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Obstetric Fistula Post Repair Follow Up: An Outreach Worker's Perspective

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Abstract: **Obstetric Fistula is a childbirth injury caused by prolonged obstructed labour leaving a woman incontinent of urine or faeces or both.The stigma associated with the condition keeps many women hidden away. A woman with obstetric fistula is too often rejected by her husband and pushed out of her village due to her foul smell. Without treatment, fistula often leads to social, physical, emotional and economic decline. Although some women with fistula display amazing courage and resilience, many others succumb to illness and despair. Kenya is estimated to have 1000-3000 new fistula cases every year where as the national treatment capacity is only 500 clients per year. With the understanding of the impact this condition has not only to the affected clients but also to the community at large, several local and international organizations are currently supporting the fistula repairs in Kenya. Review of relevant literature reveals inconsistent findings about the need for the post repair follow up for this client. This leaves program designers and their funding partners to handle the issue according to their discretion. Most projects focus on identifying fistula clients supporting them to get the surgery document the number repaired but do very little to follow up on this client. This paper gives the perspective on an outreach worker who has supported fistula clients for the last 11 years. The author looks at what is currently happening in Kenya and brings out the need for establishing post repair follow up in the programs. The paper gives case studies in the client either benefited from post repair follow up to show an amazing outcome or lost life in unclear circumstances. The paper demonstrates the effect of this follow up to the client their significant other, the community and the effectiveness of the project. It finally gives recommendation on how this can be integrated in fistula management.**

Keywords:**obstetric fistula, post repair follow up, community outreach, western Kenya**.

1. INTRODUCTION AND BACKGROUND

A fistula is an abnormal communication or an opening or hole that is where it is not supposed to be. According to Creanga and Genadry (2007), Obstetric Fistula is an opening that occurs during delivery when a woman fails to get emergency obstetric care. It is a child birth injury associated with prolonged obstructed labour and characterised by continuous leakage of urine or stool or both via the birth canal. Fistula survivors undergo a lot of physical, psychological and emotional trauma. The fistula repair addresses the physical trauma. However, the psychological, emotional and social consequences of the condition affect the client in a very powerful way far beyond the repair time, in some cases lasting her entire lifetime. When a woman has a fistula, her entire family is affected in various ways. For example she is not in a position to manage her daily chores hence is unable support her children. Her husband is also psychologically impacted to the extent that some may run away from the home and can get into drugs and alcohol as a defence mechanism. This results in unhealthy communities that affect us all.

In realizing the significance of the condition to both the client and society, several international and local organizations have rolled out various interventions ranging from prevention, care and treatment to reintegration services for the fistula survivors around the globe. Most outreach programs are structured in a way to where funding partners only take care of the client's transport to and from the medical facility for repair and fund the treatment. What happens for the clients who face the complications following treatment is often left unclear in these programs. The assumption has always been once

the fistula is fixed then the client's life is completely transformed and no complications are expected. This is an issue community outreach workers are finding to be a gap in the funding for the program.

2. NEED FOR OBSTETRIC FISTULA POST REPAIR FOLLOW-UP

Field evidence shows there is a clear need to follow up on the repaired clients in order to address any post repair complications arising after the client's discharge from the hospital. Data from WADADIA NGO in western Kenya indicate that of the 227 clients repaired between June 2014 and March 2015, 13 of then presented with post repair complications within the first month of the repair. (Wadadia 2015). This goes hand in hand with statistics from other implementing partners in western Kenya such One by One and MUMCOP. Having a clear follow up plan is essential, as it helps in early detection of complications hence preventing them from continuing to deteriorate. It also enables the program implementers to track the progress of the work and save the organization's reputation by timely addressing any challenges arising after the surgery.

Arrowsmith et al (1996) coined the phrase "obstructed labour injury complex" to encompass the extent of physical and social injury caused by fistulas. According to Arrow Smith, a high percentage of women affected by fistula, close to 80%, develop chronic skin excoriation as a result of urine irritation. They also develop amenorrhea, vaginal stenosis, infertility, bladder calculi, infection and foot drop. Kelly and Kwast (1993) established that 36.6% and 8.5% women with fistula suffered from marked weight loss, malnutrition and limb contractures respectively. . Community outreach workers may not have the clinical terms for these conditions, but they acknowledge that most of their clients exhibit symptoms that fit this description. Both Arrow Smith and Kelly's work represent a typical picture of a fistula client as seen from the community level.

Despite the understanding that fistula clients will present with different levels of complications, most project implementers still expect the clients who go in for repair to spend the same number of days at the facility undergo same level of intervention get discharged and respond in a similar way without having any complications. I find this to be stretching our imagination and asking too much of an outcome while doing so little to get it. I want to appreciate that certain projects have some level of flexibility on how to support different client needs. Some programs have accommodated the need for clients to spend more days at the facility than others and that some will need a different level of attention and medication to support in attaining holistic healing. Gynocare Fistula Centre in the western region of Kenya is one such facility that appreciates the diversity of their fistula clients and gives them individualized attention. The care in this facility goes beyond what its funding partners support. An example of such individualized attention is a case of a fistula client named "Anne**" (**Not her real name). Anne a 28 year old mother of two from Mt. Elgon Sub County was admitted at Gynocare in 2013. In addition to the obstetric fistula Anne had severe malnutrition and jiggers. The management of Gynocare admitted Anne, treated her for her Jiggers and put her on nutritional support for two whole months before deciding on repairing her fistula. When i followed up on an in September 2014 she was married and four months pregnant. This demonstrates the positive outcome of individualised care.

Someone may argue that if the focus our program is fistula then there is no justification for handling other complications. The fact is that these are not just other complications; most of them are either the causes or the effect of the fistula. Am of the opinion that anything that can affect the outcome of a fistula surgery, should be addressed if the clients have to attain holistic healing. Do the clients who get fistula surgery while having malnutrion, vaginal stenosis, bladder calculi or other infections respond to surgery within the same time and in same manner with a person who doesn't have this condition? Will they need the same post operative care? This is for the clinicians to answer.

Another argument that is commonly presented by program designers or funding partners is that complication that can affect the outcome of the surgery should only be supported at the facility prior to the repair. No provision for follow up or support once the client is discharged and goes back to the community. My question here is at what level do we evaluate the outcome of the surgery? is it immediately after the client leaves the operating room ? when they are discharged from the facility or when the client is integrated back to their community. As an outreach worker my position , is, since we identify this client from the community we can only say we were successful if we see them well and back in their community. If we don't have a follow up plan for this client; how will we know that they even recovered? How do we make them understand that whatever issues they may be having, may not be directly related to the fistula? Do we just assume all is well or wait for them to come back to the facility with major complications? Will they know or have the

courage to come?. Study on the psychosocial consequences of vesico and recto vaginal fistula in western Kenya indicate that of the 38% of clients who get recurrent fistula only 15% go back to the health facility to seek help. (Mohamed H.C et al, 2013) This is because they lose hope and their fear of not ever getting better is confirmed by this reoccurrence making them to resign to their fate. The plight in caring for these women calls for an extra effort to reach out to them, to reassure them that all is not lost in order for them to pick up the courage to seek help for the second time. This is where the psychosocial support plays a major role in the holistic healing of these clients. Counselling services help alleviate the anxiety associated with incomplete recovery as well as restoring the clients self esteem and feelings of worthiness. Family or couple counselling will ensure family involvement in the support for this client and psycho education will give this client more information on what is happening and how best they can deal with the situation.

Field observations of recovering fistula survivors' shows there is no clear cut response to recovery for these women. Even when coming from the same community and being repaired by the same facility, clients still face different challenges when back in the community. We have clients who respond very well, have no physical complications or major psychological issues once the fistula is repaired and those that that show no physical complications with psychosocial issues that may end up creating physical complications if not attended to following repair. On the other hand we have a group that ends up with physical complications which lead to psychological issues and even loss of life. Though the majority of clients are assumed to leave the facility dry and end up having a complete physical healing; about 6% of them face certain complications that either go unreported or are handled at the their local facilities and are never documented. I will cite the most recent cases where WADADIA, an outreach organization partnering on the Action on Fistula project, lost two clients on consecutive days in March of 2015 within three weeks of their repair. One of the clients died the next day after surgery while still at the hospital and the other responded well and was discharged being dry. The client went home but developed complications within five days of her discharge. When the client's family noted that she was unwell and could not eat the best they could do was to take her to the community outreach worker's home and leave her there. The son of the client was quoted saying the following to the COW, "You took her from here when she was well to help her, see what you have done, she is now your responsibility until she gets better". The outreach worker, not being a medic, was scared for her life and managed to take the client to the facility where she had been repaired. The client admitted that she had had some intestine complications even prior to the repair. She stayed in the facility for seven days but still refused to eat. The client seemed to have lost hope in leaving and had already resigned to death. The facility had to transfer her to the government hospital close to her home for fear of accumulating the bill and hostility from the family. It was so heartbreaking to see the client in a hospital bed so helpless, a woman we had taken from her home to get help, now we have to take her back so close to death. The hostility from her family didn't make the situation any better. They could not understand why a client who had lived with fistula close to 50 yrs went to the hospital walking and now she is on her death bed. They attributed the situation to the last intervention the client had and in this case is the fistula surgery, not withstanding that the client had other medical condition prior to the repair. It took the intervention of the local church leaders and administrators to calm the community down. The family decision was that the client be taken home while still alive, a request we respected and discharged the client only to get home and die the next day. This is just among the many experiences I have witnessed in my community work. Though we know death is inevitable to all humans it hurts so deep to lose a client you are trying to support under unclear circumstances, you always try to think maybe something should have been done to prevent it. Though in both of the cases it was noted that this client had other medical conditions prior to the fistula repair, the question that lingers in my mind is at what point are we to diagnose these other conditions. Is there a way that diagnosis can be done prior to the repair and its effect to the repair assessed before getting into the actual fistula repair? Is there a way this client with the understanding that they already have this condition can be supported to ensure they get a holistic healing before a crisis occurs? Can we have this diagnosis documented and even shared with the client's family prior to the fistula repair? What does this situation mean to the outreach worker, to the treatment facility and to the entire project? How do we help the community not lose confidence in our projects? How do we give them reassurance that we are not just interested in numbers but care about them as humans and want to do everything possible to ensure they receive a holistic recovery?. It is important to understand that the communities' perspective of any initiative is different from the facilities or the professionals understanding. This gap in perspective can be reduced by having a clear and supportive structure that clarifies all issues in the context in which of the communities can understand

A study conducted in Nigeria by Kabir (2004) shows that 53% of women with fistula consider themselves rejected by society. The presence or absence of children in a marriage involving a fistula survivor determines whether the marriage

will last. Murphy (1981) determined that the presence of living children may reduce the risk of separation or divorce, unless the mother has been a victim of fistula for a long time. In a study conducted by Kelly (1995) in Addis Ababa, in Ethiopia, it was discovered that 39% of women with fistula lose their husbands' support and if they simultaneously have no means of earning their livelihood, they turn to their relatives for food and sustenance; whereas 22% live on donations. Do we believe a person depending on donations for her livelihood can be able to take care of her medical issues? Yes they may get access to free treatment courtesy of any intervening organization in the region, but in the instance that these women face post repair complications that the project is not able to support in addressing then it will be like condemning them to their death beds

The level of abandonment and isolation goes beyond just the family level. The community including workmates, church members and neighbours also isolate the client. This could be attributed to cultural myths and misconceptions that can be addressed with quality psychosocial support both before and after the fistula repair. Though the client i mentioned eventually passed on she at least had an opportunity to get back to the facility as she had a trained community outreach worker in the neighbourhood, who appreciated the value of life and took her to the facility. What about clients who don't have this kind of people in their neighbourhood? or whose families will lock them in their own house rather than take them to someone that can help?. Will we ever know their predicament? Can we still argue that we supported them if we don't know their outcome?

3. NATURE OF POST REPAIR COMPLICATION FACED BY FISTULA SURVIVORS

The fistula clients with post repair complications that I have met at the community level present with the following symptoms; constipation and bloating, vaginal bleeding, spots of blood in urine, difficult passing urine, and not passing urine all together, lower abdominal pain, backache and foul smelling discharge. A few have septic wounds at the site of surgery and headaches. Most of these symptoms appear within two to three weeks of the clients being discharged from the facility.

We have always encouraged fistula survivors to take plenty of fluid after the repair in an attempt to reduce the incidence of constipation. Some of the clients get support at their nearest health facility for a small fee. The community outreach workers have, at times, been forced to step in and pay for the clients who cannot afford these minimal fees.

Gutman R.E,Dodson J.L. & Mostwin JL. (2007), reported that gynatresia and urinary incontinence develop in approximately 10% and 16% of patients, respectively, after the first repair. They go further to say that urinary diversion may be necessary when fistulas cannot be closed vaginally or in cases of severe urinary incontinence following successful closure. Gynatresia, urinary incontinence, and urinary diversion are all associated with morbidity and require expertise for proper management. This implies that more has to be done beyond just closing the fistula.

When obstructed labour is unrelieved, the presenting foetus part is impacted against the soft tissues of the pelvis and a widespread ischemic vascular injury develops that result in tissue necrosis and subsequent fistula formation. (Arrowsmith S.& Wall L.L1996),.According to Arrowsmith, obstetric fistula is the result of an injury to a broad area what he refers to as "field injury". The field injury can result in multiple birth-related injuries such as total urethral loss, stress incontinence, hydroureteronephrosis, renal failure, rectovaginal fistula formation, rectal atresia, anal sphincter incompetence, cervical destruction, amenorrhea, pelvic inflammatory disease, secondary infertility, vaginal stenosis, osteitis pubis, and foot-drop.

It would be interesting to know if the other complications occurring after repair and said to be unrelated to fistula have any characteristic of the mention field injury complications. It is also worth knowing the diagnosis made to fistula clients who return to the treatment centres within three weeks of fistula repairs presenting with symptoms that look like these complexities.

According to fistula care in the prevention and recognition of obstetric fistula package module 9, which talks about the principle of postoperative care and reintegration of women with fistula, some of the possible post-operative care complications include; secondary vaginal haemorrhage, blockage of the urinary catheter and the distension of the bladder, anuria because of the accidental litigation of the uterus or obstruction, development of the bladder stones, breakdown of fistula repair due to infection or necrosis, and urethral or vaginal strictures or infertility. It goes further to mention that in most causes these problems are not due to surgery but may worsen after the surgery. Could any of the symptoms I have mentioned be an indication of this complication? How can the lay person within the community know about this?

4. RECOMMENDATION

While it is assumed that a successful repair may well lead to a smooth transition to holistic healing, further research is needed to identify specific challenges to women's quality of life after fistula surgery. This is the only way we can understand the reality of the situation and develop intervention that will have greater impact on the communities. Documenting the client entry behaviour; whether they present with symptoms' of obstructed labour injury complex or have any history of other medical conditions should be captured upon admission. This will help us understand what kind of support this client needs both before and after the repair. It will allow us to further track if there is any significant relationship between the clients who are admitted with certain conditions and those who have post repair complications. Once the clients have been diagnosed with these complications on admission, it makes sense to evaluate the effect of this complication on the outcome of surgery before proceeding with the surgery. An informed decision should be made on how best to support this client and that decision to be communicated to both the client's family and other interested parties. Having an exit interview with all the clients before discharge will help give an indication of their condition and have an individualized follow up plan for them if something comes up. The exit interview should not only document whether the client is wet or dry but their holistic status by the time they are leaving the facility. Most importantly, have a client follow up plan where all repaired clients can have post repair check-ups within one month of their repair and possibly within two weeks. This can be done in a way so they can receive these services in the facility close to them and only those that need specialized attention should be referred. Better still if resources can allow, they can have one check up at two weeks at a facility close to them and another one month later with the surgeon who repaired them. clear arrangement will have to be made with the local facilities if they have to effectively support the process. This will include having a clear partnership agreement indicating their role in the intervention, terms of partnership and staff sensitization on the project on what to look for and the key danger signs that will need urgent referral. Psychosocial services such as counselling, psycho education and family involvement need to be factored into this follow in order to give the client not just a physical but rather a holistic recovery that will facilitate their smooth reintegration back to the community.

5. CONCLUSION

Obstetric fistula has physical, psychological and emotional implications to the clients. These effects overlap each other and can either be the cause or the consequence of each other. Treating fistula clients goes beyond fixing the hole and requires a higher level of commitment and caring. Fistula clients and their significant others at the community level do not understand why they can access free treatment for the condition but cannot be treated when they get a complication immediately after the repair. Having a clear medical follow up plan for the repaired clients gives an opportunity to address the complication the client may experience, prevent future complications as well as track success of the project. psychosocial support is a key component of the post repair follow up to enhance the client's emotional and psychological well being. If we care enough to treat, then it's worth caring enough to see the client heal. If we don't care enough for this holistic approach then maybe we should question the overall vision and mission of our interventions.

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