OPINION

Persons with severe mental health conditions should be included as a key population in HIV programmes

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Introduction

Key populations have been identified in the UNAIDS Global AIDS Strategy 2021–2026 [1] as well as in the recent South African National Strategic Plan for HIV, TB and STIs 2023-2028 (NSP) [2] for special focus, additional resource allocation and directed implementation programmes. Key populations are 'groups of people who are more likely to be exposed to HIV or to transmit it and whose engagement is critical to a successful HIV response' [1]. People in key populations also face legal and social barriers related to their behaviours that increase their vulnerability to infection [1]. In most settings, this includes MSM, transgender people, people who inject drugs, sex workers and their clients, people in prisons or other closed institutions and people with HIV. However, UNAIDS states that each country should define the specific populations that are key to their epidemic and response [1]. The current key populations account for 62% of new HIV infections globally [1] and are targeted for differentiated and intensive prevention, HIV testing and treatment resources and services. We show here that people with severe mental health conditions (SMHC) meet all the criteria for inclusion and should hence receive added attention and support.

There is a good reason to limit the number of key populations. Simply put, the broader the inclusion, the greater dilution of attention and resources. We are aware too that other persuasive cases have been made for inclusion [3]. Notwithstanding, we show here that the inclusion of SMHC is fully justified. We use the example of South Africa to illustrate this, however, the ratio of the difference between those with a SMHC living with HIV relative to the general population in lower HIV prevalence regions is generally larger than in high prevalence areas [4], and, therefore, our conclusions cover most countries.

The South African National Strategic Plan for HIV, TB and STIs 2023-2028

Following global trends [5], there has been a substantial shift in understanding and appreciation of the mental health needs of PWH in South Africa. This is well reflected in the recent NSP where people with mental disorders are included as a 'priority population' [2]. Although word counts are an imprecise and unscientific method for measuring importance and relevance, the current NSP mentions mental health 146 times, compared with just 12 in the previous one. This is not merely a change in numbers though, close examination shows that mental health is carefully woven into the plan based on available information and a clear commitment to integrating mental health and HIV/TB care. However, the concentration in the NSP is on common mental health conditions such as depression and anxiety, and

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mental health services for key populations. It does not address people with SMHC as a key group that itself requires prioritization. Moreover, people with SMHC have unique needs that require differentiated and precise responses.

Persons with severe mental health conditions

SMHC refer to a wide range of diagnoses that have common psychiatric symptoms, which persist over time and are functionally disabling. Schizophrenia, schizoaffective disorder, other psychotic disorders, bipolar disorder, and major depressive disorder with psychotic features are usually classified as severe [6]. Amongst numerous reasons to focus on this group as a key population, three stand out:

- 1. Persons with SMHC are significantly more likely than the general population to be exposed to risk factors for HIV and, because of behavioural practices, to transmit the virus [7]. In actual numbers, they not only meet the criteria for inclusion but also place a greater risk for the spread of HIV than certain groups already identified as key populations (see Table 1). Due to their mental health status, they also usually receive less HIV prevention and treatment [6].
- 2. Persons with SMHC need highly targeted HIV prevention, treatment, and care programmes. Such interventions have been shown to have proven effectiveness [8].
- 3. Including persons with any mental health condition as a key population has merit; however, it is difficult to establish HIV prevalence in this broad group and also to assess whether the HIV precedes or is a consequence of the mental health condition. Determining the prevalence of HIV in the population of people with SMHC is simpler.

Meeting the criteria for inclusion as a key population

Risk and vulnerability

Many people with SMHC engage in behaviours that increase their risk of infection, including unprotected sex with multiple partners, sex work and intravenous drug use; engage in hypersexuality during acute phases; have co-occurring substance misuse problems that can lead to sexual risks; live in shared accommodation and in institutions [6] (often same gender) where sexual activity is often not accepted and protection is not provided. Mental health conditions are also associated with lower adherence to HIV treatment [9].

People with SMHC experience both social and legal barriers that put them at greater risk of contracting and spreading HIV.

Social barriers include poor physical healthcare, perceptions that people with SMHC are unable to comprehend sex education, beliefs that people with SMHC are poor adherers to medication and thus not worth providing treatment to [10], stigmatization and discrimination based on mental health status [11], and violence and abuse [12], including sexual abuse.

People with SMHC generally receive far poorer quality physical health interventions [13]. Although people with SMHC have twice as many healthcare contacts, they receive less physical check-ups and screenings, less prescriptions, and have fewer procedures conducted [10]. They die 10–20 years earlier than the general

Table 1. Key population groups and persons with severe mental health conditions, by percentage living with HIV, proportion of adult population, number in the population, and estimated number living with HIV in that population.

Key population	Estimated percentage living with HIV	Estimated proportion of the adult (15 plus) population	Estimated number of people in the general population.	Estimated number living with HIV
Sex workers	57.9%	0.85% of adult female population ^a	187 000	108 273
Transgender persons	51.9%	2% of adult population ^b	860 000	446 340
MSM	29.9%	10% of adult population (only, mostly or equally attracted to same sex) ^c	2 150 000	642 850
People who inject drugs	21.8%	0.17% of adult population ^d	75 000	16350
Prison population	17.5%	0.34% of adult population ^e	148 000	25 900
People with severe mental health conditions	23%	1.5% of adult population	645 000	148 350

^aKonstant TL, Rangasami J, Stacey MJ, et al. Estimating the number of sex workers in South Africa: rapid population size estimation. AIDS Behav 2015;19 Suppl 1: 3–15.

^bStatistica. https://www.statista.com/statistics/1269778/gender-identity-worldwide-country/. [Accessed 26 June 2023].

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dOdendaal L. Low harm reduction coverage for people who inject drugs in South Africa. AIODSMAP https://www.aidsmap.com/news/jul-2019/low-harm-reduction-coverage-people-who-inject-drugs-south-africa. [Accessed 27 June 2023].

^eFair H, Walmsley R. World Prison Population List thirteenth edition. https://www.prisonstudies.org/sites/default/files/resources/downloads/world_prison_population_list_13th_edition.pdf. [Accessed 26 June 2023].

population [13]. The vast majority of these deaths are because of preventable physical diseases, including AIDS. AIDS-related mortality has been found to be high in people with SMHC in South Africa [14].

Legal barriers include commitment to institutions without consent and hence increased risk of HIV. Studies of closed facilities in South Africa have found high rates of HIV [15–17]. There are also laws in South Africa that restrict persons of 'unsound mind' to access the same social, civil, economic, and political rights as others. Becoming a key population would put such issues under additional human rights scrutiny and increase the likelihood of revision.

Prevalence

Inclusion as a key population requires substantially higher HIV prevalence than the general population. To determine the HIV prevalence rate amongst persons with SMHC in South Africa, PubMed and Google searches were conducted. Five studies published since 2000 were found. Three of these were in-patient and two community-based. HIV prevalence rate ranged from 19 to 29.1% [15–19].

Given that existing prevalence studies were not representative of the population, we used the available studies and conservatively estimated prevalence at 23%. The percentage of existing key populations living with HIV was taken from the NSP estimates [2]. We took the number of people with SMHC at 1.5% [20] and the population of South Africa as 60.6 million (adult population, 43 million) [21].

We then compared people with SMHC with the already identified key population groups with respect to prevalence percentages and estimated numbers in each group.

Table 1 shows that the percentage HIV prevalence in persons with SMHC is higher than two of the already identified key populations. In actual numbers, persons with SMHC living with HIV is larger than three of the five already identified groups.

Targeted HIV prevention and care programmes

It is beyond the scope of this opinion piece to outline a full list of specific interventions that persons with SMHC require. However, vital interventions that are sorely needed and are more likely to be rectified if SMHC is added as a KP include the following.

Prevention

Targeted preexposure prophylaxis (PrEP) needs to be expanded for SMHC [6]. Given concerns about

adherence in this group, long-acting injectable PrEP may prove highly appropriate to this population. Notwithstanding, people with SMHC must be given the same prevention options and choices as others. Primary prevention efforts such as correct condom use are effective for people with SMHC [8]. However, these skills must be reviewed repeatedly to maintain gains. Postexposure prophylaxis (PEP) may also be important for this group.

Custom key population prevention such as education programmes designed for SMHC are required to curtail HIV infection among this population and their partners. Specially designed and proven key population prevention programmes are easy to administer, feasible, and inexpensive [8].

Testing for and treating HIV

Routine HIV testing of people with SMHC is generally low [6], though essential [7]. Some practitioners and even family members hold the erroneous belief that people with SMHC are not sexually active and hence do not need HIV testing. This applies also in same-sex settings. With respect to treatment, HIV-positive individuals with SMHC have been found to be prescribed antiretroviral therapy (ART) less often than their non-SMHC counterparts [22]. This may be because of the mistaken belief that should a person with a mental health condition be found to be HIV positive that they would not have the capacity to take or adhere to their medication regularly. However, research shows that people with SMHC receiving quality HIV care and additional psychosocial support can achieve adherence rates comparable to those without mental health conditions [23].

Inclusion as a key population is likely to lead to a substantial increase in clear and evidence-based policies as well as support programmes for SMHC. For example, at present, there are no internationally agreed-upon guidelines to support the prevention, screening, and management of people who have both HIV infection and SMHC [6]. Development of such guidelines is probable if included as a key population. Essential interventions that have been proposed over a number of years, such as training of mental health practitioners to test and treat for HIV in persons with SMHC and special support programmes for practitioners, family members and people with lived experience [24], are far more likely to be implemented. Similarly, including mental health in the training of practitioners providing HIV services, such as nurses providing NIMART (Nurse Initiated Management of ART) is likely to increase. WHO and UNAIDS recommendations for the full integration of mental health and HIV services [5] will, in all likelihood, also be fasttracked.

In conclusion, the case for the inclusion of persons with SMHC as a key population is compelling. That this group

has not already been added is likely to be an omission resulting from a dearth of relevant information and data, combined with a lack of concerted advocacy. However, this may also be related to high levels of general discrimination and stigmatization against persons with SMHC [11]. Unfortunately, structural stigma has influenced global and local policies as well as funding to address the needs of people living with mental health conditions.

Self-advocacy by people in the current key population groups has played a critical role in governments and international agencies and organizations focusing on HIV prevention and treatment. People from current key populations have experienced intense stigma and discrimination while fighting to be heard, but they have prevailed and been included for special focus. However, being an advocate while also experiencing a SMHC may well be of a different order, making advocacy even more difficult. Recently, global organizations of peers have been formed that are seriously advocating for the rights of persons with lived experience [25,26], but given past and current neglect of many mental health issues, HIV has not yet been an advocacy priority.

We do not wish to replace this self-advocacy, but we hope that the facts and arguments here are convincing enough to get authorities to carefully consider the inclusion of persons with SMHC as a key population. This is critical to the people involved and for reaching the UNAIDS 95–95 targets.

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Conflicts of interest

There are no conflicts of interest.

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