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**THE 'TYPICAL STORY' OF OBSTETRIC  
FISTULA: THE NEED TO ENHANCE  
AWARENESS, ACTION AND FUNDS**

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**The ‘Typical Story’ of Obstetric Fistula:**  
**The Need to Enhance Awareness, Action and**  
**Funds**

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The word length stated is accurate and the work contained in this dissertation is wholly my own.

Signed

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## **ABSTRACT**

Obstetric fistula, a childbirth injury, affects the poorest women in Sub Saharan Africa and South Asia. In this dissertation I explore the representation of obstetric fistula in development organisations' rhetoric, media articles and scientific literature and how these representations relate to development discourse and practices. By conducting qualitative interviews in Ethiopia I sought to understand how people, who had not had fistula themselves, understood the causes and lived experience of the condition. I will demonstrate the social significance and historicity of words and the importance of 'selling' an issue to the public in order to enhance awareness and funds. Although the purpose of charitable appeals, media articles and scientific research surrounding obstetric fistula may be aspiring towards a positive goal, the representation of the condition is far more complex and may have negative ramifications. A 'typical story' of fistula is often promoted by various sources which often evokes and furthers stereotypical ideas of Africa in a number of ways. The 'typical story' can simultaneously engage people in the subject and also discursively disempower the very beneficiaries organisations are trying to help.

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## **INTRODUCTION AND METHODOLOGY**

Obstetric fistula is a childbirth injury usually caused by unrelieved, prolonged obstructed labour. Obstructed labour can develop during the second stage of labour, when the foetus cannot fit through the birth canal because the pelvis is too small, the baby is too big or if there is a malpresentation. If the woman in labour does not die, the pressure of the baby's head on the mother's pelvis leads to the death of tissue in the birth canal which creates a hole called an obstetric fistula. From this hole, urine and/or faeces constantly leak. The majority of women also deliver a stillborn baby. Fistula is completely preventable if obstructed labour is diagnosed early and if appropriate timely intervention occurs, which often includes the performance of a caesarean section (Wall, 2012b). Once common in Europe and North America, fistula is no longer prevalent in the west due to the advancement of obstetric services. Therefore, fistula is now typically found in the world's poorest countries where obstetric services are non-existent and/or difficult to utilise. There are currently 3.5 million women living with fistula in Sub Saharan Africa and South Asia and it is estimated that between 50,000 to 100,000 women develop fistula every year (WHO, 2010a). Fistula can be 'cured' by an operation, which is successful in 80-95% of cases (Wall, 2006:1024).

In my dissertation I will explore the representation of fistula presented in Non-governmental organisations' (NGOs) discourses, media articles and scientific literature and by my Ethiopian informants. I seek to contribute to research that critically analyses how different sources raise awareness and funds for global

development issues, and how this process may have unintended discursive and practical implications for the very people they are trying to help.

I have three main research questions:

- (1) How do different sources represent obstetric fistula?
- (2) How do these representations relate to the development discourse?
- (3) What are the implications of these representations?

The issue of fistula has been increasingly publicised in the west due to many development organisations' campaigns, media articles and scientific research about the subject. Work surrounding fistula contributes to the Millennium Development Goal Five of improving maternal health (WHO, 2010d). In 2003, the United Nations Population Fund (UNFPA) launched a global 'Campaign to End Fistula' and they now work in fifty different countries on the issue of fistula (Campaign to End Fistula, 2013). Although many organisations work towards the same goal - to prevent and treat fistula and to rehabilitate sufferers - the way that different organisations represent the condition varies significantly.

There is often a common depiction of fistula presented in these literatures, which is generally structured around three stages. Firstly, a girl, who has suffered a childhood of disease and malnutrition, is forced into marriage at an extremely young age, having often undergone genital 'mutilation'. She soon becomes pregnant and experiences complications in labour due to her underdeveloped pelvis. Then, because of the lack of emergency obstetric services, she develops fistula. Secondly, due to her incontinence, she is abandoned by her husband, stigmatised and ostracised by her

family, friends and community and is left to a life of destitution. Thirdly, if she is lucky enough to find a hospital that provides western services for operating on fistula, she can be 'cured' by a 'simple' operation, which leads to her 'rebirth' (Hamlin, 2004). I will refer to this common portrayal of fistula as the 'typical story' of fistula. Although the 'typical story' is the main focus of my dissertation, there are important variants between different sources, which I will also highlight in chapters three and four.

The development discourse is hugely significant to the representation of fistula in a number of ways. I will argue that the need to appeal to the public and donors often influences the common representation of fistula in the media, NGO discourses and scientific literature in implicit and explicit ways. I will also argue that some aspects of the 'typical story' of fistula significantly over-simplifies the causes and lived experience of fistula and can have unintended local implications. In the first chapter I will analyse five different factors that underlie the common representation of fistula, which will form the basis for the rest of my dissertation. In the second and third chapters I will address the causal factors of fistula. I will show that poverty and global and local inequalities dictate the prevalence of fistula in many ways. Although these factors are often highlighted by different sources, they are sometimes glossed over in favour of drawing attention to 'child' marriage and/or 'female genital mutilation'. In the third chapter I will explore the possible reasons for focusing on these practices and the implications of this rhetoric. Finally, in chapter four, I will suggest that the depiction of fistula-related stigma discursively disempowers women with fistula.



## METHODOLOGY

I conducted my primary field research in three places in Ethiopia in Sub Saharan Africa. Through fifteen semi-structured interviews and participant observation, I attempted to understand how my informants understood the causes and lived experience of fistula. For six weeks I volunteered at a summer school in a town called Nazaret in central Ethiopia. Dawit, the head teacher of the school, put me in contact with a number of different people to interview. I also stayed at Attat missionary hospital in rural south-western Ethiopia and visited Addis Ababa Fistula Hospital for a tour of the hospital. At the missionary hospital I interviewed (western) missionaries, local medical staff and patients. The majority of my interviews were conducted in English, except for the patients at Attat Hospital where I used an interpreter. I later transcribed my interviews and identified common themes among them. Although I interviewed people from diverse backgrounds during my time in Ethiopia, I predominantly interviewed middle class Ethiopians who had grown up in urban areas of Ethiopia. Therefore, my research mainly focuses on how 'more educated', middle-class Ethiopians understand fistula.

A number of issues affected my research throughout my time in Ethiopia. People were often extremely hesitant to be interviewed if they knew they were participating in 'research'. This was connected to anxieties surrounding the government and was also exacerbated by my identity as a 'ferenj' (white person). As a 'ferenj' I was often simultaneously treated with respect and suspicion, which contributed to complex power dynamics within my interviews. I often felt my identity

as a 'ferenj' influenced what my informants did and did not tell me. Although this issue would be difficult to overcome, it could be improved by ensuring that an interpreter was present during all the interviews. My informants would have most probably felt more comfortable and able to discuss their views with a 'local' and if they could speak in their first language. Language was also a barrier as I relied on most of my informants speaking English, which could hinder communication at times. One possible research bias also relates to the selection of my informants, as I relied on Dawit in Nazaret and Sister Rita at Attat Hospital for introducing me to people I could interview. I also only interviewed a small number of middle-class Ethiopian informants. Using random sampling and a larger sample-size would therefore enhance the reliability and depth of my findings. It is also important to note that I only discussed issues surrounding fistula with people who had not had the condition. This meant that much of my informants' knowledge came from media and NGO campaigns. Although the Ethiopian doctors and missionaries I interviewed obviously knew more about the condition, they interestingly had quite different opinions.

I have also researched many NGO and other organisations' discourses, scientific and media articles on fistula through the Internet. This has been vital to my dissertation, as there are numerous organisations working on the issue with very different approaches to the discursive representation of fistula, as well as to the practical side of prevention, treatment and rehabilitation. I will also draw on research from different countries beyond Ethiopia throughout my dissertation. One NGO that

I will focus on is that of Woman's Dignity Project (WDP) who are based in Tanzania, as they actually work against the 'typical story' in numerous ways.

## **CHAPTER ONE: DEVELOPMENT DISCOURSE AND REPRESENTATION**

This chapter explores how the development discourse relates to the 'typical story' of fistula. Hannig argues that the common portrayal of fistula gains currency because it tells a 'recognisable story' of 'women's oppression and reproductive despoilment in the Global South and their subsequent salvation through Western intervention' (Hannig, 2012:215). I aim to elaborate on this argument in more detail through exploring five factors that are fundamental to the representation of various issues in development and humanitarian discourses. These five factors generally underlie, and may fuel, the representation of fistula presented in NGO discourses, media articles and scientific literature to varying degrees, which I will show throughout my dissertation. These factors are connected to a practical reality of NGOs and the media: the need to 'sell' their projects and stories in order to engage people in the issue, raise funds and encourage people to act. Using a wide-range of literature, I will show that implicit understandings of: (1) long-standing stereotypes of the 'Third World' and Africa; (2) the passivity of victims; and (3) appeals to an underlying humanity are important in many development and humanitarian discourses. I will then discuss how (4) actively utilising development language and (5) conforming to contemporary development visions can also relate more directly to funding opportunities.

### **DEVELOPMENT DISCOURSE**

A discourse is a group of statements that provide a language for talking about a particular kind of knowledge. The language and knowledge of development is intrinsically tied up with

the 'discursive practices' of large development institutions (Hall, 2002), such as the World Bank as, well as smaller 'grassroots' organisations. Contemporary development discourse and practices have become normalised into political and economic thinking in many parts of the world. The proliferation of 'good governance', an open market and universal human rights are examples of particular western values that are widely encouraged and are asserted as 'correct' in development discourse and practices (Crewe and Harrison, 1998). In many African countries, the activities, concepts and material manifestations of development practices are widely apparent (Yarrow, 2011). During my time in Ethiopia I lived in a town called Nazaret where numerous NGO headquarters were based and USAID and Save the Children cars were ubiquitous.

However, development discourse and practices have increasingly been criticised since post-modern questioning of the superiority of western forms of knowledge. In contemporary anthropology 'development' is understood as a cultural construct (Yarrow, 2011). It is therefore extremely difficult to definitively define 'development', as the term and concept can refer to diverse things: it can be seen as a 'utopian vision'; a descriptive category; an imperialist endeavour (Escobar, 2002) or something that brings about positive socio-economic and political change. Although I will refer to the 'development discourse' throughout my dissertation, it is important to note that people have diverse views about what development is and what the impacts of development are (Rist, 2010). Some scholars argue that development discourse and practices have been a way of maintaining control over colonies post-independence as well as other less powerful countries, as the concepts and practices of development spread western values, way of life and commercial links. Said argued that 'westerners may have physically left their old colonies in Africa and Asia, but

they retained them not only as markets but also as locales on the ideological map over which they continued to rule morally and intellectually' (cited in Shrestha, 2002:104). It is problematic to generalise and condemn all aspects of development, as it would overlook the differences between development organisations and also the achievements of them. However, it is also vital to understand issues inherent in development discourse and practices for analysing the representation of fistula. I will now explore five factors that are important in many development and humanitarian appeals and in the 'typical story' of fistula.

#### AFRICA, PASSIVITY AND UNIVERSAL BIOLOGY

Firstly, the concept of development is not 'new', but instead has a long social history (Lewis, 2005). In the nineteenth century, many anthropologists believed that different societies could be categorised according to different stages of social development, which related to evolutionary notions of progress. Cultural evolutionists such as Morgan classified societies according to different levels of savagery, barbarism and civilisation (Gardner and Lewis, 1996). According to these models Africa was at the bottom of the scale and was often characterised as 'backward', 'primitive' and 'uncivilised', which were ideas also constantly reiterated throughout colonialism. Manji and O'Coill (2002) argue that the public's vision of Africa has always been informed by images of exoticism and adventure. They suggest that although the language of development is no longer explicitly racist like in the colonial era, images of Africa in contemporary development discourse often echo these deep rooted stereotypes (ibid:7), which continues to implicitly cultivate a difference between 'us' (westerners) and 'them' (non-westerners).

In a similar line of thought, Escobar argues that the 'Third World' has been produced by development discourse and practices since World War II (1995). Since the war, developing countries have been endowed with features of poverty, ignorance, powerlessness and a lack of historical agency. This image universalises and homogenises 'Third World' cultures in an ahistorical fashion. Countries were, and are, repeatedly ranked according to their level of development. Terms that suggest a 'deficiency' in some form, such as 'famine', 'poverty', 'uneducated' and 'illiterate', operate as common signifiers of less developed countries and are common terms in development projects (Escobar, 2002). One official measure of development is the 'Human Development Index', which ranks countries based on a composite statistic of education, income and life expectancy. According to this scale, Ethiopia is ranked 174 out of a total of 187 countries and is therefore classified as having 'low human development' (UNDP, 2012). Many people come to understand the 'Third World' through this language which is produced and reproduced in development theories and practices. Furthermore, Africa is often associated with 'tribal' wars, genocide, famine, corruption and failed states (Mahadeo and Mckinney, 2007), which are images that are reiterated repeatedly in western media as well as in much academic literature (see Collier, 2004 for example). Understandings of the 'Third World' and Africa are also constructed through a dialectic process of signification. The terms the 'west' and the 'Global North' are widely used in development discourse to refer to economically-advanced countries and powerful ideas cluster around the concept, such as notions of desirability, development, modernity and advancement. We thus come to understand the identity of less economically advanced countries, or the 'Global South', through contrasting them to western countries and vice-versa (Hall, 1997).

The common representation of fistula generally implies the sense of endless suffering, hopelessness and need for international assistance (Hannig, 2012), which thus simultaneously evokes stereotypes of Africa and continues to fix them in public consciousness. Pieterse suggests that stereotypes exaggerate, simplify and fix identities and that this practice tends to occur when there are inequalities of power (Pieterse, 1992). Ethiopia in particular has become synonymous with famine and poverty. Many Ethiopians with whom I discussed this topic were often keen to assert that famine was no longer a problem in the country. I met one young boy who stated that ‘you ferenj (white person) think Ethiopia always has famine. But that’s not true, we’re not hungry anymore’. Regardless of whether food security is no longer an issue or not, the association of Ethiopia with famine and poverty in the West is largely fixed (Gill, 2012).

Stereotypes of the 'Third World' and Africa in the development discourse are also connected to a focus on passivity in much development and humanitarian rhetoric. Mohanty famously critiqued feminist representations of women in developing countries and argued that the literature often creates a monolithic ‘Third World woman’ through discursive homogenisation. She proposed that much feminist (and development) literature presents ‘Third World Women’ as passive, sexually constrained, ignorant, impoverished, tradition-bound, domesticated, family-orientated and victimised (Mohanty: 1984:337-40). The ‘sameness’ of the oppression that characterises the women in the ‘Third World’ hence binds them together in one category, which means they are often seen as thoroughly oppressed, passive victims of patriarchy and not as social actors in their own right (also see Walley, 1997 and Irvine, 2011).



Furthermore, De Waal suggests that the methods employed to raise funds for humanitarian issues rely on disenfranchising and demeaning the supposed beneficiaries (De Waal, 1995). This can be seen through looking at Malkki's discussion of the established representational practices of refugees in the context of a Burundi refugee camp, as she shows how refugees are presented as utterly helpless and passive, and in need of someone to protect them and speak for them. They are largely defined by their refugee status, which omits any recognition of their individual histories and often presents them as people 'out there'. The implications of this representation are that it disconnects them from the lives of others and effectively 'dehumanises' them (1996:390). Tiktin notes that 'for help to be extended, humanitarianism often requires the suffering person to be represented in the passivity of his or her suffering, not in the action he or she takes to confront and escape it' (Tiktin, 2006:44). Such images and discourses of suffering help engage a global audience as they appeal to people both emotionally and morally (Kleinman and Kleinman, 1996:1). The common representation of women with fistula in media, NGO discourses and scientific literature commonly presents them as thoroughly passive victims, which I will expand on and criticise in chapter four.

The third common theme in humanitarian and development representations is an appeal to a universal humanity. Historically, humanitarianism has been based on the ideal of protecting, or giving protection to, what philosopher Giorgio Amamben called 'bare life'; the fact of living common to all human beings (cited in Tiktin, 2006). This shifts political being to biological being, which unites people through a universal biology and means that biology or 'survival' becomes the ground for political claim-making. In the context of Burundi, as discussed above, Malkki argues that although representational practices dehumanise refugees

in some ways, the rhetoric also appeals to a 'bare', 'naked' common underlying humanity (1996). Although humanitarianism is usually associated with conflict and general disaster (Barnett and Weiss, 2008) the above analyses can be applied to the representation of fistula. Individuals with fistula are defined by their suffering bodies and biological existence. Although fistula is presented as a problem of the 'Other' in many ways, various organisations appeal to a shared humanity and universal biology to encourage donations. For example, Freedom From Fistula state that 'we are helping women like YOU – mothers, daughters, sisters, cousins, wives, aunts, nieces...' which highlights the fact the condition could potentially affect (if obstetric services were not available) women universally (Freedom from Fistula, 2013). Stereotypical depictions of Africa, the passivity of victims and appeals to a common biology all underlie the 'typical story' of fistula as they often do in other development and humanitarian depictions. These factors may make the issue of fistula more familiar and 'digestible' to western readers, which could enhance interest in the issue (c.f. Moeller, 1999).

## DEVELOPMENT LANGUAGE AND VISIONS

This section explores more overt practices involved in the 'selling' of a story or project. Moeller explores how newspapers, magazines and television have covered international crises and suggests that there is often a rather formulaic process to this kind of reporting. She argues that if an image (for example, of starving children) worked previously to capture attention about a certain issue (for example, famine), then similar images will headline the next comparable crisis. However, to prevent 'compassion fatigue' and what she calls 'I've-

seen-it-before syndrome', journalists have to present the newest event as being more extreme or risky than a similar past situation (Moeller, 1999). Although this presents a rather formulaic and crude depiction of reporting, it highlights the reality that stories need to engage viewers. Furthermore, Yarrow, who conducted research among NGO development agencies in Ghana, suggests that workers saw the need to comply with the development discourse in order to receive funding regardless of their individual opinions. As one NGO worker said: 'you call for what is marketable. What is in there that donors are prepared to fund? So that is the reality and the donors are not going to fund what you want...' (Yarrow, 2011:36), which explicitly highlights the importance of 'selling' and 'marketing' a project in the development arena. I argue that an issue can become more appealing to people and eligible for funding when it actively utilises popular development terms and conforms to contemporary development visions.

Cornwall suggests that the language of development animates and justifies intervention and that development models, policies and practices are sustained by development 'buzzwords' (2010). Therefore the language of development is hugely important to the workings of development projects and their eligibility to receive funding. A main quality of a 'buzzword' is to sound scientific and intellectual and therefore beyond the understanding of the layperson. 'Empowerment' is a powerful 'buzzword' that is 'in vogue' in contemporary development practices (Lewis, 2005:474). Often associated with female empowerment, the concept is typically seen as a magical cure for poverty alleviation and economic development. Batliwala argues that the term has changed significantly from a noun, signifying shifts in social power, to a verb signalling individual power, achievement and status; often with economic associations (2007). Utilising this term thus helps construct the

legitimacy that development actors require in order to justify their interventions (Cornwall and Brock, 2005). The term and concept of 'empowerment' has been utilised in different fistula hospitals around the world. In the Addis Ababa Fistula Hospital, women are taught business English and how to make crafts to sell on, which are practices that thus conform to contemporary visions of economic 'grassroots' empowerment.

Ferguson (2002), in a well-known critique of development, also shows the importance of language and representation in the development arena through his critique of a World Bank report about Lesotho in 1975. He argues that the World Bank's report on Lesotho was guided by the need to construct particular 'problems' that required particular development 'solutions'. The image presented of Lesotho was that it was aboriginal, largely agricultural and in need of economic collaboration with South Africa. However, Ferguson argues that economic links between Lesotho and South Africa had been long-standing and that a large proportion of the population did not make their livelihoods from agriculture (ibid). Yet, a particular image of Lesotho needed to be presented so that development organisations could justify their investments (Ferguson, 1994). The date of the World Bank report is of course important to note, as contemporary development practices may give a more accurate and nuanced reflection of a context. However, Ferguson's piece shows the importance of development language and visions, which are also critical factors in other contexts.

The significance of conforming to development visions was highlighted in an interview with Sister Rita, a German missionary gynaecologist who manages Attat Hospital. She conveyed the tensions between representation and funding through recalling her frustrations over numerous government grant proposals. Sister Rita stated that HIV/AIDS, 'early' marriage, 'female genital mutilation' ('FGM') and fistula are always mentioned in NGO

pamphlets, church bulletins and grant proposals. On one particular occasion an official required statistics regarding 'FGM' rates and wanted to include information about this issue in the grant proposal. For Sister Rita this was completely irrelevant to the hospital and to the specific grant she was applying for. Recalling this dispute, Sister Rita then suggested that 'wanting money and aspiring to a socially correct representation of the area are two different things'. For her, the priority was for the hospital to receive money in order to enhance the facilities, which meant that she did include information about 'FGM' although she did not think it was relevant. Therefore, through referring to 'FGM' Sister Rita utilised a popular contemporary development and human rights issue, or in this context a kind of development 'buzzword', which enhanced the possibility of funding. I will expand on this argument in chapter three when I explore the significance of focusing on 'harmful traditional practices' and how this aspect of the 'typical story' relates to the discourse of development.

The 'typical story' of fistula evokes stereotypes of Africa, focuses on the passivity of victims and appeals to an underlying biology. These aspects make the common representation of fistula familiar and 'recognisable' (Hannig, 2012), which may enhance interest in the issue. Conforming to, and utilising, contemporary development language and development visions can also actively increase interest and funds. These factors often underlie and may cultivate the common representation of fistula as well as other media stories and development and humanitarian depictions.

## **CHAPTER TWO: THE DETERMINANTS OF OBSTETRIC FISTULA**

This chapter addresses the determinants of obstetric fistula. Obstructed labour occurs in 5% of births worldwide and accounts for 8% of the world's maternal mortality (WHO, 2010b). As fistula formation is one of the most common non-fatal outcomes of obstructed labour, the prevalence and incidence of obstetric fistula closely follows maternal mortality ratios. Therefore, much of what is known about the prevention of maternal mortality is directly applicable to the prevention of obstetric fistula. Lewis Wall (2012a) uses a framework that was originally developed to analyse the determinants of maternal mortality to assess the determinants of obstetric fistula. The framework uses three sets of determinants: remote determinants, intermediate factors and acute clinical factors. I outline his model and draw on my own research and other literature to explore the wide-ranging, complex causal factors of fistula.

Fistula is commonly associated with poor women in poverty-ridden rural areas (WHO, 2010c). Wall's remote determinants of fistula formation include education, occupation, income, gender equality, social and legal autonomy and community resources at the level of the individual woman, the family in the community and the community itself. Intermediate determinants include the health status and reproductive status of the individual and access to, and use of, health services, which are all affected by the remote determinants. Poverty plays a key role in a woman's health, which can subsequently influence possible complications in labour. Females, whose growth is stunted by malnutrition and/or infections and parasitic diseases during childhood often have greater complications in labour, as these factors can lead to pelvic abnormalities which can cause obstructed labour. Women in better general

health are also likely to have better outcomes should their labour become obstructed, as healthier tissues are more likely to withstand the pressure to which they are subjected to during prolonged labour.

The reproductive status of an individual involves their age, parity, marital status and prior reproductive history. Pelvic capacity continues to develop several years after menarche, which means that young girls are predisposed to obstructed labour and hence fistula due to their small pelvises. Yet, it is vital to note that women most vulnerable to obstructed labour are young girls *and* older women approaching the end of their reproductive life. In NGO discourses and media articles, the focus is predominantly on the vulnerability of young girls, often due to 'child' or 'early' marriage. However, fistula also affects older women, especially those who have previously had three or more births (Wall, 2012a).

Measures of access and use of healthcare include the location of family planning, emergency obstetric services, quality of care, receiving skilled care for labour and delivery, range of services available and intended location of delivery. The existence of emergency obstetric services is a vital part of the prevention of fistula, as any women who can access these services will not develop fistula (Wall, 2012b). In an interview with John Kelly, an obstetrician-gynaecologist who has worked in Ethiopia, Afghanistan, Ghana and Angola on the issue of fistula treatment and prevention, he strongly focused on access to obstetric care as being essential to the prevention of fistula. He stated that 'if a young girl gets pregnant in the UK she does not get fistula because she has access to appropriate emergency obstetric care when required'.

Finally, the acute clinical determinants refer to the intrapartum factors that arise when obstructed labour develops. These include the degree of fetopelvic disproportion (such as

fetal presentation and abnormalities); level and nature of obstruction (including the level of bladder filling); duration of obstructed labour; directly harmful interventions and quality of care after obstructed labour. Some forms of female genital cutting can produce fistula by direct trauma. However, Wall argues that female genital cutting is likely to be a marker of low socio-economic status in areas where fistulas are common rather than being a direct cause of it. The duration of obstructed labour can be prolonged by the 'three delays'. These are a delay in deciding to seek care; a delay in reaching a health-care facility and a delay in receiving appropriate intrapartum care (Wall, 2012a). Wall's framework thus shows that the remote, intermediate and acute determinants of fistula formation are all inextricably interlinked. I will now explore the local and global inequalities that interact with the prevalence of fistula through a critical medical anthropology perspective.

## INEQUALITIES

Critical medical anthropology attempts to analyse how inequalities in political and economic conditions manifest themselves in health conditions (Lupton, 1997) and thus links global relations to a specific context (Morsy, 1990). This perspective can be used to highlight the inequalities interacting with the prevalence of fistula, which are fundamental to understanding the issue. Numerous studies have demonstrated the connection between socio-economic conditions and maternal health. As Harrison states, 'dead and damaged mothers and infants make up a cluster of conditions resulting from one thing, very poor obstetric care. But then, very poor obstetric care is one result of the chaotic socio-economic and political systems, which is the major underlying disease' (cited in Wall, 2012a:257). It should be noted



that the concept of poverty does not solely refer to lack of income, but includes a wide array of factors, including 'capabilities', health and education status, social and material assets, vulnerability to violence and marginalisation, decision-making and power (Chant, 2008).

The concept of 'structural violence' can be used to analyse the prevalence of fistula. 'Structural violence' refers to the exclusion of a group from resources needed to develop their 'full human potential' (Galtung cited in Mukherjee, 2011:593). This concept is useful in two ways: firstly, it can be used as a macro framework in order to understand health inequalities and oppression, and, secondly, it can be seen as an experienced, lived reality in different contexts. Farmer uses it to analyse the ways in which HIV/AIDS has travelled along well-known paths of inequality of the body politic (Farmer, 2010a). He connects the experiences of women in Harlem, Bombay and rural Haiti to show that the decisions made by women in these contexts are linked into their subordinate status as women. He thus argues that where HIV/AIDS rates are high, poor women are the most vulnerable due to the social, economic, political and gender inequalities they face (Farmer 2010b). The distribution of obstetric fistula is a clear example of 'structural violence' at the global and local level. Fistula is only prevalent in developing countries where access to appropriate obstetric care is not available or difficult to access. Global and local inequalities in resources, health infrastructure and medical expertise are all intertwined with the condition. Within a country, maternal healthcare may be seen as a low political priority, which can lead to national or regional underinvestment. As Cook et al. suggest the very existence of the condition can be seen as a marker of societal and institutional neglect of women (2004). Fistula, although an individual bodily phenomena, can therefore also be seen as a visible embodiment of global and local inequalities. Although the concept of 'structural violence' can be been criticised for being

'hollow', as it points out problems but does little to identify the tools needed to address them, it is still a useful concept for analysing health issues.

At the local level, fistula is more likely to affect the poorest women who are often politically, socially and economically excluded from accessing services, even when they are available. 'Structural violence' thus often influences the 'three delays' of receiving healthcare (Mukherjee et al., 2011). The missionaries I interviewed highlighted various barriers in accessing healthcare at the local level, including bribery, cost of transport, distance from facilities, low income, gender inequalities, the cost of facilities and the prioritisation of wealthier patients. Spangler (2011), writing about a hospital in rural Tanzania, explores how the poorest women are socially and economically excluded from accessing resources despite them being available. At the hospital, women are required to buy soap, disinfectant, cotton wool, a syringe and other objects prior to childbirth. However, not all women can afford this, which means that women without these objects are often stigmatised, excluded or put off going to the health facility. Spangler thus highlights that even in places where obstetric services do exist, women still face economic and social barriers in accessing them (ibid). In Burkina Faso, research also shows that the costs of emergency obstetric care can drive women further into poverty, as women may be forced to sell important assets and borrow money to repay debts (Storeng et al., 2008).

Gender inequalities and domestic politics can also influence the utilisation of healthcare, as ideas and practices surrounding reproduction, childbirth and midwifery are deeply embedded in social relations (Browner and Sargent 2006 and Unnithan-Kumar 2003). A 'patient's story' published by the Woman's Dignity Project (WDP) describes how a woman's mother-in-law prevented her from going to hospital due to the financial costs of health services,

which prevented her from accessing immediate obstetric care before the fistula developed (WDP, 2003). Therefore, there are many potential social and economic barriers that women can face even when services are available, which are often related to ‘structural violence’ at the local, as well as global, level.

A critical medical anthropology perspective thus highlights the complexities surrounding the prevalence of fistula and shows that there are many different factors that contribute to the onset of fistula at the level of the individual, family, community and society. Poverty is a fundamental underlying cause of fistula as it is inextricably interlinked to many factors including an individual's physiology and access to obstetric care. WDP states that ‘fistula will continue to exist until fundamental inequities affecting the health of the poor are redressed’ (WDP, n.d.). Wall suggests that policies that focus on the acute clinical determinants are likely to reduce the prevalence of fistula the most rapidly. However, longer-term fistula prevention strategies need to address all the remote, intermediate and acute determinants, as they are all critically inter-connected (Wall, 2012a). The focus on ‘child’ marriage and/or ‘female genital mutilation’ that is promoted by some organisations and by my Ethiopian informants, which I will discuss in the following chapter, thus inevitably oversimplifies the causal factors of fistula, which are, in reality multi-faceted and extremely complex.

### **CHAPTER THREE: THE FOCUS ON ‘CULTURAL’ PRACTICES**

The presentation of the causal factors of obstetric fistula varies according to different development organisations, fistula prevention policies, scientific research and media articles. Some sources and the majority of my Ethiopian informants draw particular attention to 'child' marriage and/or 'female genital mutilation' ('FGM') in their representation of the main causal factor(s) of fistula<sup>1</sup>. In this chapter I question why some organisations and media articles draw particular attention to these practices (most often that of 'child' marriage), and explore the possible implications of this focus. I argue that focusing on 'child' marriage and 'FGM' may make the issue of fistula more engaging and appealing to people and donors, as the portrayal of these two practices fits into the human rights discourse and wider framework of development. I also argue that this rhetoric contributes to a distinction between the more 'westernised', 'urban' Ethiopians and the 'rural' population within Ethiopia. The focus on 'harmful traditional practices' (HTPs) overlooks the role of other determinants of fistula formation and largely ignores women who develop the condition at a later age.

#### **‘CULTURAL’ PRACTICES**

Firstly, it should be noted that some organisations neither mention 'child' or 'early' marriage and 'FGM' in the representation of the causal factors of fistula nor present them as

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<sup>1</sup> I am using the activist terms 'child'/early' marriage and 'female genital mutilation' as these are the terms used in the majority of NGO discourses, media articles and by my Ethiopian informants.

priorities in prevention programs (see Virgin Unite, 2012, MSF, 2012, Solfa, 2013 and WDP, 2013 for examples). Women's Dignity Project (WDP) highlights this on their homepage by asserting that fistula can affect women at any age: 'don't think fistula is only a young girl's problem. I got fistula when I was 29 years old' (WDP, 2013). They also cite high costs of healthcare as an 'unhealthy practice'. Their focus, and the terminology used, thus contrasts with the focus on 'harmful traditional practices' (HTPS) that is put forward by other organisations.

Some organisations and media articles draw particular attention to 'child' marriage and/or ('FGM') as being main causal factors of fistula. The World Health Organisation (WHO) state that obstetric fistula can be prevented by (1) delaying the first age of marriage, (2) the cessation of 'harmful traditional practices' (HTPs) and (3) timely access to obstetric care (WHO, 2010d). In this case, the specific HTPs they are referring to are 'FGM' and cuts or errors made by unskilled birth attendants during or after labour. The WHO's stance on the prevention of fistula implies that they consider 'early' marriage and 'FGM' as important causal factors of the condition. Furthermore, IRIN, a service of the UN's Office for Humanitarian Affairs suggests that 'fistula typically occurs when a teenage girl - pushed into an early marriage - cannot deliver a baby because it is too big for her pelvis' (IRIN, 2005) and UNFPA state that 'obstetric fistula is one of the most shattering consequences of child marriage' (UNFPA, 2012). Furthermore, Forward, an African Diaspora women-led NGO solely focus on fistula, 'FGM' and 'child' marriage, which suggests the perceived interconnectedness of these three issues. They state that fistula 'can be caused by obstructed labour due to 'FGM' type 3 and 'FGM' type 4, where cuts are made into the vagina, or by child marriage and early pregnancy' and that 'about 15% of fistula cases are caused by the

harmful practice of female genital mutilation' (Forward, 2013)<sup>2</sup>. Although this NGO suggests that prevention should tackle issues surrounding poverty, female empowerment, family planning, education and obstetric services, they repeatedly stress the importance of 'child' marriage and 'FGM' as being main causal factors of fistula throughout their discussion.

However, there are a number of issues surrounding the focus on 'child' marriage and 'FGM' as main causal factors of fistula. Firstly, there is often little distinction made between remote, intermediate and acute determinants when discussing these practices. This means that 'child' marriage, an intermediate determinant of fistula according to Wall's model (2012a), is often presented as a 'direct' cause of fistula. OperationOF (an NGO) imply this through their website design. When the viewer clicks on the 'causes' of fistula, the viewer must choose between two sub-links: (1) obstructed labour and (2) child marriage (OperationOF, 2013), which suggests that these two factors are the most important causes of fistula. Understanding that 'child' marriage is a main cause of fistula can convey the idea that the eradication of 'child' marriage will 'end' fistula. However, this suggestion dangerously simplifies the reality of the prevention of fistula, as the determinants of fistula are far more complex and multi-faceted. Furthermore, as I have discussed in the previous chapter, women of any reproductive age can develop the condition, which has been demonstrated through a study with 2,288 Ethiopian women in 2003-2006. They found that 56.8% of the women developed fistula when they were primipara and 43.2% when they were multipara. The breakdown of primiparous and multiparous women shows that women can develop fistula during their first birth (at an early age) as well as during a later birth (at a later age). Both

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<sup>2</sup> Considering the difficulty in obtaining statistics about how many women there are with fistula worldwide (Wall, 2012b), the assertion that 15% of fistula cases are caused by 'FGM' seems dubious.

groups had married at the same age (17 years) but did not develop fistula until they were on average 20.3 and 27.5 years respectively, which indicates that 'child' marriage was not a hugely significant cause of fistula in this context (Muleta et al., 2010). Therefore, the predominant focus on young girls developing fistula omits and ignores many women who develop fistula at a later reproductive age. However, more research is required on the relationship between 'child' marriage and fistula (Hannig, 2012) and the practice of 'child' marriage itself (Bunting, 2005).

There is also much dispute about the relationship between fistula and 'FGM'. Slanger et al. suggest that focus on 'FGM' has been more political than scientific and much more research on the practice is needed (2002). One issue surrounding activist literature is that it often conflates lesser and more extreme operations, which inevitably over-simplifies the practices (Obermeyer, 2003). Furthermore, Browning et al. found that there was no causal connection between Type I and Type II genital cutting and fistula (Browning et al., 2010), which is also a stance that numerous NGOs actively take (see Fistula Foundation 2013 for example). Like other studies, they suggest that female genital cutting is a marker for the presence of other significant determinants of obstetric fistula, rather than being a cause of the condition (Browning et al., 2010 and Slanger et al., 2002). I am not suggesting that these practices (particularly that of 'early' marriage) should be omitted from the representation of the causal factors of fistula; nor am I suggesting they are not moral concerns. Yet, what I do want to question is why some organisations draw particular attention to these practices.

## REPRESENTATION AND DEVELOPMENT

I will now build on an argument I made in the first chapter: that conforming to, and utilising, contemporary development visions and representations can enhance interest and funds for an issue. 'Child' marriage and 'FGM' are contemporary human rights concerns and are connected to the wider discourse of development. This may make the issue of fistula more accessible and engaging for people in the west and more appealing to donors, which, in turn, may make the issue easier to fund.

The Universal Declaration of Human Rights presumes that people are all the same and that this sameness must be protected through the regime of rights (Goodale, 2009). Human rights rhetoric largely conveys a sense of neutrality, authority and universal 'truth' (Cowan, 2003) and has acquired somewhat of an official status in international discourse (Hastrup, 2003). Major rights-based claims include the rights of the child; the rights of women; the rights to freedom from torture and the rights to bodily integrity (Shell-Duncan, 2008). Within the human rights community there is increasing concern surrounding 'harmful traditional practices' (HTPs). The term was developed by the UN after different organisations advocated for the inclusion of 'culturally' condoned forms of violence against women in the human rights discourse (Winter et al., 2002). In this rhetoric 'culture' and 'tradition' are often grouped together as the same thing. The concept refers to practices that are believed to be damaging to the health of women and girls, to be practised for men's benefit and to be justified by tradition or culture (Jeffreys, 2005). 'By harmful practices, we mean all practices done deliberately by men on the body or the psyche of other human beings for no therapeutic purpose, but rather for cultural or socio-conventional motives and which have harmful consequences on the health and the rights of the victims' (Kouyate, 2009:2).



The body has often been a site of power struggles and contestation in the development discourse (Harcourt, 2009:22). From a human rights perspective, 'child' marriage and 'female genital mutilation' ('FGM') are seen to violate the biological integrity, health and rights of the girl child and are, according to the concept of HTPs, categorically unacceptable practices. These practices are well-known human rights issues and commonly conjure up feelings of moral disapproval in the west (Shweder, 2000). Notions of abuse, coercion, subordination, oppression and lack of 'empowerment' are often at the centre of campaigns surrounding these practices. UNFPA asserts that 'child' marriage hinders the life chances of the 'Girl Child' (UNFPA, 2013) and Irvine suggests that 'FGM' is often seen to represent society's control over women (Irvine, 2011). The practices of 'child' marriage and 'FGM' also jar with western conceptualisations of children being in need of care and protection (Bunting, 2005). 'Child' marriage and "FGM" may be particularly familiar to a western audience as there has been much campaigning and discussion over these practices by large organisations (see Human Rights Watch 2013 and Amnesty International 2013) and popular television programs (see Unreported World, 2008). The practices are commonly seen as 'barriers' to social, political and economic 'progress' and development, and many human rights organisations intervene on behalf of this moral order in the aim of bringing about social change (c.f. Tiktin, 2006). Therefore, drawing particular attention to these factors may enhance interest, donations and funding, as they are contemporary, widely condemned, development and human rights concerns.

The focus on these common human rights concerns is also one way through which the issue of fistula tells a familiar story of African 'backwardness'. 'Child' marriage and 'FGM' are commonly seen as patriarchal, oppressive and belonging to the non-western

'Other'. The practices are therefore often juxtaposed to western conceptualisations of individual human rights (Irvine, 2011). Merry argues that critiques of 'culture' in the human rights discourse and in the concept of 'harmful traditional practices' (HTPs) often build on colonial ideas of 'culture' as belonging to the domain of the 'primitive', which stands in contrast to the 'rationality' of the modernised westerner (Merry, 2003). As Walley suggests, this conveys the sense that these practices are 'meaningless hangovers of a pre-modern era' and that western intervention is needed to educate the population in order to end these harmful practices (1997:420). Focusing particular attention on 'child' marriage and 'FGM' in some representations of fistula can thus feed into stereotypical ideas of 'underdeveloped' Africa in contrast to the 'developed west'. This re-tells, and reinforces, stereotypical depictions of Africa and African suffering that is common in the larger discourse of development.

#### BAD 'CULTURE'

My middle class Ethiopian informants predominantly stated that 'child' marriage and/or 'female genital mutilation' ('FGM') were the main causal factors of fistula. This view was also promoted by the Ethiopian medical professionals I interviewed, which explicitly contrasted with the views of the missionaries I talked to. A nurse in Nazaret asserted that the 'main cause is early marriage - when we say early marriage, girls less than fifteen or sixteen years. Their anatomical body is not developed'. A number of people discussed the impact of a relatively new law that has made marriage under eighteen years of age illegal. For example, one patient from Attat Hospital stated that 'before in our country, women married

at less than eighteen. Now it is not common. But because of [early marriage] women got fistula'. Furthermore, one NGO worker, who is now based in London, suggested that female circumcision is the main causal factor: 'in some cultures they circumcise everything, they leave the scars...That creates fistula'.

The focus on 'cultural' and 'traditional' practices as main causal factors of fistula has important discursive and practical implications. Firstly, Hannig, writing about her research at various fistula hospitals in Ethiopia, discusses how notions of 'good culture' and 'bad culture' are explicitly taught in the hospitals' education program on childbirth. Women are taught that 'child' marriage is 'bad culture', which is contrasted with the 'good culture' of marrying at a later age (Hannig, 2012). In this context, 'culture' is essentialised and defined as being either 'good' or 'bad', which contrasts with anthropological understandings of 'culture' being fluid and intangible (Merry, 2003 and Pries, 2002). Hannig also argues that this aspect of the education perpetuates a rural-urban divide in which the rural population are seen as less sophisticated and less developed compared to the 'modernised' urban population (2012).

Although notions of 'good culture' and 'bad culture' were not explicitly discussed in my interviews, my informants predominantly focused on 'cultural' and 'traditional' practices as being the root causes of fistula, which was presumably heavily influenced by NGO and media campaigns surrounding the issue. Only one informant explicitly highlighted problems and deficiencies inherent in the health infrastructure in the country whilst a few mentioned the importance of going to hospital. Although some informants mentioned these factors, they largely focused (or refocused) on 'child' marriage as being the main causal factor of fistula. This often implied that 'culture' was a 'cause' of fistula. This was explicitly suggested by a

doctor based at Attat Hospital, as she stated that girls ‘are promised at birth. Then they marry at 12 and develop fistula...this is culture’.

Furthermore, as in other aspects of the development discourse, my informants often spoke of fistula in terms of a lack or deficiency on behalf of the rural population (c.f. Escobar, 2002). Farmer discusses how ‘blaming the victim’ is a recurrent theme in the history of epidemic diseases such as HIV and typhoid. For example, failure to drink pure water, failure to use condoms, ignorance about public health and hygiene has often been the focus in literature (Farmer, 2010b). My informants often highlighted the lack of knowledge about fistula, childbirth and western medicine in the rural parts of Ethiopia, which, in contrast, was knowledge my informants possessed. One informant made statements surrounding such ‘lack of knowledge’ five times during his interview such as, ‘it's a knowledge thing - they don't have any knowledge about different sicknesses’. This kind of rhetoric cultivated a distinction between ‘us’, the more educated urban informants, and ‘them’, the rural population within the country. My informants’ focus on the knowledge and practices of women with fistula (although hugely important for fistula prevention policies) seemed to implicate the fistula-sufferer and their families as bearing some form of responsibility for the condition due to their ‘bad’ practices and ignorance. This also seemed to produce and reproduce the idea that fistula was a ‘rural’ problem, and not something that affected the lives of ‘urban’ Ethiopians. This was because (a) there are services in the urban centres, (b) ‘urban’ Ethiopians did not practice the ‘cultural’ or ‘traditional’ practice of ‘child’ marriage and (c) because they had western knowledge about illness, health and childbirth. Therefore, my informants' discussion of the causal factors of fistula often seemed to express, and could possibly contribute to, a conceptual rural-urban divide within Ethiopia.

In this chapter I have argued that focusing particular attention on ‘child’ marriage and/or ‘FGM’ in some representations of fistula may relate to the need to ‘sell’ a story and obtain funds. The focus on these ‘harmful traditional practices’ is one way through which the ‘typical story’ evokes and confirms ideas of African ‘backwardness’, which also has unintended implications within the country. However, it is extremely problematic to focus predominantly on ‘cultural’ factors as main causal factors of fistula, as this omits the significance of poverty and other determinants. Fistula should not (solely) be understood in terms of ‘cultural’ issues but should be seen in relation to the social, economic and political context. The focus on ‘harmful traditional practices’ as causal factors of fistula thus ignores other determinants of fistula and largely neglects women who have been, or are, affected by fistula at an older age.

## **CHAPTER FOUR: STIGMA AND DISEMPOWERMENT**

The depiction of fistula-related stigma is a vital part of the ‘typical story’ of fistula. In this chapter I will analyse the representation of fistula-related stigma from different sources as well as from my informants in Ethiopia, arguing that the common representation over-simplifies the lived experience of fistula. The typical portrayal of fistula-related stigma propagates notions of the ‘Third World Woman’ (Mohanty, 1984) and homogenises women with fistula as passive victims, which discursively disempowers them. I will draw on different sources to suggest that women with fistula may not always be stigmatised to the extent that it is portrayed in the literature, and that they can and do assert agency in different ways.

### STIGMA

In the ‘typical story’ of fistula, women with the condition are commonly described as ‘socially invisible’, (Cook et al., 2004:74), ‘hidden, shamed, and forgotten’ (Donnay and Weil, 2004:71), ‘socially segregated’ (WHO, 2010d) and in ‘deep depression’ (Johnson and Johnson, 2013). It is predominantly asserted that *all* women face extreme levels of stigma and ostracism due to their condition. For example, ‘regardless of how their fistulas are formed, the destinies of the victims are invariably the same: a life of physical and psychological pain, social isolation and humiliation’ (FAWCO, 2012). Nicolas Kristoff writing for the New York Times describes women with fistula as ‘perhaps the most wretched people on this planet...She stinks. She becomes a pariah. She is typically abandoned by her

husband and forced to live by herself on the edge of her village. She is scorned, bewildered, humiliated and desolate, often feeling cursed by God... They are the lepers of the 21st century', (Kristof, 2009). This rather sensationalist portrayal of stigma is extremely emotive, brutal and shocking and conveys a sense of utter hopelessness that women with fistula ubiquitously face. This is thus one way through which the issue of fistula captures people's attention. The rhetoric simultaneously compels people to feel pity for women with fistula and also to condemn the stigma they face. This can further be seen through a discussion of an individual's experience: 'they put her in a hut at the edge of the village and took off the door — so the hyenas would get her that night' (2009). The rhetoric implies that husbands, family and community members typically and deliberately worsen a woman's plight through their uncaring and inhumane treatment. The portrayal of fistula-related stigma thus creates a platform for western intervention, as outside help seems to be the only possible opportunity that could improve their lives (Hannig, 2012).

During interviews, my Ethiopian informants also invariably mentioned the severe stigma and ostracism experienced by women with fistula. In fact, I was often surprised at how accurately my informants echoed the exact words in the media campaigns surrounding fistula. Words such as 'stigmatisation', 'ostracism', 'shunned', 'thrown away' were repeated in my interviews. An informant who worked for a women's rights NGO explained that 'most of the time I heard that they are stigmatised by their parents, their husbands, even by their society. Because of the bad smell all persons will not accept them... they will put her in another separate home'. This clearly echoes common portrayals of fistula-related stigma in the media and NGO discourses. Despite their lack of personal contact with fistula in most cases, they often forcefully asserted that high levels of stigma did inevitably occur. One

nurse I spoke to claimed that ‘women with fistula don't have knowledge. They do not think it is curable. Because of that they neglect it [and people] isolate her. The parents do not care’. In response to this, I asked ‘does this always happen?’ He answered without hesitation, ‘yes, always!’ A young doctor I talked to at Attat Hospital, who had actually had some experience of fistula, also drew on media campaigns when discussing the stigmatisation of fistula: ‘on television, the mother who developed fistula is always crying [because] she remembers that her husband divorced her. Everyone dropped her’. Although my informants mainly focused on the problems of ‘smelling’ and ‘leaking’, some also discussed the problems surrounding the possible inability to bear more children. Dawit, the teacher whom I lived with, stated that this factor is hugely significant in relation to the possible stigma experienced by women with fistula, as infertility is an extremely problematic issue in itself in Ethiopia. He commented that infertility for women in rural areas ‘is the biggest thing. It's a feminine thing. She's female so she *should* have children...These people don't just want to have one child. They want to have *lots* of children’. This quote also alludes to another finding discussed in the previous chapter; that the ‘typical story’ of fistula conveys and produces a division between the ‘traditional’, ‘rural’ population and more ‘westernised’ ‘urban’ Ethiopians within the country. The stigma was discussed as another problem of the rural population, which further alienated my informants from the issue and continued to cultivate a distance between them and the rural population they were talking about.

The images of the ‘brutal family’ and the ‘passive victim’ of fistula promoted by NGOs, the media, scientific literature and by my informants both evoke and feed into stereotypical ideas of Africa often presented in the development discourse. The depiction of the stigma and abuse as practised by the family and community evokes ideas of ‘barbarism’,



'savagery' and African 'backwardness', which again contributes to stereotypes ideas of Africa having 'underdeveloped' behaviours and practices compared to those in western countries. This depiction is juxtaposed to fistula-sufferer's passivity, which also conforms to common representations of beneficiaries in development and humanitarian discourses as discussed in chapter one. Women with fistula are presented as utterly passive, voiceless, oppressed victims, and not as individual actors (Walley, 1997), which feeds into stereotypical and racialised understandings of the 'Third World Woman' (Mohanty, 1984). This representation subsequently strips them of all individual agency, which discursively disempowers and disenfranchises them and suggests that they need an outside voice to speak 'for' them (De Waal, 1995).

## DIGNITY AND AGENCY

The experience of fistula undoubtedly affects the lives of women and research has shown that stigma is experienced in different ways. One piece of research conducted by Women's Dignity Project (WDP) and EngenderHealth in Uganda found that the majority of women reported stress, anxiety and depression and that in some cases women do suffer alienation due to the onset of fistula (2007). Therefore, I do not wish to downplay the importance of rehabilitation as focused on by numerous organisations (see Healing Hands of Joy, 2013). However, research has also shown that family and community members do not *always* stigmatise women with fistula to the degree that it is portrayed as in the media.

Hannig argues that husbands, family and community members are often supportive and that people often express pity, empathy and an overarching sense of commitment and

care towards women with fistula. She states that 'although fistula is associated with...the obliteration of motherhood, the event of fistula brings into relief a broader set of relations and connectedness that affirm - rather than deny - a person's being in this world' (Hannig, 2012:126). She discusses one particular patient called Yashume, who had fistula for over twenty years. Although Yashume experienced a few incidents of stigma, she was never overtly affronted with hostility or ostracism. Instead, she was expected to attend social events and host them in return and her kin cared for her in different ways, such as by bringing her injera (Ethiopian bread). Furthermore, research from Uganda suggests that although some form of stigma does often occur, nearly all of the women with fistula were supported by at least one person in their family or community. This research showed that some husbands helped their wives with chores or assisted them with basic needs, such as buying them soap. One woman related that 'my husband encouraged me by asking: 'for how long shall you keep back and not interact with other people? Be courageous, pad yourself and go to your friends' (WDP and EngenderHealth, 2007:5). This image of a supportive and caring husband is the antithesis of the common portrayal of the husband who instantly divorces his wife as soon as she develops fistula. Although stigma may happen in many cases, it is simplistic to assert that all women are divorced and 'shunned', as this ignores acts of compassion and support.

Furthermore, women with fistula are individual social actors who can, and do, assert agency. One woman with fistula in Uganda had eleven children with her husband *after* developing fistula, which shows that some women can also support a large family with the condition (WDP, 2003). Hannig highlights acts of agency through discussing how in some cases, contrary to popular depictions, it is actually the women who demand divorce rather

than the men. She asserts that in some instances it is 'the wife who blames her husband for her botched birth, permanently returns to her family on her own accord, demands half of her property back, and files for divorce' (Hannig, 2012:119). Research also shows that women 'cope' with fistula through different means, including 'being courageous', praying, going to church and doing exercises (WDP and EngenderHealth, 2007). Women also used sanitary padding and washed regularly as a way of coping with the day-to-day lived experience of fistula. Sister Rita recalled how a woman, who had come to Attat Hospital with her husband, had inserted a rubber 'stopper' into the hole, which temporarily blocked her incontinence. This ingenious coping mechanism is an example of how one individual with fistula tried to regain control over her body and is a clear example of individual agency. Therefore, women with fistula are not inevitably passive sufferers, but attempt to cope with fistula and regain bodily control in different ways.

Solely focusing on the women's plight and stressing their passivity feeds into the emotional appeal of the issue and evokes ideas of African 'backwardness', which may help the issue of fistula 'sell' and capture attention. However, this representation over-simplifies the lived experience of fistula. Women with fistula assert agency in different ways and have diverse individual experiences, which thus means that they should not be invariably categorised as passive 'victims'. Women's Dignity Project (WDP) actively works against the typical depiction of women with fistula and often highlights their 'dignity', 'resilience' and 'strength' despite the huge barriers they face. They assert that 'girls and women with fistula deserve our praise, not our pity' (WDP, n.d.). This portrayal is positive and inspiring, as it conjures up an image of admiration, hope and compassion rather than a sense of distance, pity and victimhood

## **DISCUSSION**

Issues surrounding obstetric fistula are extremely complex and the prevention and eradication of the condition is certainly not a simple objective. In order to raise awareness and get funding for the issue, fistula needs to be described, discussed, represented and commented on. This happens in many different contexts around the world; in global arenas with development experts and medical professionals, with local and medical staff in the countries directly affected, and in western countries where NGOs present their need for funding. The representation of obstetric fistula has great social significance and the words that are included (and not included) have great power in implying and conveying meaning. The development discourse is largely presented and understood as 'truth'; often with little question of its historical origins and social significance. Yet, discourses are related to their creators and are contingent on the context and time in which they exist. As Nietzsche states, 'all things are subject to interpretation; whichever interpretation prevails at a given time is a function of power and not truth' (cited in Cornwall, 2010:471). Like depictions of other issues in development discourse and practices, the common representation of fistula relates to historically charged understandings of the 'Third World', Africa and the passivity of victims. The representation of fistula, like that of other issues, often utilises and draws on contemporary development language and visions. These factors may help the typical representation gain currency, enhance awareness of the issue in the west and increase funding for projects.

Some aspects of the 'typical story' have discursive, and possibly practical, implications within Ethiopia and in the international arena. One general implication of the

common representation of fistula, as I have argued throughout, is that it reinforces negative stereotypes of Africa, which continues to cultivate a difference between Africa and the west. During my time in Ethiopia I also found that many Ethiopians directly echoed NGO and media depictions of fistula. They re-told the 'problems' surrounding 'cultural' or 'traditional' practices, the lack of knowledge and brutal stigma and rarely mentioned issues surrounding the health services, economic barriers and poverty. In the west, the issue of fistula is seen as a 'foreign' problem, as it no longer exists in western contexts. In a similar vein, my middle class informants, whose rhetoric was heavily influenced by the language from NGO and media campaigns, often discussed the issue as something that did not, and would not, ever concern them. Although this is probably true, their rhetoric seemed to express and further a conceptual divide between the urban, more educated and 'westernised' population and the less educated, 'tradition-bound' rural population.

Another possible implication surrounds the attention drawn to 'child' marriage and/or 'female genital mutilation' in some representations of the causal factors of fistula. This rhetoric often concentrates on the 'culture', knowledge and practices of the women affected by fistula. Although these factors are important, the prevalence of fistula relates to wide-ranging, multi-faceted factors including poverty, socio-economic barriers to treatment, education, lack of family planning and poor health services. Merry argues, the tendency to 'culturalise' problems in development discourses means that people often come to understand 'women's subordination in terms of cultural practices that oppress them rather than the economic or political problems their communities faces' (2003:63). Therefore, focusing on 'child' marriage and/or 'female genital mutilation' could lead to an under-representation of other critical factors which could thus redirect awareness, attention and

resources from other fundamental factors such as obstetric services and poverty. However, the representation of fistula is not always problematic, as demonstrated through exploring the rhetoric and policies of the Women's Dignity Project (WDP) in Tanzania. Yet, the need to 'sell' a story in the media, and the need for development organisations to obtain donations and funding, may influence the common representation of fistula in significant ways. This can subsequently over-simplify the complex causes of fistula and also the individual lived experience of the condition.

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