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Editorial

Role of communities in AIDS response

The world has been experiencing a terrible epidemic of human immunodeficiency virus (HIV) over the last 40 years[1]. HIV causes progressive immunodeficiency and if untreated almost invariably leads to an AIDS-defining illness and then premature death[2]. AIDS is an acronym for acquired immune deficiency syndrome; the surveillance definition was proposed by the Centers for Disease Control and Prevention in 1982 to investigate the mystery illnesses first seen in some communities in the USA who had no reason or recognised cause for immunodeficiency[3]. Very soon after a retrovirus was isolated, accurate diagnostic tests were developed, and the dreadful truth became clear - HIV/AIDS was pandemic with millions of adults and children infected or already dead.

Sub-Saharan Africa has always borne the brunt of the epidemic, with around two-thirds of the estimated cases and deaths over the decades. In many African countries and communities, HIV is a generalized epidemic largely spread by sexual intercourse and affecting sexually active men and women alike, with many children becoming infected *in utero*, during birth or via breast milk. With such community-wide risks and rates of infection, a whole of population response with a public health approach is needed[4], which focuses on both prevention and treatment, which promotes behavioural change such as condom use to reduce sexual transmission, adherence counselling in life-long therapy and ways to combat the challenges of stigma and discrimination[5].

The theme for the World AIDS day this year is that communities make the difference[6]. The African countries that have done the best to confront HIV and implement successful HIV and AIDS control programmes have had strong political leadership; a vibrant civil society that is non-judgemental but compassionate and engaged communities that expect and often have to demand appropriate resource allocation for all the necessary interventions. Civil society is the sum of community groups[7]; and the countries that have successfully controlled and reversed the epidemic, have achieved this through strong and cohesive community responses[8].

The scale of the challenge in South Africa in particular is enormous: unfortunately, some groups miss out on otherwise effective programmes and remain with high levels of infection, morbidity and mortality. Young men and adolescent girls remain particularly vulnerable, despite multiple efforts to target them and implement proven behavioural change, prevention and treatment interventions. Both these groups tend to lack strong community cohesion and representation in national or regional decision-making forums. Lack of community unfortunately perpetuates the epidemic[8].

In other regions of the world, HIV tends to be more focused in particular communities with specific risk factors, who experience what epidemiologists call a concentrated epidemic. In the USA, where AIDS surveillance was first carried out, it was soon obvious that three communities at least were particularly impacted: homosexuals, individuals of Haitian heritage and haemophiliacs[1,3]. Of the 'three Hs', as they were sometimes initially referred to, haemophiliacs were considered 'innocent', whereas Haitian-heritage people were already discriminated against as a poor immigrant community and gay men were blamed for bringing it on themselves with their 'unnatural' sexual practices.

The gay community responded, as their peers, colleagues and partners wasted away and then died with purpose and with anger. They refused to be blamed, dismissed or further marginalized. Governments across

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the rich industrialized world, particularly in the USA, could not ignore their collective activism in directly confronting prejudice, stigma and discrimination. Some clinicians were better than others: nurses were usually more empathetic than doctors initially and led the way[9]. Nor could wider society afford to ignore and dismiss this health emergency, as all could be at risk and die from ignorance.

Such activism drove wide-scale awareness campaigns that succeeded when they were non-judgemental and non-stigmatising. Politicians and decision makers were shamed or pressurised to allocate appropriate and sufficient resources to deal with the multiple emerging challenges. The biomedical research community reacted with speed with ring-fenced funding and unprecedented developments were achieved in diagnostics, clinical management and effective therapeutics. The dramatic advances in diagnostics now extend way beyond HIV - for example, with single-patient point-of-care tests, or salivary-based rather than whole blood or serum-based assays[10].

The speed of drug development is almost unprecedented, with well-tolerated and low-toxicity combination therapy now available in single-pill co-formulations enabling the 'one-pill-once-daily' strategy to now be the standard of care for most patients. Recently, this has been extended to effective short-course treatment and cure (in most patients) for hepatitis C infection[10]. Safe, tolerable antiretroviral combinations have also enabled pre-exposure prophylaxis to be evaluated and implemented-driven by community pressure and taking a lead from malaria and tuberculosis control programmes where chemoprophylaxis has been standard practice for generations. Only the older generations involved with HIV will appreciate just how far and fast we have gone, to me the most powerful example is how communities take responsibility and make a real and lasting difference that impacts all - rich or poor, adult or child, gay or straight.

Another consequence of the community activism that emerged as the AIDS epidemic unfurled was the uncomfortable truth - for some clinicians at least - that the patient often knew more than the doctor. This activism confronted the traditional healthcare paradigm and upended the parochial and one-sided clinical consultations that characterized the doctor-patient relationship several decades ago. Younger clinicians may not recognize how revolutionary it was to deal with a patient as an informed equal, and fully involve them in clinical decision-making. Such approaches are now the norm across almost all jurisdictions, to the benefit of all patients in acute or chronic, long-term care. It is particularly relevant with antiretroviral therapy and for non-communicable diseases where there is effective treatment but not cure, and treatment needs therefore, to be lifelong.

India has a concentrated epidemic, with significant regional differences in risk profiles and exposed and at-risk communities, only to be expected in such a populous and diverse subcontinent[11]. HIV/AIDS control programmes do well where there are cohesive communities which receive support to develop and implement targeted interventions. The National AIDS Control Organisation (NACO) has, by international comparisons, been very successful at an aggregate country level in both HIV prevention and treatment[12]. It has been most successful with behavioural change or delivering antiretroviral therapy when it meaningfully engages with communities most impacted by HIV and which have been encouraged to engage with the NACO and State-level agencies to develop cohesive community responses. In the non-governmental [non-governmental organization (NGO)] sector, the *Avahan* projects that focus on female sex workers and which have paid special attention to developing significant community engagement and fostering community leadership have been particularly successful[13]. Neither government-led nor NGO-led programmes have done well where communities struggle with stigma and discrimination and remain marginalized: consider the States, particularly in the northeast where HIV transmission is driven by injecting drug use. Clearly in India as elsewhere, communities make a huge and positive difference where they are included, and failure to develop meaningful interactions inhibits programmatic success[11,12].

What is the future? With HIV infection, now a chronic, treatable but incurable condition, like many non-communicable diseases such as hypertension or type 2 diabetes, the focus of health systems must be to embrace a universal health care (UHC) approach: to promote relevant behavioural change and lifestyle interventions; to screen at the population level and to implement long-term, lifelong treatment interventions[14]. These will succeed where communities are engaged and will struggle if they are not actively involved. This is the lesson from HIV: UHC is predicated on recognizing that communities make a difference and without meaningful engagement, it will struggle to succeed.

***Conflicts of Interest*:** None.

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