ISSN: 2993-656X

Research Article International Journal of Endocrinology Research and Reviews

Quality of Life After Obstetric Fistula Among Women in Developed Countries

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Submitted: 2023, Nov 17; **Accepted:** 2023, Dec 08; **Published:** 2023, Dec 13

Citation: Neville, C. W. (2023). Quality of Life After Obstetric Fistula Among Women in Developed Countries. Int J Endo Res & Rev. 3(2), 45-51.

Abstract

This research aimed to evaluate the correlation between the experience of obstetric fistula and quality of life. Extensive research exists explaining obstetric fistula and the associated effects among women in underdeveloped countries; however, there is a lack of research pertaining to women who have experienced this condition in developed countries. We surveyed women who experienced obstetric fistula in developed countries. Participants were identified by their association with a social media support group for women affected by obstetric fistula (n= 68). Participants completed the Ferrans & Powers Quality of Life Index to provide data relating to their perceived quality of life after experiencing obstetric fistula. An overall score calculated from four subscales determined total quality of life scores. Each scale evaluated the participants' perception of their satisfaction and the importance of particular items and assigned a score from 0-30 based on participant response. Quality of life scores ranged from 4.27 to 29.58, with an average score of 19.4. The results revealed a significant correlation between obstetric fistula and diminished quality of life. The subscale with the lowest scores was the Health and Functioning subscale with a minimum score of 1.12 and maximum score of 29.54.

Keywords: Obstetric Fistula, Quality-Of-Life, Ferrans & Powers' Quality of Life Index

1. Introduction

Quality of Life after Obstetric Fistula among Women in Developed Countries An obstetric fistula is defined as abnormal epithelial-lined connections between the vagina and either the bladder (vesico-vaginal fistula) or the rectum (recto-vaginal fistula) leaving a woman with uncontrollable leakage of urine and/or feces from their vagina. Although the prevalence of obstetric fistulas is a known global concern, there is a common misunderstanding of its occurrence in developed countries. According to, developed countries have eliminated obstetric fistulas, claimed obstetric fistulas have been eradicated in high-income countries. Because of this misunderstanding, there is lack of published research regarding obstetric fistulas in developed countries, requiring further study to identify the existence of obstetric fistulas and the effect on a woman's quality of life. With the lack of information regarding obstetric fistulas in developed countries, there are limited medical professionals experienced with the condition, which potentially increases the distress experienced by the women affected [1-5].

The occurrence of obstetric fistulas is so prominent across the globe that the World Health Organization (WHO) has implemented a worldwide campaign to reduce the number of obstetric fistulas identified the lack of robust data concerning the epidemiology of obstetric fistulas, while explained the need for published material identifying the consequences associated with obstetric fistulas. There appear to be no available data on the understanding of obstetric fistulas as a public health concern in the United States [6-9].

Current literature fails to recognize the presence of obstetric fistulas in developed countries. Women with obstetric fistulas have the potential to experience severe physical pain, psychological distress, social abandonment, and multiple other adverse effects, which negatively affect quality of life. By gathering data from a specific target sample of women living in developed countries who have experienced obstetric fistulas, the overall effect on their lives will be identified as well as potential coping mechanisms that have allowed the women to improve their perceptions towards their overall quality of life.

This study identifies the common perception among women with obstetric fistulas relating to their social, economic, and family environments as well as the extent to which a woman's quality of life is affected in developed regions, as it will differ from those in underdeveloped regions.

2. Literature Review

Approximately 85% of birthing women will sustain some perineal trauma, resulting in either short or long-term morbidity [10]. Women with obstetric fistulas are often embarrassed and self-conscious because of the side effects associated with obstet-

ric fistulas. According to, many women are shunned and abandoned by their husbands and family because they are considered unclean from the constant leaking of urine and feces. Shame related to the offensive smell and inability to clean, results in ostracism from families and communities. Women being ostracized by their communities is especially common in underdeveloped countries. An accurate understanding of the total number of cases of obstetric fistulas each year is difficult to determine, due to the high incidence of obstetric fistulas in underdeveloped countries, which lack the ability to accurately report and gather data. It is estimated that at least 50,000 to 100,000 women each year experience a new obstetric fistula, totaling 2 to 3 million women globally living with obstetric fistulas [6, 7].

Although the occurrence of obstetric fistulas is more common in countries with limited medical services, the presence is still a concern in developed countries. As stated, there are no reliable data on the true incidence of fistulas; however, the risk of this condition exists anywhere [11]. claimed that the once-common issue of obstetric fistulas has been eradicated in Europe and North America due to improved medical treatment, which is proven by the forced closure of a New York fistula hospital in 1895 due to the extreme decrease in obstetric fistula incidence. identified the existence of obstetric fistulas in the United States by completing a retrospective study of data containing details of cases in the United States from 1979 to 2006, where women were admitted as inpatients because of diagnosed fistulas from pelvic surgical intervention, radiation therapy, inflammatory disease, or obstetric trauma. The retrospective study identified that vesicovaginal and colovaginal repair numbers remained stable while rectovaginal fistula repair declined due to the increase of cesarean section and decrease of episiotomy use [12].

3. Pathophysiology

An obstetric fistula is defined as abnormal epithelial-lined connections between the vagina and either the bladder (vesico-vaginal fistula) or the rectum (recto-vaginal fistula) leaving the woman with uncontrollable leakage of urine and/or feces from their vagina. According to deBeche-Adams and Bohl (2010) fistulas can be the result of congenital malformations or acquired etiologies including childbirth, infection-related abscesses, malignancies, operative trauma, and inflammatory bowel disease, along with rare cases resulting from fecal impaction, radiation treatment of vaginal cuff, bacterial infection, and sexual assault.

During childbirth, multiple complications can result in obstetric fistula. These complications can include prolonged pressure against the wall of the birth canal, causing the vaginal tissue to thin and allowing for fistula creation; added pressure to the vaginal wall, causing the tissue to tear and resulting in perforation; or use of episiotomy with failed repair [13]. During obstructed labor, the unborn child is unable to pass through the birth canal because of incorrect rotation of child or small pelvis size. According to, the occurrence of obstetric fistulas in underdeveloped countries, such as Sudan, is a result of young, underdeveloped girls becoming pregnant. In most cases, an obstetric fistula is caused from prolonged obstructed labor and results in incontinence of urine and/or fecal material [14-16].

As mentioned, obstetric fistulas can be a result of perforation of tissue during childbirth otherwise known as obstetric perineal trauma. These tears or lacerations can be either intentional by way of episiotomy, or from unexpected tearing of tissue due to infant size in relationship to the birthing mother's vaginal canal [17]. noted that approximately 5% of vaginal deliveries result in a tear, and when repaired promptly after labor, healing is 90% to 95% satisfactory. The lacerations, whether by episiotomy or tearing, are classified as either first, second, third, or fourth degree tears.

Episiotomy has been identified as a contributing factor to obstetric fistula; however, it is also identified as a method to avoid obstetric fistulas. Clinical reasoning underlying episiotomy is that by creating a precise surgical laceration during child delivery, the tissues are able to be repaired immediately with fewer complications than if no episiotomy was performed, which would result in uneven tearing and increased inflammation. According to, and it is not clear if the use of episiotomy assists in preventing obstetric damage. Fistulas present either immediately postpartum from undiscovered fourth-degree tears or in 7 to 10 days, following what was thought to be a successful repair. Understanding that episiotomies have a connection with obstetric fistulas, whether negative or positive, displaying statistics on the use of episiotomies may help to understand the association between the two. Inadequate repair, post-repair breakdown, or the incidence of infection may all cause fistula development.

According to the United States reports a rate of 48% of vaginal deliveries where episiotomies were used, Sweden is lower at 9.7%, Latin America is higher at 90%, and Taiwan is the highest using episiotomies 100% of the time during vaginal deliveries. The WHO recommends the decreased use of episiotomies as research has shown little benefit to the implementation [18].

4. Treatment

A successful fistula repair depends on the overall condition of the patient's vagina and rectum or bladder, as well as the patient's ability to withstand a potentially radical operation. Surgical repair of obstetric fistula is usually possible; however, women may find barriers to accessing care such as limited availability of qualified surgeons experienced with fistula repair. Obstetric fistulas are devastating to the patient due to the embarrassing symptoms and challenging for the surgeon due to the high failure rate of repair. In the case of an obstetric perineal trauma, repair is required and in regions with modern medical intervention, the repairs are usually completed immediately following injury. However, if the tissue is too damaged, there is greater risk of failed repair. In some cases in which tissue is highly inflamed repair is postponed. In the case, that tissue is extremely inflamed from tear or failed immediate repair, it is recommended to postpone repair for 3-6 months after occurrence of obstetric fistula allowing tissue to heal, leaving the woman with an open wound either between the vagina and rectum or between the vagina and bladder. stated that most successful repairs are completed on the first attempt, when subsequent attempts are needed, the likelihood of successful outcome deceases. However, the success rate of initial and subsequent surgical repair ranges from 65% to 95%

and decreases with additional attempts.

5. Quality of Life after Obstetric Fistula

Few studies have examined the social consequences for women with fistulas (Blum, 2012). It is important to understand the consequences of the damage to the physical and mental wellness of the patient, as women suffer from more than just a fistula; the entire person is damaged. The care of women with fistulas requires sympathetic understanding and encouragement due to the increased intensity of emotional reaction [19]. Childbirth can cause women to have feelings of misunderstanding, anger, guilt, and confusion, all which cause anxiety, depression, and reluctance towards future pregnancy. Many women with obstetric fistulas experience feelings of shame and abandonment [20-22].

Women who experience obstetric fistula can become withdrawn from their loved ones and society due to the embarrassment of their symptoms including constant drainage of fecal material through their vagina causing uncontrollable odor, passage of gas through the vagina, passage of fecal material through the vagina, chronic foul smelling vaginal discharge, subsequent dyspareunia, discomfort, fecal incontinence, urinary incontinence, infection, ulcerations, nerve damage, secondary infertility, damaged vaginal tissue eliminating sexual activity, and paralysis of the lower legs [23].

According to although in developed regions obstetric trauma is most likely recognized and repaired, up to 59% of women who experienced the trauma will have some degree of fecal incontinence. stated that one-third of women experience persistent incontinence post-surgery. In many cases especially in developing regions, about 90% of women experiencing obstetric fistula have lost a child in the process.

The physical effects are overwhelming for the women who experience obstetric fistulas; however, the psychological effects can be more devastating stated that the physical symptoms of obstetric fistulas cause severe emotional distress affected every aspect of the woman's daily life. stated that about one-fourth of women suffer from postnatal depression, and up to one-half present with sexual difficulties. According to, fistulas are generally a quality-of-life issue; patients with the embarrassing pathology suffer from significant psychological and social effects that jeopardize their quality of life. For example, the family of a fistula survivor may forbid her from preparing food or participating in family activities stated that vaginal injuries prevent women from completing expected duties such as manual labor and sexual intercourse with their husbands, which in some societies can be devastating. The attitudes and perceptions towards women with fistulas varies by region, however the longer the woman has the fistula, the more likely it is that the husband will divorce her, resulting in a life of exclusion.

According to, women with an obstetric fistula report increased mental health impairment, depression, decreased self-esteem, and decreased quality of life resulting from social isolation and mental health dysfunction. A quantitative study revealed that at least 73% of women with obstetric fistulas were found to have depression, while 17% contemplated suicide. Patients in Ethiopia were found to have a 100% occurrence of psychological disorder after obstetric fistula, and 40% of those women seriously consider suicide. When a condition such as obstetric fistulas affects the psychological wellbeing of an individual to the point of considering suicide, attempts need to be made to support the victims. There is lack of research pertaining to women in developed countries and their quality-of-life after obstetric fistula occurrence, indicating a need for further research in this area. The purpose of this quantitative descriptive study was to determine the overall effect of obstetric fistula on quality of life among women living in developed countries.

6. Methods

6.1. Research Design

This study used a quantitative, cross-sectional survey design. Participants were recruited from Living with Obstetric Fistula and Living with RVF/VVF (Rectal Vaginal Fistula/ Rectal Vaginal Vesico), private support groups established through the social media tool Facebook. The study targeted all members within the two groups, which consisted of 378 members. Permission to recruit participants from these groups was granted by the group administrators. Participants were required to meet the following inclusion criteria: female, living in a developed country at time OF occurred (United States, Canada, United Kingdom, Australia, Singapore), personally experienced an obstetric fistula. Inclusion criteria was established by the sample deriving from two support groups identified specifically for obstetric fistula as well as items included in the questionnaire [24]. Participants meeting the following criteria were excluded from the study: male, living in an underdeveloped country, never experienced an obstetric fistula.

6.2. Sampling methodology. A nonprobability purposive sampling methodology was used to obtain data from women in one of two obstetric fistula support groups maintained on a social media source (Facebook).

7. Survey Development

The Ferrans and Powers Quality of Life Index (QLI) Generic Version III was used to measure quality of life. The QLI measured both satisfaction and importance regarding various aspects of life, the QLI provides five scores regarding quality of life: overall quality of life, health, and functioning, psychological/ spiritual, social and economic, and family. The survey instrument includes Likert scale type questions to evaluate the quality of life perceptions. The survey is composed of two major sections that identify either the participant's satisfaction or importance with 66 different questions to determine overall perception of quality of life [25, 26]. Reliability of the instrument is supported by Cronbach's alphas, which have been published in 24 studies providing support for internal consistency of subscales. According to content validity was supported by extensive literature review of issues related to quality of life, and construct validity was supported by strong correlations between total QLI scores and Campbell, Converse and Rodgers measure of life satisfaction.

To gain demographic information, multiple choice, true or false, and yes or no items were included in the current study, which identified the correct target population. The use of the Quality of Life Index survey tool does not require permission for use unless being used for profit or electronically therefore, a request was sent to Dr. Carol Ferrans to gain permission for the electronic version of the generic form. Dr. Ferrans approved the use of the electronic version of the survey tool and granted permission.

8. Demographics

Participant demographics included participant current age, age when obstetric fistula was experienced, country where participant was living at time of obstetric fistula occurrence, whether a surgical repair was completed or not, time frame of repair compared to initial injury, number of repairs, identified incontinence issues post-surgical repair, and degree of incontinence.

9. Data Collection

Participants were invited by group administrators to participate by a post in the Facebook groups. The post was presented as an invitation letter describing the rationale for the study. Participants were asked to respond to the questions in relation to their experience with obstetric fistula. Reminders were posted in the Facebook groups throughout the study to gain adequate participation. The posts to Facebook also provided a direct link to the Survey Monkey questionnaire where the data are stored. After the data was collected via Survey Monkey, data was imported into IBM SPSS Statistics version 23.0 for analysis.

10. Statistical Analysis

Statistical analysis was completed using descriptive statistics to evaluate the central tendency, counts, and frequencies of data collected in regards to quality of life perception after obstetric fistula experience. Data obtained from questions within the Ferrans and Powers QLI were scored and interpreted using the technique outlined by. Each participant's QLI responses were calculated and placed into five categories including (a) total quality of life score, (b) health and functioning subscale score, (c) social and economic subscale score, (d) psychological/ spiritual subscale score, and (e) family subscale score. Descriptive statistics were calculated to address the research question related to the effects of obstetric fistula on overall quality of life among women in developed countries, including frequency distribution, measures of central tendency such as mode, median, and mean, and measures of variability including range and percentiles.

11. Results

11.1. Participant Demographics

A total of 84 women of the target population of 378 completed the survey, resulting in a 33% response rate. Of the 33%, 16 participants failed to complete the Quality of Life portion of the survey and were excluded. Therefore, 68 women were included in analysis. Participant characteristics are presented in Table 1.

Table 1: ***Participant Demographics***

Age	**Current Age**	**Age at time of OF**	**Age at time of OF Dx**	**Time since Dx**	**Valid %**
<18	0.0	1.5	1.5	< 3 months	4.4
18-25 years	5.9	16.2	13.2	3-6 months	2.9
26-30 years	13.2	30.9	27.9	7-11 months	1.5
31-35 years	39.7	35.3	35.3	1-2 years	20.6
36- 40 years	19.1	7.4	10.3	> 2 years	70.6
41 years and over	22.1	8.8	11.8		
Current Status of OF	**Valid %**	**Treatment Status**	Valid %		
Healed, no comp*	4.5	Seeking treatment	25.0		
Healed, minor comp*	37.9	Being treated	20.6		
Healed, severe comp*	7.6	Treatment completed, satisfactory results	36.8		
Healing, no comp*	6.1	Treatment completed, unsatisfactory results	17.6		
Healing, minor comp*	22.7				
Healing, severe comp*	21.2				

Note. OF = Obstetric Fistula.

Table 1: Dx = Diagnosis

Percentages reported from valid percent

Comp = complications

The majority of participants (71.2%) indicated their obstetric fistula occurred in the United States, with 10.6% in the United Kingdom, 7.6% in Canada, and 10.6% in Australia. Participant ages ranged from 18 to over 41 years, with the most frequent age category 31-35 years (39.7%). Age at time of obstetric fistula occurrence, as well as age when diagnosed, ranged from <18 to 41+ with the most common age as 31-35 years. Time since obstetric fistula occurrence ranged from <3 months to >2 years with most women reporting a period of >2 years. Most women reported their current obstetric fistula status as healed with minor complications (37.9%). When asked about treatment status, 36.8% of participants reported completed treatment with satisfactory results, 25% were currently seeking treatment, 20.6% were in the treatment process, and almost 20% completed treatment but with unsatisfactory results.

12. Obstetric Fistula and Quality of Life

Quality of life scores were examined on a wide range of items on the five scales provided by including total quality of life, health and functioning subscale score, social and economic subscale score, psychological/ spiritual subscale score, and family subscale score. Each scale evaluated the participants' perception of their satisfaction and the importance of particular items and assigned a score from 0-30 based on participant response.

Total quality of life scores were determined by an overall score calculated from four the subscales. Quality of life scores ranged from 4.27 to 29.58, with an average score of 19.4. Average score on the Health and Functioning subscale was 17.55 (minimum = 1.12, maximum = 29.54). The Social and Economic subscale found an average score of 20.78, with a minimum score of 5.25 and a maximum score of 29.29. Within the Psychological / Spiritual subscale, there was an average score of 18.22, a minimum score of 5.29, and a maximum score of 30. The Family subscale reported an average score of 23.86, the highest average among all subscales. The low was a score of 3.60 and the high score was 30. Scores were compared to a study reporting results of a healthy population to determine diminished quality of life Table 2.

Quality of Life Findings

Study	Population	Health and Functioning Subscale	Social-economic Subscale	Psychological/ Spiritual Subscale	Family Subscale	Total Quality of Life
Obstetric Fistula and Quality of Life	Women with Obstetric Fistula	17.55	20.78	18.22	23.86	19.4
Ferrans and Powers (1985)	Healthy Population	21.38	22.30	22.34	23.08	21.67

Note. Mean scores based on a 0-30 scale.

Table 2: Compared to the study, women with obstetric fistula do report some decrease in overall quality of life and among most of the survey subscales.

13. Discussion

The overall purpose of this study was to evaluate the association between obstetric fistula experience and quality of life. The study findings indicate and emphasize the need for acknowledgement of the effect to a woman's quality of life after experiencing obstetric fistula. Women who had experienced obstetric fistula did have diminished perceptions regarding quality of life compared to a healthy population. Obstetric fistulas present implications not only physically but also psychologically, social, and with family relationships. While some health conditions may allow the patient to adapt, daily annoyances associated with urinary and fecal incontinence influence a woman's daily activities so much that it is questionable if similar adaptation and acceptance can occur. It may also be difficult for women with an obstetric fistula to maintain psychological health. Surveyed women revealed an average quality of life score of 19.4/30. Results support the existing literature recognizing diminished quality of life among women who have experienced obstetric fistula. Using the evaluation-based measurement, all areas of quality of life appear to be negatively influenced by obstetric fistula.

When survey responses were examined further, it was revealed that the category with the lowest average score was Health and Functioning subscale with a minimum score of 1.12/30. The extreme low score could correlate with the qualitative responses within the open comment section of the survey, which indicated fear of increased issues with age, decreased sexual activity, control over life, post-traumatic stress, emotional and psychological stress, failed surgeries, and the inability to retain physician support and care. The qualitative responses also revealed that women with obstetric fistula distance themselves from family and friends in order to prevent embarrassment from fear and stress associated with incontinence, which correlates with most previous studies involving obstetric fistula.

The study limitations included low response rate of only 68 participants completing the survey in its entirety, as well as limited demographic statistics such as race, ethnicity, and perception of quality of life at time of obstetric fistula occurrence. Low response rates may be a result of the inability to properly market the study, as the target population were members of a closed group with social media, which only allowed women who have

experienced obstetric fistula to access the group. Therefore, marketing was the responsibility of the group administrators and not in the control of the primary researcher.

It is recommended that to further the research in this area a qualitative study allowing participants more opportunity to share personal thoughts and experiences be completed in the future. The questionnaire provided an open comments section for the women to express their thoughts and feelings regarding obstetric fistula and quality of life. However, because of the study structure, limitations prevented a full understanding of these personal responses.

14. Conclusion

Most women in developed countries develop or discover an obstetric fistula post discharge from the hospital and may not report symptoms due to shame or social stigma, resulting in facility-based data regarding the occurrence of fistulas to underestimate the prevalence of the problem [27]. No woman should endure a condition that is both preventable and treatable. It is understood that there are high rates (50,000 – 100,000) of obstetric fistulas in developing regions; however, there is little to no literature regarding the prevalence in developed regions. As state knowing the prevalence and incidence of new obstetric fistulas occurring every year is simply insufficient to develop a sustainable program. Given the continuing occurrence and morbidity of this maternal health condition, the effect of obstetric fistulas on the lives of women justifies closer inspection. It is recommended that a qualitative study be conducted in order to get a more detailed interpretation of an obstetric fistula's effect on a woman's quality of life [28-31].

Declarations

Ethical Approval

All participants in the study were given information pertaining to interest of the study and acknowledged that by completing the survey they were providing consent to the study.

Funding

The study was funded by the author and there were minimal monetary costs associated with the study.

Availability of Data and Materials

All information pertaining to data have been included in the manuscript within the methods and results sections. However, any additional details can be provided by the author at any time as information is stored in an Excel file as well as an SPSS file owned by the author.

Conflicts

There are no conflicting interests between the author and the research that was conducted. Dr. Casey W. Neville is the guaranteeing author, as well as the only author.

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