Women's Experiences of Rectovaginal Fistula: An Ethno- Religious Experience

Fatemeh Touhidi Nezhad
Kermanshah University of Medical Sciences
Rostam Jalali (ks_jalali@yahoo.com)
Kermanshah University of Medical Sciences https://orcid.org/0000-0003-1781-9939
Fozieh Karimi
Kermanshah University of Medical Sciences

Research article

Keywords: rectovaginal fistula; Phenomenology; qualitative study; lived experience

Posted Date: October 11th, 2019

DOI: https://doi.org/10.21203/rs.2.15932/v1

Version of Record: A version of this preprint was published on June 19th, 2020. See the published version at https://doi.org/10.1186/s12905-020-00992-w.

Abstract

Background: Obstetric fistulas are one of the most tragic injuries that occur after difficult, prolonged childbirth without timely intervention. These fistulas cause discomfort to patients and result in emotional, social, and even physical suffering. The aim of the present study was to explore the experiences of women with rectovaginal fistula in Kamyaran city, in Kurdestan province, west of Iran. Methods: In a phenomenological study, 16 patients, healthcare personnel and patients' families were investigated. Purposive sampling was performed and Study participants were interviewed in-depth semi-structured interviews. All interviews were audio-recorded, transcribed verbatim (word by word) and analyzed by Colaizzi's method. In order to determine the validity of the study, Lincoln and Guba's criteria, which include credibility, dependability, transferability, and confirmability, were considered. Results: Five general themes and ten sub-themes emerged after investigating interviews. Themes include religious harassment the sub-theme of being defiled), fail (subthemes of loss and negative attitudes, disrupted sex (the subtheme of sexual dissatisfaction), consequence (three subthemes of sleep disturbance, mental crisis, and isolation), and ultimately panic (three subthemes of humiliation, secrecy, and fear). Conclusion: The rectovaginal fistula is a complex and multifaceted problem with social, individual, familial, religious, and ethnic-environmental dimensions, so there is no simple solution to interact with this problem and there is a need to find a solution, considering the dimensions of the problem and plan for help these patients cope with their disease, and take steps to fully treat it.

Background

Maternal health refers to the health of mothers during pregnancy, childbirth and postpartum childbirth. Each mother who wishes to have a baby wants to have safe childbirth, care, and support during and after childbirth [1]. Obstetric fistulas are one of the most tragic injuries that occur after difficult, prolonged childbirth without timely intervention, and this fistula is a duct between the vagina and the bladder or rectum, which frequently causes urinary and fecal incontinence [2]. These fistulas can also be seen following sexual trauma, especially in the younger sex group [3]. Although eradicated in industrialized countries, this complication continues in low-income countries, affecting poor and vulnerable women [4]. The World Health Organization (WHO) estimates that 50,000 to 100,000 new cases of obstetric fistula occur each year and there are more than two million women with fistulas in sub-Saharan Africa and South Asia [5, 6]. These fistulas cause discomfort to patients and result in emotional, social, and even physical suffering [7-10]. In addition to such suffering, these patients are often rejected by their community and husbands and have poor health [10, 11], consequently, depression and psychological complications are the consequence of the disease [8, 10, 12], and the problems somewhat persist even with this complication is repaired [13, 14]. The obstetric fistulas have multiple effects as well as medical and psychosocial outcomes, and urinary and fecal incontinence makes it difficult to maintain proper health for individuals and to perform routine social and occupational activities [15]. Lack of awareness and knowledge of the cause and treatment of fistulas by family and community members may lead to misconceptions that may then expose these women to greater stress and stigma, making their overall

quality of life very poor and unbearable [4, 14, 16, 17]. Few studies have been conducted on the social consequences and structure of the society in which these women live; on the other hand, although there are large number of these patients in Iran, there has been no qualitative study determining these women's experiences, especially in areas of Kurdish culture. Therefore, the aim of the present study was to explore the experiences of women with rectovaginal fistula in Kamyaran city so that care decision makers support and manage these patients and make appropriate interventions by understanding the experiences of these patients.

Methods

The present study was conducted in the first 8 months of 2019. When the study was approved by Kermanshah University of Medical Sciences Ethics Committee, 16 patients, healthcare personnel and patients' families were investigate using descriptive phenomenology and the Colaizzi's method. This method allows the researcher to express the meaning and nature of phenomena in their own language and to explore their understanding of the phenomenon. In this approach, the perception of each person is considered as a unique person, but the sum of them contributes to achieve a better understanding of the phenomenon.

Participants

Purposive sampling was performed on 16 participants, including 14 patients, 1 midwife, and 1 family member (mother) in Kamyaran (western Iran). Study participants were coordinated for interviewing after obtaining written informed consent at their preferred location (often a clinic consultation room). Participants were known samples of rectovaginal fistula who referred to the clinic for follow-up treatment, were able to speak Persian or Kurdish Languages and completed the consent form. Sample size was determined based on data saturation criteria so sampling continued until data saturation and emergence of no new code [18]. The presence of a midwife, and a patient's family member were present to maximize variability among participants.

Data collection

Data were collected using in-depth semi-structured interviews. Before starting the interview, attempts were made to establish commination using general questions. Interviews were conducted in a quiet and private environment, with an average interview duration of 50 minutes. Participants’ permission over recording the interviews was obtained and they were assured that the interviews would remain confidential and won’t be used except for the purpose of the research and that the names and profile of the participants would remain confidential. Interviews focused on women's experiences of living with rectovaginal fistula and the following questions were asked:

What is your experience with living with rectovaginal fistula?

What is your understanding of living with rectovaginal fistula?

How others (family, community) reach to your illness)?

How do you cope with the rectovaginal fistula?

It should be noted that all patients spoke Kurdish.

Analysis

All interviews were audio-recorded, transcribed verbatim (word by word) and translated to English, where applicable. Pseudonyms were used to maintain anonymity. Data analysis was guided by that described by Colaizzi's method. Two researchers examined all transcripts for accuracy and completeness against the original notes before data was ready for coding. The researcher carefully studied and reviewed the first interview several times in order to understand and be informed of the participants' experiences, and then underlined meaningful words, phrases, and statements which were related to the discussed issue, and extracted important sentences or first codes. Then the meaning of each expression was explained. In other words, from each statement, a concept expressing an individual's meaning and attitude was extracted. After encoding, the concepts were carefully considered and sorted according to similarity. Subsequent interviews were also analyzed. The results were combined to reach a more comprehensive description of the phenomenon under study and more general categories were thus developed. The results were reviewed to obtain clear concepts and they, in addition to being abstract, were completely unambiguous in order for the readers to capture the concepts derived from the study [19]. Finally, to validate the findings, there was one face-to-face interview session with some participants being asked some questions about the results. When results were confirmed by the participants, the findings were verified.

In order to determine the validity of the study, Lincoln and Guba's criteria, which include credibility, dependability, transferability, and confirmability, were considered [20]. To this end, this study focused on long-term engagement, continuous observations, the control of the codes and categories by experts, a diverse sampling in terms of age and cultural background, and the accurate reporting of details and study steps. The codes and interviews were submitted to and confirmed by qualified experts in this field. Furthermore, the participants were used to confirm the accuracy of the interpretation of the data.

Ethical considerations

This study was approved by the Ethics Committee of Kermanshah University of Medical Sciences (IR.KUMS.REC.1398.514). After explaining the research objectives and procedures, informed consent forms were completed and signed by the participants. Participants were assured of complete confidentiality of all their information. The location and time of the interviews were set by the participants. The principles of "no-harm," in which the research should not be detrimental to the participant and "confidentiality" were followed.

Results

A total of 14 patients with rectovaginal fistula participated in the study and the mother of one patient and one treatment staff (master of obstetrics) were interviewed to ensure maximum variability. Most participants had low educational level and all were housewives. The most important cause was difficult childbirth and sex (Table 1).

Table 1: demographic characteristic of participants

Participant no	Marriage	Job	Education level	Age	Cause of fistula	Number of children
1	Married	Housewife	Secondary	24	First sexual intercourse	0
2	Married	Housewife	Primary	41	prolonged labor	3
3	Married	Housewife	Primary	28	prolonged labor	2
4	Married	Housewife	Illiterate	71	History of colon surgery	9
5	Married	Housewife	Illiterate	48	History of hysterectomy	4
6	Married	Housewife	Primary	27	First sexual intercourse	2
7	Married	Housewife	Secondary	39	History of colon surgery	3
8	Married	Housewife	Secondary	19	First sexual intercourse	1
9	Married	Housewife	Secondary	28	prolonged labor	2
10	Married	Housewife	Primary	35	prolonged labor	1
11	Married	Housewife	Secondary	40	prolonged labor	2
12	Married	Housewife	Secondary	38	First sexual intercourse	3
13	Married	Housewife	Primary	27	prolonged labor	1
14	Separated	Housewife	Secondary	29	First sexual intercourse	2

Five general themes and ten sub-themes emerged after investigating interviews (Table 2).

Table 2: Concepts and categories extracted from the experiences of women with rectovaginal fistula

Themes	Sub-themes	Codes
Religious harassment	being defiled	Fear of invalidating ablution
		Fear of invalidating prayer
		Fear of not praying
		Fear of defiling the mosque
Fail	Loss	Not pleasant
		To be destroyed
		Being terrible
	Negative attitude	Feel the change of life
		No hope for recovery
		Distrust of the doctor
Disrupted sex	Sexual dissatisfaction	Decrease sex frequency
		Escaping sex
		Making excuses for not having sex
		Having stress during sex
Consequences	Sleep disorder	Sleeping late
		No having deep sleep
	Mental crisis	Fatigue
		Getting angry
		Having pressure
		Being bored
		Feeling bad
	Isolation	Having an impact on the family
		Instability in life
		Escaping parties
		Decreased communication
		Fear of being in the public
Panic	Humiliation	To be ridiculed
		Feeling embarrassed
	Secrecy	Hiding the problem
		Fear of raising the problem
		Hard to explain the problem
	Fear	Always worried
		Fear of eating enough food
		Fear of disgrace
		Always thinking of being in trouble
		Permanent fear of bad smell

Themes include religious harassment (the sub-theme of being defiled), fail (subthemes of loss and negative attitudes, disrupted sex (the subtheme of sexual dissatisfaction), consequence (three subthemes of sleep disturbance, mental crisis, and isolation), and ultimately panic (three subthemes of humiliation, secrecy, and fear).

One of the main themes was the religious harassment theme. Study participants had difficulty performing their religious duties due to their illness, so they blamed themselves religiously and were not prepared to perform religious activities.

"... Only since I have no control over my urine, defecation and gas, my Wuzoo doesn't remain intact for a long time. While I'm praying, I'm always afraid that it breaks my prayer...." (Participant 3).

Or they were afraid of polluting religious sites. "I do not go to the mosque because I am afraid to defile the mosque" (participant 11).

Another important theme was fail, which included two sub-themes of loss and negative attitude. Study participants often regarded the illness as the loss of everything and saw the future as bleak.

In this regard, one participant said, "To be honest, the disease destroyed my life... let alone lacking control over your urine, defecation and gas" (Participant 2).

"It's very bad to be suffering from the filthiest thing. I myself am very angry in front of my eyes woe betide others and I pray that it will be treated "(Participant 13).

Some participants also regarded the disease as an unpleasant experience and were sometimes desperate. "I have nothing to say but well everything to me was contrary to my dreams and wishes up to this point. Only the first few years of my life were good and financial problems would not allow me to touch happiness at that time, but I wish people did not have all the pain at the same time" (Participant 5).

Another main theme of this study was disrupted sex. Participants were sometimes dissatisfied with their sex, and sometimes escaping it.

"Well, the relationship is a two-way thing and I must be content with it, but (he) always does its job and doesn't care about anything" (Participant 7).

"Both my husband and myself hate sex" (Participant 9).

"In the early course of the disease, as soon as my husband suggested me to have sex, I said that I'm on my period, and have spotting, then I had a fight with him without planning. Now I have no sex with him once a month" (Participant 14).

Another main theme referred to by participants was panic and fear. Constant humiliation, secrecy, and fear are part of their lives. They always think no to be humiliated and ridiculed and their name dragged through the mud because of the current situation.

"But my husband mocked me for expelling gas during sleeping a couple of times" (Participant 1).

"I'm so embarrassed to fart, especially my children are boys" (Participant 6).

"What can I say to my family, it's hard for me to explain a bit" (Participant 4).

"I'm not always worried that my daughter or my son will notice this" (Participant 2).

Another main theme of this study was the consequence. The consequence of this complication for patients in this study was isolation, sleep disturbances, and mental crises. Patients often fall asleep later than others, lest they expel gas at bedtime, in addition to being a light sleeper so that I can manage defecation if it happens. The consequences of the disease often made them nervous and were in a state of mental crisis. On the other hand, these patients have cut family relationships and have often been isolated.

"At night, I always let my husband sleep, then I sleep, and I sleep after making sure he has slept" (Participant 1).

"I try to control as far as I can, but I'm not satisfied. I'm tired of every single second of my life." (Participant 12).

"I especially have to stay in the bathroom for a long time and get angry" (Participant 7).

"And I always try to squeeze my legs if I'm standing next to somebody. It is interesting that the pressure continues until it's expelled." (Participant 4).

"I reached the stage between hope and hopelessness" (Participant 1).

"It has a big impact on my commuting. I used to go to the village for a week and stayed at my mom's house, but I don't want to go now and I feel like I’m in touch less frequently " (Participant 10).

“But I'm scared to be in the public and that fear has caused me living in a small family facing some difficulty in daily commute" (Participant 8).

Discussion

The results showed that the study participants were religiously harassed, are always in a state of fear and anxiety, and in addition to suffering from disrupted sexual health, reached a stage of despair and helplessness, and the disease consequences led them to isolation and mental crisis. Similar studies in different cultures have had similar narratives.

Religious harassment was caused by disease interfering with the practice of religion, and in fact, unlike the Boscaglia’s study, which regarded religion and spirituality as a solution to women's disease management [21], the disease was a barrier to religious practices and caused suffering in them. In other studies, the disease has sometimes been regarded as a punishment by God [22]. In contrast, some studies have viewed religion as a way of coping with diseases and have identified lack of coping as a sign of depression and cognitive impairment [23, 24]. It seems that relying on religion for disease management, as well as interfering with religious practices can have positive and negative consequences; however, overall religion’s benefits are greater and can be used for disease management.

Sexual dysfunction in patients with fistula is a major concern and has been discussed in various studies, although the present study emphasized sexual dissatisfaction, pointed to escaping sex and having stress during intercourse. In another study, escaping sex is called fear of the future lacking a partner, not getting married, and not getting pregnant were among concerns of the patients [11]. Lack of close contact with the husband has been cited as a serious and painful problem [25], and efforts to maintain family and marital relationships have been regarded as important issue in systematic review and qualitative metasynthesis [26]. Women are concerned of the fact that their husband sees them defecating during sexual intercourse [15], which even leads to the fear of divorce and remarriage by the husband [27].

Patients with fistulas often think that their lives have come to an end and regard it as failure. Having a negative attitude and feeling worthless bother them. The combination of constant presence of problem and loss of role leads to feelings of worthlessness [28], and women lose self-confidence [15], and the combination of these negative attitudes, physical symptoms, and the reactions of relatives result in these consequences in these patients. These consequences manifest in the form of mental crises, sleep disturbances and social isolation. All consequences, except for sleep disorders, have been also expressed in similar studies such as sadness, depression, and social isolation [11, 25, 28].

Patients were in constant fear, and none of the patients in the present study disclosed their disease to non-family members, and found it necessary to keep it a secret, which has been confirmed by various studies. This has led to psychological consequences in these patients [11, 15, 25, 26, 28, 29].

Conclusion

The rectovaginal fistula is a complex and multifaceted problem with social, individual, familial, religious, and ethnic-environmental dimensions, so there is no simple solution to interact with this problem and there is a need to find a solution, considering the dimensions of the problem and plan for help these patients cope with their disease, and take steps to fully treat it. Moreover, we should pay attention to risk factor of this disorder and prevent early marriage while improving health facilities to prevent problems.

Abbreviations

WHO: World Health Organization

Declarations

Acknowledgements

We are grateful to the Student's Research Committee, Kermanshah University of Medical Sciences which supported us in this research.

Funding

Student's Research Committee, Kermanshah University of Medical Sciences, grant no 980478.

Availability of data and materials

Datasets are available through the corresponding author upon reasonable request.

Authors'contributions

RJ contributed to the design, Ft statistical analysis, participated in most of the study steps. RJ and FK prepared the manuscript.. All authors have read and approved the content of the manuscript

Ethics approval and consent to participate

This study conducted by the Student's Research Committee, Kermanshah University of Medical Sciences, grant no 980478. Identity letter obtained from deputy of research and technology to collecting data. This research approved by ethics committee of deputy of research and technology – IR.KUMS.REC.1398.514.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no conflict of interest.

References

1. Sandall J, Hatem M, Devane D, Soltani H, Gates S: Discussions of findings from a Cochrane review of midwife-led versus other models of care for childbearing women: continuity, normality and safety. *Midwifery* 2009, 25(1):8-13.
2. De Bernis L: Obstetric fistula: guiding principles for clinical management and programme development, a new WHO guideline. *International Journal of Gynecology & Obstetrics* 2007, 99:S117-S121.
3. Grossin C, Sibille I, de la Grandmaison GL, Banasr A, Brion F, Durigon M: Analysis of 418 cases of sexual assault. *Forensic science international* 2003, 131(2-3):125-130.
4. Wall LL: Obstetric vesicovaginal fistula as an international public-health problem. *The Lancet* 2006, 368(9542):1201-1209.
5. Mselle LT, Kohi TW: Healthcare access and quality of birth care: narratives of women living with obstetric fistula in rural Tanzania. *Reprod Health* 2016, 13(1):87.
6. Betrán AP, Torloni MR, Zhang J-J, Gülmezoglu A, Section WWGoC, Aleem H, Althabe F, Bergholt T, de Bernis L, Carroli G: WHO statement on caesarean section rates. *BJOG: An International Journal of*

Obstetrics & Gynaecology 2016, 123(5):667-670.

7. Donnelly K, Oliveras E, Tilahun Y, Belachew M, Asnake M: Quality of life of Ethiopian women after fistula repair: implications on rehabilitation and social reintegration policy and programming. *Culture, health & sexuality* 2015, 17(2):150-164.
8. Muleta M, Hamlin EC, Fantahun M, Kennedy RC, Tafesse B: Health and social problems encountered by treated and untreated obstetric fistula patients in rural Ethiopia. *Journal of obstetrics and gynaecology Canada : JOGC = Journal d'obstetrique et gynecologie du Canada : JOGC* 2008, 30(1):44-50.
9. Turan JM, Johnson K, Polan ML: Experiences of women seeking medical care for obstetric fistula in Eritrea: implications for prevention, treatment, and social reintegration. *Glob Public Health* 2007, 2(1):64-77.
10. Weston K, Mutiso S, Mwangi JW, Qureshi Z, Beard J, Venkat P: Depression among women with obstetric fistula in Kenya. *International Journal of Gynecology & Obstetrics* 2011, 115(1):31-33.
11. Gebresilase YT: A qualitative study of the experience of obstetric fistula survivors in Addis Ababa, Ethiopia. *International journal of women's health* 2014, 6:1033.
12. Muleta M, Rasmussen S, Kiserud T: Obstetric fistula in 14,928 Ethiopian women. *Acta obstetricia et gynecologica Scandinavica* 2010, 89(7):945-951.
13. Wilson SM, Sikkema KJ, Watt MH, Masenga GG, Mosha MV: Psychological symptoms and social functioning following repair of obstetric fistula in a low-income setting. *Maternal and child health journal* 2016, 20(5):941-945.
14. Yeakey MP, Chipeta E, Rijken Y, Taulo F, Tsui AO: Experiences with fistula repair surgery among women and families in Malawi. *Glob Public Health* 2011, 6(2):153-167.
15. Changole J, Thorsen VC, Kafulafula U: "I am a person but I am not a person": experiences of women living with obstetric fistula in the central region of Malawi. *BMC Pregnancy Childbirth* 2017, 17(1):433.
16. Adler A, Ronsmans C, Calvert C, Filippi V: Estimating the prevalence of obstetric fistula: a systematic review and meta-analysis. *BMC pregnancy and childbirth* 2013, 13(1):246.
17. Ahmed S, Holtz S: Social and economic consequences of obstetric fistula: life changed forever? *International Journal of Gynecology & Obstetrics* 2007, 99:S10-S15.
18. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K: Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and policy in mental health and mental health services research* 2015, 42(5):533-544.
19. Morrow R, Rodriguez A, King N: Colaizzi's descriptive phenomenological method. *The psychologist* 2015, 28(8):643-644.
20. Polit DF, Beck CT: Essentials of Nursing Research: Appraising Evidence for Nursing Practice: Lippincott Williams & Wilkins; 2013.

21. Boscaglia N, Clarke DM, Jobling TW, Quinn MA: The contribution of spirituality and spiritual coping to anxiety and depression in women with a recent diagnosis of gynecological cancer. *International journal of gynecological cancer : official journal of the International Gynecological Cancer Society* 2005, 15(5):755-761.
22. Ano GG, Vasconcelles EB: Religious coping and psychological adjustment to stress: a meta-analysis. *Journal of clinical psychology* 2005, 61(4):461-480.
23. Steglitz J, Ng R, Mosha JS, Kershaw T: Divinity and distress: the impact of religion and spirituality on the mental health of HIV-positive adults in Tanzania. *AIDS and behavior* 2012, 16(8):2392-2398.
24. Watt MH, Wilson SM, Joseph M, Masenga G, MacFarlane JC, Oneko O, Sikkema KJ: Religious coping among women with obstetric fistula in Tanzania. *Glob Public Health* 2014, 9(5):516-527.
25. Mselle LT, Kohi TW: Living with constant leaking of urine and odour: thematic analysis of socio-cultural experiences of women affected by obstetric fistula in rural Tanzania. *BMC women's health* 2015, 15:107.
26. Bashah DT, Worku AG, Mengistu MY: Consequences of obstetric fistula in sub Sahara African countries, from patients' perspective: a systematic review of qualitative studies. *BMC women's health* 2018, 18(1):106.
27. Nweke DN, MN. I: Psychosocial experiences of subjects with vesicovaginal fistula: A qualitative study. *Global Journal of Medicine and Public Health* 2017, 6(1):1-8.
28. Khisa W, Wakasiaka S, McGowan L, Campbell M, Lavender T: Understanding the lived experience of women before and after fistula repair: a qualitative study in Kenya. *BJOG : an international journal of obstetrics and gynaecology* 2017, 124(3):503-510.
29. Lavender T, Wakasiaka S, McGowan L, Moraa M, Omari J, Khisa W: Secrecy inhibits support: A grounded theory of community perspectives of women suffering from obstetric fistula, in Kenya. *Midwifery* 2016, 42:54-60.