

Original Research Article

Association of socio-demographic and obstetric factors with obstetric fistula patients' perceptions towards life fulfillment in Kitovu Hospital, Uganda

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ABSTRACT

Background: To date, obstetric fistula is one of the major public health challenges among the poorest, young women and girls in rural communities in low and middle-income countries. There is scarce information on the association of socio-demographic and obstetric factors with the obstetric fistula patients' perceptions towards life fulfillment which compelled this study.

Methods: A cross-sectional survey using a semi-structured questionnaire was done among 390 obstetric fistula patients registered within the past two years to the time of data collection at Kitovu Hospital, Masaka, Uganda. Pearson's Chi square correlation was used to determine the association of socio-demographic and obstetric factors with perceptions towards life fulfillment using SPSS 25.0.

Results: A larger proportion of obstetric fistula patients 226 (57.9%) had negative perceptions while 164 (42.1%) had positive perceptions. Maternal age, repair status, outcome of repair, self-perceived level of incontinence, and number of living children were statistically associated with patients' perceptions towards life fulfillment at a P-value less than 0.001, marital status, p value of 0.005, and overall duration lived with fistula, p value of 0.009. A greater number of patients with tertiary education, 5 (83.3%) had positive perception, however, the association was not significant with a p value of 0.059. Fistula type, region of residence, and number of repairs were not statistically significant.

Conclusions: Thus, socio-demographic and obstetric factors influence patients' perceptions towards life a great deal. Efforts should focus on fistula prevention and timely repair so as to minimize probable experiences likely to result in negative perception that would eventually impede life fulfillment.

Keywords: Beliefs, Fulfillment, Maternal health, Obstetric fistula, Perceptions, Social reintegration

INTRODUCTION

Up till now, obstetric fistula is a public health challenge among the poorest, young women and girls in rural communities in low and middle-income countries.^{1,2} It results from prolonged obstructed labor when the fetal parts exert excessive pressure against soft tissues of the

vagina resulting in ischemia and eventual necrosis of these tissues hence a fistula. A created fistula allows uncontrollable leakage of urine or fecal material or both through the vagina.^{3,4} These are accompanied by offensive odors thus women with the condition are socially ostracized and abandoned. They suffer shame, humiliation, loss of dignity and hope.^{1,5,6} They also suffer

comorbidities such as reproductive organ damage, kidney disorders, infections, amenorrhea, neurological disorders and secondary infertility.⁷ Unfortunately these are marginalized women whose voices and grievances are unheard by anybody except silence which knows the degree of their pain.⁵

The repair of fistula is life renewing, restores joy, hope and dignity.^{3,8} It is largely possible with up to 90% success rate especially for uncomplicated fistula. Nonetheless, the backlog is very high.¹ Globally, about 2 to 3.5 million women of reproductive age are living with fistula and almost all of them live in Sub-Saharan Africa and South Asia.⁹ Uganda has one of the highest obstetric fistula prevalence of 2 percent with an annual incidence rate of 1900 women.⁵ A larger proportion of these patients is young, very poor, illiterate and economically incapacitated. Due to such characteristics, they are not able to seek timely medical care during child labor, secondly, they delay to seek treatment having developed obstetric fistula. A report by WHO in 2019 on the international day to end obstetric fistula, highlighted a fistula patient who had spent twenty-two years with untreated fistula and this limited her mobility, and productivity.⁵

Women with fistula are blamed by society and treated as outcasts. Others are kept in the backyard in small huts built specially for them. Cultural beliefs, perceptions and myths surround the cause of obstetric fistula. Studies mention of witchcraft, curses, and misfortunes as the perceived causes of fistula.^{2,10} A participant in a study done in Uganda in 2019 stated that she was despised by her in-laws who blamed her for extending her curse to their family.³ In another study in Malawi, findings indicated that a patient perceived the cause of obstetric fistula as either witchcraft or the devil at work. She attributed to her condition to her husband who was unfaithful during the period she was pregnant. Several other participants in the same study had similar views. Another one believed it was magical powers.¹⁰

Considering these beliefs and anticipated stigma, patients tend to give up on social life in fear of embarrassment. Besides, stress incontinence is also common among successfully repaired patients.¹¹ Thus, they avoid social gatherings and are generally dissatisfied. They live in fear of involuntary disclosure, and do everything possible to hide the condition. Their routines are changed and their normal life trends are affected.¹⁰ Therefore, their life fulfillment remains a dream as they are considered social misfits. Some give up on marriage and if they did, they would not want their new partners to know of their past experiences. They would even want to relocate and start life a fresh.¹² Patients report loss of sexual desire, feeling of worthlessness and inferiority complex. They develop negative perceptions towards life as a reaction towards the reactions of their close relatives and friends.¹⁰ However, those whose are not abandoned and are

supported by family, friends and spouses show positivity and endure the life shattering experience.¹²

Given such perceptions, the study found it significant to determine the association of the socio-demographic and obstetric factors with the obstetric fistula patients' perceptions towards life fulfillment. Although the repair of fistula has great positive outcomes but, life fulfillment or satisfaction among obstetric fistula patients is inadequate.^{3,13} Life fulfillment in this case refers to the assessment of feelings and attitudes towards life. The extent to which the patients or people evaluate their overall quality of life is paramount. Life fulfillment also known as life satisfaction is much broader, stable and long lived than happiness. It is a feeling about life and how pleased one is with what is going on. The factors contributing to life fulfillment include the work conditions, relationship dynamics, support systems, personal development, and overall wellbeing.¹⁴ As such, it was sought important to determine the association of the socio-demographic characteristics and obstetric factors with the perceptions towards life fulfillment among the obstetric fistula patients at Kitovu Hospital, in Uganda. The procedure taken to achieve this objective follows.

METHODS

Study design

It was a cross-sectional descriptive survey using quantitative research methods; a semi-structured questionnaire to collect and analyze data.

Study setting

The study was conducted in Uganda being the third globally as far as obstetric fistula prevalence is concerned. Kitovu Hospital was selected for this study being a fistula repair center with the highest repair rates in the country.¹⁵

Study participants

The study participants included only obstetric fistula patients who attended the fistula camps between January 2019 and September 2019.

Sample size

Sample was determined using sample size calculation for cross-sectional studies:

$$N = \frac{Z_{1-\alpha/2}^2}{d^2} pq$$

Where, 'N' is the desired sample size, 'Z'; is the standard normal deviation at 95% confidence level which is equals to 1.96, 'p' is the proportion in the target population estimated to have characteristics being measured. According to the University College Dublin, (2018), Kitovu Hospital about 885 patients annually, yet the entire country repairs about 2560.^{15,16} Therefore, Kitovu

Hospital repairs about $(885/2560) \times 100 = 34.57\%$ which is approximately $35\% = 0.35$ of the total repairs done across the country. 'P' is 0.35, but, $q = 1 - p = 1 - 0.35 = 0.65$, 'd' is the level of statistical significance set which is equal to 0.05. Therefore sample size,

$$n = \frac{1.96^2 \times 0.35 \times 0.65}{0.05^2} = 349$$

i.e., sample size is 349 participants.

An additional 57 participants who had taken part in the pretest of the tool were included making an overall sample size of 406. However, none response rate was 4% which reduced the number of participants to 390. Among these, 192 had had fistula repair and 198 had not yet had fistula repair.

Inclusion and exclusion criteria

All obstetric fistula patients who had been registered by Kitovu Hospital within a period of two years before the time of data collection had an equal opportunity of being selected despite their repair status. Patients whose fistulas were earlier repaired were excluded. Also, only those who consented to participate were included.

Data collection tools

A semi-structured questionnaire was used to measure patients' socio-demographic and obstetric factors and their perceptions towards life. The socio-demographic characteristics were measured using a Molassiotis, (2013)'s tool which was modified to match this study.¹⁷ The socio-demographic characteristics included: age which was categorized into ≤ 18 years old, 19-29 years old, 30-39 years old, 40-49 years old, 50 years and older, levels of education which were categorized as primary and below, secondary, and tertiary, marital status which was measured as single, married, separated/divorced, and widowed, and region of residence which was categorized as northern, eastern, western, and central. The obstetric factors were measured by a modified El Ayadi, et al post fistula repair reintegration instrument.¹⁸ The variables of interest included: type of fistula which was categorized as vesico vaginal fistula, recto vaginal fistula, and complex fistula, repair status categorized as repaired, and unrepaired, duration lived with fistula categorized as less than a year, one- three years, four- six years, seven or more years, outcome of repair categorized as successful and unsuccessful, patient perceived level of incontinence which was categorized as severe, moderate, and mild, number of times the fistula had been repaired categorized as once, twice, thrice, four or more time, duration before initial repair categorized as less than a year, one to two years, three to four years, and five or more years, time after repair to data collection categorized as < 6 months, 6 to 12 months, 13 to 18 months, and 19 to 24 months, the number of children alive measured as nil, one to two, three to four, and five or more. The patients' perceptions

towards life fulfillment were measured as good (positive) or bad (negative) based on Menec, (1999)'s scale which was modified.¹⁹

Reliability and validity of the tools

The tool was pretested at Kitovu Hospital, Masaka, Uganda during the January, 2019 camp session among 30 unrepaired and 27 repaired obstetric fistula patients. The tools were edited. Research assistants were trained and the questionnaire translated into Luganda and Kiswahili languages.

Ethical consideration

Ethical approval was sought and obtained from the National Council for Science and Technology, Uganda under IRB number HS361ES.

Data management and analysis

The responses to the semi-structured questionnaire were entered, coded, cleaned and analyzed using a Special Package for Social Scientists (SPSS) 25.0, a computer software for analyzing quantitative data. Missing data was excluded during data entry. Pearson's Chi square correlation was used to determine the association of socio-demographic and obstetric factors with perceptions towards life fulfillment among obstetric fistula patients in Kitovu Hospital, Uganda.

RESULTS

Association of sociodemographic and obstetric factors with the obstetric fistula patients' perception towards life fulfilment

The sample for the pilot study was combined with the sample size for the actual study making it 390 participants. In reference to Table 1, findings indicate that age, marital status, repair status, the duration lived with fistula, outcome of repair, and severity of incontinence had a significant effect on the obstetric fistula patients' overall perception towards their life fulfillment. For example, a larger proportion of the obstetric fistula patients who were eighteen years of age and below and those above thirty years of age had negative perceptions towards life compared to those who were nineteen years to twenty nine years of age among whom 50.3% had positive perception while 49.7% had negative perception towards life. Age was statistically associated with patients perception at χ^2 value of 21.02 and p value of < 0.001 .

For the marital status, 52.1% of those that were married had positive perceptions while 47.9% of the married patients had negative perceptions about life. Unlike the separated and divorced group where 111 (62.4%) of them had negative perceptions and about 67 (37.6%) had positive perceptions with χ^2 value of 12.780 and a p value of 0.005.

Table 1: Obstetric fistula patients' perceptions of their overall life fulfillment.

Variables	Positive N (%)	Negative N (%)	Total	χ^2	P value
Age (years)					
≤18	28 (48.3)	30 (51.7)	58	21.02	<0.001
19-29	92 (50.3)	91 (49.7)	183		
30-39	26 (37.7)	43 (62.3)	69		
40-49	13 (31.0)	29 (69.0)	42		
>50	5 (13.5)	32 (86.5)	37		
Total	164 (42.2)	225 (57.8)	389		
Level of education					
Primary and below	134 (40.2)	199 (59.8)	333	5.661	0.059
Secondary	25 (49.0)	26 (51.0)	51		
Tertiary	5 (83.3)	1 (16.7)	6		
Total	164 (42.1)	226 (57.9)	390		
Marital status					
Single	34 (43.6)	44 (56.4)	78	12.780	0.005
Married	61 (52.1)	56 (47.9)	117		
Separated/divorced	67 (37.6)	111 (62.4)	178		
Widowed	2 (11.8)	15 (88.2)	17		
Total	164 (42.1)	226 (57.9)	390		
Type of fistula					
Vesicovaginal fistula	146 (43.8)	187 (56.2)	333	3.391	0.184
Rectovaginal fistula	10 (35.7)	18 (64.3)	28		
Complex fistula	8 (27.6)	21 (72.4)	29		
Total	164 (42.1)	226 (57.9)	390		
Region					
Central	88 (42.9)	117 (57.1)	205	3.453	0.327
Eastern	30 (35.3)	55(64.7)	85		
Northern	21 (52.5)	19 (47.5)	40		
Western	25 (41.7)	35 (58.3)	60		
Total	164 (42.1)	226 (57.9)	390		
Repair status					
Repaired	136 (70.8)	56 (29.2)	192	128.564	<0.001
Unrepaired	28 (14.1)	170 (85.9)	198		
Total	164 (42.1)	226 (57.9)	390		
Duration lived with fistula (years)					
<1	58 (52.3)	53 (47.7)	111	11.528	0.009
1-3	45 (46.9)	51 (53.1)	96		
4-6	27 (35.1)	50 (64.9)	77		
>7	34 (32.1)	72 (67.9)	106		
Total	164 (42.1)	226 (57.9)	390		
Outcome of repair if ever repaired					
Successful	131 (82.9)	27 (17.1)	158	63.001	<0.001
Unsuccessful	5 (14.7)	29 (85.3)	34		
Total	136 (136)	56 (29.2)	192		
Level of incontinence					
Severe	10 (7.5)	124 (92.5)	134	42.174	<0.001
Moderate	7 (10.8)	58 (89.2)	65		
Mild	17 (51.5)	16 (48.5)	33		
Total	34 (14.7)	198 (85.3)	232		
How many times have undergone obstetric fistula repair?					
Once	98 (73.7)	35 (26.3)	133	2.180	0.536
Twice	24 (61.5)	15 (38.5)	39		
Thrice	12 (70.6)	5 (29.4)	17		
Four or more times	2 (66.7)	1 (33.3)	3		
Total	136 (70.8)	56 (29.2)	192		

Continued.

Variables	Positive N (%)	Negative N (%)	Total	χ^2	P value
Duration lived with fistula before initial repair (years)					
<1	54 (80.6)	13 (19.4)	67	7.180	0.066
1-2	38 (73.1)	14 (26.9)	52		
3-4	19 (59.4)	13 (40.6)	32		
≥ 5	25 (61.0)	16 (39.0)	41		
Total	136 (70.8)	56 (29.2)	192		
Duration after repair to the time of data collection (months)					
<6	76 (64.4)	42 (35.6)	118	6.413	0.093
6-12	29 (78.4)	8 (21.6)	37		
13-18	14 (82.4)	3 (17.6)	17		
19-24	17 (85.0)	3 (15.0)	20		
Total	136 (70.8)	56 (29.2)	192		
How many of your children are alive?					
Nil	31 (32.6)	64 (67.4)	95	20.565	<0.001
One-two	90 (53.9)	77 (46.1)	167		
Three-four	18 (43.9)	23 (56.1)	41		
Five or more	23 (27.4)	61 (72.6)	84		
Total	162 (41.9)	225 (58.1)	387		

Also, about 86% of the patients whose fistula had not yet been repaired had negative perceptions about life while about 71% of the repaired group were positive and hopeful with χ^2 value of 128.564 and a p value of less 0.001.

The overall duration lived with fistula equally had a significant effect on the patients' perceptions towards life with χ^2 value of 11.528 and a p value of 0.009. A large number of patients who had lived with fistula for less than a year; 58 (52.3%) exhibited positivity and hope while 53 (47.7%) were negative about life. More of those who lived with fistula for more than one year generally had negative perceptions about life. For example, among the patients who lived with fistula for one to three years, 51 (53.1%) had negative perceptions while 45 (46.9%) had positive perceptions. Among those who lived with fistula for four to six years, 50 (64.9%) had negative perceptions, while 27 (35.1%) had positive perceptions. A similar trend was observed among those who had lived with fistula for seven and more years, among whom 72 (67.9%) had negative perceptions while 34 (32.1%) had positive perceptions. A direct relationship was observed across the overall duration lived with fistula and the perceptions of the patients. The longer the duration lived with fistula, the higher the possibility of negative perceptions towards life fulfillment.

The outcome of repair was statistically significant with χ^2 value of 63.001 and a p value of <0.001. Among the patients who had had successful repair, 131 (82.9%) had positive perceptions while 27 (17.1%) had negative perceptions. Only 5 (14.7%) of the patients who had had unsuccessful repair had positive perceptions compared to 27 (85.3%) who had negative perceptions.

The obstetric fistula patients with severe and moderate incontinence had about 90% of them with negative life enthusiasm while those with mild incontinence had about 52% of them still hopeful and positive in general terms with a statistical significant level of less than 0.001.

The number of children they had alive also affected their perception towards life fulfillment. Those without any child alive and those with higher numbers of children of more than three had negative perceptions towards life than those with one to two with $\chi^2=42.174$, and a p value of <0.001.

A greater number of patients with tertiary education, 5 (83.3%) had positive perceptions about life fulfillment, whereas a lesser number of those with primary level of education 134 (40.2%) and secondary level education 25 (49.0%) had positive perceptions towards life fulfillment. However, the association was not statistically significant with χ^2 value of 5.661, and a p value of 0.059 perhaps due to the fact that the majority of the patients 333 (85.4%) had primary level of education.

The type of fistula, region of residence, and the number of repair the patient had had, the duration lived with fistula before repair for those that had been repaired and the time lag after repair to data collection were not statistically significant as far as the patients' perceptions towards life fulfillment were concerned.

Generally, a larger proportion of obstetric fistula patients 226 (57.9%) had negative perceptions towards the overall life fulfillment while 164 (42.1%) had positive perceptions. This is represented in Table 2.

Table 2: Frequency of obstetric fistula patients' overall life fulfillment.

Variable	Frequency	%
Overall fulfilment		
Positive (good)	164	42.1
Negative (poor)	226	57.9
Total	390	100.0

DISCUSSION

Association of socio-demographic and obstetric factors with the obstetric fistula patients' perception towards life fulfillment

How people judge and value prevailing circumstances is significant for their life fulfillment. Life satisfaction or fulfillment is subjective, and it is based on the particular attributes an individual finds personally meaningful.¹⁴ This study found that a greater number of obstetric fistula patients had negative perceptions towards life and this was attributable to the patients' age, marital status, repair status, overall duration lived with fistula, outcome of repair, severity of incontinence and the number of children alive. Studies in various geographical locations indicate that patients are majorly adolescents and young adults, with economic hardships, rural residents and with low level of education.^{1-3,20}

Economic and emotional stress were reported to be associated with poverty among women living with fistula.²¹ A study in Burkina Faso noted that two thirds of the fistula patients were in polygamous marriages and many others are separated with.²² These studies simply state these characteristics but do not indicate their effect on patients' perceptions towards life fulfillment.

The duration lived with fistula potentially affects the patients' quality of life. A number of studies indicate longer periods lived with fistula with socio-economic effects.^{3,22} Some patients may end up being divorced by partners who hoped they would recover soon.^{3,23} Those with severe incontinence, and those whose fistula has failed to close after several attempts of repair face embarrassment, shame and rejection.^{11,22} In fact, it is referred to as a life changing social calamity with deep roots in gender inequality.^{2,22,23} A blind fistula patient in Ahmed and Holtz's review study wished to have the fistula repaired other instead of the blindness due to the unfathomable associated stigma. They feel helpless, ashamed, sad, dependent, and worthless. The most reported traumatizing moment is that of child loss and failure to meet sexual demands of their partners. Some patients blamed themselves for the condition as well as the death of the baby while others are blamed by in-laws.⁴ A study that was carried out in Tanzania noted that women's experiences were associated with societal perceptions and cultural understanding of women.²⁴ Such perceptions inhibited women from voluntary disclosure of the condition and avoided any situation that could

potentially lead to involuntary disclosure.¹⁰ Many lived with the condition for many years due to fear of going in public and whenever they decide to seek treatment, they travel to very far located health centers where they are not likely to encounter anyone who knows them.¹¹

The feeling of shame and guilt affect their social interactions.^{25,26} The findings of this study are closely linked with those of Ahmed et al, but his were mainly focusing on the socio-economic consequences other than the likely perceptions. Ahmed's study noted mental trauma and anguish resulting from sudden social isolation.²³ Patients may be abandoned or sent back to their parents' homes where they are also denied to engage in activities such as cooking, social events and cultural rituals. The issue of divorce, separation and rejection is highlighted by a number of studies.^{3,10,12,26} But these studies were majorly concerned with psychosocial experiences or challenges other than how such experiences shape the patients' perceptions towards life fulfillment.

Having endured such traumatizing experiences, patients perceive themselves as socio misfit, social burden, and believe they are not people anymore. They doubt their self-worth and live in fear, and anguish. Some of them even contemplate suicide.^{10,26} People experiencing stressful situations as those among by obstetric fistula patients report less contentment with their lives. Support systems have the potential to reduce stress and play an important role in mediating its' detrimental effects. A sense of social connection and support strongly correlate with level of satisfaction.²⁷

A study that investigated trajectories post repair noted a decline in social stigma, and negative perceptions with time.⁸ Bomboka's study in Uganda also noted restoration of hope, dignity, joy and recovery of marriages among those who had successful repair and those with social support.³ Similar patterns were reported by a study in Tanzania by Denis, et al, where patients who were joyfully welcomed home after repair easily reintegrated and reported optimism towards a number of life domains.¹² These studies did not link these experiences to socio-demographic and obstetric characteristics and the likely perceptions towards life fulfillment. Thus, this study lacked sufficient data aligned to its objective.

Therefore, if negative perceptions should be reversed among obstetric fistula patients, timely and effective repair of the fistula should be the initial step.^{3,8} Individualized counseling should also be done. It should acknowledge and address the negative impact of fistula especially towards relationships, feelings, and thought processes. At the same time, health literacy should be done during which the patient should ask questions about her condition and given time to disclose her hopes and anxieties. Self-efficacy should be built through skills training and relaxation exercises done and emphasized.⁴

Family support, and attitude change are encouraged as they instill positivity and enable patients to cope easily.³

CONCLUSION

Socio-demographic and obstetric factors influence patients' perceptions towards life a great deal. This is due to vulnerability and overall experiences endured, patients develop negative perceptions which may go on even after repair. Unfortunately, their voices and grievances are unheard by policy makers. Efforts should focus on fistula prevention and timely and effective repair so as to minimize probable experiences likely to result in negative perception that would eventually impede life fulfillment.

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