Addressing the Needs of People with Schizophrenia in South Africa During the COVID-19 Pandemic

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Research indicates that most people with Schizophrenia from low to middle-income countries do not receive adequate healthcare. Inadequate policies, lack of funding, poor service planning and neglect are some barriers to adequate care. Intrinsic barriers to care include stigma, lack of insight, and pathways to care that are often driven by cultural beliefs, and many systemic challenges. South Africa was not spared from the scourge of COVID-19, hosting a third of all reported cases in Africa. In a country with disparities, it would be of interest to get insight into the situation concerning the healthcare needs of people with Schizophrenia during the pandemic. A pandemic such as COVID-19 placed enormous strains on already limited and unequally distributed health care resources. In this paper, we discuss: (1) The South African healthcare system (with respect to Schizophrenia care). (2) COVID-19 policies related to the care of people with Schizophrenia (testing, access to vaccine). (3) Managing people with Schizophrenia amid the COVID-19 pandemic. (4) Recommendations.

Key words: South Africa/Schizophrenia/policies/outco mes

Introduction

Research has shown that people with Schizophrenia do not have adequate access to care in low to middle-income countries (LMICs).^{1,2} Poor access to care is often attributed to intrinsic factors such as the lack of insight,

stigma, and extrinsic factors such as socioeconomic status and pathways to care.¹ In South Africa (SA), like other LMICs, inadequate policies and poor service planning further exacerbates access to care.^{3,4}

In recent years, discrimination and indifference by the SA government towards mental healthcare initiatives have led to the inhumane treatment of many people with Schizophrenia.⁵ Apathy towards people with Schizophrenia is evident in the Life Esidimeni tragedy scandal.⁶ The global age standard point prevalence of Schizophrenia is approximately 0.28%.⁷ Despite low prevalence rates, 80% of people with Schizophrenia who live in the LMICs do not receive optimal psychiatric care.⁸

This report discusses South African healthcare in relation to people with Schizophrenia pre and during COVID-19. First, we appraise the healthcare system's strengths and weaknesses. Second, we explore how the healthcare system responded to the needs of people with Schizophrenia by examining the policies implemented at the time. Third, we report on our observation of how people with Schizophrenia fared during the pandemic. Lastly, we give recommendations from the lessons learned during the pandemic.

A Brief Introduction into the South African Healthcare System

The South African healthcare system is ranked number 1 in Africa and 56 in the Global Healthcare Security Index,

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an estimate of healthcare pandemics preparedness.⁹ Despite this, SA ranks lower than other LMICs such as India and Sri Lanka. SA has seen several progressive healthcare reforms over the past 2 decades, reflecting the transformation plan from the apartheid era which was characterized by discrimination and marginalization of people of color across all basic needs, including healthcare. Many years post-apartheid, the healthcare system remains inefficient and inequitable.¹⁰ Right to healthcare access is a human right in SA despite disparities between the poor and the wealthy.

Because of the political landscape, South Africans often resort to social mobilizations and campaigning (such as the Treatment Action Campaign) to access care. For example, the era of President Mbeki was characterized by HIV denialism and apathy with regards to HIV. However, today SA has one of the most advanced and largest HIV services and research programs among LMICs, if not globally. 10

SA's healthcare system consists of public and private sectors. 10,12 The private sector is smaller and better funded, whereas the more extensive public sector lacks resources. In part, this is the legacy of apartheid, but the socioeconomic inequality that characterized the country's current landscape also perpetuates this disparity. Only 8.9 million (14.83%) South Africans are beneficiaries of private health insurance.¹² The public healthcare system, therefore, caters for an estimated 80% of the population, composed mainly of people with low or no income.¹² The funding for public healthcare is through government allocations from National Treasury to, particularly, the provincial governments.¹³ The provincial governments provide all public healthcare, from primary to tertiary and quaternary. The current health expenditure (CHE) in SA as a percentage of gross domestic product (GDP) is approximately 9%. However, only half of the CHE is spent on the public healthcare sector. 12 The expenditure is even bleaker for people with Schizophrenia as SA only spends 5% of its public health budget on mental healthcare, 13 with no uniformity among the provinces.

In line with human rights, the SA government implemented a program to decentralize and integrate mental health services into primary health care. 14 One of the goals was to discharge all chronically hospitalized patients and integrate them into their communities. These progressive reforms are, however, hindered by a lack of adequate planning and funds to run the service efficiently. As a result of poorly planned deinstitutionalization programs in the country, many people with mental illnesses have died after being placed in inappropriate facilities. The healthcare system, including mental healthcare, remains hospital-centric with a lack of integration between mental healthcare and general healthcare. 15 South African mental healthcare budget remains focused on hospital care despite South African policies meant to improve community-based mental healthcare services.

In the private sector, the situation is sometimes complicated by the South African legislation that compels health insurance providers to fund hospital care with poor mental healthcare financing in primary healthcare settings. ¹⁶ The funding for inpatient mental healthcare is limited to 21 days of in-hospital care per beneficiary of private health insurance per year. ¹⁶ People with Schizophrenia have minimal access to care in the private sector because of this restricted funding for mental healthcare. Most people with Schizophrenia are therefore treated in the public health sector.

Despite the hospital-centric funding model for mental healthcare in the public sector, SA has deinstitutionalized mental health services considerably. As a result, chronic beds numbers rapidly fell from 70 per 100 000 in 1994 to 35 per 100 000 in 2004.¹⁷ However, there are still limited services for community-based mental health services. In addition, human resources for mental healthcare in SA remain challenging. Although the ratio of psychiatrists to the general population in SA is 1.53 psychiatrists per 100 000.¹⁸

The shortage of psychiatrists is further worsened by limited government resources to fund training posts in SA and the emigration of South African trained psychiatrists. ¹⁸ Public health facilities regularly run out of essential medications, the so-called drug stockouts. The constant interruption of the supply of antiretroviral and anti-tuberculosis medications reflects this problem. Antipsychotics, the backbone of the appropriate treatment of Schizophrenia, have not been spared from this. ¹⁹

The deficiencies in the healthcare system's design in SA add further barriers to care access for people with Schizophrenia. Studies from LMICs also show that this is further complicated by pathways to care for people with Schizophrenia, who often seek alternative care before seeking biomedical interventions.²⁰ Several factors. including social and infrastructure factors (e.g., rural areas), also contribute to the low detection rate and access to care in South African communities.3 However. the traditional healers are often the first point of contact for most people with Schizophrenia, according to a study by Veling et al.²¹ Moreover, in SA, common mental illnesses are generally more prevalent than globally reported, and only a quarter of people receive treatment for them.²² While the true incidence of schizophrenia remains unknown, it seems likely that most people with Schizophrenia do not receive adequate treatment.

An Overview of COVID-19 Policies in Relation to the Care of People with Schizophrenia

To curb the spread of COVID-19, SA implemented strategies such as lockdowns, provision of testing, timeous infection notification, contact tracing and social isolation or quarantines.^{23,24} Because of the previous communicable disease burden such as HIV and TB, SA was swift

to act as it was aware of the impact of delaying preventive interventions.²⁵ Also, these past pandemics provided the necessary experience to curb the spread of infectious diseases. As a result, the country could deploy massive contact tracing teams to conduct door-to-door visits.²⁵ Furthermore, the contributions of SA to scientific breakthroughs related to COVID-19 reflect the advancements in research and infrastructure in infectious diseases.²⁶

People with Schizophrenia constitute a high-risk population for transmission of infectious diseases.²⁷ Lack of insight, poor housing, poverty, and barriers to care are potential factors leading to infection transmission.²⁷ However, like anywhere in the world, access to testing for people with Schizophrenia was not flagged as a priority. In SA, COVID-19 testing can be done in private (for a fee) and government-funded laboratories. The capacity of the private laboratories was far better than that of the public laboratories, with 80% of the tests performed in private laboratories.²⁸ Because this requires either medical insurance or money, it suggests that most South Africans who do not have access to medical insurance were unable to access this test. While there has been an attempt to scale up the testing in the public sector, this resulted in a massive backlog and significant delays in turnaround time.²⁹ A situation of this nature negatively affects those who are socioeconomically disadvantaged, such as people with Schizophrenia.

Chaos and confusion characterized the vaccine rollout in SA, leading to significant delays and wastage.³⁰ The vaccine rollout was implemented in a phased manner as per the World Health Organization directives. However, people with Schizophrenia were not prioritized despite mounting evidence for increased risk of infection and mortality associated with Schizophrenia. Sophisticated registration systems were implemented for accessing the vaccine, a potential barrier for people with Schizophrenia.³¹ This electronic vaccination data system can be accessed via a computer or mobile device and requires an Internet connection. Access to such devices and the centralization of vaccination sites pose a significant barrier for poor people such as people with Schizophrenia.³¹

Managing People with Schizophrenia Amid the COVID-19 Pandemic

The preceding sections have highlighted some of the failings and the barriers to care access for people with Schizophrenia. With the implementation of lockdowns, traveling and movements were prohibited unless deemed essential.³² This often required a permit from authorities. Access to healthcare was excluded from these restrictions. However, regulations such as capping the number of passengers in public transport led to an almost complete cessation of traveling, a significant hurdle for people with Schizophrenia. They often travel long distances to access care.³²

During the pandemic, the Department of Health published guidelines for mental health service delivery, which stated that access to mental health care should be maintained as usual while following COVID-19 protocols.³³ Additionally, the South African Society of Psychiatrists, a non-governmental organization comprised of psychiatrists who advocate for mental health, issued a media statement expressing their dissatisfaction regarding the repurposing of beds (including psychiatry beds) to manage COVID-19 patients.³⁴ Through this campaigning and social mobilization, psychiatric beds, were the least affected by the pandemic.

Continued care for people with Schizophrenia is a cornerstone for best outcomes and relapse prevention.³⁵ Outpatient visits are often tailored to the needs of individual patients. While stable patients may need fewer visits per year, it is not uncommon to have people that need weekly or monthly visits. Recently diagnosed, unstable and recently discharged patients often require re-evaluation in short intervals (weekly).³⁵ For some patients, this was achieved through previously prohibited telemedicine to consult patients during the pandemic.³⁶ This ensured that social distancing was always maintained, and continued care was not compromised.

A subgroup of people with Schizophrenia requires frequent monitoring of various biological markers. For example, clozapine is prescribed to people who do not achieve symptom remission or control from first-, and second-line antipsychotics or those with moderate to severe tardive dyskinesia. Clozapine mandates monitoring of the white cells, which may range from weekly to monthly depending on the duration of treatment.³⁷ Also, long-acting injectable (LAI) antipsychotics are administered by either a nurse or a doctor.³⁸ Both these scenarios mandate a person to visit a hospital physically. Fear of hospitals and other health facilities was observed during the pandemic as these were deemed "hotspots" for contracting infections.³⁹

Inpatient care was not restricted during the pandemic. Traditionally the psychiatric wards are not designed to meet infection control standards. 40 Patients often share spaces such as dining halls, showers, and toilets. Limitations of this nature were the biggest hurdle for hospitals that cared for people who were acutely ill and unable to appreciate the risk of infections.⁴⁰ Thus, mental healthcare workers had to devise interim strategies to mitigate infection transmission while maintaining the highest standards of care. While there was no clear guidance from the national government, a combined effort from different hospital psychiatric subunits was essential. In one of the cities in SA, it was decided that some of the 72-h observation units would only admit psychiatric patients who tested positive for COVID-19. Alternatively, the specialized psychiatric hospital admitted only patients who were COVID-19 negative.

A study conducted in KwaZulu-Natal (one of nine provinces in SA) found that there were only a quarter of beds (25%) available of the number needed to satisfy the needs of its residents (based on national standards and norms). ⁴¹ Due to this, patients with acute psychiatric conditions are generally housed in largely unsuitable medical wards. ⁴² Because of these, categorizing hospitals according to COVID-19 status was not ideal for some hospitals.

How did People with Schizophrenia Fare During the COVID-19 Pandemic?

To the best of our knowledge, there is no published data on potential relapses that might have been linked to COVID-19 infections and lockdowns. However, some evidence shows that people with Schizophrenia were more likely to relapse during the lockdowns due to medication discontinuation and the psychological consequences of isolation, quarantine, and other restrictions of lockdowns. In addition, relapse is associated with lockdown, anxiety about getting COVID-19, and lack of medication, as anecdotal evidence suggests.

From our observations, the number of patients requiring acute admission for schizophrenia relapses did not increase in our hospitals during the pandemic. A study conducted in KwaZulu-Natal found that during the strict lockdown levels, there was a significant decline in daily all-cause admission in hospitals. This was linked to the restrictions that were implemented in some of the lockdown levels..43 Fear of going to health care facilities due to possible infections also adversely affected seeking hospital care or admissions during the pandemic.³⁹ Lockdown restrictions such as the total ban on the sale and consumption of alcohol could have protected against relapse for people with Schizophrenia.44 There is evidence that comorbid alcohol use is associated with poor medication adherence and relapse in people with Schizophrenia. Also, family interactions imposed by "stay home" regulations improved psychosocial support and, perhaps, treatment adherence of people with Schizophrenia.

Social interventions by our government, such as the implementation of the COVID-19 social relief grant and mandatory shelter for homeless people, were some of the interventions that could explain the decline in Schizophrenia relapses. 44 Improving access to social services such as shelters and nutrition aid to improve mental health could potentially prevent relapses in people with Schizophrenia.

During the early lockdown periods, tobacco and smoking were prohibited.⁴⁴ High rates of smoking are seen in people with Schizophrenia. Whether nicotine alleviates some of the psychopathologies in these people remains unclear.^{45,46} However, the sudden cessation of smoking is well known to lead to withdrawals which

may potentially cause a worsening of Schizophrenia.⁴⁷ Therefore, it is plausible to expect that the abrupt cessation of smoking during the lockdown restrictions would have resulted in relapses in SA. However, the ban on cigarette trading led to an increase in the illicit cigarette trade. Filby et al⁴⁸ found that only 9% of smokers succeeded in quitting during the lockdown, and 93% were able to obtain cigarettes from illicit sources.

There have been no published statistics on COVID-19-related morbidity and mortality rates in people with Schizophrenia in SA. People with Schizophrenia, however, have increased rates of chronic illnesses such as diabetes and hypertension. They are also more likely to smoke. All these factors are risk factors for severe COVID-19 and mortality.

A study was conducted in sixty-four hospitals from ten African countries, including SA, to examine the association between resources, co-morbidities, critical care interventions and mortality outcomes in COVID-19 patients. ⁴⁹ Unfortunately, mental illness was not included as one of the examined comorbid illness variables. SA experienced an excess of natural deaths compared to previous years during the pandemic's peak (in addition to the documented COVID-19-related death). ⁵⁰ Outbreaks of COVID-19 amongst staff and patients in psychiatric institutions were reported. ⁵¹ However, there have been no reports yet that have found mortality to be higher than the general population.

Discussion

People with Schizophrenia represent a vulnerable population often neglected. Poor socioeconomic status, lack of insight, stigma, and other extrinsic barriers to care significantly impact the quality of life and lifespans. While COVID-19 was addressed in a robust and scientifically valid manner from infection prevention, severe disease mitigation and relatively problematic vaccine rollout, people with Schizophrenia were not prioritized.

Even though mental healthcare was permitted during the pandemic, government guidelines were inadequate to guide clinicians. Concerns including fear of hospitals, inadequate transport, and structural deficiencies (psychiatric wards) necessitated comprehensive attention. Information from the pandemic is valuable. The information can be used to empower the transformation of mental health care services beyond pandemics since some of these issues, such as access to basic needs, are persistent for people with Schizophrenia. Access to these needs is also the determinant of outcomes for this population. Therefore, as the government builds toward universal health coverage (National Health Insurance), 10 a paradigm shift should occur in allocating resources to tackle the general neglect of mental healthcare services. Therefore, we make the following recommendations:

Care access and social welfare

- 1. Acknowledge that people with Schizophrenia deserve prioritization.
- 2. Plan healthcare services with community leaders to tackle barriers to access.
- 3. Educational campaigns and integration of traditional health practitioners into mainstream mental healthcare.
- 4. Ensure that community mental healthcare services are strengthened to minimize barriers to care access.
- 5. Provision of basic needs (housing, nutrition) for people with Schizophrenia.
- 6. Removing legislative barriers to care, such as restrictions on hospital stays.
- 7. Authorize pharmacists to administer LAI.
- 8. Include primary healthcare in the monitoring of white blood cells in people taking clozapine.

Infrastructural reconfiguration and revitalization

- 1. Design psychiatric wards to meet the requirements of infection control.
- 2. Develop medical equipment that is appropriately suited for psychiatric ward use.

Conclusion

Crises often provide opportunities for innovation and improved healthcare. However, due to the status quo, healthcare practitioners become complacent about the burden and barriers to care faced by people with schizophrenia. COVID-19 has again brought to light the need to revise and re-examine our healthcare system policies, planning and implementation beyond the pandemic. Evidence-based approaches such as task sharing or decentralizing LAI and blood monitoring in LMICs should be investigated.

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