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Independent observer of the Global Fund

In South Sudan, debate on how to maintain HIV treatment adherence during times of war

More than 700,000 people have fled their homes since conflict erupted in mid-December in South Sudan, which has compromised their safety and security and made them more exposed to the risk of illness and other public health challenges. But for the estimated 6,617 people living with HIV who are taking anti-retroviral treatment supported by the Global Fund, being far away from their home clinic has become a matter of life or death.

Many of the displaced have made their way to the Juba Teaching Hospital, in the capital, waiting patiently on worn and cracked plastic chairs to be seen, to be tested and to hopefully be sent away with the medication they need to maintain their treatment regimen. Adelina Drasa David, who coordinates treatment at the hospital said that there have been an estimated 300 new patients in her waiting room since mid-December, coming from all over the country.

Jovia Akello is one of those people. After fighting erupted in her hometown of Bor, the capital of Jonglei state and about 200km from Juba, she was among the thousands who hurried into the bush to avoid being caught in the crossfire. But her hasty departure meant that she left everything behind – including the ARVs she has been taking assiduously since 2011.

“I was so worried, because I know that stopping [the medicine] even for 24 hours is really bad,” she told Aidspan in Juba, where after more than two weeks in hiding she finally caught a ride in the back of a truck to the main hospital in town to replenish her stocks and resume her treatment regimen.

John Pitia was not so lucky. He’s been off his treatment for more than a month because his wife, in a panic because of the fighting, fled to her parents’ home up-country, accidentally taking with her his

medication.

HIV prevalence in the world's newest country is estimated at 2.6%, but fluctuates considerably by region, reaching 6.8% in Western Equatoria state – home to more than half of the people currently taking ARVs – and barely achieving 0.3% in North Barh El Ghazal. Most of the people on ARVs are concentrated in urban areas, like Western Equatoria's capital, Yambio. But the challenge in this recent conflict is that the fighting has also been concentrated in urban areas, forcing people from their homes and into the bush – and away from their clinics.

Even at the best of times the condition of South Sudan's health infrastructure is dire. Years of isolation and intermittent instability have left most facilities without even the basics – like refrigeration or a steady source of electricity.

Under a health systems strengthening allocation in its HIV grant, UNDP has since October 2010 been allocated some $47 million from the Global Fund to address some of these facility challenges. Of the $23 million that has been disbursed, some has been spent to equip 14 out of the 22 ART sites supported by the Global Fund with generator-powered refrigerators. But even they can't run 24 hours per day and breakdowns remain a problem.

But beyond the structural limitations of the facilities themselves lies the more serious challenge of ensuring that drugs and equipment are distributed and available in the more remote – and more volatile – parts of the country. In towns where fighting was fierce, it's sometimes hard to know what they have, what they need and what they are running short of. Numerous NGOs and UN bases have been entirely looted by gunmen.

The challenge of stock-out is made worse both by the conflict and the delays that have been the result of the departure of international partners because of security reasons, according to Dr Emmanuel Lino, in charge of the Ministry of Health's HIV program.

"Because of the crisis, most of the expatriate personnel for the international NGOs and the UN agencies were evacuated, so it makes coordination all that much harder," he said.

The administrator of the Juba Teaching Hospital's VCT clinic, Benjamin Lokio Lemi, ticked off some public facilities that were bare of medicine. "We're looking for solutions in coordination with the health ministry, trying to figure out how to supply them," he said. "In the meantime, we're cobbling together ways to get drugs to the people in need."

One way is to place trust in the drivers of commercial vehicles headed out on the dicey journey. A packet of drugs is given to the driver, telephone numbers are exchanged and license plates noted and then, according to Drasa David of the Juba Teaching Hospital, all that is left to do is wait for the phone call announcing that the driver has reached his destination.

And even in Juba, the fighting has had consequences for treatment. The teaching hospital's ARV clinic was closed for three days at the beginning of the conflict, but has reopened despite safety concerns. And while most of the laboratory equipment is functioning, the blood chemistry analyzer has been broken since early December –just weeks after the last routine servicing on the machine covered by the Global Fund grant was conducted.

Funds to repair the machine will come from a March disbursement of some $2.8 million dollars, said Madelena Monoja, the UNDP focal point for the Global Fund grants in South Sudan. The disbursement is the latest tranche of transitional funding approved in 2013 worth nearly $12 million.

The gap has had serious consequences for patient care, said laboratory technician Francis Victor, making

it difficult if not impossible to monitor patients' clinical response to treatment.

Patient care during times of crisis is complicated enough, without the additional burden of assessing unmet needs among an ever-growing number of displaced people, most of whom have arrived in Juba's temporary camps without even knowing their status.

The government has mobilized teams to discreetly offer voluntary testing in the camps, but the burden of fear, stigma and a profound lack of knowledge is preventing them from being as effective as possible, said Dr Lino. A Household Health Survey conducted in 2010 found that fewer than 10% of the Sudanese population had solid awareness of the disease, how it is transmitted, and effective ways of preventing transmission.

An equally profound lack of awareness and training among health professionals – including doctors, nurses and clinicians – means that there is limited secondary detection capacity, or automatic recommendation for HIV screening among patients presenting with respiratory illness or other maladies that would indicate the possibility of infection.

"In general, we have to do more testing," Dr Lino said. "We have to be able to provide everyone with access to services at all levels, instead of being limited only to screening centers."

Such limits are related to resources, he added, since once funds are programmed, it is very difficult to use them in a more flexible manner. Grant money from the Global Fund was consigned to ARV purchases, and cannot now be used to purchase more diagnostic tests, which had been the purview of the US AIDS response program PEPFAR until recently. The complementarity of donor funding is useful, Dr Lino acknowledged, but when there are unfilled gaps, it is very difficult to shift money around to fill them.

"We are in a state of emergency and need to respond fast," he said, "and we can't."

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