

Vesicovaginal fistula (VVF) is one the most common and most distressing complications of gynecological surgeries and vaginal deliveries. It has been a cause of social menace for women since centuries with the first recorded reference described in 1950 BC.[1] It has been known since ancient times with the first surgical repair described back in 1663.[2] It is estimated to affect more than 2 million women worldwide.[3] The incidence of VVF in developed countries is 0.3–2%; however, in developing and underdeveloped countries, its exact incidence is not known due to underreporting of cases.[4,5] In developed countries, iatrogenic injury during gynecological surgeries is the most common cause of VVF.[6] However, prolonged obstructed labor accounts for most of the cases of VVF in developing nations.[7] Hysterectomy has been the most common gynecologic surgery accounting for iatrogenic injury, leading to VVF.[8] Whereas early marriage leading to childbearing in immature pelvis, malnutrition and poor perinatal care standards are some of the reasons, leading to obstructed labor in developing countries.[2]

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VVF not only affects the patients physically but it also has grave psychosocial and financial consequences. Physical consequences such as continuous urinary incontinence, recurrent urinary tract infections, catheter-related problems, multiple surgical procedures, and damage to the reproductive organs have been described in the previous studies.[3,9] Loss

of the neonate, rejection from the family and society, lack of job opportunities, and lack of sexual activity lead to devastating psychosocial and financial consequences.[10] In Nigerian study, majority of the patients claimed to have lack of support, feeling of worthlessness, and feeling of them being a burden to society.[11]

VVF continues to be studied since more than four decades. However, these studies were majorly focused on its etiology and treatment. The psychological and social implications were given limited importance for the major part of these researches. Most of these patients end up losing their babies due to prolonged labor. In India, where motherhood is considered sacred, these patients are frequently socially stigmatized, leading to ominous psychological consequences. Furthermore, being a patriarchal society majorly, inability to perform household and religious work drives these women toward constant neglect from their husbands and family members. Since there is a lack of literature on these implications in Indian scenario, this study was performed with the objective of understanding the perceptions and difficulties faced by such patients.

In this study, we present an in-depth qualitative analysis of the perceptions of patients with VVF. Specifically, this study focuses on their psychological and social experiences. To the best of our knowledge, it is first such study in Indian population.

MATERIALS AND METHODS

The study was conducted in the urology department of a tertiary care center in Eastern India. It was a qualitative descriptive pattern study. It involved in-depth interviews (IDI) of 18 patients with VVF who were going through or have undergone treatment for VVF after taking informed consent.

All the IDIs were taken by the first author. Interviews were in depth and were pilot tested for getting basic structure of questionnaire. Based on it, a semi-structured interview guide with open-ended questions was prepared. Duration of the interviews was not fixed beforehand. IDIs were conducted in a private room according to convenience of participant and were conducted in front of a female attendant. Field notes were taken by the interviewer at the time of interview. A follow-up interview was planned if there was lack of clarity in responses after the interview. Audio recordings were done for all the IDIs. The descriptive content analysis was performed manually. At the first descriptive coding of the text information was done and categories were formed by merging similar codes together. The consolidated criteria for reporting qualitative research guidelines were followed in this study.

Before beginning of the study, approval was taken from the Institutional Ethical Committee of the relevant institute.

RESULTS

The age group of the participants in the study ranged from 20 to 60 years and duration of suffering from VVF was 3 months to 18 months. Eight of the women had a history of hysterectomy while 10 of them had a history of obstructed labor. All the patients were of poor economic strata. Twelve of them belonged to rural area and the rest belonged to urban area. Of all the patients, nine patients were illiterate, six had primary education, and only three of them had secondary education. Eight of the patients were employed previously in household jobs such as cooking and cleaning, while the rest were all homemakers. All the patients were comfortable with the local language. The duration of IDIs ranged from 19 min to 38 min.

The IDIs were started after detailed explanation of the whole procedure when the permission was asked to start, five of the patients were anxious and wanted to know whether they will be cured or not. Five of the patients were eager to tell about their problems with one of them saying "yes doctor, I am suffering a lot and I want to speak." After the analysis of the IDIs, five categories were identified, namely, understanding of the disease, initial reaction of the patient, reaction of the husband and family, personal and physical discomfort, and social implications.

Category-1 – Understanding of the Condition

When the patients were asked about the condition, three patients had absolutely no idea what they were suffering from with statements such as "I don't understand what is happening." Rest 15 patients complained that they have some urinary problem and there "urine doesn't seem to stop." When they were asked the origin of leak, 10 patients thought that urine leaks "from where they urinate." However, eight of them understood clearly that it leaks from the vagina. When they were asked about the reason behind this condition, 14 of them were well informed about the actual reason, i.e., iatrogenic injury in eight patients and obstructed labor in six patients. However, two of them blamed the delivering doctor and two of them believing that "god has punished them."

Category-2 – Initial Reaction of the Patient

When asked about their initial reaction or perception of the disease, five patients said that "they don't understand what was happening." Four patients were "embarrassed and tried to hide" the condition from their spouse. While nine of them were "depressed for the loss of the baby and felt helpless," seven of them were "furious" at the previous treating doctor.

Three patients of "scared of not being able to deliver in future," three were "scared of another surgery," and three of them were "scared of their family members" for undergoing a failed delivery or surgery. Three of them were "scared of not getting cured" and two of them felt that "god has punished them for their wrong deed in the past." Three of them were scared of getting divorced.

Category-3 – Reaction of the Husband and Family Members

When asked about their husband and family, half of the patients claimed that their husband and family are "very supportive" and want her to get cured as soon as possible, whereas two of them said that they were supportive initially and now seem to have lost interest due to long treatment duration. Two patients claimed that their husband was furious at the previous doctor. Two patients claimed that their "husband blames them for the loss of baby and will divorce and remarry" and three of them said that "husband blames her for not being able to have sexual intercourse." Six of them told that their "mother in law blames them for losing the baby." However, one of them said that the "mother in law blames the female baby for bringing bad luck to the family." Only one patient claimed that her child tries to stay away from her due to the bad odor she carries.

Category-4 – Personal and Physical Discomfort

When they were asked about their personal problems, 15 of the 18 patients were "frustrated due to the lack of sexual intercourse." All patients were "irritated of the leak, skin excoriation, and bad odor around them." While four patients were unhappy that they have to visit the toilet frequently, six of them were tired of using an extra cloth or diaper all the time. Four of the patients felt "devastated due to the catheter-related pain and recurrent infections." Four of them were "depressed due to the poor behavior of their family members." "Unable to do household work" and "religious work" were claimed by four of the patients. Three of them claimed that they were "unable to join their job" and seven of them were "worried about the financial burden" it is imposing on the family.

Category-5 – Social Implications

When they were asked about their social life, 13 of them were "embarrassed to go out and socialize." Five of them were "depressed because their family is ashamed of them" and do not want them to socialize. Five of them were unhappy because the "society tries to stigmatize them and that some people consider her disease communicable." Only three patients claimed to have "no effect on social life as the family members were very supportive." Furthermore, four of them claimed that people are not giving them work "because they feel they are unhygienic."

DISCUSSION

The patient characteristics in our study were consistent with the previous literature with the previous history of obstructed labor and hysterectomy being the most causes of VVF.[6,7] All the patients were of poor economic strata, majority of them were from rural area and were illiterate or had received only primary education. These findings correspond to the previous studies that concluded low status of women, poor education, and lack of state of art medical facilities predispose the patient to VVF.[12,13] Whereas when asked about the reason behind the condition, majority of the patients had idea about it, two of them blamed their previous doctor and two of them believed that god has punished them due to some wrong deed they have done. This finding was also consistent with the previous study.[14] The initial reactions of the patients', namely, embarrassment, depression of losing the baby, fear of the future, fear of divorce, fear of subsequent treatments, punishment by god, and anger against the previous treating doctor were all seen in our patients which were consistent with the previous studies.[15] Reactions such as husband blaming the patient for loss of baby, lack of sexual intercourse, threatening of divorce, and mother in law blaming for the loss of the baby were also seen which were not uncommon in the previous studies.[16] Findings about personal and physical discomfort were consistent with the previous studies such as nearly all the patients were irritated of continuous leak, bad odor, genital skin excoriation, and frustrated due to lack of sexual activity, tiresome frequent cloth change and toilet visits, recurrent catheter-related problems, and poor behavior by the family members.[17] Furthermore, problems with religious and household work, financial burden due to unemployment and treatment costs were not uncommon in literature.[9] The social implications in our study, namely, lack of social interaction due to low self-esteem, stigmatizing due to the perception of communicable disease in society, family members' not supporting social interaction due to embarrassment, and social avoidance due to bad odor were also consistent with literature.[9,18]

Our study, however, had some unique responses with respect to understanding of the condition. In our study, three of the patients had no idea about the disease and to our surprise 10 of 18 patients thought that the urine leaks from the urethra and not from vagina which was not noticed in previous such studies.[14,19] In our study, the reaction of husband and family members was also found unique as half of our patients claimed that to have very supportive husbands and family members which were not reported previously. Furthermore, blaming the female child for bringing bad luck in the family was one of the rare reactions found in Indian population, corresponding to high rate of female feticide in India.[20] Furthermore, some of our patients also claimed to have no effect on social life due to excellent family support which was not seen very often in literature.

One of our study's major strength is it being first of its kind in Indian population. It shelves deeper into the lives of women with VVF and helped us to understand some differences in psychological and social implications in Indian scenario in comparison to other countries. Small sample size can be considered as our primary limitation, although most of the qualitative researches are done with small sample size and reproducibility to larger population is a known advantage of such studies.

CONCLUSION

VVF continues to be caused of physical, psychological, and social discomfort. This study helps us to have deeper knowledge of the lives and perception of patients with VVF. It highlights the importance of psychological and social problems that a patient faces other than the physical discomforts and promotes the use of multidisciplinary approach toward the treatment of such patients. This study not only promotes provision of better health care and educational services for women, it also promotes the idea of family education, counseling, and overall knowledge transfer for the society to be included in the better management of patients with VVF. Furthermore, excellent family support as seen in half of our patients encourages the value of family support in such menacing conditions.

REFERENCES

1. Kumar S, Kekre NS, Gopalakrishnan G. Vesicovaginal fistula: An update. Indian J Urol 2007;23:187-91.
2. Margolis T, Mercer LJ. Vesicovaginal fistula. Obstet Gynecol Surv 1994;49:840-7.
3. Wall LL. Obstetric vesicovaginal fistula as an international public-health problem. Lancet 2006;368:1201-9.
4. Eilber KS, Kavaler E, Rodríguez LV, Rosenblum N, Raz S. Ten-year experience with transvaginal vesicovaginal fistula repair using tissue interposition. J Urol 2003;169:1033-6.
5. Cowgill KD, Bishop J, Norgaard AK, Rubens CE, Gravett MG. Obstetric fistula in low-resource countries: An under-valued and under-studied problem systematic review of its incidence, prevalence, and association with stillbirth. BMC Pregnancy Childbirth 2015;15:193.
6. Tancer M. Observations on prevention and management of vesicovaginal fistula after total hysterectomy. Obstet Gynecol Surv 1993;48:337.
7. Tahzib F. Epidemiological determinants of vesicovaginal fistulas. Br J Obstet Gynaecol 1983;90:387-91.
8. Armenakas NA, Pareek G, Fracchia JA. Iatrogenic bladder perforations: Longterm followup of 65 patients. J Am Coll Surg 2004;198:78-82.
9. Kabir M, Abubaker I, Umar U. Medico-social problems of patients with vesico-vaginal fistula in Murtala Mohammed specialist hospital, Kanno. Ann Afr Med 2004;2:54-7.
10. Ahmed S, Holtz SA. Social and economic consequences of obstetric fistula: Life changed forever? Int J Gynaecol Obstet 2007;99 Suppl 1:S10-5.
11. Nweke D, Igwe M, Uwakwe R. Psychiatric morbidity among subjects with vesicovaginal fistula in Abakaliki, South East Nigeria. Br J Med Med Res 2017;19:1-8.
12. Muleta M. Socio-demographic profile and obstetric experience of fistula patients managed at the Addis Ababa fistula hospital. Ethiop Med J 2004;42:9-16.
13. Walley LR, Kelly J, Matthews MK, Pilkington B. Obstetric fistula: A practical review. Rev Gynecol Pract 2004;4:73-81.
14. Gebresilase YT. A qualitative study of the experience of obstetric fistula survivors in Addis Ababa, Ethiopia. Int J Womens Health 2014;6:1033-43.
15. Khisa AM, Nyamongo IK. Still living with fistula: An exploratory study of the experience of women with obstetric fistula following corrective surgery in West Pokot, Kenya. Reprod Health Matters 2012;20:59-66.
16. Hollos M, Larsen U. Motherhood in Sub-Saharan Africa: The social consequences of infertility in an urban population in Northern Tanzania. Cult Health Sex 2008;10:159-73.
17. Browning A, Fentahun W, Goh JT. The impact of surgical treatment on the mental health of women with obstetric fistula. BJOG 2007;114:1439-41.
18. Tafesse B, Muleta M, Michael A, Aytenfesu H. Obstetric fistula and its physical, social and psychological dimension: The Ethiopian scenario. Acta Urol 2006;23:25-31.
19. Alio AP, Merrell L, Roxburgh K, Clayton HB, Marty PJ, Bomboka L, *et al.* The psychosocial impact of vesico-vaginal fistula in Niger. Arch Gynecol Obstet 2011;284:371-8.
20. Anupama S, Durge P. Female feticide in India: A social evil. J Obstet Gynaecol India 2010;60:503-6.

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