

Finding a way through

Professor Jackie Hoare, who recently became the first psychiatrist on the GMC specialist register for neuropsychiatry, speaks about the challenges faced by young people living with HIV in South Africa, and how research and remodelling care systems can help.

There were no dedicated mental health services for young people and adolescents living with chronic illness,” says Professor Jackie Hoare, describing the scenario when she became Head of the Division of Liaison Psychiatry at the University of Cape Town’s (UCT) Groote Schuur Hospital in 2011. “And in our context, the most prolific chronic illness in young people is HIV.”

Nearly 80% of all young people with HIV live in sub-Saharan Africa (SSA). In South Africa, declines in mortality among perinatally infected children have contributed to the ‘youth bulge’, which accounts for a large part of the overall population living with HIV. This is in addition to growing numbers of the SSA youth population who have acquired HIV behaviourally.

“The risk of mental health problems and neurocognitive impairment among adolescents is particularly high in young people living with HIV,” says Professor Hoare, who, as a neuropsychiatrist, has sought to support this vulnerable group both clinically and via research. Based at Groote Schuur Hospital, a Western Cape, government-run facility, she delivers mental health care to some of the region’s most vulnerable young people. “And of course, you can’t separate out poverty, vulnerability, mental health issues and HIV.”

Very early on, it became clear to Professor Hoare that working from clinics in traditional psychiatric spaces simply didn’t work. She describes “sitting in clinic

“Nothing means anything unless teens like it, want it and feel safe there”

with 15 appointments booked, but only two turning up”. So, she remodelled her services for people living with HIV and other chronic illnesses.

“Rather than my team being a separate entity, psychiatry is integrated into other outpatient and inpatient services – not just for young people, but for adults, too,” she says. “Now, I don’t deliver any care outside of existing physical healthcare. Instead, I go to oncology, to infectious diseases, to obs and gynae, etc.”

Normalising access to mental health services was particularly important, as stigma about HIV and mental health problems had significantly contributed to the failure of the traditional psychiatric services delivery model. “Now, the idea that you, for example, go and get your chemo and then see your psychiatrist or psychologist on the same day is normalised within that service. It’s not seen as stigmatising or as a weakness; it’s seen as being all part of the oncology service.”

Professor Hoare’s growing body of research has investigated various

aspects of what it is to live with HIV for young people. Since South Africa began its large-scale rollout of antiretroviral therapy (ART) in 2004 for children, a first generation of perinatally infected children has survived to adolescence and young adulthood. This meant that there were critical gaps in the understanding of HIV-associated central nervous system (CNS) disease and mental health outcomes for this population.

So, to begin with, Professor Hoare’s research sought to establish what was happening. “My team and I developed a model for understanding the spectrum of neurocognitive disorders in kids and adolescents,” she explains, as one had only existed for adults before that. “This involved using novel neuroimaging techniques and testing neurocognitive ability and functioning longitudinally to map the underlying pathophysiology of HIV on the developing CNS.”

Rates of major HIV-related neurocognitive disorders have dropped from 50% to around 8 or 9% since the rollout of ART began. “However, the difficulty is the persistence of minor neurocognitive disorders experienced by up to 50% of all children and adolescents

living with HIV, despite them being on ART and virally suppressed,” says Professor Hoare. “The effect of the virus’s chronic inflammatory process on the brain during neurodevelopment is very different than its effect on an older adolescent who acquires HIV via sexual transmission. It’s a profoundly different ball game.”

Gender discrimination and gender-based violence in South Africa also fuel its HIV epidemic. Adolescent girls and young women are prime targets of gender-based violence and they are acquiring HIV at more than double the rate of boys of the same age. “For young girls and women who live in poverty, transactional sex with older men is a sad and real problem,” says Professor Hoare.

“Condoms just don’t fly here, particularly in poorer communities, because there’s a huge amount of HIV stigma,” she says. “If you ask someone to use a condom, the assumption is you must be HIV positive. So, condom use is abysmal in South Africa.”

Faced with this, Professor Hoare began work with pre-exposure prophylaxis (PrEP) – the use of antiviral drugs to prevent the spread of HIV. “PrEP became an important tool in our kit to protect young women and adolescent girls,” she says.

She undertook an effective two-year study to understand factors affecting PrEP services for adolescents and to guide PrEP messaging to address their uptake, adherence and perception of risk. “The PrEP programme in South Africa has become a very successful part of HIV prevention.”

Over time, South Africa has risen to the challenge of its vulnerable HIV population; it now has the largest ART programme in the world to match the size of the problem, and has made huge improvements in getting people to test for HIV in recent years.

Professor Hoare has also had success in creating a community model of healthcare to look after young people. Recently she has been working with NGOs, the South African Department of Health and UCT to create the Adolescent Centre of Excellence (ACE), a one-stop health centre providing counselling services, physical healthcare services, sexual and reproductive health services, HIV and TB testing and rapid initiation of treatment on site.

Other models of care for adolescents in South Africa are combined with adult care, which adolescents find stigmatising. “They don’t like it. They don’t go to it,” says Professor Hoare. “It’s so important to listen to what they want, for them to be involved in the model.”

So, the ACE will be unique in catering only for young people and, at their request, will include pinball machines and pool tables, as well as computers with wi-fi to help them do their homework as many of them live in areas without it. “Nothing means anything unless teens like it, want it and feel safe there.”

The ACE was due to open last year but was delayed due to the coronavirus pandemic, at which point Professor Hoare threw herself into clinical work on the frontline. She is now applying her knowledge and research skills gained working in NeuroAids and neurovirology to understanding NeuroCOVID. “I’m going to use a very similar model for understanding the inflammatory process by using novel neuroimaging techniques,” she says.

Across this extensive body of work, Professor Hoare shows deep commitment to developing healthcare that can make differences to vulnerable people’s lives. “Doing research has provided me a light so that I don’t feel overwhelmed by the lack of resources. Because I really feel that I can do something. I can’t fix everything; this is such a complex society. But sometimes, little things matter.”



Professor Jackie Hoare