EXECUTIVE SUMMARY

STRUGGLE FOR MATERNAL HEALTH BARRIERS TO ANTENATAL CARE IN SOUTH AFRICA

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AMNESTY INTERNATIONAL Too many women and girls are dying needlessly in South Africa during pregnancy or shortly after giving birth. One of the reasons is that they delay accessing antenatal care.

In 2000, the South African government promised to reduce the number of maternal deaths by three quarters, from 250 to 38 per 100,000 live births. In subsequent years the number rose significantly and, despite a recent fall, it still stands at 269. Experts believe that 60% of the deaths are avoidable.

Why the increase? One reason is that nearly a third of pregnant women are living with HIV. Over 40% of maternal deaths are linked to HIV.

Another reason is delayed access to antenatal care.

Commendably, antenatal care is free in South Africa's public health system. However, many women and girls delay going to clinics until the later stages of their pregnancy. This can have grave consequences, especially for pregnant women and girls living with HIV.

Nearly a quarter of avoidable maternal

deaths in South Africa are linked to late or infrequent access of antenatal care.

To understand the barriers to early and continuous antenatal care, Amnesty International spoke to women and girls, as well as health care workers, in KwaZulu-Natal and Mpumalanga provinces during field research conducted between March 2013 and September 2014.

The research highlighted three key barriers women and girls said led them to delay or avoid antenatal care:

 lack of privacy and patient confidentiality at clinics, particularly in relation to HIV testing;

 lack of information about sexual and reproductive health and rights, including lack of patient-friendly services;

• persistent problems associated with the availability and costs of transport to health care facilities.

South Africa's Constitution protects the rights to health, equality and nondiscrimination, and many sexual and reproductive rights. South Africa has also ratified human rights instruments that require the government to respect, protect and fulfil the rights of women and girls to health, equality and non-discrimination, and their sexual and reproductive rights.

WHY EARLY ANTENATAL CARE IS VITAL

Early antenatal care detects and treats health problems and screens for complications that may develop in a pregnancy.

It connects pregnant women and girls with the health system, so they are more likely to give birth in hospital or with the help of a skilled birth attendant.

Antenatal care should also offer vital lifestyle health advice, social support and counselling to pregnant women and girls.



For pregnant women and girls living with HIV, the earlier the care, the better the health prospects for the mother and the lower the chance that the virus is transmitted to the foetus.

The government recommends at least four antenatal care visits during pregnancy, starting at 12 weeks. Unfortunately, over half of pregnant women and girls wait until the second half of pregnancy, and many do not go four times.

ANTENATAL CARE AND HIV TESTING

Since 2010 the government has provided immediate antiretroviral treatment for pregnant women who test positive for HIV to protect their own health during pregnancy. Admirably, these policies have begun to reduce the number of maternal deaths.

However, Amnesty International has found that implementation of the HIV testing and treatment programmes has not been without problems, some of which have caused women and girls to delay seeking antenatal care.

"Stigma still follows those diagnosed with HIV infection and women often present late for testing for HIV." South African government Above: Schoolgirls playing in KwaZulu-Natal, where over 40% of pregnant women and girls are living with HIV. Due to the government's successful prevention of mother to child transmission programme in the last decade, the percentage of babies born with the virus has fallen dramatically from over 20% to 2.7%. Amnesty International encourages the government to maintain its commitment of reaching zero transmissions. Early access to antenatal care is an important part of achieving that goal.

Cover: Mbali Ndlovu and her sister Zanele (holding her baby) at their homestead in Uthungulu District, KwaZulu-Natal, South Africa, January 2014

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LACK OF PRIVACY AND CONFIDENTIALITY

One of the key problems is that women and girls are scared that their HIV status will become known because of lack of privacy at clinics. Their fear is understandable given that the stigma attached to people living with HIV remains high in South Africa, particularly in rural communities.

People waiting at dawn outside a clinic in Mpumalanga to ensure they will be seen by a nurse. Overcrowded clinics, understaffing and lack of training breach patients' privacy and deter some pregnant women from seeking early antenatal care.





Eighteen-year-old Busisiwe (not her real name) lives with her baby girl, mother and siblings in an isolated homestead in KwaZulu-Natal. The family somehow survives on a tiny income from social grants.

When Busisiwe was four months pregnant, she went to the antenatal clinic because she wanted to know if she was HIV-positive so that she could protect her foetus if necessary. She had to walk, a journey that takes between 60 and 90 minutes each way.

She said that at the clinic, the health care workers shouted at her in public for being pregnant when so young and didn't attend to her. So she left, without receiving antenatal care or being tested. She explained: "I was worried about testing at the clinic. They started to shout at me 'why are you frightened' and I don't feel better about that, so I think it was a good idea to test [elsewhere]."

Busisiwe later tested for HIV at her school, but by that stage she was eight months pregnant.

When she went into labour, Busisiwe asked a neighbour to drive her to the hospital as she didn't have the R250 (US\$24) it would cost to hire private transport.

The neighbour took her to the nearest clinic, where staff called an ambulance. The ambulance took three hours to arrive. Busisiwe said:

"[The staff] showed me one of the beds and they said I must wait there for the ambulance and they left me there. They didn't come back again until the ambulance arrived."

Despite her ordeal and lack of adequate treatment, she gave birth to a healthy baby.

Women and girls told Amnesty International that they felt more exposed to HIV-related stigma during pregnancy, and to domestic violence and abandonment. Clinics often lack the infrastructure, proper procedures and sufficient numbers of suitably trained staff to protect patient confidentiality.

Some antenatal clinics use designated rooms, waiting areas or queuing systems for women and girls living with HIV, so it is possible for everyone at the clinic to know their status. Some use distinct files or medicine containers for people living with HIV, again exposing patients' status. Some of the buildings used are so small, or inappropriately constructed, or overcrowded that there is little chance that conversations or medical procedures can be kept private.

Women and girls also complain that health care workers shout out or inappropriately share information about their HIV and pregnancy status.

The Constitution says, "Everyone has the right to privacy". In the context of health services, this includes: the right to informed consent – the government must take measures to ensure that women and girls can give informed consent to procedures affecting them; and the right to confidentiality – the government must ensure that patient confidentiality is protected.



LACK OF INFORMED CONSENT

The widespread perception that the HIV test is a mandatory part of antenatal care raises other fears in women and girls that can lead them to delay or avoid antenatal care.

Many worry about finding out that they are living with HIV and then having to tell their partner, risking abandonment and abuse. Some also know that the counselling and other support services at the clinic are inadequate or absent, and fear the health consequences of living with HIV.

Health care workers often talk about testing for HIV in pregnancy in a way that fosters this perception of compulsion. South Africa's and international guidelines make clear that health care workers must ensure that women and girls give informed consent before they are tested for HIV. The health care workers must also provide counselling before and after the test that enables women and girls to make informed decisions. "No one at home knows my status, they would be too judgmental."

A woman living with HIV in KwaZulu-Natal

"[1]f I go for antitretrovirals, my line is that side. All the people in this line they know these people are HIV. That's why people are afraid to come to the clinic."

A woman in Mpumalanga

"All the pregnant women are sitting together, but they divide them by HIV status into different rooms. It is not right." A woman in KwaZulu-Natal

"All pregnant women are tested. They are not allowed to say they are not ready for the test."

A counsellor in Mpumalanga



Above: A teenage mother in Mpumalanga province. In South Africa, 8% of pregnancies are among girls aged under 18, but they account for 36% of maternal deaths.

Above left: Billboard opposite a clinic in Mpumalanga. Because HIV testing is part of antenatal care, significantly more women than men in South Africa are tested – 52.6% compared to 37.5%. As a result, women are often blamed for the virus, and become additionally vulnerable to abandonment and domestic violence, just when they are coping with pregnancy and learning to live with HIV. "What would help is for us to get a tarred road... because even the mobile clinic can't come when it is raining." A women in KwaZulu-Natal



"I was seven months pregnant. We had to wait for the counsellor [at the clinic]... and this made me late. There was no transport so I had to hitchhike."

Nokwethemba Sikhakhane, a crèche teacher, and her two-week-old daughter

A ROAD TOO FAR

In South Africa's vast and often hilly rural communities, acute problems with transport compound all the other difficulties faced by pregnant women and girls.

The roads in some areas visited by Amnesty International are of such poor quality that they become impassable when it rains. Even when it is dry, ambulances will not go beyond a certain point.

For many pregnant women and girls, there is no public transport option, so they walk to the clinic – often an hour or more each way. Indeed, this is the most common way of reaching health care facilities nationally.

The costs of paying for a seat in a minibus "taxi" or bakkie (a van converted to take passengers, which can be an unsafe option for pregnant women) can pose serious financial problems.

As a result, many pregnant women and girls delay or avoid going to the clinic simply because they can't afford to pay for the transport.

In emergencies the cost of private transport to hospitals is prohibitive – up to R900 (US\$80). High unemployment means that most households in rural areas rely on government social grants. Few of the households that Amnesty International visited had monthly incomes above R1,000 (US\$95). "It's hard because we travel on gravel road. It becomes a bumpy ride that is very uncomfortable for pregnant women. But there is nothing can do, just have to accept the situation."

A woman in KwaZulu-Natal describing journey in a bakkie to the antenatal clinic



The scarcity of ambulances in some districts means that women often spend up to half their monthly income to pay for transport to get to a hospital in time to give birth. This money is then not available for other essential expenses, such as food and items needed for the baby.

Women and girls may also end up giving birth without medical help at home or on the side of a road as they can't afford to hire a car when the ambulance doesn't turn up – an all-too-common experience.

South Africa's Constitution says that everyone has the right to have access to health care services. This means that all health facilities and services must be physically, economically and socially acceptable to all, and within safe physical reach for everyone, especially marginalized groups.



A bakkie wends its way along a perilous, dirt road in KwaZulu-Natal's Uthungulu district. The district had the third highest rate of maternal mortality in health facilities in South Africa in 2012/13.

'I WISH I'D KNOWN MORE'

Lack of information about sexual and reproductive health and rights in South Africa has devastating consequences for individuals, communities and society as a whole. It is contributing to a high rate of unplanned pregnancies, particularly among girls; the spread of HIV; and late access to antenatal care.

Amnesty International found that the benefits of early antenatal care were largely unknown or were misunderstood by the women and girls interviewed. Complaints about the standard of care received from health care workers were also common. As

Under the right to health, the government must ensure "the right to have family planning education" and "provide adequate, affordable and accessible health services, including information, education and communication programmes to women especially those in rural areas". a result, many women and girls seek antenatal care late.

Nationally, over half of the annual 1.2 million pregnancies are recorded as unplanned.

Many women and girls Amnesty International spoke with described the difficulties they faced accessing information on contraception, pregnancy, termination of pregnancy and prevention of HIV.

They also lacked information about protection against HIV and the skills needed to negotiate condom use.

Girls suggested that comprehensive sexuality education in schools should be available for all students. Women and girls said that it would be better if their partners accompanied them to antenatal care to also test for HIV. Nearly all health care workers interviewed by Amnesty International said that they wanted training on how to provide information about sexual and reproductive health and rights, especially to adolescents.

"Most of them, they don't even know what it means to be pregnant, there is no idea [about] what they are facing, because they haven't spoken to anybody at home so they don't know what the meaning of pregnancy is, what lies ahead." A nurse talking about pregnant teenage girls



These four young women in Mpumalanga were all teenage mums. They said they had not used contraceptives before they became pregnant and believe more information about contraception should be provided to girls and boys at an earlier age at school.

ACTION NEEDED NOW

Amnesty International recognizes the recent successes South Africa has made in improving access to health care for all South Africans and tackling the HIV epidemic.

However, Amnesty International has found that problems implementing some government initiatives combined with longstanding social and economic inequalities lead to delayed access to antenatal care. This can contribute to the unacceptably high number of women and girls who are still dying needlessly each year during pregnancy or shortly after giving birth in South Africa. Among other recommendations set out in the report, Amnesty International is calling on the government to:

Ensure that all branches of government are involved in the response against maternal mortality, HIV and gender-based discrimination, and develop programmes to promote safe pregnancies and deliveries, including by addressing the social and economic challenges women and girls face accessing early antenatal care.

Abolish all health system procedures that compromise patient confidentiality, such as the use of specific files for HIV treatment, separate queues and designated waiting areas for people living with HIV. Increase awareness about patients' rights, particularly the right to informed consent.

Improve knowledge about sexual and reproductive health and rights, including through comprehensive sexuality education that involves men and boys.

Urgently address the persistent lack of safe, convenient and adequate transport, and the poor condition of roads, including through subsidized or free transport, grants to pregnant women and girls to cover transport costs, improving road infrastructure, and improved transport options.





Amnesty International is a global movement of more than 3 million supporters, members and activists in more than 150 countries and territories who campaign to end grave abuses of human rights.

Our vision is for every person to enjoy all the rights enshrined in the Universal Declaration of Human Rights and other international human rights standards.

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