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AMNESTY INTERNATIONAL SUBMISSION TO OHCHR'S REPORT ON THE TECHNICAL GUIDANCE

INTRODUCTION

Amnesty International welcomes the opportunity to contribute to OHCHR's report on the application of the technical guidance on the application of a human rights-based approach to the implementation of policies and programmes to reduce preventable maternal mortality and morbidity ["Technical Guidance"].¹ In this submission, we are highlighting our research from Nepal and Zimbabwe specifically on maternal morbidities, and the challenges women and girls face in accessing preventive care and treatment for these health conditions.

UTERINE PROLAPSE IN NEPAL

In 2014, Amnesty International published its report, "*Unnecessary burden: Gender discrimination and uterine prolapse in Nepal*". Uterine prolapse is a painful and debilitating condition in which the pelvic muscles are unable to support the uterus and it starts to descend into the vagina. Medically established factors which increase the likelihood of a woman developing uterine prolapse include giving birth at a young age, having many children within a short space of time, inadequate nutrition, lack of rest during and immediately after pregnancy and prolonged or difficult labour, including use of harmful birthing practices.² Symptoms include backache, difficulty in walking, sitting, lifting objects and carrying out daily tasks. In addition to physical symptoms of pain and discomfort, women in Nepal told Amnesty International about the negative impact of the condition on women's mental health and about emotional and physical abuse women sometimes suffer as a consequence of experiencing uterine prolapse.³

Women and girls in Nepal suffer from high rates of uterine prolapse. At the time of publication of Amnesty International's report in 2014, there had been no comprehensive study on the prevalence of uterine prolapse in Nepal and the different methodologies used in the studies which had been conducted mean that they found different prevalence rates. A population-based study conducted in 2006 by UNFPA found a 10% prevalence rate.⁴ However, smaller scale studies focussed on specific regions found higher rates of around 37%.⁵ While globally, older women are at greatest risk of getting this condition, a striking factor about the pattern of uterine prolapse prevalence in Nepal is that it affects relatively young women.⁶ Furthermore, available studies showed that the geographic regions, caste groups or communities with high levels of gender discrimination tend to have higher rates of uterine prolapse.⁷

The Technical Guidance acknowledge that "patterns of maternal mortality and morbidity often reflect power differentials in society and the distribution of power between men and women"⁸ and that "maternal mortality and morbidity is a product of discrimination against women, and denial of their human rights, including sexual and

¹ Report of the Office of the United Nations High Commissioner for Human Rights, Technical guidance on the application of a human rights-based approach to the implementation of policies and programmes to reduce preventable maternal morbidity and mortality, A/HRC/21/22, 2 July 2012 ["Technical Guidance"]

² Amnesty International, "Unnecessary burden Gender discrimination and uterine prolapse in Nepal", ASA 31/001/2014, page 7 ["Unnecessary Burden"], <https://www.amnesty.org/download/Documents/8000/asa310012014en.pdf>.

³ Unnecessary Burden, page 19.

⁴ UNFPA, Status of Reproductive Morbidities in Nepal, Institute of Medicine, Kathmandu 2006.

⁵ Pradhan, S. "Unheeded Agonies - A Study on Uterine Prolapse Prevalence and its Causes in Siraha and Saptari Districts", Women's Reproductive Rights Program (WRRP), Centre for Agro-Ecology and Development (CAED), Kathmandu, Nepal, 2007

⁶ Health Related Quality of Life of Women Suffering from Pelvic Organ Prolapse: before and 9 to 11 months after surgical interventions, Ministry of Health and Population and United Nations Population Fund, 2013

⁷ Unnecessary Burden, page 21.

⁸ Technical Guidance, para 13.



reproductive health rights.”⁹ They also points out that human rights based approach to reducing preventable maternal morbidity and mortality requires that States take all appropriate measures “to eliminate discrimination against women, including gender-based violence, forced and early marriage, nutritional taboos, female genital mutilation/cutting and other harmful practices.”¹¹ Amnesty International’s report documented how, in Nepal, gender-based discrimination was both a cause and consequence of uterine prolapse. Nepali women experience high rates of uterine prolapse and many experience it at a younger age because gender discrimination in their daily lives exposes them to multiple risk factors for the condition, described in detail below. Women with uterine prolapse are then at risk of suffering further discrimination and gender-based violence because their condition may prevent them from engaging in physically hard work or in sexual activity that is expected of them. These themes emerged repeatedly in Amnesty International’s interviews with women and girls in Nepal.

*Access to contraception and health care:*¹⁰ The majority of the women Amnesty International interviewed, both in focus group discussions and individually, said that they and their husbands had never used any form of contraception. The report also noted that women and girls faced barriers accessing antenatal care. Government figures confirmed this; at the time of publication of the report, across Nepal an average of 35% of women were not able to participate in decisions about their own healthcare. This figure rose to 55% for Muslim women.¹¹

*Workloads:*¹² Similarly, lifting heavy objects and carrying heavy loads can strain the pelvic muscles particularly during pregnancy and soon after women give birth. Consequently, undertaking physical labour involving heavy lifting during and after pregnancy is a risk factor for uterine prolapse. Most of the women who spoke to Amnesty International said that although they understood the risk associated with their work, they had no choice but to do it. Furthermore, the vast majority of women interviewed by Amnesty International had taken significantly less rest than is recommended by the government after giving birth.

*Unsafe birth practices:*¹³ Unsafe birth practices contribute to the risk of uterine prolapse. Women participating in focus group discussions told Amnesty International that the majority of women they know give birth at home with untrained helpers (usually Traditional Birth Attendants or older women from the local area). These risks are often exacerbated by the prevalence of harmful traditional practices, such as *chaupadi*.¹⁴ The Dalit women participating in the focus group discussion in Mugu district told Amnesty International that most of them had given birth to their children in the insanitary conditions of the cowshed without a skilled birth attendant although a few had gone to the district hospital.

*Malnutrition:*¹⁵ Malnutrition and under-nourishment caused by a lack of nutritious food during and after pregnancy are risk factors for uterine prolapse in Nepal. Amnesty International’s report documented how gender discrimination results in women being denied equal access to food and this, combined with food shortages at particular times of year, results in under-nourishment or malnutrition.

*Lack of adequate information:*¹⁶ Amongst the women Amnesty International spoke with in Nepal who had uterine prolapse, the majority had not heard about the condition before they experienced it. Women whom Amnesty International spoke with in focus group discussions who had heard about the condition had mainly got information from other women in their neighbourhood or knew about it because they had a family member or friend with the condition.

⁹ Technical Guidance, para 14.

¹⁰ Unnecessary Burden, page 32

¹¹ Maternal and Child Health in Nepal: The Effects of Caste, Ethnicity and Regional Identity, Ministry of Health and Population, Kathmandu, March 2013

¹² Unnecessary Burden, page 35

¹³ Unnecessary Burden, page 39

¹⁴ There is a common belief, particularly in western Nepal, that women and girls are “impure” and “untouchable” after childbirth and during menstruation. As a result, families and communities regulate what and whom women and girls may touch during this time. They are forced to leave their house and live in a cowshed or in a separate hut constructed specifically for that purpose.

¹⁵ Unnecessary Burden, page 44

¹⁶ Unnecessary Burden, page 46



Given there was no comprehensive prevention strategy for the condition, Amnesty International, jointly with other NGOs working on uterine prolapse in Nepal, developed an advocacy campaign calling on the government to adopt a comprehensive prevention strategy for uterine prolapse, which includes also measures to address gender discrimination and empower women to claim their sexual and reproductive rights, including through recognizing uterine prolapse as a human rights issue and educating women and girls, families and communities about the risk factors for uterine prolapse and about women's sexual and reproductive rights. This is in line with the Technical Guidance's recommendation that a national plan to address preventable maternal mortality and morbidity must "explicitly include additional actions necessary to enable women to effectively enjoy their sexual and reproductive health."¹⁷

In conclusion, qualitative interviews by Amnesty International, combined with existing governmental quantitative data and reports by non-governmental and inter-governmental organizations, demonstrated that the risk factors for uterine prolapse were widespread and systemic in Nepal and closely linked to pervasive gender-based discrimination. While the government of Nepal had laws, policies and programmes in place to address some risk factors, the report found that these were insufficient to reduce women's and girls' exposure to uterine prolapse. Governmental action was either inadequate or not well implemented.

OBSTETRIC FISTULA IN ZIMBABWE

Between 2018 and 2019, Amnesty International conducted research on obstetric fistula in women and girls in Zimbabwe. Amnesty International is yet to publish its findings. Obstetric fistula is a medical term for a hole that develops between the vagina and the bladder and/or rectum and is caused by prolonged pressure on those tissues during an obstructed labour.¹⁸ It is considered the "most devastating" maternal morbidity,¹⁹ as it occurs after the trauma of an obstructed labour and results in continued incontinence of urine and/or faeces.

The exact number of women and girls in Zimbabwe who have experienced obstetric fistula while giving birth is unknown. Though Zimbabwe has a Maternal Mortality Ratio (MMR) of 651 for every 100 000 live births, it can be expected there is a devastating prevalence and incidence rate of obstetric fistula in the country. Senior health officials in Zimbabwe have estimated as many as 50 women and girls suffer pregnancy related morbidities - including obstetric fistula - every day.²⁰ WHO indicates that generally, the number of maternal injuries, or 'morbidities' may be up to 30 times higher than the number of maternal deaths.

Since 2013, the Ministry of Health and Child Care in Zimbabwe, with support from UNFPA, Women and Health Alliance International (WAHA) and partners, has provided access to surgical fistula repair. The program has focused on "providing obstetric fistula services at selected hospitals", with quarterly Obstetric Fistula Camps for affected women taking place at Chinhoyi Provincial Hospital since 2015.

Our research has shown a correlation between the crisis in the health system in Zimbabwe and occurrence of fistula cases. When Zimbabwe's MMR peaked in 2010, delays in seeking and accessing healthcare accounted for two thirds of maternal deaths.²¹ Medical experts explained to Amnesty International that cases of obstetric fistula would be expected to have occurred during this period.²² Subsequent and ongoing challenges within the health system continue to undermine access to quality obstetric care and increase the risk of new cases occurring. The government's efforts to increase access to treatment for obstetric fistula risk being totally undermined, unless the government can

¹⁷ Technical Guidance, para 35.

¹⁸ L Lewis Wall, Overcoming phase 1 delays: the critical component of obstetric fistula prevention programs in resource-poor countries, BMC Pregnancy and Childbirth 2012, 12:68. Wall www.biomedcentral.com/1471-2393/12/68 Page 2/13

¹⁹ Ahmed et al. Double burden of tragedy: stillbirth and obstetric fistula. The Lancet Global Health, Comment Vol. Issue 2, PE80-E82, February 01, 2016 [www.thelancet.com/journals/langlo/article/PIIS2214-109X\(15\)00290-9/fulltext](http://www.thelancet.com/journals/langlo/article/PIIS2214-109X(15)00290-9/fulltext)

²⁰ Firoz et al. Measuring maternal health: focus on maternal morbidity, Bulletin of the World Health Organization 2013;91:794-796. doi: <http://dx.doi.org/10.2471/BLT.13.117564> www.who.int/bulletin/volumes/91/10/13-117564/en/

²¹ United Nations in Zimbabwe Periodic Publication, Issue Paper Series, Paper 1 2013, www.zw.one.un.org/sites/default/files/UN-ZW_IssuePaperSeries-1_MMR_June2013.pdf (hereafter UN Issue Paper Series, Paper 1 2013).

²² Report of the Office of the United Nations High Commissioner for Human Rights, Technical guidance on the application of a human rightsbased approach to the implementation of policies and programmes to reduce preventable maternal morbidity and mortality,(2012) ref: A/HRC/21/22, para 8

²² Amnesty International meetings with two Senior Professors of Obstetrics, one in South Africa and one in Zimbabwe, October 2018.



simultaneously act to prevent new cases occurring.

Obstetric fistula has physical, psychological, social and economic impact on women and these consequences can affect families and communities. Women told Amnesty International researchers that they have suffered abuse and gender-based violence following their injury. They also reported experiencing cruel and discriminatory treatment from husbands, relatives, neighbors and community members. Some women reported losing jobs because of stigma related to their incontinence. Amnesty found that women with obstetric fistula and childbirth related incontinence took great care to conceal their condition and to maintain their cleanliness as best as they could. Women reported taking baths at least 3-4 times a day as well as facing enormous challenges in accessing the hygiene products and clean water needed to maintain their health and dignity. Obstetric fistula limited their economic independence and ability to work making it impossible to afford basic hygiene products such as soap, laundry detergent, sanitary pads, cotton wool, petroleum jelly and creams needed to bath and prevent blisters or sores.

Fistula is preventable and treatable. Women and girls face significant barriers to accessing timely healthcare during labor, increasing their risk of experiencing obstetric fistula. Many women have failed to get access to skilled birth assistance and emergency obstetric care. Delays in seeking medical help can be attributed to religious and traditional beliefs, personal choices, economic constraints, and fear of death in the formal health system.

Amnesty International documented the following barriers in accessing treatment for obstetric fistula:

Lack of Information about fistula and potential for treatment: Many women interviewed by Amnesty International did not know what they suffer from and saw fistula as a disability. They recounted how they had struggled to find information about the causes and treatment of their condition. Some interviewees were told by nurses that this is a lifelong condition and others thought their condition was untreatable. At community level, the condition has also been linked to superstitious beliefs resulting in some women turning to spiritual or traditional healers. Women reported that they had no information about the government's obstetric fistula treatment program and most also lacked information about obstetric fistula in general.

While Amnesty International did not interview healthcare workers,²³ senior doctors and officials in the Ministry of Health and Child Care who spoke to Amnesty International, indicated that many healthcare workers may lack the necessary information about obstetric fistula to correctly diagnose the condition or advise women on treatment

Costs: Fistula is often termed the disease of the poor. While the Zimbabwe government has a "free maternal health policy", this policy relates only to giving birth and does not cover any hospital treatment for maternal morbidities.²⁴ Women who suffer maternal injuries in child birth like obstetric fistula need to pay the equivalent of US\$150-4000 for repair surgery. Amnesty International noted that women who suffered from fistula had reported leaving hospital with child birth related debt which did not cover treatment of fistula. Such debts increase familial poverty and further prevent women's access to treatment for their injuries. In addition to the fees for health services, finding money for transports costs was reported as another major barrier to health services and information for women with maternal injuries.

Amnesty International found that the government of Zimbabwe has not taken necessary steps to identify the number of fistula cases in Zimbabwe nor address significant barriers pregnant women and girls face in accessing quality maternal health services and emergency obstetric care.

RECOMMENDATIONS

Amnesty International encourages the OHCHR in preparing its report to highlight the following policy recommendations to States to prevent and address maternal morbidities:

- Prioritize universal access to comprehensive range of sexual and reproductive health information and

²⁴ Amnesty International meeting with maternal health expert gynecologist, Harare, November 2018.



services including modern methods of contraception, including emergency contraception, safe and legal abortion and maternal health services. Ensure that all women and girls have barrier free access to such services; and strengthen awareness-raising efforts, targeted at women, girls, men and boys on available sexual and reproductive health services;

- Raise awareness and ensure the availability of information in communities and families, on the causes of specific morbidities and their prevention, including the importance of giving birth with skilled medical care;
- Ensure that women and girls who have experienced maternal morbidities have access to the health care and treatment they need, and that their health needs are supported for the duration of the waiting period for treatment, so they are able to continue with education and employment while waiting for treatment;
- Ensure that women and girls who suffer from maternal morbidities and are awaiting surgery can access hygiene and sanitation products and provide training programmes for doctors providing treatment for women with maternal morbidities;
- Remove barriers to prenatal care, including by strengthening the health care systems' ability to provide patient-friendly services based on non-discrimination, respect for patient's confidentiality and informed consent;
- Develop programmes to promote safe pregnancies and deliveries, including by addressing the social and economic challenges women and girls face accessing early antenatal care and maternity units / skilled birth attendants;
- Develop comprehensive strategies and programmes for prevention of maternal mortality and morbidity, which include also improve knowledge about sexual and reproductive health and rights, including through comprehensive sexuality education that involves also men and boys, and tackling underlying gender discrimination in society and empowering women and girls to make their own decisions in relation to their sexual and reproductive health;
- Put in place measures to collect accurate prevalence and incidence data to determine the scale of maternal morbidities. This data should be disaggregated by relevant characteristics including those that are protected grounds for discrimination, including region, age, ethnicity, race, religion, and income-levels, among others;
- Monitor the impact of all policies and programmes implemented to address maternal morbidities to ensure that the policy or programme is of benefit to all women and girls, without any form of discrimination or coercion. States should take prompt action to improve the situation where data suggests that women and girls from specific groups are disproportionately disadvantaged or excluded from the benefits of the policy or programme;
- Raise awareness of medical personnel about patients' rights and introduce confidential complaint mechanisms within health care services to address patients' grievances and provide redress in cases of violations of patients' rights;
- Ensure opportunities for equal and meaningful participation of all individuals and communities affected by the health policies and programmes, particularly women and girls, in priority setting, planning, implementation and monitoring of the health care provision.