



Case Study Series
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Towards an AIDS-Free Generation by 2030: How are South African Children, Adolescents, Caregivers and Healthcare Workers Coping with HIV?

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Abstract

We are committed to an AIDS free generation by 2030 – nine short years away. This paper reflects on the global and South African data on new infections, total number of children and adolescents living with HIV as well as data on vertical transmission. The paper includes the voices of key stakeholders in the quest to end HIV in children so that lessons from their experiences can be used by policy makers in strengthening services.

Keywords

Children, adolescents, caregivers, healthcare workers, HIV, stigma, psychosocial support

Introduction

The world has known HIV for 40 years yet there is no cure or a vaccine. However, we have other tools to prevent the transmission of HIV as well as antiretrovirals that can prolong life. What is the state of the epidemic especially as it relates to children and adolescents as we enter the third decade of the 21st century? The world committed to an AIDS free generation by 2030. With less than a decade to achieve this goal, how are children, adolescents, their caregivers and their providers coping with this challenge?

This paper reports on the latest global and South African data on HIV in children and reflects on presentations made by key voices in this epidemic during a webinar hosted by the Clinton Health Access Initiative (CHAI) South Africa, Paediatric Treatment for Africa (PATA), the AIDS Foundation of South Africa (AFSA) and Wits Reproductive Health Institute (WITS RHI) in December 2020 entitled “What can we learn from children and adolescents living with HIV”.

How many children and adolescents are living with HIV?

According to the Rome Action Plan (Elizabeth Glaser Pediatric AIDS Foundation et al, 2020) in 2019 1.8 million children between the ages of 1-14 years were estimated to be living with HIV. However, only 52.7% of these children were diagnosed and on treatment. More than 850 000 children are not on treatment and 100 000 children lost their lives as result of illnesses associated with AIDS. UNAIDS (2020) estimated that 150 000 children were newly infected in 2019 alone. While this figure is high it represents a 52% decline from new

infections in 2010 - largely driven by the decline in vertical transmission from 23.15% in 2010 to 11.35% in 2020.

Amongst adolescents, UNICEF (2020) estimated that in 2019, 460,000 10 to 24 year olds were newly infected with HIV, of which 170,000 were between the ages of 10 and 19. UNICEF further estimated that among 15-19 year olds in Eastern and Southern Africa, only 27% of adolescent girls and 16% of adolescent boys were tested for HIV in the past 12 months with rates being even lower in West and Central Africa and South Asia. Among 10-19 year olds living with HIV in 2019, there

were 34 000 deaths globally from AIDS associated causes.

For South Africa, the Thembisa 4.3 model (Johnson and Dorrington, 2020) estimates suggest some progress but that relatively high infection rates persist:

- New HIV infections at birth declined from 18 300 in 2010 to 3 600 in 2019 (a decline of 80%);
- A 63% decline in infections during the breastfeeding period, from 22 000 to 8 000;
- Total infections in children under 15 years of age was estimated to have declined from 409 585 in 2010 to 313 109 in 2019 – a 23.6% decline;
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- Total infections in children under 15 years of age was estimated to have declined from 409 585 in 2010 to 313 109 in 2019 – a 23.6% decline;
- New infections in children under 15 years of age declined from 33 811 in 2010 to 12 260 in 2019 – a 63.7% decline; Incidence in 15-24 year-old adolescent girls and young women declined from 2.98% in 2008 to 1.3% in 2018 and a decline from

1.03% to 0.33% in adolescent boys and young men in the same period.

In short, the challenge of HIV in children and adolescents has not gone away! So how do young people, their caregivers and providers cope with HIV? We invited an adolescent, a caregiver and a provider to share their experiences on a webinar so that we can learn from them in thinking about how services can be improved. These are their stories as transcribed and edited from the webinar.

Voices of an adolescent living with HIV, a caregiver, and provider:¹

Perspective of an adolescent living with HIV

“My name is Tumi, from Mabopane, Gauteng. I’m 24 years old. Before I get into anything else, I would like to give you a brief of who I am and how I got here. I was diagnosed with HIV in 2014. I was a teenager and I was pregnant. When you start pregnancy check-ups, you have to be tested for HIV, and it was then that I found out I was HIV positive. Luckily for me, I had a health worker who was very well experienced, calm, understanding and loving. I went through everything

with her and she was so great. I decided to take the pills and I started treatment from that very day as I didn’t want to waste time because I was pregnant.

I needed to make a life and be mature about the situation. Yes, it hurt, but I cannot change what happened. So, after that day I took my pills until I gave birth; but after I gave birth I decided the clinic was not private enough for me. I felt that I was not given privacy at that clinic, so I defaulted. But I did not default for long, it was because I had pneumonia. The doctor felt she needed to know why I defaulted and I explained to her that I defaulted because I didn’t feel I had privacy at my clinic. So, my doctor moved me to another clinic, a better clinic where privacy is everywhere. After she moved me to the new clinic, I felt welcomed, and I felt like I belonged there! Kopanong clinic is the best!

Let me talk about living with HIV as a teen, it was never easy and I do not believe that it will ever be easy with all the stigma that is around us. It doesn’t matter how much we teach people about HIV, living with HIV as an adolescent is still very difficult. Our society is not very welcoming or understanding. I also feel secluded; every day of my life people will be like, “oh, that one has AIDS.” I feel like people still lack so much knowledge, and even if they have it, they still think that people living with HIV should be secluded. I feel like we are not supposed to live, we don’t really have a voice; even though we have a voice, are we doing to be listened to? Being HIV positive is like being bottled, you do not live life the way you want to live it. And I think it is because we don’t accept ourselves; but if today I say, “I’m going to accept that I am HIV positive”, then life becomes very easy. But at the same time, life is also difficult because we are so young and we are living in a very judgmental world. So, for us to get out there and say, “I am HIV positive,” can be hard. I remember the first time I joined the Youth Care Club group at a Kopanong clinic, I met a lady who said to me, “Oh, you are also HIV positive. Yoh, but it doesn’t show.” I asked her, “How do they look? We are not different from anyone else.” So just take care of yourself, things will turn out better for you. Living in South Africa with this disease with all the stigma and judgmental people is tough but live your life the way you want to live it whether people accept you or not. Living with HIV as an adolescent is very

¹ Names changed to maintain confidentiality

deep in this country because people don't know about this disease, but if we can try and make people in South Africa learn more about HIV, maybe we'll have a better generation".

Perspective of a caregiver of an adolescent living with HIV

"My name is Thembi. I live in KwaZulu-Natal with my 14 year-old daughter. I struggled a lot raising her because she is infected with HIV, and I only found out about her status when I took her to the clinic because she was very sick. At the clinic, the nurse advised HIV testing for both me and my child and we found out we were both HIV positive; this news was shocking and it was difficult to accept our status. We were given treatment, and we had many questions that we did not have answers to. We later realised we got it from my mother, because we were helping her when she was sick, and we did not use gloves. My mother did not tell us about her status, and we have a lot of questions that we cannot get the answers to as she has passed away.

I really struggle to raise my child as a single parent since I don't have a job and I don't have any family members to support me and I feel alone. When we got back from the clinic, we felt like everyone knew our status. Someone from the community saw me at the clinic collecting my medication, and she started calling me names. People asked why she was calling me names, and she told them that I am HIV positive. People stopped inviting me to functions and I did not feel like a part of the community. Even if I go to the shopping mall, people point at me; my child was not coping at school and she spent a lot of time alone. She always felt tired and did not eat well.

What helped me was the introduction of the AIDS Foundation of South Africa (AFSA) team at the clinic. The AFSA team started to visit me at home and build relationships with me and my daughter in order to teach us how to live with HIV. They invited both of us to support groups which has helped a lot as I got to meet other parents and children who are HIV positive. My child was happy to know she was not alone, and she was chosen by AFSA to be a peer supporter to support other children her age. Creating job opportunities for people living with HIV will help to minimise stress".

Perspective of a healthcare worker

"My name is Phumi. I'm a social auxiliary worker in Johannesburg. I provide services in a project in partnership with the Department of Health (DoH) to reach our 90-90-90 strategy. Today I will be talking on

the healthcare worker perspective on treating children and adolescents living with HIV. I have divided the challenges into two: namely, challenges with the health care system and challenges with the services being provided. The first challenge with the health care system is space. One would have to find a way to get space to service adolescents; this increases patients' waiting time to get services. Staff find it difficult to find space to provide Adolescent Friendly Youth Services and to create child friendly spaces. These services are part of a comprehensive programme, and therefore healthcare workers may see it as additional work and priority is therefore given to other activities in the facility.

Another challenge with the health system is confidentiality. Confidentiality remains one of the biggest challenges within the health system, as there is shared confidentiality amongst the healthcare workers which makes the adolescent feel uncomfortable and reluctant to take up services. For example, in one of the facilities that we support, there is a small community and everyone knows everyone, including healthcare workers, so an adolescent may be reluctant to be seen at the clinic.

Challenges with the services being rendered includes the reluctance from caregivers. Some caregivers are reluctant to be referred with their children for psychosocial interventions because of non-disclosure, and other parents may not be ready for any psychosocial services. But when they are receptive, they find that there are actually a lot of services they can be provided with, such as disclosure services and referral to Community Based Organisations. This brings me to my next point, disclosure. After testing positive, disclosure is rushed for initiation to be done, which may lead to poor adherence to treatment or loss to follow up as they will not be ready to take up treatment. As you probe and build that rapport with the clients, you find that many of the children and adolescents have never been disclosed to before, whether partially or fully. This may cause treatment fatigue and lead to poor treatment adherence, stunted growth and mental health issues in children and adolescents. Another challenge with the services rendered will be the roving of staff. The psychosocial teams rove from one facility to another. This is a challenge in that a lot of adolescents are missed, especially those that visit the facility on days that the roving team is not at the facility.

Furthermore, what is not working well are the referrals for mental health services for adolescents living with

HIV within the health system. It is difficult to link these adolescents to mental health services or to psychologists. Psychologists are always booked with long waiting lists, and priority is not given to children and adolescents living with HIV.

We can better support healthcare workers by providing debriefing sessions as they deal with a lot of social and emotional issues at the facilities. For example, they may experience traumatic stories from their patients, which may lead them to either being depressed or having feelings which they take home and do not deal with. Also, opportunities for professional development and supportive supervision should be provided for healthcare workers. Acknowledge healthcare workers on their successes and on the improvements in their patient's health and mental state.

We still have a long way to go to retain our children, adolescents and youth in care, especially during this COVID-19 period. There are a lot of challenges, which include a lack of employment, retrenchment and illnesses which all affect treatment adherence. Together, we can save more precious lives”.

The lessons from these voices are critical for policy makers and managers alike charged with strengthening the systems and services provided to children and adolescents living with HIV as well their caregivers and healthcare providers. Equally, these voices should resonate with academics charged with training healthcare workers, nurses, medical doctors, psychologists, social workers etc. to ensure that healthcare workers are able to provide confidential, non-judgmental, person-centred care that is appropriate for young people.

Discussion

Global and South African data on HIV in children and adolescents suggests significant declines in new HIV infections over the last decade. However, the number of young people living with HIV remains significant – noting that this is a chronic disease and will require life-long treatment and psychosocial support. In addition, the number of infections through breastfeeding is still high which means that more needs to be done to ensure that pregnant women are tested regularly during their pregnancy, initiated on anti-retrovirals and provided with appropriate psychosocial support to ensure high levels of adherence to treatment to achieve sustained viral suppression during and post the breastfeeding period.

The perspectives of the three respondents clearly point to different but complementary experiences. These include: insufficient information and psychosocial support for those infected and caring for children and adolescents living with HIV as well as healthcare workers; inadequate access to psychologists to whom to refer children; challenges with disclosure of one's status; lack of privacy and confidentiality; stigma and exclusion; lack of space for and inadequate prioritization of child, adolescent and youth friendly services; support for HIV positive children and adolescents in school; and socio-economic challenges, especially for single mothers.

There are numerous statements from these HIV infected and affected individuals that suggest that the health system is currently not adequately responsive to the needs of young people and their caregivers, and that stigma and discrimination are still a significant part of their daily experiences. While Department of Health policy and guidelines exist to strengthen adolescent friendly services, it is clear that greater efforts are needed to strengthen these services (James, Pisa, Imrie, et al, 2018). The importance of supportive healthcare workers to young people is critical to ensure that they are able to cope with their HIV diagnosis as well as the challenges with disclosure and adherence to medication. This support also needs to be extended to primary caregivers . Caregivers report challenges with coping with children diagnosed with HIV, the stigma that they experience as well as financial implications related to funding transport to clinics (Mafune Lebesse and Nemathaga, 2017).

The ability of front-line healthcare workers to refer children and adolescents for mental health services continues to present a challenge. This combined with the psychosocial needs of healthcare workers themselves, strengthens the case for greater investment in these services. The gaps in the mental health services country-wide have been frequently cited in the literature. These include: shortage of mental health professionals especially in rural areas, the need for increased investment in mental health services including the need for adequate financing and infrastructure, as well as a call for task shifting (Petersen, Lund, Bhana et al, 2011; De Kock and Pillay, 2017; Docrat, Besada, Cleary, et al, 2019).

Health workers, especially nurses, on the frontline of dealing with HIV and now COVID-19 also struggle to deal with the trauma of disclosure, treating large numbers of patients as well as poor adherence. These issues are compounded by personal challenges that

health workers also deal with (Makhadoa and Davhana-Maselesele (2016). This suggests the need to strengthen psychosocial support as well as occupational health and safety services for front line health workers – an issue reinforced by the current COVID-19 pandemic.

Conclusions

In order for the world and South Africa to reach a generation free of AIDS by 2030, much work remains at the system level as well as at the individual level. There are indications that progress in the reduction of HIV in children and adolescents has been mixed and in some cases has stalled which cannot be accepted:

“Since 2010, there has been significant success in the prevention of mother-to-child transmission (PMTCT); however, in recent years that progress has stalled. While new HIV infections among younger children are on the decline, new HIV infections among adolescents are decreasing too slowly to substantially reduce their overall risk. HIV treatment – the access to and uptake of antiretroviral treatment (ART) – for children living with HIV has seen weaker progress compared to pregnant mothers living with the virus” (UNICEF, 2019).

South Africa needs to increase investment in the resources needed for an AIDS free generation. This includes working with communities, people living with HIV and healthcare workers at the front line to co-create the conditions for ending HIV as a public health threat.

The voices of young people living with HIV, their caregivers and healthcare workers at the front line are critical and must be heard. The voices heard during the webinar were clearly calling for the co-creation of health – the involvement of all in the design and delivery of health services. It is only by listening to these voices that the health system and society at large can relate to their lived experiences and provide the services that they require. As former President Mandela said: “The true character of society is revealed in how it treats its children” (Nelson Mandela Children’s Fund, 2015).

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