Graduate School of Development Studies

From Trauma to Rehabilitation and Reintegration:

Experiences of Women Facing the Challenges of Obstetric Fistula in Addis Ababa, Ethiopia

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Contents

List of Acronyms

AAFH	Addis Ababa Fistula Hospital
FGD	Focus Group Discussion
FHI	Family Health International
GOs	Governmental Organizations
HIV	Human Immunodeficiency virus
MoH	Ministry of Health
NGOs	Non Governmental Organizations
OF	Obstetric Fistula
STDs	Sexual Transmitted Diseases
TV	Television
UNFPA	United Nations Population Fund
USAID	United States Agency for International Development
WHO	World Health Organization

Abstract

Obstetric Fistula causes considerable damage to the lives of women in the developing world. This medical complication is mostly a problem of the poor and the powerless. Interestingly, despite the vast array of published reports on the medical aspects of the complication, no traceable work has been done on the post treatment psychosocial and economic situations of the victims. In this research the post treatment lived experiences of six women with fistula were analyzed. A. Sen's and M. Nussbaum's capability approach were used as the theory through which to view the problem, the situation of these six women pretreatment, during treatments and post-treatment. In addition, little attention is given to those women who have received treatment from the Addis Ababa Fistula Hospital and reintegrated into society while still suffering from the psychosocial and economical consequences of stigmatization and discrimination. This paper tries to qualitatively investigate such neglect for it has significantly contributed to the consequential underestimation in the development of policies and strategies to address the problem. The study also sees these experiences from the feminist stand point and employs further investigation techniques using aspects of intersectionality and other factors based on the highlights of information generated from the perception of the issues of fistula as discussed by the society and media. Thus, this paper argues that exclusion and stigmatization by society worsen the psychosocial and economic challenges of reintegration for victims after treatment. In addition to broadening the knowledge base on OF, the paper sets salient policy interventions sought to alleviate the challenges of rehabilitation and reintegration of victims.

Relevance to Development Studies

Obstetric fistula is a serious, life threatening and often debilitating medical condition that affects thousands of women in developing countries. The causes of OF relate significantly to many contemporary development issues such as the traditional practice of early marriage, lack of accessible medical infrastructure and lack of education and understanding of reproductive health issues. The paper tries to present the postoperative rehabilitation/reintegration challenges of women with fistula based on capability approach and hence poverty as denoted by A. Sen and M. Nussbaum. The study provides a qualitative insight for future researchers to extrapolate further for similar disabilities using the theories of capability and exclusion.

Keywords

Addis Ababa, Early marriage, Exclusion, Gender, Obstetric Fistula, Obstructed labor, Rehabilitation, Reintegration

1 INTRODUCTION

1.1 Background of the Study

Obstetric Fistula (OF) is a medical condition that involves an opening or perforation between the vagina and the bladder or the vagina and the rectum. Though global in its prevalence it is very rare in the developed world and its cause is mainly from malignant diseases, radiation therapy, or surgical malfunctions during delivery (Goodwin and Scardino 1980, Langkilde et al. 1999). In the developing world, OF is a gynaecological complication leading to urinary/faecal incontinence resulting mainly from prolonged obstructed labor. Even though there might be minor inter-country differences, the complication is mainly due to adolescent pregnancy from early marriage exacerbated by lack of access to emergency obstetric care (Kelly 1995 and Wall 2004 in Muleta et al.(2008).

Women affected by OF are often abandoned by their husband, stigmatized by their community, physically debilitated and even blamed for their condition. Social isolation and abandonment often lead to low self-esteem, depression and prolonged emotional trauma (Wall 2006:1203). Cumulatively, these women have remained largely invisible to policy makers both in and out of their countries. As a result, it has been difficult to determine the exact prevalence of OF. Very little serious attention has been directed toward this issue globally, a condition which the British Journal of Obstetrics and Gynaecology recently referred to as "the scandal of the century" (Graham 1998). Astonishingly, a wide spectrum of estimates, beginning with a more conservative assessment suggests that there are 33,000 new cases each year in West Africa to 130,000 new cases each year for the continent(Abou-Zahr 2003:9, Vangeenderhuysen et al. 2001). For example, in Ethiopia, clear estimates of the condition cannot be obtained as victims live in isolation and exclusion and are therefore difficult to identify. Thus, underestimating the data is a concern and a problem as noted by a reputable fistula surgeon who had long served at Addis Ababa Fistula Hospital in a personal communication. A

factor further escalating the prevalence of the complication is that the capacity to repair obstetric fistula lags far behind the rate of incidence. To avert the trend, UNFPA conducted a pioneering needs assessment study in collaboration with EngenderHealth in nine African countries in order to better understand and mitigate the mechanisms of the complication (UNFPA and EngenderHealth 2003).

OF victims are mainly from rural areas where no proper education on maternal health and related reproductive rights that could halt early marriage are available. As young women and girls are denied their reproductive rights, they are forced unwillingly into sexual relations that routinely lead to unwanted pregnancy and mostly OF (UNFPA and EngenderHealth 2003). Similar study conducted on fistula patients admitted to the AAFH between May 1999 and February 2000 indicated that 83% of those who were married at average age of 15 had fistula at delivery before they reached the age of 20(Muleta 2004).

An effective fistula treatment should be comprised of healing the wound and accompanied by psychosocial therapies to assist women in regaining their self-esteem and to facilitate possible socio-economic reintegration. To my understanding no identifiable qualitative work has yet been done to address this issue.

1.2 Problem Statement

Lack of access to emergency obstetric care greatly contributes to the high rates of OF. A recent study estimates that there are 26,000 Ethiopian women living with this disability (Muleta et al. 2008, Muleta 2004).

OF victims are prone to worsened poverty, economic dependence on relatives/family members and deep social stigma that is likely to drive them towards depression (Wall 2006:1203). The victims are mostly unaware of the existence of the fistula treatment hospital due to their extreme isolation from society and hence a lack of access to information. If a woman is aware of the hospital services, she is then likely to lack transportation to the facility or the resources to obtain transportation. The practical policy interventions sought by the government of Ethiopia seem to be overshadowed by other more

prevalent and therefore priority maternal health issues (MoH 2006)[1]. Nonetheless, the AAFH (with its subsidiary mini hospitals) is the only centre delivering free treatment and post treatment rehabilitation including psychosocial therapy and skills training to victims despite the magnitude of the complication.

This research focuses on those victims who visited the hospital and received treatments (including post treatment rehabilitation). These women travelled from very far distances to the hospital and never returned to their village for fear of the horrifying stigma and isolation they would likely experience. The study assesses how these victims cope with the psychosocially and economically traumatizing and physically debilitating consequences of OF and explores their responses to the services they receive from the hospital.

1.3 Relevance and Justification

Little work has been reported on the post treatment, psychosocial and economic situation of the victims despite the vast array of reports on the medical aspects of the complication. For example, Goh et al.(2005) reported the high intensity of mental dysfunction of patients prior to surgery; Browning (2007) summarized the poor prognosis of OF with circumferential vesicovaginal (bladder-vagina perforation) and urethra-vaginal fistula (urethra-vagina perforation); Nielsen et al.(2009) highlighted the improved quality of life and social reintegration after fistula closure, though one-third of the follow up study manifested ongoing distress. Other studies by Muleta et al. (2008) on the health and social problems encountered by treated and untreated obstetric fistula patients in rural Ethiopia depict unfortunate results that women with OF encounter on-going health, psychological, and social consequences that are not completely alleviated by repairing the fistula alone. Thus, the issue of OF should go beyond surgical treatment and should contain more wider

[1] Ministry of Health (MoH) (2006) National Reproductive Health Strategy. Addis Ababa.

perspective of it such as support for reintegration into the community with proper follow-up(Muleta et al. 2008).

To that end a detailed analysis of the socioeconomic obstacles confronted by OF victims who participate in postoperative rehabilitation and reintegration programs will be made using A. Sen's and M. Nussbaum's social exclusion theory and capability approach. Women's experience is further explored from a feminist stand-point perspective as dictated in David and Sutton (2004) that the significant objectives of feminist research is a reflection of women's practical contact with and observation of facts or events.

1.4 Research Objectives and Research Questions

1.4.1 Research Objectives

The main objective of this research is to make a contribution to the body of knowledge on the lived experiences of women with fistula. This research will shed insight into how these women deal with first social exclusion and later reintegration into the society. Furthermore, the study will set plausible short-term and long-term recommendations on salient policy interventions directed at mitigating the consequences to which so many OF victims are confronted.

1.4.2 Main Research Question

How do women with fistula deal with the psychological, social and; economic consequences of exclusion and stigmatization from society; and how do they respond to rehabilitation and reintegration services?

Research Sub - Questions

- What psychological, social and economic challenges do women with fistula experience before and after they receiving treatment?
- What are the coping strategies of women with fistula with regard to exclusion and stigmatization?
- What are the services provided to assist these women with fistula?

- How are fistula issues discussed in the society and what attention is given to the issue by the media?

1.5 Methodology of the Research

Primary Data

The study was conducted in the capital Addis Ababa for four weeks using life story interviews with women with fistula, focus group discussion (FGD) with members of the society and interviews with pertinent health care providers.

Life History of Six Women with Fistula

Qualitative data generation via life story interviews allow close up exposure to the subjects thorough visual inspection of non-verbal bodily expression of emotions and intentions (Atkinson 1998:20). The significance of qualitative study is to give detail information on the issue under analysis and explain the lived experiences of the research participants (Marshall and Rossman 2006). In this study, the subjects are provided with ample thought space to share their distress and agony and personal details based on the consent defined. A careful observation of participants' body language was made during the interview.

The interviews were conducted in private areas using the researcher's native language "Amharic". Each participant gave oral consent before the interview was conducted and the interviews were electronically recorded. I used an in - depth interview guide which is comprised of investigating issues like the background information of the women with fistula, their personal feelings, opinions and experiences related to obstetric fistula and their perspective on the issue in relation to culture, society, economic status, gender inequality, policy interventions and the long term needs of victims, as well as their feelings and opinions related to social exclusion and the psychosocial interventions needed to integrate OF women back into society.

The selection of the research participants for the life history interview was identified through the snow ball sampling method. This method was an

appropriate procedure to select potential participants in order to build a network of contacts and to increase the number of participants as it would have otherwise been difficult to access many of the women with fistula. In this study, six women with fistula who were able and willing to narrate their life story were interviewed.

Focus Group Discussion with Members of the Society

FGD was also used to obtain a greater insight into how the community perceives women with fistula and social factors contributing to the causes and consequences of OF. The participants in the FGD were selected with the criteria that they have stayed near the AAFH and women with fistula for ten to fifteen years. One of the FGD participants was a land lady for (several/many) victims. The other participants were neighbors of the land lady and the victims. All the FGD participants were members of the civil society. Accordingly, ten participants (3 men and 7 women who are between 40 and 50) were picked to participate in the FGD. The FGD was electronically recorded after permission was received from the participants and lasted for two hours. It was meant to supplement life story interview.

Interview with Pertinent Health Care Providers

Interviews were conducted with key informants from government (health officials) and non government organizations and intervention centre directors working on fistula. The key informant interviews are meant to get insight into the modes of interventions provided by the respective centres and their role in reintegrating victims back into the society.

Secondary Data

Published and unpublished secondary data on fistula such as reports on the cause, consequence and prevalence (UNFPA and EngenderHealth 2003); policy guidelines and strategy papers; government and non government reports on fistula; websites; documentary films ("A walk to beautiful" by Engel

Entertainment Production Inc.) and media coverage about fistula (Live convocation speech by Catherin Hamline on 24 July 2010 on Ethiopian television; Live TV talk show host by Mulu Muleta on 6 August 2010 on the same network) were also used to analyze and contextualize the findings of this study.

Data Analysis

All the primary data generated through life history interview, community FGDs and interview with pertinent health care providers were analyzed, transcribed, categorized and summarized manually. The literal quotes and descriptions of responses are presented and analyzed in the respective chapters.

Reflexivity and Ethical Issues

The Amharic documentary movie (with English subtitles), "A walk to beautiful" depicting the hidden, traumatizing and inhumane lived experiences of fistula victims in Ethiopia aroused my sense of curiosity and triggered my conscience as a student of Women, Gender and Development. I wanted to inquire about their lives beyond the physical repair of the fistula.

The study focuses on those fistula victims who went through all the many agonizing processes of social exclusions because of the offensiveness of their urinary incontinence before joining the intervention centre and then subsequently underwent rehabilitation and practiced reintegration after treatment.

The painstaking task of reaching these subjects stretched all the way to standing near the main gate of the AAFH and approaching, in a culturally appropriate manner, one of the respondents entering into the hospital for her biannual follow up appointment. I identified myself to her and clearly explained the objectives of my study after which she provided me with her contact address to set up the interview. I created a mutually understanding and cooperating relationship with her that renders her assistance in identifying

another woman with a fistula, a friend of hers. The first week of data generation, I managed to regularly visit their shanty homes and make detailed observations of their living condition while compiling their stories as dictated. Such close approach from an outsider is wonderful to these victims for they have lost their self esteem due to repeated and lasting exclusion from the society. Ultimately I managed to choose six respondents out of fifteen for the in depth interview in order to qualitatively reflect on the research questions.

Participants were reassured that their names would not be used and their responses, to any of the questions, would not be passed to anyone else and no reports of the study would ever identify them. If a report of results is published, the information would appear anonymously. The interview was voluntary. Additionally, they were informed that non-participation or refusal to respond to the questions would have no effect now or in the future on services that they or any member of their family may receive from any service provider. In this study, only volunteers participated.

1.6 Limitations of the Research

The study largely relies on life stories narrated by the victims themselves. By its very nature life histories based studies demand considerable time investment to thoroughly and meticulously narrate the situation. Therefore, the method chosen for this study is constrained by time factor to conduct further field work to rural places to analyze the rare situation of women cured from the complication and successfully integrated to their village of birth. Moreover, due to their old age and other unforeseen psychological situations, some of the respondents had no clear cognitive map of the sequence of events back to the age of onset of the complication there by depicting the precarious nature of sole reliance on such methods of data generation.

1.7 Organization of the Paper

This paper has eight chapters. Chapter one deals with the background of the study, problem statement, objectives of the study, the research methodology and limitations of the research. Chapter two focuses on the theories that are

emphasized in the study and also analytical framework used in the analysis of the findings of the research. Chapter three provides an overview of life histories of six women with fistula. Chapter four focuses on the pretreatment life of women with fistula and how they were dealing with early marriage and childbirth. Chapter five explains about the women's response to the treatments of rehabilitation and reintegration services. Chapter six focuses on their current conditions and how they are dealing with their post treatment life and analyzes the intersectional dynamics of rehabilitation and reintegration. Chapter seven looks into how the fistula issues are discussed and perceived by the society and also how the media talks about it. Finally, chapter eight gives the conclusions based on the findings and presents the reflections of the journey of the research.

2 THEORETICAL AND ANALYTICAL FRAMEWORK

This study made in depth qualitative observations and analysis with victims to invigorate denial of capability due the psychological, social, and economic consequences of exclusion and stigmatization on the basis of social exclusion and capability theoretical approaches developed by Amartya Sen. Women with fistula are not only physically debilitated but are also in need of rehabilitation and reintegration programs to restore their personal and community life. Such programs should encompass psychological, social and economic considerations to comprehensively address their needs. I see obstetric fistula as far beyond a medical issue and assertively believe that the victims demand access to those post treatment programs to restoring their capability for a better future.

The physically traumatizing scenario of fistula hampers the proper bodily functions of the victim and hence denies her full potential, necessitating the involvement of Martha Nussbaum's capability approach for critical analysis of the observations. Consequently, from a feminist stand-point, the study also identifies gender specific regimen of programs required by women with fistula in order to successfully reintegrate them into the society.

2.1 Social Exclusion

I used the ensuing description of social exclusion as reviewed in Silver (1995) noting that to be excluded one should be excluded from the following major elements:

> "[A] livelihood; secure, permanent employment; earnings; property, credit, or land; housing; minimal or prevailing consumption levels; education, skills, and cultural capital; the welfare state; citizenship and legal equality; democratic participation; public goods; the nation or the dominant race; family and sociability; humanity, respect, fulfilment and understanding" (Silver, 1995 in Sen (2000:1).

Social exclusion has been located within the field of poverty studies as a form of capability deprivation. This conceptual connection provides equal theoretical foundation for the approach to social exclusion and helps us to expand the realistic use of the approach (Sen 2000). According to Sen, poverty is the lack of certain basic capabilities to do something. In my view, fistula

victims are not supported by the society to participate in any role. Moreover, they are not emotionally supported to face the stigma related to the offensive smell or contamination of urine as a result of incontinence. This ultimately serves to end access to the community and hence they hide in darkness, living at the mercy of their family members to survive from day-to-day. Moreover, poverty includes not only income and material absence but a multidimensional dynamic experience consisting of vulnerability and exclusion. The major non material aspects to be considered are the segregation of the poor from participation in any way into opportunities and activities(Chant 2003). Thus, I strongly believe that the prevailing stigma and discrimination experienced by the women with fistula falls under the domain of the broader conceptual framework of social exclusion.

2.2 Capability Approach

In this research, I looked at fistula victims in terms of their history of disability due to the complication and their potential for reintegration. In that regard, it was significant to use A. Sen's and M. Nussbaum's capability approach.

Health is a major issue in Sen's capability approach, whether it is considered a part of an individual's well-being or whether health equity is considered as a part of the justice of social arrangements (Sen 2002). According to Sen, physical impairment is an example of the personal characteristics that should be taken into account in assessing poverty and personal well-being. Sen argues that the goal of human development and poverty reduction should be to expand the capabilities that people have in order to enjoy their 'valuable doings and beings'. This description has been collectively coined as functionings and it further suggests that poverty is not just related to income-deprivation but individual capability as well.

In this study, I used also Nussbaum approach as she criticized Sen's approach as not gender sensitive/specific enough and gives less emphasis to body's health and integrity. Nussbaum (2005) dictates that two of the capabilities denied by the victims of obstetric fistula could be a lack of bodily health and integrity as manifested by being unable to have good health.

Therefore, her approach could implicitly narrate the living experiences of these women from a gender sensitive perspective and the repercussions of the physical experience of their functionings.

Both, Sen and Nussbaum reiterated that a lack of self esteem and deprivation of decision making capabilities could exacerbate poverty. In this research these theoretical frameworks are used to investigate the salient ingredients for restoring confidence and building on opportunities for a successful recovery from the psychological and socio-economic devastation of stigmatization, exclusion and impoverishment.

Similarly, according to Nussbaum (2006), all beings are equally capable provided the social contract provides an avenue to realize that potential. Hence the capability approach is a helpful framework for defining disability. Under the capability approach, disability may be analyzed at two levels, as a deficiency of capabilities or as a deficiency of functionings. At the level of personal characteristics, this study used the concept of disability as a physiological, mental, or anatomical loss. In terms of capabilities and functionings, deficiency is the relations between the resources accessible to the person, their personal characteristics (e.g., impairment, age, gender) and the environment in which they live (Mitra 2006). Therefore, physical body integrity and hence the right to have an intact body is as important and it is one of the capabilities in the total characteristics of being and functioning. Thus, restoring the physical ability of these women is a leap towards reclaiming their proper social order augmented by concomitant psychosocial therapies. As a result, I believe that applying Sen's and Nussbaum's capability approach helped to analyze how victims are capable and resilient to deal with their vulnerability.

2.3 Intersectionality Approach to Analyze Women's Experiences

In this study, I used the very extensive definition of gender given by Joan Scott in Kent (1999) that gender is social consciousness ascribed to the sexual differences between men and women with respect to their physical, mental, moral and emotional representations as defined by nature for their roles and

activities. The experience of women with fistula cannot be described and analyzed only in terms of gender because gender does not function in a vacuum. To that end, I employed Collins (1990) theory of intersectionality.Her matrix of domination, from a feminist perspective, envisions intersectionality as different identities that flow together and result in identity politics; power relations that will result in different forms and practices of exclusion and discrimination; different social advantages and disadvantages; and finally, hierarchies and privileges.

I looked at the intersections of meanings and intersectionality of the situation of the women with fistula. Recognizing the fact that obstetric fistula occurs only to women suggests that both sex and gender have a strong relationship to the occurrence of fistula and the subsequent socio-economic consequences. Unequal gender relations are the major factor in relation to social inclusion and exclusion. The agency of women with fistula and their capability to cope with life intersects with factors like gender, power politics related to body integrity, marriage, age, class, religion, sexuality and disability. For instance, under development of the woman's pelvis because of her prematurity is the cause of labor obstruction and hence lack of knowledge of reproductive biology is another intersecting factor. In addition, the body physical feature of the victims, i.e. the bad odour coming from urinary incontinence often results in exclusion and stigmatization from society. The socio-economic class of the woman may have also an impact in the inclusion and exclusion of their experience. If the woman has gotten treatment in the very beginning of the condition she might not suffer from social exclusion. Accordingly, the women's right to health and well-being intersectionality will be explained in the next paragraph.

2.4 Women's Right to Health and Well -being

Women have the right to attain the highest level of sexual and reproductive health and autonomy. They have the right to access information that can make this possible and the right to make decisions about their reproductive health free from inequity and intimidation (Sen and Batliwala 2000). However, even

though OF is largely preventable and treatable, it remains one of the most neglected issues in maternal health and rights (Ahmed and Holtz 2007). As a result, the reproductive and sexual rights of women with fistula have not been fully taken in to consideration. Since women with fistula do not know that reproductive health is a fundamental right, they are exposed to severe exclusion and stigmatization. Therefore, in my belief reinstating fistula victims' capability will give them greater confidence and exercise of sexual health rights. Furthermore, Sen and Batliwala(2000:16) stated that freedom for responsible decision and control over one's own issues of interest such as sexual and reproductive health, free of coercion; discrimination and violence are major domains of the human rights of women. Accordingly, the condition of OF transcends sexual health needs and denies basic health rights and entitlements.

By extension of Nussbaum's approaches in terms of bodily health and integrity and intermarriage of physical and sexual health, I contend that women with fistula are women whose rights to physical integrity have been violated and whose rights to health and well-being are not also fully achieved. Consequently, even though restoring their physical integrity is given attention, much is sought to entitle to their overall wellbeing. As Chatterjee (1988) in Sen and Batliwala (2000:26) state, full engagement in social life demands securely exercising physical and mental well being in addition to freedom from violence and abuse and hence overall body integrity. To that end, in this study those fistula victims who have undergone an intensive rehabilitation period (which comprise training on reproductive rights) are given due focus for they are excellent informants in relation to understanding pre-and post-treatment rights and entitlements.

The extensive definition of reproductive health of the International Conference on Population and Development (ICPD) programme of action consists of all the elements that I require to analyze reproductive health issues in this study. Accordingly, reproductive health transcends beyond the proper functioning of the reproductive system and encompasses also a complete state of physical, mental and social wellbeing. Reproductively health individuals have a satisfying and safe sexual life and are capable to give birth to their discretion.

They have the inherent right to have access to family planning methods of their choice that are not against the law as well as obstetric care for safe pregnancy and child delivery to a healthy infant (in Sen and Batliwala 2000:15).

Other intersecting factors are also worth scrutinizing as atrocities OF traverse the complexities of reproductive health and rights deprivation issues affecting sexuality/marital affairs (Trouong 1990). A study done in Malawi for example detailed a variety of impacts to women's ability to have sex. For some women the shock was small and they could manage and envisage their situation adequately that fistula did not impede with intercourse (Yeakeya et al. 2009:506). A study in Ethiopia on the other hand showed that the majority of respondents keep in mind that their first sexual encounter lead to an obstetric fistula(Muleta et al. 2008). Hence, while sexual relations may be considered a pleasure, the reality is different for fistula victims. Therefore, it is another intersectional factor related to exclusion and inclusion from the society. Last but not least are issues of socio-cultural and ethnic background and their relationship to values surrounding early marriage. For example, I grew up in a part of Ethiopia where early marriage is rampant and have witnessed relatives' attitude towards it in terms of keeping family ties and sustaining dignity at the expense of the life of the young girl. All these factors influence positively or negatively women's well-being.

2.5 Framework of Analysis

The lived experiences of OF victims demand a tailored analytical exploration that takes into consideration all the factors since the onset of the complication including but not limited to early marriage and childbirth. Hence, pre-treatment, during treatment and post-treatment determinants will be categorically analysed based on the response obtained. Current information on fistula issues as presented, discussed and seen in the media and the society will also be highlighted. I have structured the analytical framework of this paper in such a way that the theory of capability will be utilized at all stages pre-treatment, during treatment and post treatment as depicted in the ensuing paragraphs. Analysis will also be made on the experiences of women with

fistula throughout in terms of their agency, rights, entitlement, disability and exclusion as analytical tools.

3 THE LIFE HISTORY OF THE SIX WOMEN WITH FISTULA

This chapter discusses the details of the life history of the respondents with regard to their pre-treatment, during treatment and post-treatment situations. Geographically, one of the respondents was from the Southern while the remaining five respondents were from the Northern region, a place where early marriage is widely practiced. Even though five of the participants had more or less similar experiences of stigmatization and exclusion, the degree of stigmatization and exclusion differed from one respondent to the other because of their personal and environmental characteristics. Five of the interviewed respondents were struggling with stigma and discrimination from society. In contrast, one of the respondents was able to reintegrate into society after treatment despite having a severe fistula problem. Generally, the psychosocial and economic consequences of exclusion and discrimination from society and their reaction to the available rehabilitation and reintegration program was more or less the same. In the next paragraphs a brief narration of their backgrounds and an overview of their differences and commonalities will be presented.

Toyba

Toyba, born in a locality called Derra, in the Wollo province, is the oldest of one brother and two sisters. She was married to a stranger husband at 13 without being asked for her consent. After two years she was divorced from her first husband (due to his bad drinking habit), and married to her second husband that was arranged by family. Her second husband was believed to have good character but like her first husband, he was neither literate nor did he support her desire to attend school. Sadly, her pregnancy from her second husband ended up in obstructed labor. Though her village was close to a health station it was her bad fortune that all the health care personnel were out on field work during her labor and thus she ultimately ended up with a traditional birth attendant. Due to the odour of urinary incontinence, her husband, family members and relatives with the exception of her father abandoned her. Her father was so compassionate for that he made her bed, washed her clothes and

took care of all the other hygienic processes necessary. She remained in this situation until she heard about the AAFH from foreign aid workers in the region. Toyba soon after travelled to the capital with her father carrying an ordinary hand written application or "referral" letter drafted by a member of her village. She first arrived to the Addis Ababa Black Lion Hospital and was later referred to the AAFH where she was admitted after waiting for 15 days on her own in a rented room.

Due to the severity of her case and her allergic reaction to catheters, which could have permanently solved her incontinence, she was unable to make a complete recovery and she still lives with the incontinence despite the hospital's efforts. Otherwise, she has been given a biannual medical check up for her ailments. She lives on only $10 support she receives from the hospital and a couple more dollars generated from selling simple handcrafts made when she feels healthy. Living in rented shanty room, miserable and hopelessness, she threatens, at times, to commit suicide.

Zayda

Zayda who does not exactly know her date of birth was raised by a single mother and step father married to her mother. She was raised in a Muslim family with nine siblings. As she got older disagreements and confrontations with her stepfather escalated and ultimately resulted in an arranged marriage to a stranger when she was only nine. She stayed with her first husband for four years and eventually divorced him and married again to a second husband from whom she became pregnant at an early age. Not surprising, the pregnancy culminated in labor obstruction. Her brother asked a traditional birth attendant/healer to treat her but she was not interested to attend traditional birth method. The traditional healer did not know that child delivery obstructions are most commonly due to an underdeveloped and narrow pelvic canal and forcefully pulled the obstructed fetus out of the vagina, damaging the vesicovaginal tracts which later lead to urinary incontinence. Zayda reported passing out for a good length of time and waking up with a strange sensation of wet bedding due to uncontrollably leaking urine. Her mother, cursing herself for the unfortunate destiny of her daughter started searching for a cure.

During this period they heard about the St. Paul Hospital and managed to make the trip. Unfortunately, the treatment provided to Zayda was unsuccessful. Zayda later moved to the capital in search of alternative treatment options for the fistula. She found the AAFH and was provided treatment. Due to the chronic nature of her fistula, the treatment was not able to completely repair the perforation and therefore her outcome was only modestly better than her previous condition.

Zayda is working as a day labourer, laundering clothing to win her daily bread. She additionally receives almost $10 a month from the hospital and pays extra care to maintaining her personal hygiene so as not to offend her neighbours. Even as close to the traditional norm of living as she is, she cannot invite neighbours for a coffee for fear that they might notice the physical consequences of her condition such as smells and stains on her clothing. She thus lives in devastating isolation!

Almaz

Almaz was around 12 years old when she was ceaselessly pressured by her older sister to marry a stranger priest. Neither Almaz nor her mother consented to this marriage. She also represents the youngest of the fistula victims I interviewed for this study. Almaz's sister believed that if Almaz married a priest she would be safe from STDs and would have a lasting marriage as a priest would not divorce her. However, a year after marrying Almaz ended up be pregnant. She was only able to visit her nearby health station once. Nonetheless, her pregnancy ultimately ended up in obstructed labor and hence a fistula was later diagnosed at a nearby health facility that also referred her to the AAFH. Between the onset of the complication and her referral to the hospital, her family were giving due care for her unfair agony.

The fistula hospital admitted her immediately and was able to surgically correct the condition with a catheter-supported urinary line ... her incontinence was cured. After the surgery, she was treated in the specially designed rehabilitation centre of the hospital called the "Desta mender" or village of joy. In this village she was given the chance to engage (together with others) in income generating opportunities such as food services, mopping and

laundering, feeding and milking cows and all sorts of other skills based activities. In addition, Almaz and the other fellow patients were also given education on topics such as premature marriage, nutrition, fistula, HIV, and all sorts of reproductive health issues. This information resulted in a paradigm shift in her thinking about how marriage should be and how devastating early marriage is for young girls.

Recent changes to the centre have resulted in the provision of particular skills trainings of interest to the patients in order to help them establish independence. Almaz took advantage of the program and also focused on teaching her fellow patients. She was paid a monthly salary of nearly $100 which she later used to start her new life, integrated back into society while pursuing school in the evenings. Almaz prefers to stay in and around the capital, Addis Ababa, instead of going back to her home village for two reasons. Firstly, for her regular checkups she prefers to be in close proximity to the hospital and secondly she can avoid physically demanding chores in the rural context that would compromise her relatively healthy life.

Belaynesh

Belaynesh is close to 50. She was born in Degadamot, Gojjam and was the last daughter in a family of seven children. She was in an arranged marriage to a stranger who was illiterate at the age of 12, but she initiated divorce almost immediately. However, at the age of 13 she was remarried to her second husband and shortly thereafter became pregnant. Her pregnancy culminated in labor obstruction lasting three days. Relatives used all of the traditional means available to ease the obstruction, including massaging her abdomen using flux oils. Fortunately, after days of labor she gave birth to a live baby. Unfortunately she was left with an obstetric fistula and hence urinary incontinence. Shockingly, Belaynesh was raped and became pregnant with her second baby while still suffering from an OF. All of this was emotionally devastating her.

Belaynesh is now the mother of two children and only survives at a level of absolute poverty and misery. A fellow woman from her village familiar with the city of Addis Ababa helped her find the AAFH. Luckily the hospital

admitted her immediately and tried to cure the fistula. The hospital helped her settle in a nearby suburb of the city. She receives monthly financial support from the hospital and continues as an outpatient.

Subsistence wise, Belaynesh has been supported by humanitarian and aid agencies for a long time but once these aid agencies ceased their support she started to involve herself in making handcrafts, embroidery and similar other tasks. That way she makes a living for herself and her younger son in their shanty room in which the older son already abandoned them to live on the street. She has lost her self esteem after this complication happened to her. As the urinary incontinence creates smells and stains, she always embarrasses and excludes herself. However, she is getting old now and lost her hope for recovery to a normal pre-fistula biology.

Belaynesh is so critical of the hospital's administration for denying any employment opportunity suiting her physical situation such as janitorial services and government for giving little attention to support fistula patients in general. Needless to say, she has no any steady source of income except that of the occasional cotton threading she does for a company which paid her extra $2 and $3 more on top of the monthly allowance from the hospital.

Tayech

Tayech who was raised in a family of six children came to the Hospital 40 years ago from her village in Hener, southern region. The cause of her fistula is characteristically different from the rest of the respondents. At 14 she was married to her stranger without her consult and became pregnant at 17. When her labor was obstructed during delivery, one of her relatives, summoned during the labor, cut her perineum with a razor blade to "widen" and ease the delivery of the child. Unfortunately this intervention also left Tayech with an obstetric fistula and urinary incontinence. Consequently, her husband abandoned her for another woman immediately and so did her family. Tayech likened her passiveness at the time to animals that accept what the parents say no matter what the circumstance.

Due to the severity and unique nature of Tayech's fistula a complete cure was not achievable. Nonetheless, the hospital continued to support her with a

regular monthly allowance to cover her room rent. Unfortunately the present day rehabilitation program of the hospital did not reach out to Tayech and others of her generation of fistula victims. Tayech does not receive any support from any of the administrative levels of the government either. Her desperation to life pushed her to become a nun where she spends her time in the church and lives off the charity of fellow followers of the religion.

Workie

Workie was born in Lasta, Wollo province and married at nearly 15 years old to a stranger who was illiterate. She immediately, became pregnant and unsurprisingly, ended up in obstructed labor that lasted for one exhaustive week. A relative who was a traditional birth attendant physically pulled away the still-birth. The forced removal of the still-birth culminated in a fistula and urinary incontinence. Consequently, her husband, relatives and most of her extended family members, except her brother, abandoned her. She was forced to live in hiding and darkness for three years, considered to be an embarrassment and shame to her family. Mercifully, and against the will of her mother, her brother managed to get Workie to the AAFH where she got treatment that enabled her to walk without suffering from incontinence.

However, Workie had to wait for one month before being admitted to the hospital. No one was willing to accommodate her because of the smell and stains of urinary incontinence. While in the waiting area, she was given transient life saving treatment at the Black lion hospital in Addis. Individuals who accidentally happened to approach her to help were also subject to stigma and discrimination, as is the case for most other victims. Exceptionally, Workie is now married to a new supportive husband and living her life in a government rented house. She receives a $10 month allowance from the hospital and with her husband's income from a government organization and the support of her current neighbours she was able to successfully reintegrate back into society.

4 EXPERIENCE OF EARLY MARRIAGE AND CHILDBIRTH AMONG WOMEN WITH OBSTETRIC FISTULA

In the ensuing section a detailed presentation and analysis of the experiences of early marriage, childbirth and sexual relations, lack of choice and rights in decision making and lack of body health and body integrity in the living experiences of the six interviewed women will be conducted from both a feminist stand-point and capability approach perspective. The deficiencies in the capabilities at this stage are education, lack of health facilities and professionals, lack of awareness about sexual and reproductive health and lack of support from natal and marital family members.

These women have been unfairly and unjustly victimized due to denial of their sexual rights and decision-making authority. Starting with the marriage proposal all the way to sexual relations and pregnancy they have experienced powerlessness to exercise their own agency and dominance by their husbands (Sen and Batliwala 2000).

All of them did not have prior acquaintance with their husband before their wedding. Moreover, none of the women were even consulted for their opinion on an arranged marriage to a stranger. The worst situation is that most of the women were married at or less than 13 years of age to a much older husband. A particular example is Zayda's case;

> "I got married at the age of 9 and my first husband age by the time I married to him was about 15 years. He was arranged by family and elder in a traditional marriage system. I had no idea when my wedding ceremony was being prepared but my mom told me just two days before the wedding ceremony that the preparation was for me."(Zayda)

> "I was not consulted and even pre - informed when I was to marry my husband. I was like animals who just passively accept what the parents had to say. It is not like the present generation who can refuse not to marry the person of not their interest." (Tayech)

Article 16 of the universal declaration of human rights, as stated by Jensen and Thornton (2003), reads, "Marriage shall be entered into only with the free and full consent of the intending spouses', and that 'Men and women of full age…are entitled to equal rights…". But, specifically in the Northern

part of Ethiopia early marriage is a rampant phenomenon for different reasons. A couple of reasons were stated by Zayda;

> "...As I was always in disagreement and quarrel with the step father my mother advised and at the same time forced me for an early marriage as an escape from that frequent confrontation with the step father at the age of 9." She also stated that "even though there is a government by-law prohibiting early marriage there is still family arranged subtle early marriage in rural places like my birth place (Borena). She also explained that "even sometimes my parents and generation of their likes also point their fingers to government not to indulge into their family affair... and as any decision on the future life of these children is the sole right of the parents only." (Zayda)

The same goes for Almaz but for different reasons. She recollects her past trauma and the complication and reasons she was forced by her older sister to get married to her ex-husband by saying that;

> "....My sister always pressured me to get married so that I will have a focused and stable life even at that premature age of me." (Almaz)

From this we can understand that Almaz could not practice her agency and her developmental stage of maturity did not allow her to make decisions in her own interest, even if she had a right to make decisions. Furthermore, the cultural context of her ethnicity it is a taboo for the family and disrespectful for the girl to refuse a marriage proposal for they are meant fulfil promises in order to maintain cross family ties and sustain dignity.

One of the negative consequences of the practice of early marriage is that young girls are usually not allowed to (continue to) attend school. From the above findings we can observe that early marriage means termination of education despite the will of the girl. Almaz was unable to stand up for her own rights and to refuse early marriage. She explained her case as follows;

> "...My mother wanted me to pursue with my school. I was a fifth grader but my second immediate older sister's-in-law wanted me to meet with my husband as they are close to each other. I was trying all the means not to get married but to continue with my school but all to no avail. They hide all my school materials such as notebooks and text books away from sight." (Almaz)

Conclusively, early marriage is a representative example of the violations of the basic rights of the child. According to Article 21 of the 1990 African Charter on the Rights and Welfare of the Child cited in Alemu (2008) *"Child marriage and betrothal of girls and boys shall be prohibited and effective action including*

legislation shall be taken to specify the minimum age of marriage to be 18 years." In addition, the newly adopted criminal law of Ethiopia (2005) cited in EGLDAM et al. (2005)[2] clearly stipulates the minimum age of marriage for women to be 18 years and with the full consent of both wedding parties. Unfortunately, knowledge of and respect for the law is limited among many parts of rural Ethiopia.

These women are denied of their reproductive rights as they were forced into sexual relations that lead to early pregnancy and ultimately OF. In some cultural contexts early marriage is accompanied by a traditional consensus to force the husband to refrain from having forced sexual relations with his wife during the first four years of marriage. This practice is known as "Egid"[3]. Nevertheless, it is in very rare instances that these consensuses are applied and honoured. For example, Zayda replied that;

> "My first husband trespassed that traditional consensus and forced me to have sexual relations with him and I had no clear knowledge of my reproductive rights to protect myself from such abuses." (Zayda)

The preceding response depicts the domination of men over women on the issue of sexuality. This supports Trouong's (1990) argument that sexuality issues have to be understood in terms of power inequality among men and women. Therefore, sexual power relations play a central and major role in the root causes of fistula. Complementary to what Chatterjee (1988) in Sen and Batliwala (2000:26) stated that body integrity means not only freedom from violence and abuse, but security in and control over one's body as well as the right to physical and mental well being in order to participate fully in social life. Belaynesh's unfortunate rape encounter is a case in point. She was raped after she received treatment for her fistula. I believe that her right to physical/body integrity was dishonoured and abused and her control of her own body was violated. In addition, the post-treatment rape of Belaynesh signals that

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[2] EGLDAM, UNIFEM and UNFPA (2005), Early Marriage in Ethiopia: Law and Social Reality. EGLDAM is the former National Committee for the prevention of harmful practices.

[3] Which literally means abstinence

reintegration can easily be hampered by denial of respectful human rights to live free from coercion.

In a similar comment, Almaz reflected on her past trauma related to the complication and the reason she was forced by her older sister to get married to her ex-husband, thus denying her right to choose a perfect partner for herself;

> "They believed that if I got married to a priest from the Ethiopian Orthodox Church by that age of 12 and as a young early school grader and follower of the same church I would be saved from any STDs as it is customarily believed that a priest never divorces and has a lasting marriage....sadly, the outcome was to my disadvantage putting me in a confused world of adulthood without any promise of motherhood and missed golden times of adolescence."(Almaz)

Another unfortunate situation is that these women had no control of their bodies even during labor and delivery. Their agency was taken over by family members and traditional healers in contradiction to their basic reproductive rights as noted in Sen and Batliwala (2000:15). The unanimous response delivered by the respondents highlights the fact that the expecting mother has no control of herself and her right during delivery-she has no choice. Instead, parents and close relatives are summoned to brainstorm and to elect to forward a traditionally known "midwife" who will use available materials including traditionally made oil to massage the abdomen and razor blades to cut the umbilical cord and "widen" the perineum. Midwifes in this context are typically operating without any knowledge of the detrimental consequences of their actions, particularly those involving forced removal of the child or cutting the perineum. In her appalling reply to this question, Tayech for example reiterated that;

> "...When my labor was obstructed for three days, one of my relatives randomly cut the pelvic floor muscles with razor blade to get the still birth and that is how the urinary incontinence and hence OF occurred."(Tayech)

I looked at the women as physical victims as well as a social being in terms of their own capability to cope with the psychosocial and economic consequences of exclusion and stigmatization from society. The agency of these women and their capability to cope with life is not merely on the basis of gender, but also in relation to the power politics that govern bodily health and

integrity, marriage, sexual relations, ethnicity, religion, class and age. All my respondents are from the same ethnic background called Amhara except Tayech. Intuition dictates that OF is much more prevalent and has a much higher correlation with this ethnicity for the mere fact that early marriage is widely practiced amongst Amhara. Young girls in this ethnic group are visualized as physical entities meant to sustain family dignity and maintain cross family ties without realizing the repercussion of the later on the physical, mental and social well being of young girls. Predominantly, the sources of that pressure are parents and community elders according to Alemu (2008).

Even though there could be many reasons that contribute to the complication of OF, the most important one is a lack of understanding on the consequences of early marriage in the life of young woman. They could not exercise their own agency when they got married and could not make decisions regarding who and when they married. In addition, the wider age discrepancy between the couples further exacerbated by the lack of education increases the prevalence of child marriage. This age discrepancy affects the level of communication, mutual understanding and the balance of influence within the family. In her disfavor, this situation gives men considerably more power and control over his wife at the very least and marital instability, termination of education (if any) and vulnerability to abuse, pregnancy and so on at worst. Not surprising, these husbands immediately abandon their wives once they realize that they are OF victims (at least from among the respondents of this research).

Even if all the subjects of this study were married and took the responsibility of housewife, none of them were accompanied by their husbands when they left for treatment to the hospital. Toyba explained her experience as;

> "...My second husband was a good one but he left me because of my fistula case and he did not even attempt to help me with my complication in any way." (Toyba)

Unfortunately, all the respondents were ultimately divorced and therefore did not go back to their village as their husband got re-married to another woman. Toyba for example illustrated that;

> "He was waiting for me for about five years but now I am informed that he converted his religion and married to another woman and that is the reason why I did not go back to my place."(Toyba)

I observed that feasible re-marriage and reinstallation of family life of these women to pre-fistula periods is highly influenced by the causative sexual and child delivery experiences of their complication. Tayech for instance decided not to go back to her village because of the divorce as she explained in her own words;

> "....Once I became fistula victim my husband abandoned me and got married to another woman immediately. I have nothing in hand to carry and get back and settle to my village."(Tayech)

But Almaz had a different experience for her husband was waiting for her despite her lack of interest in returning to him. She developed this phobia because of the traumatic experience associated with him. She explained that;

> ".....I am not interested to be with him any more as I have no any positive thing about him. All this reproductive complication is due to marriage with him at my early age."(Almaz)

Nonetheless, what is evident from the findings of this study is that remarriage, before the occurrence of fistula, but still at an early age was a common practice among the respondents. For example, In the case of Zayda as per the traditional norm of her community, her mother was asked to give her for another arranged marriage. Also Belaynesh affirmed that;

> "I tried to escape from my first husband and threatened my father that otherwise I would commit suicide and he let me stay single for a brief period of time. Then I was remarried to my second ex-husband after some months while I was still 13." She continued "...I divorced my first husband because I did not like his complexion." (Belaynesh)

In the very beginning she did not make her own choice and her marriage was arranged and ended with divorce. A fair exercise of agency and delivery of her rights seems tolerated by her father. It may be because he understood the unfortunate coincidence of losing her mother with the arranged marriage to a stranger. It appears that Belaynesh's first escape was with a laissez-faire nod from her father. By implication if parents are influenced by other intersecting factors of cultural background at or during the marriage proposal or before

fulfilling the marriage promises, they may give their daughter a chance to refuse the early marriage even for a transient period of time.

In Ethiopia, most of the time families are supportive when help is needed unlike in the scenario of fistula victims. The major reason for this lack of help is the bad odour arising from urinary incontinence. In most cases, mothers are supportive for their children unlike the case of Workie. Workie was considered an embarrassment to her family and in every possible way she was asked to hide and alienate herself in darkness from the family in order to not be evicted from the house. Workie remembered how her brother felt her agony and helped her find the appropriate treatment for her case by dictating as;

> "My brother was trying to escort me to Addis Ababa for my fistula treatment but my mother prohibited him from doing that otherwise she swore to curse him by all means of which refuted her request and saved my life." (Workie)

Similarly, Toyba remembers how her father was looking after her way better than her mother did. Because of this fistula case she loved her father more than her mother unlike what most people do.

Though, Zayda's case is different, she and her mother tried to find remedies for the complication. Unfortunately, she lost her mother during the process of treatments over the years. Zayda always feels that her physical and psychological agony might have contributed to her mother's unfortunate death. Once she lost her mother, she decided to move to the capital in order to live close to her treatment. She started a new life as a daily labourer by laundering other family's clothes.

In addition to lack of support from their husband, these women are incapable to reclaim their possession of properties due to the gender power relations which overall negatively affects reintegration. A particular example is what Toyba experienced;

> "My second husband was a good one but he left me because of my fistula case and he did not even attempt to help me with my complication in any way..." she continued, "...normally a woman takes her half when divorced but the worst thing about fistula is that woman takes her to the hospital and never go back to her village for she is left with nothing from her husband but the complication and its socio-economic consequences." (Toyba)

Furthermore, it is crucial to acknowledge the significance of the concept of disability. Mitra (2006) argues that deficiency is a result of the relations between the resources accessible to the person, personal characteristics and the environment. For the sake of traditional belief, most rural families want their daughter to give birth at home instead of modern health care facilities. Thus, due to such an unfair mixture of factors related to age and a lack of accessible medical facilities, victims are obliged to live with their physical disability.

OF affects women in rural Ethiopia due to unavailability of information on their reproductive rights and how they can make use of them, even with regard to the right of medical intervention and assistance. In my one on one chats with Almaz, she explained that there are many who live in shame, hiding their situation for fear of stigmatization and discrimination, in addition to lacking information on treatment possibilities. One possible factor that may contribute to lack information is denial of access to sexuality communication at the household level. OF victim who grew up in such cultural norms tend to accept the complication for granted as if they are obliged to live with it.

Lack of well trained healthcare professionals in proximity to help with midwifery is another added factor. The victims had to travel for many miles during obstructed labor to eventually deliver the child. For instance, Almaz and Toyba had to travel to a nearby health post and in turn were referred to the next higher health care centre or hospital while still in the midst of obstructed labor. They had to travel on horseback to reach their intended destination thereby worsening the complications and further deteriorating their health and that of the unborn child. The older the obstructed labor, the less likely it will be curable and vice versa. For example, the experience of Zayda is worth describing as she put it in her own words;

> "I was not conscious when I gave birth to my baby as my urinary bladder was ruptured due to over accumulation of the urine because of the over five days of obstructed labor ... and found out that my bedding was getting wet every morning I woke up.... nonetheless, the treatments given to me were not able to heal my urinary complication."(Zayda)

5 WOMEN'S RESPONSE TO THE TREATMENTS OF REHABILITATION AND REINTEGRATION SERVICES

The AAFH is the first fistula treatment hospital providing free services to the poor and neglected destitute women from rural Ethiopia. These women reach the hospital, sometimes after weeks of obstructed labor, may or may not be cured depending on the nature of the complication. Once the patients are admitted the utmost effort is exerted to cure the complication at all available cost. Once the treatment is done the patients will be assigned to the recently opened rehabilitation centre called "Desta mender" where they are provided with all sorts of psychosocial therapies and income generating skill training. Once they pass through the rehabilitation program, the hospital provides free transportation services to those who wish to reintegrate back into their village; and a monthly allowance of nearly $10 for those who wish to stay in or around the capital.

Effective fistula treatment consists of a triangulation of services that includes repairing the perforation to address physical health, psychosocial therapy to address mental and emotional health and income generating skill building to address economic survival. The whole of these services are intended to facilitate reintegration of the victim as a productive member of society. This chapter presents women's responses to the treatment and services provided during rehabilitation and reintegration.

The respondents in this research were from rural part of Ethiopia and came from a low socio-economic class with little to no access to education and information. As a result, these victims did not get medical treatment right after the occurrence of the problem or before the effects of social exclusion and isolation were felt. Therefore, they experience both a huge physical problem as well as issues living within the society. Workie's experience is a case in point;

> "The obstructed labor continued for one week in 1979. After one week of exhaustion one of her relatives who is believed to "know" midwifery in the traditional way forcefully pulled the still birth and she passed out and lost her consciousness and had the urinary incontinence and stayed like that for three years in shame without getting any medical treatment." (Workie)

Because of lack of information on accessible treatment and the lack of support from her family to receive treatment, she suffered a lot from the social exclusion. However, once she received the treatment she got some relief and remedy. Every time she feels some kind of uneasiness and sickness she immediately goes to the hospital and gets treatments. With the additional support of her husband and some of her neighbours, she has been able to reintegrate back into society. The treatment was helpful at least in the sense that she able to walk upright with proper posture. As a result she is very thankful for the medical treatment she received from the intervention centre.

None of the respondents had information as to what their reproductive rights were and how they could make use of them, including the right to have the fistula repaired and have intact body. Almaz guaranteed that there are many who live in shame, hiding their situation, cast out and discriminated against. She forwarded that;

> "I believe that there may be many more people of similar situation but do not know of any particular person of interest at that time. I thought I was the only victim of this by that time....and did not know where to go for the treatment. Once I visited my parents years back I approached a lady and advised her to approach the hospital for her situation as well." (Almaz)

Nonetheless, it seems that Almaz is not satisfied with use of catheter for urination as physical treatment as she reiterated it as "...in general the treatment is taken as the best alternative not an absolute solution to my physical complication."

Unfortunately, the rest of the respondents in this research were among the first batch of patients to visit the hospital. In the early periods of the hospital program establishment there was a great deal of hearsay and bad information regarding the admission and the services offered. For instance, Toyba carried an ordinary application letter written by a local man with a six grade level of education. She described it as;

> "There was aid commission in 1984 managed by foreigners and it was from them that I heard about fistula for the first time. The health personnel in the local health station had not advised me during my pregnancy about fistula and other related supposed reproductive complications. It was a lay man who started to tell and write an application about my case and refer me to the hospital in 1988. I presume that he was a sixth grader student during the Hailesellassie I regime. The

> hospital immediately accepted me but told me to wait for 15 days in rented houses before starting the unfortunately incurable complication of mine."(Toyba)

The hospital currently has a reputation for treating complications. As a result it is being used as role model for similar other hospitals in the developing world. In a personal interview I made with Mulu Muleta, a seasoned fistula surgeon, she reported that there are thousands of success stories for effective treatment of the complication depending on its nature and the age of the victim. Unluckily, the respondents of this research have the complication in one way or the other but at a lesser degree of severity. That is either by permanent closure using catheter based channels or relatively better physical situation due to the treatment and healing of most of the wound associated with the fistula. For instance, Almaz who was 13 years of age when she experienced the complication described the treatment in this way;

> "For about six months after obstructed labor and still birth I was taken care of by family and then went to the nearby health station in a town called Bichena. Then they referred me to the AAFH which welcome me and continued to give me the specific treatment for a year. The treatment they gave me were need specific to my situation. The treatment would not obviously regain the original natural situation but still help me live a life away from my urinary incontinence by using catheter and surgical closure of the natural urinary line. By doing so, I am thankful for no offensiveness and alienation has occurred as a consequence."(Almaz)

I am the first person to know these details other than the staff and her patient friends from the hospital and the "Desta mender". No one else knows of her treatment, even her parents have no detail of the status of the treatment. I think she is afraid to tell her treatment story due to the stigma and discrimination attached to fistula.

In the case of the other respondents, there is a bit of improvement in their physical situation after treatment though no complete cure was observed. The lack of a cure to their fistula complication could be a manifestation of its severity and post-labor length of time it took to reach the hospital. The severity of the problem could be exacerbated by another pregnancy and labor. Belaynesh's case is a point worth mentioning as she put it in her own words;

> "...then I was remarried to my second ex-husband after some months while I was still 13. Then I got pregnant and the obstructed labor stayed for three days and relatives tried all the traditional means of massaging my pregnancy using flux oils

> so that the labor could be eased but to no avail. Then the fistula happened and lead to urinary incontinence. Then I got back to home with my incontinence but was raped again and got pregnant and give birth to a second baby boy but still with a fistula complication. The AAFH gave me every treatment possible and always rushes to them whenever I feel sick and still I am living with it."(Belaynesh)

Once the patients received the treatment they were given a regular biannual appointment to assess their progresses, overall health and the status of their fistula. However, the regimen of checkups and additional fistula treatments are case dependent as put by Toyba's remark;

> "Every 6th month I had to go back to the hospital and check the status of the fistula but they always tell me that there is no fistula and they dare to give me a catheter to which I am allergic to. But once I started to lose weight continuously and went back to recheck the complication and they started to tell me there is fistula (hole) all over again and they told me to take bed. To that end, I had to make blood test and they informed me that I am positive for HIV and that in turn put me to another psychological distress and it was my friend who was on my side on that day as I am confirmed to be hit by a double edged harsh sword of life exacerbated by absolute poverty and was even attempting to commit suicide. This is the life I am living now."(Toyba)

Zayda explained the kind of education she was provided in her stay at the AAFH. She was only in the hospital for 15 days and was given basic Amharic alphabetic literacy education. This may not have been entirely helpful as she had prior knowledge of this alphabet. But she thinks by now the breadth and depth of the lessons given is much deeper and wider than the basic literacy education at that time. Lessons include topics such as prevention and mitigating mechanisms to avoid similar reproductive complications in the future.

Training for Reintegration

Presently, one of the hallmarks of the AAFH is its post treatment schedule of psychosocial therapy and income generation skills training strategies for victims in the specially designed rehabilitation centre. The major task of this centre is to enable the victim regain their self esteem and receive training in some sort of income generating activity while at the same time involving them in educational services on topics such as reproductive health and literacy. It is worth noting that the rehabilitation centre is a new development in the progress of the hospital. The earliest patients of the hospital (including my

respondents) did not have the opportunity to benefit from these services. Nonetheless, Almaz (who is relatively younger than the rest of the respondents) benefited from the rehabilitation centre and described her experience as;

> "In addition to the medical treatment provided, I was given handcrafts and other skills training program mostly supported by foreigners. Income generated from sell of those handcrafts is also shared to us. In addition, we were also given educational opportunities in health topics such as early marriage, nutrition, fistula, HIV, and all sorts of reproductive health. We had the chance to learn from one another and teach each other on such and similar topical issues of interest. These opportunities and experiences helped me standout and guide an independent life in the society."(Almaz)

The other respondents had also the opportunity of getting post treatment income generating skills training though no mention of psychosocial therapy was noted by all of them. For example, Workie remembers the handcrafts skills training given to her and how she used it "...in old days, I used to make handcrafts for sell but now I am not able to work on anything and have no income source".

In most cases OF is curable (as stated by Mulu Muleta) and the victims can live a normal life but in some situations it is not curable. This depends on the nature of the complication and the length of time the obstructed labor continued.

With the exception of one surgeon providing fistula surgery in Arbaminch hospital, free fistula surgery is offered only by AAFH and its outreach centres. There are other NGOs working on fistula eradication programs either by themselves or by partnering with AAFH. For instance, USAID works with AAFH by providing fund for fistula prevention and treatment, UNFPA, intra health international (working on awareness creation and transporting patient to fistula treatment centres and have their own fistula prevention project in the Amhara Region), EngenderHealth, Pathfinder and FHI and other local NGOs support in-patient identification and referral.

The exhaustive list of organizations in the preceding paragraph implies no direct roles on post treatment rehabilitation and reintegration except AAFH. Therefore, it is imperative to suggest that others working on maternal health,

and women and youth empowerment could be involved by educating the society about the devastating impact of OF and helping and empowering the victims to smoothly reintegrate and become productive citizens.

None of the respondents mention receiving any help from NGOs or GOs. Respondents were recommending what should be done to satisfy their basic needs. Belaynesh suggested that;

> "Any of the organizations should make thorough and in-depth observations as to how we are living and suffering from the complications. We are the most stigmatized and discriminated subsection of society, living in shame and isolated from any social life and activities to build themselves." (Belaynesh)

There is newly established nongovernmental waiting centre called the Trampleg Rose Inc. for obstetric fistula victims. The centre functions by using key informants with proper knowledge areas where early marriage is rampant to identify and locate OF victims. The victims are then provided with free vehicle transportation to the centre where they will be provided with all the available pre-treatment psychosocial therapies before being admitted for medical treatment to an assigned private hospital. Once the fistula is treated, the patients are relocated back to the centre and offered income generating skills training and rehabilitation programs to help them settle and guide an independent life at a later stage of reintegration. Presently, the centre is facilitating interest free microloans to the treated and rehabilitated patients so that they can become economically independent and reintegrate more successfully back into the community as productive citizens.

Highly likely it appears that the situation of OF in the country is so cumbersome that a coordinated and focused integration of governmental and nongovernmental organizations is critically sought to help the victims get treatment and reintegrate. Organizationally, a joint operation between such waiting centres and the other fistula hospitals could greatly supplement the post treatment and rehabilitation procedures of the latter to relieve patients of their economic misery.

6 THE INTERSECTIONAL DYNAMICS OF REINTEGRATION

This section of the paper discusses the dynamics of intersecting factors that contribute to a smooth reintegration for the women interviewed. Factors worth analysing include gender, class, age, religion, family and self awareness about modern medicine and presence and /or absence of children.

According to the information shared from my dialogue with Mulu Muleta and the victim interviews, all of the research participants except Almaz receive a monthly stipend of close to $10 to help them cover certain expenses such as house rent. However, a simple budget analysis shows that the stipend is far too little to cover all necessary expenses. The findings of this study reveal that victims engage in other income generating activities such as laundering other families clothing and as daily labourers in construction sites. The meagre income generated from these activities is so scanty that it would not even cover their own personal hygiene costs from month to month. The sheer pain of stigma due to the offensiveness of the odour effectively coerces these patients to prefer regular and daily cleanliness to food. Representatively, Zayda explained her situation as;

> "On top of the nearly $10 monthly stipend from the hospital, I engage myself in family laundering to earn additional scanty income of $ 2 to $ 3 per month out of it and whenever I feel healthy as daily labourer on construction sites to fill the gap. Nonetheless, sometimes all this is not sufficient to cover the cost of my own personal hygiene costs to clean up the urine and faeco-urine stains due to the incontinence. At times, such meagre income and expenses will leave me with nil to afford a once per day meal. So miserable life! " (Zayda)

I believe that stigmatization and social exclusion due to urinary incontinence is a crippling and debilitating driver of worsening poverty for these women. However, (Almaz) the youngest of the respondents working for the rehabilitation centre of AAFH and cured from incontinence has a modest income of around $100 a month and uses this to help her family of seven siblings (mostly for her parents). From Almaz's particular case, I contend that the smooth reintegration of these women is intersected by a complete cure from the complication (as positively affected by her younger age), the successfulness of postoperative training given by the rehabilitation centre and

the family's attitude towards it which enabled the patient reach to the treatment centre at the earliest time possible.

Besides, the degree of hopelessness and misery and the tone of satisfaction/dissatisfaction related to treatment at the hospital also seem to correlate with the presence or absence of children. Hence the postoperative mental situation tends to intersect with family circumstances. Understandably, the responsibility shouldered by a single mother that has been abandoned by her husband and close family members is significant in terms of the physical, emotional and economic strain. Belaynesh who was a fistula victim at 13 and became a mother of two and is now close to 50 years of age, remarked on her miserable post treatment life as;

> "I am hopeless and have no future plan but always feel guilty and cursed for my sons' future for being borne from me and have no any special skills training given to me from the hospital by then to help me guide a self sufficient life at later stages of post treatment."(Belaynesh)

Respondents of this research have no children except Belaynesh. Unfortunately, they all delivered still birth for their first birth and did not give birth for the second time. The fistula complication happened when Belaynesh gave birth to the first baby boy and the complication still existed when she was gave birth to the second baby. However, she did not see any further exacerbation of the urinary incontinence and associated complication after the second delivery. The worst situation is that her helplessness tends to lead to be a generational poverty for her kids. One of them has already started to live by the street in plastic shanty housing because she was not able to accommodate in her shanty room. She reported that everyone in her neighborhood knows that she is a fistula patient and so she is stigmatized and even insulted for her condition. She is living in a room without any electricity and hydro installations and she used rain water harvested from roof drops during rainy season and use that for all purposes including drinking and cleaning.

On the other hand, Almaz was worried about her health situation instead of having children. This may be because of her traumatic experience related to a complicated birth that ultimately leads to her condition as she put it in her own words as;

> "I wish to have kids and wanted to have but all depends on the status of my health situation. If my health situation does not permit me to do so I will not worry much for that. What I need is to stay healthy for the rest of my life and going to school and develop myself."(Almaz)

From the findings of this study it appears that consented remarriage after OF is an unlikely scenario. But Workie remarried willingly and has stayed with her second marriage. At first, she was excluded by her family and neighbours. But once she received the treatment, she did not intend to go back in fear of further exclusion and stigmatization. For that reason, she needed someone to stay beside her and therefore had an interest in getting married again as coping strategy. She explained that her husband is supportive and nice to her. With him she has been able to start a new life living comfortably and eventually reintegrating into society.

This research reveals that the two major livelihoods that serve as coping strategies are remarriage or exit from such social arrangement. Tayech left her birth village and the social context she was familiar with to live in the church - that is her exit strategy. She is now close to 50 years old and has left secular life to live as a nun in one of the monasteries of Addis Ababa. She is using form of exit as coping strategy to relief stigma. Her choice was not to be part of the society but to be a nun due to the incredibly deteriorating and incapacitating life situation she experienced as a result of urinary incontinence. Tayech is a victim and suffering tremendously but she is also exercising her agency. She has convinced herself that she better wait for her final days by serving God and living in faith instead of aspiring for improvements in her life situations. Thus, she has thereby lowered her expectations of life to the most basic level. With younger fistula patients, I believe that hope reigns and drives these patients to live their life expecting tomorrow to bring a brighter future and cure from their complication. But as they get older all that disappears and they tend to seek asylum from their misery in socially secluded environments. This justifies the argument that ideal rehabilitation and reintegration regimens should be delivered immediately postoperative in order to halt self isolation. Tayech's desperation was commented as;

> "I make plastic shopping bags and also thread cotton since long time to supplement the monthly $10 I receive from the hospital for my room rents and

> make a livelihood. My daily meals and the rest of the expenses including my personal hygiene costs to clean up the urinary stains is covered by donations and charity handed over to me from individual citizens seeking God's eternal blessings by helping the poor and destitute like me. So literally that is the life of a nun." (Tayech)

Interestingly, the opportunity to serve as a nun in the Ethiopian Orthodox Church provides a sanctuary for self abandoning followers and it seems that Tayech made advantage of that in order to cope with the harsh economic misery she was burdened with due to her physical disability. This implies that post treatment reintegration plans should recognize the critical role of the church, particularly for its passionate followers, and the church's ability to understand the unfair and unjust causes of fistula and its consequences to victims.

On a positive note, Workie's brother shared her agony and escorted her to the AAFH where she got the treatment to be able to walk upright. Additionally, while she was in the hospital, one of the security personnel was so helpful to her and treated her like his daughter and stayed at her side for humanitarian assistance until he passed away a year ago. He was even stigmatized because he treated her well. I believe that her experiences of support by her brother and the security personnel nullified the "male factor" in her complication and even became a positive association in her post-fistula relationships and marriage. She was eager to remarry and her motive to get re-marriage acquired success. Interestingly, she got a helpful husband and she sticks with him because he supports her and helped her to reintegrate. Workie wanted to have a child and that may have been a reason to get remarried while Tayech (the nun) was getting old and perhaps had no hope to have children.

Even though optimism for a better tomorrow inversely correlates with the age of the victims, especially for uncured fistula patients, others factors such as family awareness about modern health practices, the economic situation of the family members, and the cultural background/ethnicity might define the respective coping strategy they use.

Family awareness about modern health practices could be a determining factor in the possibility of cure and post-treatment reintegration of the victim. For instance, Almaz's family was keenly keeping her abreast with information

from the local health facility at the very onset of her complication in order to get a referral to the fistula treatment hospital. In addition, economic situation of the family of these patients could allow them to seek better treatment for the complication. Almaz's story of no discrimination and stigmatization from her family and neighbors as a result of bad odour could be facilitated by her family's particular economic situation and of her siblings' who refused her early marriage. In other words, the class of her family helped Almaz to receive treatment before she was stigmatized and before her fistula case becomes severe. As Almaz is also younger than the other respondents, and the other respondents were from the group of patients who did not receive psychosocial therapy from the AAFH, all of these supports helped her to reintegrate into society. Though the circumstances of her reintegration into society are different, Workie acknowledges present supports saying that;

> "…There is generational difference in the awareness of fistula in that, the present generation of fistula victims has better treatment services than the previous ones." (Workie)

Unfortunately, one way or the other, the respondents of this research do not get relief from their physical disability and are afraid to go back to their birth place. They are staying in the city and not reintegrating into the same situation. These women share some commonalities in their reasons for not going back to their birth place and reintegrating into the same social regimes.

Challenges of Reintegration *in the Same Social regimes*

OF victims share commonalities of interest at all stages of the complication starting from early marriage and denial of agency on decision-making and through the ensuing challenges of reintegration. Most of them have been stigmatized and alienated by the community, including family members and hence denied a social role in the community as a result of their disability. However, the degrees of the preceding factors involved determine the extent to which reintegration is possible (or impossible). The next paragraphs address the cross-section of common of interests and coping strategies of the respondents, if any.

The desperation observed from the research group is well manifested in their expressed frustration to get back to their village and re-establish their original life. All of the women generally attribute the lack of immediate access to health services for regular checkups and hence recognize poverty as a deciding factor. Accordingly, the best survival option is to stay close to the AAFH. The convocation speech by Catherine Hamline on 24 July 2010 at the Addis Ababa University and TV host interview with Mulu Muleta aired on 6 August 2010 by the Ethiopian television honoured the hopes bestowed by the five satellite fistula hospitals established across the different regions of the country. These mini fistula hospitals could provide immediate health services to returning patients who choose to reintegrate back into their village. Another important consideration is the lack of economic support for rehabilitated patients. Tayech's response is a case in point;

> "I have nothing in hand to carry and get back and resettle there. I do not even have my proper health to work like any citizen of the country neither does I know of my future plan. I have no idea of what to do in the future and all my future is on the hands of almighty."(Tayech)

The sheer scar of the psychological trauma that discourages these victims is mirrored in their frustration to smoothly reintegrate with their families, neighbours and communities. Hence, actual reintegration of patients requires a triangulation of services including providing immediate health services access, supporting economic independence and nullifying the fear and anxiety due to severe alienation. For instance, Workie, even with a supportive husband explained her social circumstances as;

> "It is a world where there is neither sympathy nor discrimination with some of my neighbours. I am not that close to my neighbours and they have no idea of who I am and that I am a fistula victim and my social life is just a passerby interaction. I have to hide my situation to avoid the ensuing discrimination and alienation that would further traumatize me worse than the physical deterioration I am living with."(Workie)

To her dismay, Zayda also had to use such specific survival strategy in order to exist with limited social life and self exclusion in fear of upcoming stigma as;

> "In my present address I live extra cautiously that my neighbours will not detect any of the physical consequences of my case. Still it is my due vigilance that is

> enabling me live my life as you can see me now. Despite customary to our traditional norm, I will not invite my neighbours for a coffee fearing that they might notice any of those physical consequences of my case such as smells and stains on my clothing. Otherwise, if need be and have to go out for social occasions such as comforting families of the deceased, I stay with them briefly and come back to my place immediately. That is how I am living (with extra caution). I believe that my case is not attributed to bad luck but rather lack of social comfort from others is the traumatizing sting that venoms me for my life."(Zayda)

If social acceptance is supported by close relatives, reintegration could be easier as long as there is a health facility in the proximity to monitor post treatment progress. Indeed, family is the core social institute that critically intersects with the possibility of success following postoperative reintegration therapy. The peak of stigma and social discrimination occurs when patients are alienated by close family members, such as parents and siblings, to whom they are primarily dependent for economic and psychological support. Furthermore, these patients demand imperative actions for they are physically disabled and have lost their bodily integrity that would enable them to work in ordinary situations and conditions. Hence the scale of poverty is substantial due to a denial of capability. Almaz's meticulous response is an exemplary case in point;

> "There are a couple of reasons that necessitate for my stay in and around the city of Addis Ababa and instead of going back to my village. The first and most important one is that preference to be close to the hospital as there may be any unforeseen post treatment problems that need immediate diagnosis. The other one is uncertainty to find a job in my village that suites my physical situations. Fortunately enough most of my close relatives are living in and around Addis Ababa and have no worry of any of isolation issues as all of them are most welcome of me. Thank God!"(Almaz)

Toyba additionally explains her reasons why she did not go back to her birth place and reintegrate into the same social situation as;

> "I am not able to go back to my birth place with this shame on the one hand and my relatives and cousins are all almost passed away and I do not know to whom I will reintegrate to." (Toyba)

From preceding remarks we can observe that even if these women were expected to go back to their place of birth and reintegrate into the same social regimes, they are faced with considerable challenges due to the aforementioned reasons. These challenges of reintegration may be reduced by the mini fistula

hospitals that can provide immediate health services to patients returning to their birth place.

7 FISTULA ISSUES IN THE EYES OF THE MEDIA AND SOCIETY

I strongly contend that the lack of awareness of the unjust and unfair consequences of fistula is a root cause of the complication, including denial of social roles and economic opportunities for reintegration. As a fulfillment of the study, I went onto explore the depth and scope of the issue through the eyes of the media at the national level. I solicited the perspectives of Mulu Muleta and Catherin Hamlin related to their recent media exposure as well as the insights of the neighbors and representative community members and also other actors who are working on fistula and presented it in the ensuing paragraphs.

Dr. Mulu Muleta is one of the seasoned gynaecologists working on obstetric fistula. She received the prestigious ATHENA international award and the Federation of the International Association of Obstetric Gynaecologists award for her remarkable career excellence in the treatment of obstetric fistula. She was hosted on a weekly Amharic TV show called "Arhibu" that aired on 6 August 2010 from 9-11 AM local time and broadcast to millions of viewers from all corners of the country. The show gives the opportunity for the viewers to make a virtual phone call and pose all pertinent questions that are either professional and/or personal. As a result, Mulu Muleta was able to share her invaluable career experience but also deliver her advice on the best possible interventions available to reduce, if not to stop, the occurrence of obstetric fistula.

In addition, Mulu together with other colleagues working on OF are also song writers, teaching the larger audience about the devastating impact of this complication on the lives of young woman through music. The songs are released and broadcast via local and national radio transmissions throughout the country.

Currently, Mulu is stationed out of the AAFH in order to reach the larger public. By training fellow physicians and involving herself at the teaching hospitals, particularly the Medical faculty of the Addis Ababa University, she is able to continue to share her expertise. According to her, the major motive to

join the teaching arena is to train more general practitioners to effectively treat OF. Moreover, she travels to other medical schools across the country to train students at their respective schools on OF as a part of their curriculum thereby addressing one of the critical issues - a lack of skilled medical staff who can address OF outside of the Addis Ababa. Such emergency obstetric care can reduce the risk of discrimination and stigma due to prolonged urinary incontinence.

Coincidentally, the Addis Ababa University bestowed an honorary doctorate degree to Catherine Hamlin on 24 July 2010 for her relentless work on OF. The entire convocation procession as well as her speech to nearly ten thousand students from the graduating class of 2010 was televised with a live transmission via Ethiopian television. In 1974 Catherine Hamlin, together with her late husband, Reg Hamlin, established the prototype AAFH to treat poor and destitute fistula victims from all corners of Ethiopia.[4] In addition to the AAFH, her medical and administrative leadership has also successfully established five more satellite fistula treatment hospitals in Bahirdar, Mekelle, Harar, Yirgalem and Metu. Hamlin is a reputed and UNFPA recognized fistula surgeon. She meticulously developed internationally recognized techniques to treat the complication. Among the notable recognitions she has received from around the world are Companion of the Order of Australia (26 January 1995), Centenary Medal for "long and outstanding service for international development in Africa" (1 January 2001), the Global Health council's "Best practices in Global health award" (2004), the prestigious "the right livelihood award" (2009) and she received a nomination for the Nobel Peace Prize in 1999[5].

I asked a couple of young women by the street if they knew Hamlin and her works. I was surprised to learn that her convocation speech was the very first time they had heard about her and her noble deeds. I find it compelling to

[4] http://www.hamlinfistula.org/our-hospital/autobiography.html accessed on 8 October 2010.

[5] http://www.hamlinfistula.org/our-hospital/awards-and-nominations.html accessed on 8 October 2010.

forward that her heartbreaking speech was an opportunity to expose the incapacitating and humiliating impact of fistula by reaching a larger audience, particularly young women who are the direct victims of the complication.

Nonetheless, it seems that the media are leaning in tandem with the policy recommendations of the government in their sole focus on the factors that lead to OF instead of post fistula psychosocial and economic considerations.

Furthermore, the FGD was conducted in order to obtain a complete insight into how communities perceive women with fistula and communities' attitudes and feelings about the experiences of women with fistula. The FGD participants mentioned that early marriage is the major cause of fistula. One of the participants in the FGD is living near to the Addis Ababa fistula hospital and was landlady for women with fistula for a long period of time. And the rest of the FGD participants were her neighbours and therefore had awareness about the issues confronting fistula victims. The FGD participants revealed that women with fistula have problems coping with the psychological, social and economic consequences of exclusion and stigmatization from society. According to the discussion, the major reason for stigma and discrimination from the society is due to the bad odour. Neighbours are afraid to enter the rooms of fistula patients and also think that the bad odour might cause disease. They suggested that the reasons why women with fistula do no return to their homes includes: stigma and social discrimination prior to treatment; their husbands were likely to remarry, a lack of relief from their fistula problem; and finally, as most of the women are from the rural areas of Ethiopia, they may prefer to stay near the hospital in and around the capital city.

The FGD participants explained that women with fistula are stigmatized and discriminated from social and religious gatherings due to the smell of the urine. One of the FGD participants (the landlady of the women with fistula) explained that "when the fistula patients were rented a room in my house, nobody was coming and visiting me fearing the bad smell of the urine; my neighbours were blaming me for letting the fistula women in my house and stinking the neighbourhood." Besides, the FGD participants mentioned that women with fistula are ascribed as "fistula women" and useless people in

society. Due to this exclusion, women with fistula suffer tremendously, particularly as they attempt to hide themselves away from society. The participants explained that the women with fistula are excluded due to the bad odour and even if some of the victims tried to keep themselves clean they do not have enough money to buy detergents.

The FGD participants explained that now fistula issues are starting to be raised in the media but caution more is needed in order to raise awareness about fistula in the rural parts. In addition, they explained that the media has to reveal the socio-economic miseries of women after treatment, including the difference between a complete and incomplete recovery. The FGD participants recommended that a lot has to be done to reduce the prevalence of fistula and also noted that there should be a special program that focuses on reintegration and rehabilitation. Further, the FGD participants put a lot of emphasis on the need for collaboration between governmental and nongovernmental organizations to assist victims in getting treatment and reintegrating them back into the society.

Lastly, I realized from the interview held with the different health care professionals that the vast array of psychosocial crisis encountered by OF victims is beyond the shoulder of the AAFH and its subsidiary satellite fistula hospitals. Functionally, the operational procedure for the hospital is either through referral system from regional health stations or through direct admission of the patients in person. Subsequently, accounting for the discrimination and alienation brought on by the urinary incontinence, the proportion of OF victims who break the cultural blockade to travel to the hospitals and receive treatment needs further investigation. The actors explained that today, fistula issues are discussed by the media and the community, though the emphasis remains on halting the causes of it and not on the psychological and socio economic consequences of the condition.

8 CONCLUSION

The analytical framework in the aforementioned chapters discussed the detailed lived experiences of six rural women with fistula currently staying in the capital city. With perspectives of pre-treatment and during treatment experiences, the study mainly focused on the post-treatment circumstances of these women, including the issue of accessible rehabilitation and reintegration, a subject that seems to have been overlooked by other studies and government policy strategies. Furthermore, this paper tries to evaluate cooperating factors involved namely gender power relations, sexual rights, access to entitlements and other intersecting factors and their implications on denial of capability. Consequently, coping strategies to avoid exclusion and stigmatization; and perceptions and coverage of the issue by the general public and media are addressed. Ultimately, the study highlights salient policy interventions sought while broadening the knowledge base on the psychological, social and economic consequences of OF.

For women with OF, denial of their sexual rights and the right to make decisions about reproduction free from inequity and intimidation, starts from the point of the marriage proposal and continues all the way through sexual relations and pregnancy. Women and girls are shown to be largely powerless to exercise agency while men (husbands) are the dominant decision-makers. As they are denied their sexual rights, these women are forced into unwanted sexual relations that lead to unwanted pregnancy and ultimately OF. Moreover, understanding of early marriage as a mechanism to sustain family dignity and maintain cross family ties is not balanced with a clear understanding of the repercussion of early marriage for girls. It is worth mentioning the recently adopted criminal law in Ethiopia that prohibits early marriage before the age of 18 and marriage without the full consent of both wedding parties. However, the critical point is increasing social awareness of this new by-law, especially in rural areas where OF issues are dominate.

The AAFH provides treatment and tries to cure fistula whenever possible. However, the probability of curing the complication is affected by

factors such as the severity of the complication that in turn is determined by the age of the woman, the length of time birth was obstructed and the time taken to reach the hospital after obstruction. Despite the thousands of success stories, this constellation of factors seems to hamper successful repair of the fistula. Similarly, though all of the respondents of this study except one were not a part of the recent development of the rehabilitation centre, the commonalities of the factors involved in challenging a smooth reintegration process necessitate exploration in order to identify a comprehensive cure. Social exclusion due to the offensiveness of the bad odour leads to a loss of self esteem, an inability to reintegrate and limited access to social roles and economic opportunities. It seems that the current rehabilitation programs at the hospital targets restoring self esteem and economic empowerment through specific skills training.

Interestingly, it seems that other intersecting factors such as age, presence/absence of children, family background and religion also have a role in determining the exit mechanism and coping strategies used to remedy the situation of isolation. While hope for a better future seems inversely related to age, the degree of family awareness about modern medicine and the attitude towards the OF victim and presence/or absence of support from the latter seem to be the most important factors related to successful reintegration after treatment. The absence of need specific economic opportunities in the village of origin is another critical component to addressing reintegration. Almost all of the respondents commented that they had nothing to do as their physical disability deprive them from being involved in the prevailing heavy duties of living in rural Ethiopia.

Notably, the finding suggests no major reliable organizational evidence to support the physical complication and post fistula psychosocial trauma of these women except AAFH. These women are facing more severe psychological, social and economic consequences due to stigmatization and discrimination from the society. It is of paramount importance to focus on ways to halt early marriage, as is being done by both governmental and NGOs, but none of them have addressed the debilitating post-treatment life situation victims routinely

experience. I believe that the issue of fistula is beyond the carrying capacity of one hospital and therefore keen attention is required from other NGOs working on maternal and youth issues, and from the government itself to address the challenges of rehabilitation and reintegration. NGOs working with orphans and the destitute could relieve victims who have children, thereby discontinuing generational poverty. While others working on women empowerment would provide access for those young victims in need of further education. By and large, the media seems to emphasize the issue of early marriage as a factor contributing towards unwanted pregnancy and vulnerability to reproductive health complications such as OF. To my knowledge, no viable emphasis seems to be offered in relation to the post-treatment socio-economic miseries and challenges confronted by OF victims.

Finally, the paper tried to present the postoperative rehabilitation or reintegration challenges of these women as a result of the social stigma and exclusion they experience. The findings of this study justify A. Sen's deprivation of capability as a cause of poverty while providing evidences for M. Nussbaum's lack of body health and integrity as an added factor towards the same end. This research ultimately provides a qualitative foundation for future researchers to extrapolate further on similar disabilities and to conduct an analysis using the theories of capability and exclusion.

References

Abou-Zahr, C. (2003) 'Global Burden of Maternal Death and Disability', *Br Med Bull* 67(1): 1-11.

Ahmed, S. and S.A. Holtz (2007) 'Social and Economic Consequences of Obstetric Fistula: Life Changed Forever?', *International Journal of Gynecology & Obstetrics* 99: S1:S10-S15.

Alemu, B. (2008) 'Early Marriage in Ethiopia: Causes and Health Consequences', *Exchange on HIV/AIDS, sexuality and gender* (1): 4-6.

Atkinson, R. (1998) *Life Story Interviews, Sage University Paper Series on Qualitative Research Methods*. Vol. 44. Thousands Oaks: CA.

Browning, A. (2007) 'The Circumferential Obstetric Fistula: Characteristics, Management and Outcomes.', *International Journal of Obstetrics and Gynaecology*. 114(9): 1172-1176.

Chant, S. (2003) *New Contributions to the Analysis of Poverty: Methodological and Conceptual Challenges to Understanding Poverty from a Gender Perspective*. Santiago, Chile: United Nations.

Collins, P.H. (1990) *Black Feminist Thought: Knowledge, Consciousness and the Politics of Empowerment*. New York: Routledge.

David , M. and C.D. Sutton (2004) *Social Research. The Basics*. London: Sage.

Goh, J.T.W., K.M. Sloane, H.G. Krause, A. Browning and S. Akhterd (2005) 'Mental Health Screening in Women with Genital Tract Fistulae.' *International Journal of Obstetrics and Gynaecology*. 112: 1328-1330.

Goodwin, W.E., and P.T. Scardino (1980) 'Vesicovaginal and Ureterovaginal Fistulas: A Summary of 25 Years of Experience', *J Urol* 123: 370-374.

Graham, W. (1998) 'The Scandal of the Century.', *Br J Obstet Gynaecol* 105: 375-376.

Jensen, R. and R. Thornton (2003) 'Early Female Marriage in the Developing World.', *Gender and Development* 11(2): 9-19.

Kent, S.K. (1999) *Gender and Power in Britain, 1640 - 1990*. II New fetter Lane, London EC4P 4EE: Routledge.

Langkilde, N.C., T.K. Pless, F. Lundbeck and B. Nerstrom (1999) 'Surgical Repair of Vesicovaginal Fistulae: A Ten-Year Retrospective Study.', *Scand J Urol Nephrol* 33(2): 100-103.

Marshall, C. and B. Rossman (eds) (2006) *Design Qualitative Research*. (4 edn). Thousand Oaks: CA: Sage Publications, Inc.

Mitra, S. (2006) 'The Capability Approach and Disability', *Journal of Disability Policy Studies* 16(4): 236-247.

Muleta, M. (2004) 'Socio-Demographic Profile and Obstetric Experience of Fistula Patients Managed at the Addis Ababa Fistula Hospital', *Ethiopian Medical Journal* 42(1): 9-16.

Muleta, M., C.'. Hamlin, M. Fantahun, R.C. Kennedy and B. Tafesse (2008) 'Health and Social Problems Encountered by Treated and Untreated Obstetric Fistula Patients in Rural Ethiopia. ', *International Journal of Obstetrics and Gynaecology*. 112: 1328-1330.

Nielsen, H., L. Lindberg, U. Nygaard, H. Aytenfisu, O. Johnston, B. Sorensen et al. (2009) 'A Community-Based Long-Term Follow Up of Women Undergoing Obstetric Fistula Repair in Rural Ethiopia.', *An International Journal of Obstetrics and Gynaecology* 116: 1258-1264.

Nussbaum, M. (2006) *Frontiers of Justice: Disability, Nationality, Species Membership.* Cambridge, MA: Harvard University Press.

Nussbaum, M. (2005) "Women's Bodies: Violence, Security, Capabilities", *Journal of Human Development: Alternatives Economics in Action* 6(2): 167-184.

Sen, A. (2002) 'Why Health Equity?', *Health economics* 11(8): 659-666.

Sen, A.K. and Asian Development Bank. Office of Environment and Social Development (2000) *Social Exclusion: Concept, Application, and Scrutiny*. Citeseer.

Sen, G. and S. Batliwala (2000) 'Empowering Women for Reproductive Rights', in H. B and G. Sen (eds) *Women's Empowerment and Demographic Processes: Moving Beyond Cairo,* pp. 15-35. Oxford University Press.

Trouong, T.D. (1990) *Sex, Money and Morality: Prostitution and Tourism in South-East Asia.* London: Zed Books Ltd.

UNFPA and EngenderHealth (2003) 'Obstetric Fistula Needs Assessment Report: Findings from Nine African Countries', New York. UNFPA and EngenderHealth.

Vangeenderhuysen, C., A. Prual and D. Ould el Joud (2001) 'Obstetric Fistulae: Incidence Estimates for Sub-Saharan Africa', *Int J Obstet Gynecol* 73: 65-66.

Wall, L.L. (2006) 'Obstetric Vesicovaginal Fistula as an International Public-Health Problem', *The Lancet* 368: 1201-09.

Yeakeya, M.P., E. Chipetab, F. Tauloc and A.O. Tsuid (2009) 'The Lived Experience of Malawian Women with Obstetric Fistula', *Culture, Health & Sexuality* 11: 499-513.

Appendices

Annex I: Interview Guideline for Life Story Data Collection

General Characteristics of the Respondents

The following questions were asked about their personal information: age, ethnicity, school attendance, current work, live with partner, husband age, husband school attendance, age at the time of first marriage, age at the time of first pregnancy.

The questions below were guidelines in each interview and for clarification other probing questions were also asked.

Women with Fistula before Treatment

- Did your family consult you to get marriage?
- When did you get OF? At what age?
- How many time OF occurred?
- How many children do you have?
- How was the new responsibility of being mother and fistula victims?
- When did you develop OF? On the delivery of the first/second birth?
- Did you have information of maternal care and seeking behavior before?
- Is there any cultural influences and male dominance continue to hinder you from seeking health care?
- For how many hours obstructed labor was occurred?
- Who monitored the labor?
- Was there transport problem?
- After what time you reached to the hospital?

Institutional support

- What are the interventions given by the centres to reintegrate with the society?
- How do you experience the rehabilitation services provided by the intervention centre?
- Do you gained or missed from the intervention centre?

Post treatment Life

- After the hospital with whom you started to live?
- After you come back from the hospital does your husband/kids/families/neighbors welcomed you?
- What happened to you after you have left the intervention centre?
- How the communities perceive fistula victims?
- Do you know about reproductive and sexual health and right are the major issues in fistula concerns?
- Are there any other fistula victims that you know and who do not receive the treatment yet?
- How the media, government (health offices) and non government organizations, intervention centres look at the fistula issues and being discussed and what kind of interventions are proposed?

- What is your plan in the future?

Annex II. Focus Group Discussion Guide for Society

- Do you know what fistula means?
- How do women with fistula deal with psychological, social, and economic consequences of exclusion and stigmatization from society?
- What kind of assistance available to support women with fistula?
- Are they receiving assistance from the immediate family and societies?
- How the communities perceive fistula victims?
- How the media, government (health offices) and non government organizations, intervention centers look at the fistula issues and being discussed?
- What do you suggest that should be done to reintegrate them with the society?

Annex III. Interview with Health Care Providers

- Are you working on fistula?
- Do you have network with other organization that is working on fistula?
- If your organization has networking, how you are working on fistula with other organization?
- What are the psycho social interventions given by the intervention centres to reintegrate women in to the society?
- Do you know that the intervention program is helping them to reintegrate with the society?
- How fistula victims experienced the reintegration and rehabilitation programs given by the intervention centres?
- How do women with fistula deal with psychological, social and; economic consequences of exclusion and stigmatization from society?
- What kinds of interventions are planned?
- How the communities perceive fistula victims?
- How the media, government (health offices) and non government organizations, intervention centres look at the fistula issues and being discussed?