Restoring Women’s Dignity: Preventing and Treating Obstetric Fistulas in India

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All characters, organizations, and plots described within the case are fictional and bear no direct reflection to existing organizations or individuals. The case topic, however, is a true representation of circumstances in India. The case scenario is complex and does not necessarily have a correct or perfect solution, and thus encourages a judicious balance of creative yet perceptive approaches.

The authors have provided informative facts and figures within the case and appendices to help teams. The data provided are derived from independent sources, may have been adapted for use in this case, and are clearly cited such that teams can verify or contest the findings within their recommendations, if it is pertinent to do so. Teams are responsible for justifying the accuracy and validity of all data and calculations that are used in their presentations, as well as defending their assertions in front of a panel of knowledgeable judges representing different stakeholders.
Introduction

As the Panchayat ate their meal, they began to discuss the most pressing issues faced by members of their village located in Southern Assam. Aditya Chauhan, the leader of the Panchayat, sat silently while each member raised their concerns, but he kept returning in his mind to a private conversation he had had with a distraught villager just days before the gathering. The man’s pain was so immense he couldn’t help but share in his grief. All of a sudden, Aditya Chauhan stood up and made an announcement. “We have to care for our women. It has been brought to my attention that there are women in our village who are of ill health—with no help to be had. My own sister has been living with this bad condition since she had her first child,” he proclaimed. “She cannot have a normal life now. Her husband’s family has rejected her and he beats her.” Chauhan paused as he had not prepared for this and felt unsure as to how approach this issue with the elders. One of the elders interrupted his train of thought, “This is not the life we want for our people, we must find a way to help those where it is needed.” After much discussion amongst the group it was decided that they would write the Northern Zonal Council and ask them to send help. Later that evening as Chauhan sat down with his ink and paper to write the letter, he realized he knew little about the actual condition his sister and other women in his village suffered from. He decided to compile perspectives of the local physician, a government official, and other village women over the following weeks.

Chauhan sat under a tree to find some relief from the summer sun. He took out the letter he had rewritten for the fourth time and read it one last time.

Dear Advisory Council,

The women of our village are in dire need. An odd condition is affecting their health and the health of their children. Below are words from our local physician.

“In the past year, there have been 3 new cases among the 63 women that gave birth in our village that I have encountered. During prolonged childbirth, damage to the vaginal, bladder, or rectal walls can lead to urine and stool seeping into the vagina and can cause soiling problems. A young woman named Madhuri was in labor for several days, and flooding from rains delayed my arrival. The baby was stuck in the birth canal for a very long time, and when I was finally there to do the delivery, the baby was stillborn. A cesarean section would have saved the baby and prevented the injuries to the mother. Although I am able to perform cesarean sections, I can only do this type of surgery at the hospital in town, not in this small village. I have not been trained on repair of these fistulas, so she and other women with similar conditions have to live with the leakage, and the stigma that goes with it. A couple months later, Madhuri disappeared. She is not the only woman in our village who has had a fate similar to this.” –Dr. Kapadia
To further understand Madhuri’s story, one which is shared by many women here, I offer some words from Madhuri’s sister-in-law.

“A couple weeks ago, my sister-in-law, Madhuri, disappeared. She was only 15. After the devastating loss of her first child, she did not heal properly. She leaked fluid and feces and became immobilized. Her legs could no longer carry her. She stopped drinking water and became even sicker and more dehydrated. Due to her foul smell, my brother (her husband) left her and the family banished her to another room in the hut. My brother spread rumors to cover up what he had done while Madhuri was left isolated in the hut for days on end. I always felt bad, but I did not know what I could do. I guess she finally escaped and left. Our village needs medical help.” – Rohini Gupta

In seeing how our own local government could help us I became aware of several issues.

“There are many pressing needs that require our support. Unfortunately, our funding can only sustain our current health centers. With such far spread villages we cannot build centers for each village, let alone equip them with electricity and extensive medical supplies. We support many health initiatives that can benefit your village but currently cannot offer additional support.” – Unnamed official

Our Panchayat requests the governments help in addressing this matter.

Sincerely,

Aditya Chauhan

Chauhan was satisfied with his work. He finally emerged from under the shade and headed to the post to deliver his letter. As he walked down the dirt road he thought of his sister and hoped they would send help soon.

**India’s State of Health**

*Progress on the Millennium Development Goal (MDG) 5: Improve Maternal Health*

The target of MDG 5 was to reduce maternal mortality by three quarters between 1990 and 2015, as indicated by the maternal mortality ratio (MMR) (number of women die due to pregnancy or a related factor) and the proportion of births attended by skilled health personnel. Despite the decrease in the number of reported annual maternal deaths in India from 1,000,000 in 1991-2001 to 44,000 in 2011-13 (see Appendix B), 120 women reportedly die each day in India due to a cause related to pregnancy (Social Statistics Division, Ministry of Statistics and Programme
Implementation, 2015). Actual numbers are suspected to be even higher as many maternal deaths go unregistered as many deaths occur outside of hospitals and registration systems are limited in their coverage. In the year 2000, India accounted for 20% of all maternal deaths worldwide (Mavalankar, Vora, & Prakasamma, 2008). Despite the country’s economic growth, it continues to struggle with meeting MDG 5. Lack of management capacity, that inhibit access to quality obstetric and emergency obstetric care, and systematic monitoring have been identified as reasons why India’s initiatives to promote maternal and child health, especially in rural areas, has fallen short (Mavalankar et al., 2008). Over the past five decades, India has also struggled to create a midwife training system that meets community-level needs, but in 2009, 76.2% of births were attended by skilled health personnel (Social Statistics Division, 2015). By 2013, this number had increased to 87.1%, which includes government and private hospitals, or qualified professional (Social Statistics Division, 2015). Due to these statistics, progress in India towards MDG 5 is considered “slow or off-track” (Social Statistics Division, 2015, p. 22).

Though improvements to meeting MDG 5 have been made, a review of India’s progress by state reveals that a bulk of the burden is concentrated within select regions and states. Compared to estimates of other states, Assam (MMR 300), Uttarakhand (MMR 285), Jharkhand (MMR 208) reported some of the highest estimates of maternal mortality ratio (Social Statistics Division, Ministry of Statistics and Programme Implementation, 2015). While experts believe Jharkhand may make their goal, Uttarakhand and Assam will likely miss their targets (see Appendix C). Having a skilled birth attendant lowers the risk of complications and time a woman goes without treatment, thus more trained birth attendants are needed to reduce maternal and infant mortality. Some states have been successful in reaching 100% coverage of births attended by trained health professionals, with other regions, such as Jammu & Kashmir, coming close. Larger states such as Jharkhand, however, represent the lowest performing states (see Appendix D for distribution of skilled health professionals across states). Within each state, disparities still exist between urban and rural areas. Health care service gaps tend to exist in rural areas (Social Statistics Division, Ministry of Statistics and Programme Implementation, 2015). Moving forward, the National Health Mission aims to strengthen linkages of care at the community level to improve these health outcomes.

**Fistulas in India**

Obstetric fistula is an abnormal opening between a woman’s vagina and bladder or vagina and rectum, often occurring after obstructed labor (see Appendix A). Although a minority of small fistulas may close spontaneously with proper medical management, this opening almost always persists without treatment, leading to permanent incontinence of urine or feces. Particularly in conditions where fistulas occur, there may be no treatment or management options, leading to ongoing incontinence, infections, and damage to the reproductive system (World Health Organization, 2006).

Although there have been issues with the measurement of cases of obstetric fistula, the WHO reports that globally 50,000-100,000 women develop fistula each year, and that there are
currently 2 million untreated cases (World Health Organization, 2012). Two studies specifically in India have reported prevalence rates of 0.86 and 2.60 cases per 1,000 women of reproductive age, although there is some concern whether these studies are representative of the general population (Adler, Ronsmans, Calvert, & Filippi, 2013). Another study in India found the prevalence of ever experiencing a fistula as high as 3.4% in some districts (Gulati, Unisa, Pandey, Sahu, & Ganguly, 2011).

Many organizations have focused on the prevention of fistula, which the WHO states is primarily through delaying first pregnancy, avoiding harmful traditional practices, and having access to timely care (World Health Organization, 2006, 2012). Most cases in developing countries are due to obstructed labor, secondary to cephalopelvic disproportion and lack of access to adequate care. Delaying age of first pregnancy can ensure women are not too small for the pregnancy (cephalopelvic disproportion), and increasing access to timely care can prevent long episodes of obstructed labor (World Health Organization, 2006). Once a fistula has occurred, the definitive treatment is a surgical closure. Barriers to fistula repair include knowledge about treatment options, financial ability to pay for surgery, availability of skilled surgeons, and concurrent infections (World Health Organization, 2006).

**Barriers to Treatment**

Accessing adequate healthcare services can be difficult in India due to many factors including, but not limited to, social, financial, and structural barriers. One of the most salient barriers for women requiring sexual and reproductive health care treatment is the possibility of stigmatization and its associated social repercussions (Iyer, 2014; Nudelman, 2013). Personal embarrassment over the condition along with stigma inhibits the individual from seeking medical care. In addition, lack of sexual and reproductive knowledge, or cultural inhibitions to discuss these topics, may lead to a woman accepting these conditions as ‘normal post-partum healing’ rather than seeking care. Even if women are able to overcome the stigma attached to having a fistula, the cost of health care and access to a medical facility present additional barriers. The average cost per patient for the treatments of obstetric fistula ranges from 100-450 USD (Fistula Foundation). This includes the cost of surgery, as well as post-surgical and rehabilitative care. For many people in India these costs are prohibitive; approximately 30% lives under the poverty line (Department of Rural Development, 2011). Beyond the cost of care, individuals may not have access to a facility where treatment is offered. The majority of people in India (73%) live in villages and only 2.5% own a vehicle (Department of Rural Development, 2011). The ability to access a medical facility is further complicated by the fact that many villages do not have paved roads. The overall lack of healthcare infrastructure and trained medical professionals poses a number of challenges for improving social and health outcomes for women with obstetric fistulas. Aside from these barriers, women often have competing domestic priorities that lead them to place their own health care as the lowest priority.

**Determinants of Health Care Access**
Women’s empowerment (the power to make decisions within the household and gender role attitudes) (Kishor & Subaiya, 2008) and autonomy (the power to make decisions within the household, freedom of movement, and financial autonomy) (Jejeebhoy & Sathar, 2001) are important determinants of women’s access to health care in general, and specifically among women utilizing pregnancy related services in India (Mistry, Galal & Lu, 2009). The United States Agency for International Development (USAID) has stated that a woman’s ability to make decisions about her own health care is a central component to insuring individual well-being, as well as a salient driver of population-level health improvement (Kishor & Subaiya, 2008). Despite this assertion, women in India and other low- and middle-income countries typically do not have autonomy over their own health care. Rather, patriarchal norms within the family dictate that a husband and his parents are chief decision makers over a woman’s health care access, particularly during pregnancy and childbirth (Koenig & Foo, 1992). At issue is not only gender hierarchies that place young women in the lowest position within the family, but also the dynamics of decisions related to the control of household finances and spending (Kishor & Gupta, 2009). Even with autonomy, women have to believe that their health is a priority before they will utilize available services.

Multilevel factors act as barriers for women to access health care; we provide a few examples at each level. At the individual level, girls and women are at high risk for pregnancy complications; the median age of marriage is 16.8 years (Kishor & Gupta, 2009). At the interpersonal level, access to transportation, inadequate assessment of the risk for the mother, perceptions of the quality of care received in the hospital, and costs of care are all factors that weigh heavily on the decision to seek health care during pregnancy (Blanchard, Bruce, Jayanna et al., 2015; Jat, Deo, Goicolea et al., 2015; Mahapatro, 2015). At the community level, rural location, density of poverty and density of illiteracy are associated with decreased odds of maternal health care utilization (Singh, Kumar, Rai & Singh, 2015). At the district level, the number of Primary Health Centers per person and the number of open beds for labor affect maternal health care utilization (Singh et al, 2015). Of note, two-thirds of women in India die while seeking emergency care during childbirth (Montgomery, Ram, Kumar, & Jha, 2014). Therefore, increasing women’s education, financial autonomy and decision-making ability all factor into increasing health care access, particularly during pregnancy and childbirth.

The influence of religion on health care seeking behavior

Though there are wide variations in gender and kinship norms across regions, women of different religious faiths share similar experiences to accessing reproductive and sexual health care services. Within India, social systems differ by regions. Compared to the South, women in the Northern region have been found to have less exposure to outside communities, have less autonomy and ability to control their lives, and fewer opportunities for controlling economic resources (Dyson & Moore, 1983; Basu, 2005; Jejeebhoy, 2000).
Women from each of the major religions in India have expressed concerns, which represent potential barriers towards health seeking behavior. At the individual level, Hindu women prioritize modesty and often do not seek reproductive health care services for fear of having to undress or discuss their genitourinary system (Purnell, 2013). Similarly, Muslim women have reported that a major source of anxiety with regards to regular health check-ups are pelvic exams and pap smears (Matin & LeBaron, 2004). Common reasons that Christian women do not seek maternal health care medical services are lack of knowledge about existing services and having previously had a complication during pregnancy labor or post-delivery (Olayinka, Achi, Amos, & Chiedu, 2014). At the interpersonal level, a majority of Muslim women agree that Muslim women require male permission to attend medical appointments (Salam, 2008). Furthermore, negative attitudes of health care providers have been a noted reason among Christian and Muslim women for not seeking reproductive medical care (Olayinka et al., 2014). At the community level, Hindu families’ fear of being stigmatized for a family member’s medical condition can lead families to prevent access to healthcare for that individual (Purnell, 2013). At the societal level, Hindus’ belief in karma creates a fatalistic attitude towards illness where an individual cannot complain about a health condition or symptoms because they believe it is the will of God (Purnell, 2013). Cultural norms in Islam dictate that it is inappropriate to seek medical attention for sexual and reproductive health, especially since infertility or cancer can lead to rejection or divorce, or discuss sexual history with medical providers (Purnell, 2013). While some of these barriers may appear tied to a specific religious faith, there are many similarities across religious and ethnic groups. Though a spectrum of experiences and beliefs about seeking reproductive health care can be found across each of the aforementioned religions, these concerns should to be addressed when they present as a barrier to seeking health care.

**Social impact of obstetric fistula**

Fistulas are devastating to the women who endure them. Affected women are often immediately driven from their marriages and are abandoned by their families and communities. As a result of being forced into isolation, their poverty and malnutrition are aggravated, resulting in illness, and possibly death. The condition often occurs in young girls who were married early and become young mothers. Because they are preventable and treatable, obstetric fistula violates human rights at many levels and contributes to growing health disparities, including inequalities between women and men, younger and older women, educated and less-educated, as well as between women in developing countries and developed countries. It has been shown that it is the younger women who are more likely to develop an obstetric fistula, with 50-80% of women below age 20 developing fistulas (Cook, Dickens, & Syed, 2004).

Fistula is commonly considered a “social calamity” (Harrison, 1983). Women who develop this condition are ostracized because the condition is viewed as a sexually transmitted disease, a bad
omen, or ‘God’s punishment’ (Ahmed & Holtz, 2007). The condition, as well as the treatment they receive from their community, causes women to live their lives with fear, shame, and pain. Even women who are cured of the condition are never treated the same way again; they are not allowed to cook or participate in any social activities (Ahmed & Holtz, 2007). There is a complete lack of understanding of the issue. The stigma is considered one of the worst issues with fistulas, causing great emotional and psychological harm to the women who suffer from them. In addition, the obstructed labor that typically causes fistulas often leaves the mother mourning the death of her child (85% of women lose their child) while fighting for her own survival (Ahmed & Holtz, 2007).

Health Infrastructure in India

India is divided into twenty nine states; each comprised of multiple districts with varying health needs. Because of the differences in population-level needs and resources available across these different states, the Government of India developed a decentralized health system that functions based on district level health plans. The district unit is a geographically bound area that has a clear health system structure whereby the district hospitals function at the highest level serving up to a million persons, community health centers aim to serve 80,000-100,000 persons, primary health centers aim to serve 30,000-50,000 persons, and the health subcenters aim to serve 3,000-5,000 persons at the community level (Kalita, Zaidi, Prasad, Raman, 2009). Under the National Rural Health Mission, the Government of India declared an overarching goal to achieve quality and equitable care within their public health services throughout the country (Kalita et al., 2009), making the role of these district health plans all the more important.

Though the district level health plans offer a more flexible way to address the difference in health issues that exist across the country, the unique approach for each district also presents challenges in collecting standardized district and state level data. A brief dive into the sexual and reproductive health indicators of the four district health plans within four states known to have high prevalence rates of fistula are presented below (see Appendix E).

Uttarakhand: Dehradum District

The district of Dehradum is located within the state of Uttarakhand and is comprised of a population of 1,698,560; 53% of which is located in an urban setting. Approximately 85% of the population is literate, though males report higher rates of literacy (90.32%) than females (79.61%) (Office of the Registrar General & Census Commissioner, 2011). Only 14.67% of all births are delivered in an institution, with 17.51% of those resulting in a C-section. More women (53.58%) utilize skilled birth attendants. The maternal mortality rate, however, is 315/100,000, with an infant mortality rate of 44/1,000 births.
Assam: Dhubri District

The district of Dhubri is located within the state of Assam and is comprised of a population of 1,948,632; roughly 88% of which is located in a rural setting. Dhubri is one of the most densely populated districts in India, containing 584 persons per squared kilometer. It is also a Muslim majority district, with 75% of its population self-identifying as Muslim. Approximately, 48% of the population is literate, with low rates among men (55.91%) and women (40.04%) (Office of the Registrar General & Census Commissioner, India, 2011). There is a maternal mortality rate of 4/1,000 and an infant mortality rate of 78/1,000 live births. Almost 16% of births are delivered in an institution and only 3.8% are attended by a skilled birth attendant. 17% of all births are delivered between the mother’s age of 15-19 and 7.2% of women use family planning methods (District Programme Management Unit, 2011).

Jharkhand: Gumla District

The district of Gumla is located within the state of Jharkhand and is comprised of a population of 1,025,656; roughly 80% of which is located in a rural setting. Nearly 67% of the population is literate (Office of the Registrar General & Census Commissioner, India, 2011). Almost 18% of births take place in a health institution and only 8.9% are attended by a skilled birth attendant. There is a maternal mortality rate of 302/1,000 and an infant mortality rate of 46/1,000 live births. Additionally, 34.9% of women use family planning methods and 36.3% of girls marry before the age of 18 (Government of Jharkhand, Department of Health & FW, 2012).

Jammu & Kashmir: Pulwama District

The district of Pulwama is a largely agricultural district located within the states of Jammu and Kashmir and is comprised of a population of 457,883; a total of 550 villages. Roughly 65% of the
population is literate, with men reporting literacy rates (75.41%) nearly double that of women (35.81%) (Office of the Registrar General & Census Commissioner, India, 2011). Pulwama has a maternal mortality rate of 300/100,000 and an infant mortality rate of 40/1,000 live births. Approximately 61% of births take place in a health institution and 76% are attended by a skilled birth attendant. There are 0.89 doctors per 1,000 persons (Government of Jammu & Kashmir, 2007). The territory of Kashmir is difficult to obtain health surveillance data on due to the fact that it is a disputed territory between India and Pakistan since the late 1950’s. Though India claims this territory, much controversy still exists today, especially as Pakistan and many of the people living in that territory do not recognize this claim (Pakistan Mission to United Nations, 2015).

**Conclusion and Request for Proposals**

It has been nearly a year since Chauhan sent the letter on behalf of his village and the government of India has finally decided to fund a pilot program to address the occurrence of fistulas in their Northern territories. Chauhan’s was not the first report they had received shedding light onto this issue, and they were finally prepared to respond. Though they recognize the multifaceted nature of this health problem, they have decided to invest in a plan to eliminate obstetric fistulas. Having just identified a number of highly qualified teams to conduct the pilot project working towards this goal, they are optimistic. A working committee including experts on reproductive health, medicine, health infrastructure, health policy, and human rights has been assembled and tasked with overseeing the selection of the team that will carry out the pilot project. Proposals will be heard on April 9, 2016.

You are a part of one of the teams selected to submit a proposal. You must develop a 5 year plan to reduce new cases and/or existing cases of fistula using the most effective evidence-based methods. Given the large population and limited funds, you will need to prioritize efforts as they relate to prevention and treatment. If selected, your team will receive $30 million over 5 years. If your project is successful by year 5, the government plans to allocate funds to expand it to other regions. A successful proposal must include the following criteria:

- Focus on one of the following states: Uttarakhand, Assam, Kashmir & Jammu, Jharkhand
- Outline strategies to reduce new cases and/or treat existing patients with obstetric fistulas
- Address appropriateness of proposal for other states if expanded
- Addresses cultural, structural, and medical infrastructure barriers
- Measures effectiveness and impact of your program
- Includes budget and timeline, considering sustainability
References


Nudelman, A. (2013). Gender-Related Barriers to Services for Preventing New HIV Infections Among Children and Keeping Their Mothers Alive and Healthy in High-Burden Countries. [Discussion Paper]. UNAIDS.


Appendices

Appendix A. Anatomy of a Fistula

http://www.ukfistulafund.org.uk/uploads/1/5/5/0/15501732/17891

"Obstetric Fistula Locations Diagram" by VHenryArt - Own work. Licensed under CC BY-SA 4.0 via Commons - https://commons.wikimedia.org/wiki/File:Obstetric_Fistula_Locations_Diagram.png#/media/File:Obstetric_Fistula_Locations_Diagram.png
Appendix B. Approximate Number of Maternal Death/year in India

(Social Statistics Division, Ministry of Statistics and Programme Implementation, 2015)
Appendix C. MMR Likely Achievement in Major States

Source: Office of Registrar General of India
Appendix D. Percent distribution of live births attended by skilled health personnel

Source: Office of Registrar General of India
Appendix E. Map of India with States of Focus
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