

Spring 2017

Shifting Mental Health from the Back Burner: An Investigation of the Mental Health Treatment Gap

Eva Hanorah Stanton
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SHIFTING MENTAL HEALTH FROM THE BACK BURNER: AN INVESTIGATION OF
THE MENTAL HEALTH TREATMENT GAP

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South Africa: Social and Political Transformation

Spring 2017

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Acknowledgements

Firstly, I would like to thank my advisor Benjamin Roberts, for his thoughtful and measured recommendations. They have surely helped make my project the best it can be. Without his time and energy, this project would not have been possible. Next, I would like to thank my program director, Imraan, for his endless patience with my questions, willingness to engage in debate, and excellent restaurant recommendations. To Shola, for her tireless warmth and pragmatism, Scott for his careful comments and attention to detail, and Sdu for his patience, music, and great sense of humor. To Brian for not laughing too much at my poor pronunciation of isiZulu and to Bonga for his seeming perpetual optimism. To the Mtolos, Mthembus, and Stewarts whose hospitality made my time in South Africa immeasurably more special. To the staff of Café Jiran and Falafel Fundi for keeping me well fed, caffeinated, and allowing me to sit and in their restaurant's for an embarrassingly long period of time. To all of my interview participants for their willingness to engage with my questions and to share a piece of their lives with me, despite the tight timeframe. To my family and friends back home, and the staff of Columbia's Office of Global Programs for their support in making this semester possible. Finally, to twenty-one of my peers on the program, each of which has shaped my trip, and helped make this time one of the most meaningful periods in my life. *Ngiyabonga!*

Abstract

The purpose of this research project is to investigate solutions to the so-called ‘mental health treatment gap’. The need for scholarship in this area is underscored by the recent tragedy in the Gauteng province, which has brought the neglect of the mental health sector into the public eye. Through semi-structured interviews with six key stakeholders in the fields of mental health and health policy this project seeks to better understand the causes of the mental health treatment gap and the impact National Health Insurance (NHI) rollout may have on access to quality mental healthcare. Sub-themes explored include: the integration of mental healthcare with primary healthcare, participatory policymaking, the role of stigma, private sector buy-in to the public mental health sector, and the effect of the Life Esidimeni tragedy on national discourse around mental health. In their interviews, participants identified unique challenges facing the sector due to the widespread stigmatization of mental illness and its consistent neglect by government and funders. Although they express serious concerns about NHI’s chance of success in the near future, participants pointed to the integration of mental health services with chronic care, improved management, and education campaigns as improvements which can be made to the sector in the near future, regardless of policy change.

Introduction

On the 19th of June, 2015, Ms. Qedani Mahlangu, Member of the Executive Council (MEC) for Health in the Gauteng Province, addressed the Provincial Legislature at the vote on the 2015-16 Health Budget. In the speech, Mahlangu announced a decision to “save and generate revenue of R1 billion that can be redirected to implementation of essential services” (Mahlangu 25). In order to do this, the province had decided to terminate their contract with the private hospital group Life Healthcare. As a result, they were to relocate nearly two-thousand mental health patients at Life Healthcare's Esidimeni facility to Non-Governmental Organizations (NGOs) between October 2015 and March 2016. As a result, 91 mentally ill patients died in the province between March 23rd, 2016 and December 19th 2016, despite numerous protestations against the move from family members of the patients.

In the Health Ombuds' investigation into the deaths, the office described the move as “done in a hurry [...] with chaotic execution; in an environment with [...] no culture of primary mental health care” (Makogoba 2). Patients were reportedly shuttled into NGOs like an “auction cattle market” with no consideration of the resources that were required to treat prior medical conditions, such as epilepsy and hypertension. Staff transported elderly or incapacitated patients via bed sheets instead of wheelchairs, and failed to notify families of the patients move; even today, some continue to search for relatives. In its Final Report, the Health Ombuds office deemed the conduct of the Health Department and NGOs to be “most negligent and reckless and showed a total lack of respect for human dignity, care and human life” (Makogoba 2).

Unfortunately, the de-prioritization of mental illness is not unique to MEC Mahlangu or even the Gauteng Province. According to the 2015 Rural Mental Health Campaign, South Africa has no systematic record of mental health expenditure and the most accurate information,

gathered in a 2007 World Health Organization (WHO) report, shows that the Northern Cape, Mpumalanga and the Northwest Province spend only 5% of their budgets on Mental Health (Sunkel 2016). The funding that does exist is largely funneled into psychiatric hospitals or drug-based treatments for severe psychiatric illness, with little attention paid to disorders such as anxiety and depression, despite their high prevalence in the population (Schneider 154). Indeed, it is estimated that 75% of South Africans suffering from mental disorders do not receive any treatment. This forms what is referred to as the ‘mental health treatment gap’ (Schneider 154).

This trend is especially sobering because the purge of funding for mental health treatment, as was done in the Gauteng province, actually costs the government far more than it saves. There is a bidirectional relationship between poor mental health and poverty, and mental illness has been shown to exacerbate the ‘quadruple burden of disease’ facing South Africa in the 21st century—1) maternal and child illness, 2) infectious diseases, 3) non-communicable diseases, and 4) injury (Schneider 154). Most shockingly, research estimates that the government spends only USD \$59 Million on mental healthcare each year, while the total cost of lost income of South Africans living with mental disorders is USD \$3.6 Billion (Schneider 156).

The question of how to reverse this clearly illogical trend has not been ignored globally, nor by South African policymakers. The government has passed legislation addressing the pivotal role that mental health must occupy in a functional healthcare system as early as 1997 with Chapter 12 of the White Paper on the Transformation of the Health System and appearing most recently in the 2013 Mental Health Policy and Strategy Plan. This plan “aims to realize the integration of mental healthcare into a comprehensive primary health care” (Schneider 155). However, despite the high level of commitment to improving mental healthcare at the national

level, there still is a lack of understanding of how to sustainably pay for the mental health services that are necessary to diminish the treatment gap.

The dialogue around mental illness coincides with another national healthcare debate: the country's shift to National Health Insurance (NHI). Indeed, Mahlangu began her speech on the 2015-16 health budget by citing the Freedom Charter's proclamation that, "free medical care and hospitalization shall be provided for all" and championing the roll out of NHI, calling it the "vehicle to achieve the vision set out by the Freedom Charter" (Mahlangu 2). She continued, and spoke to the inequality that remains in the healthcare system, noting that 16,088 beds in the province serve the 79% the citizenry that are uninsured, while 16,276 serve the remaining 21% with medical aid. Despite the staggering inequality in these figures, numbers are even worse in other areas of the nation. Indeed, for three consecutive years, the Gauteng province has been rated number one in the country at meeting National Core Standards (NCS), a measure of the province's success at ensuring "availability of service where our people live and work, access to medicines at all times, and introducing healthcare infrastructure of the 21st century" (Mahlangu 2).

Inequality has led the South African health system to be described as 'two-tiered', with a highly functioning private system serving the wealthy few, and a sorely underfunded and under-resourced public system for the rest (DoH 1). NHI is the government's attempt to create a 'unified health system' that provides all South Africans access to quality health care no more than five kilometers from their home, regardless of their socioeconomic status. Primary healthcare has been described as the cornerstone of the country's health system and becomes increasingly important as the transition to NHI begins the first year of its second phase. A key element of the second phase of NHI rollout, is concerned with accrediting 'ideal clinics', which

are described by Health Minister Aaron Motsoaledi as, “in pristine condition [...] efficient, effective, and attractive for our people” (Mamaila 5). Assuming NHI is successful, community based care in the country would greatly improve. Unfortunately, success has not come easily and the policy has received significant criticism. Critics have called it a “Rolls Royce solution when we cannot even afford a Toyota Tazz” (Mamaila 5). Still others raise concerns about the timing of NHI, arguing that the “government’s fourteen-year timeline for NHI is truly unrealistic given the challenges facing the public sector” (Emmerich 38).

Unfortunately, given the shaky status that mental health occupies in South African healthcare, its future under NHI is even less certain. Addressing the mental health treatment gap would require the country’s mental healthcare sector to serve roughly quadruple the population it serves today. Furthermore, in order to achieve the goal set out by the 2013 Strategy Plan, existing mental health treatment must shift from a few, relatively well-resourced psychiatric hospitals to largely underserved primary health clinics across the country. This necessitates not only financial resources, but careful research, management, and expertise. Indeed, if the tragedy in Gauteng has proven one thing, it is that mental health reform in South Africa cannot and must not wait; it is literally a matter of life and death. If the NHI rollout will take over fourteen years, is it an effective way to ensure that mental health coverage reaches more South Africans? If NHI comes too late, or worse, does not temper the issue at all, what other solutions exist?

The primary objective of this project is to investigate the effect that the country’s shift to NHI will have on access to quality mental health treatment and on closing the treatment gap. It seeks to explore solutions to either replace, expand upon, or revise the NHI White Paper in order to diminish the gap. Through this project, I will investigate the following questions: How can mental healthcare be effectively and affordably integrated into primary healthcare? Do mental

health professionals and academics feel their feedback is heard and incorporated in the development of health policy? To what degree does stigma against mental illness influence access to quality mental health treatment? What is the most effective way to engender ‘buy-in’ and trust in the public mental health sector? Finally, how will the recent tragedy in Gauteng affect national discourse around mental health?

The first part of this paper consists of an overview of existing literature on the historical inequality in the health sector, National Health Insurance, and the history and present state of mental healthcare in South Africa. The next portion is a discussion of the primary research I conducted, beginning with an explanation of methodology and an acknowledgement of the limitations of this study. Next, the primary research findings are presented and analyzed thematically. I first discuss factors that participants argue have contributed to the treatment gap. Next, I explain participant understandings and criticisms of NHI, and finally, their proposed solutions for how to improve access to mental health treatment in South Africa. Ultimately, their discussions make clear that while the mental health sector faces significant and unique issues as a historically neglected field of medicine, there are tangible changes that can be made to improve access to treatment irrespective of policy change.

Literature Review

Despite the economic growth and political transformation South Africa has undergone since transitioning to democracy, the country continues to face significant health challenges. Coovadia *et al.* (2009) explain in *The Lancet* that “although South Africa is considered a middle income country in terms of its economy, it has health outcomes that are worse than those in many lower income countries [...] South Africa is one of twelve countries where child mortality has increased, not decreased since 1990” (817-18). However, health outcomes in South Africa are not uniformly bleak. Rather, they are divided along lines of class and race. Indeed, any discussion of healthcare in South Africa is inextricably linked with a discussion of inequality. The inequality seen in the health system has necessitated country’s rollout of its universal health insurance plan, NHI, which began in 2012 and is set to complete by 2025. Whether NHI will be successful in achieving this goal has yet to be seen. In the early years of the rollout the health department has faced significant hurdles.

Notably, the government has come under heavy criticism following the recent patient deaths in Gauteng. Unfortunately, the tragedy is exemplar of the consistent neglect of mental health by the medical community, both within South Africa and worldwide. Yet in recent years, policymakers, private citizens, and members of the medical community have urged for changes in the way that mental health is prioritized. The shift to NHI is to be a pivotal transition for the country’s health system, and, as scholar Inge Petersen suggests, can also be an opportune moment to “leverage additional resources for mental healthcare” (“Integrating Mental Health into Chronic Care” 10). Beginning with the historical roots of the racial inequality in the health system and moving to a discussion of NHI and mental healthcare, I seek to contextualize the tensions around the treatment of mental disorders in South Africa today.

On historic racial inequality in the South African Healthcare System

Coovadia *et al.* (2009) explain that the current inequality and dysfunction of the South African public healthcare system is rooted in the racist policies of the country's past. For instance, the authors explain that the discovery of diamonds and gold in 1867 and 1888, respectively, led mining to become the cornerstone of the South African economy. In order to function lucratively for foreign investors, mines ran on the labor of the low-paid, majority Black-African workforce. To gain this labor force, "a combination of coercive legislation, taxes, restrictions on access to land and means of production, and punitive control of desertions served to enforce migration of male laborers to the towns. This system greatly undermined the rural black agricultural economy." (Coovadia 818). Because the government reserved the majority of land for white ownership, they did not provide adequate space for the hundreds of thousands of Black African migrant workers moving into cities in order to work at the mines. This created cramped, unsanitary living conditions which were conducive to the spread of diseases, particularly tuberculosis. The migratory nature of the work and high turnover rates led the illness to be easily transmitted to rural areas when workers returned home (Coovadia 818). Thus, present day inequality in South Africa is linked to the exploitation of the Black working class.

The inequality in health outcomes has been intensified because South Africans of color, particularly Black South Africans, were historically barred from access to healthcare. Healthcare in South Africa has been segregated since 1887, when the Public Health Amendment Act separated health facilities by race. The white supremacist minority used segregation as an excuse to neglect the provision of facilities for people of color. In 1942, the Gluckman Commission improved access to healthcare by establishing community health centers, which were precursors to today's model of community-based primary healthcare. Unfortunately, the

National Party came to power in 1948, halting Gluckman's efforts and forcibly moving Black South Africans into segregated "homelands", called bantustans. When the bantustans were created, each had its own health department which acted quasi-independently under the supervision of the state. The fourteen health departments focused on hospitals, not primary healthcare, and the government allocated inadequate funding for their operation, leaving them unable to function effectively (Coovadia 825). These factors gave rise to the 1971 'Inverse Care Law', which is defined as the inverse relationship between population health needs and availability of healthcare: the populations with the greatest need for care have the least access to it (Harris *et al.* 117).

In 1994 when the post-apartheid government came to power, it inherited a deeply divided state. Although the African National Congress (ANC) united the nation's healthcare, resources were still unevenly distributed both geographically and between levels of care—in 1994 over 80% of resources went to hospitals and only 11% to primary care services (Coovadia 828). Despite continuous efforts to equalize the system over the past two decades, the authors argue that South Africa's neoliberal economic policies post-1994 did not address the need for wealth redistribution in the country and thus have not reconciled the inequality lingering from apartheid policies. Furthermore, Coovadia argues that in recent years, good policies in public health have fallen flat due to ineffective leadership and management by government (Coovadia 817).

Coovadia's concerns are substantiated by the findings of Harris *et al.* (2011) reported in the *Journal of Public Health Policy*. The researchers conducted a survey of 4,668 households which examined access to healthcare across three dimensions: availability (i.e. distance and travel mode to health care facilities), acceptability (i.e. healthcare user satisfaction), and affordability (i.e. cost burden of healthcare relative to total household expenditure). For

affordability they defined spending over 10% of healthcare costs as 'catastrophic'. The study confirmed that poor, Black-African, rural South Africans experience inequitable access to care (Harris *et al.* 104). The authors emphasize that efforts to increase access to healthcare must encompass both a system that is equipped and available to provide services and a constituent body that is informed so that they may make empowered decisions (Harris *et al.* 103). Their findings confirmed the divisions in care between South Africans that can pay for private care and those that cannot: 88.4% of respondents did not have medical aid, and 43% of these respondents spent 'catastrophic' amounts of their household expenditure on healthcare, as compared to just 4% of those respondents with medical aid. The divisions between healthcare for those in the private sector and those in the public sector are stark, and begin to explain these findings. As Harris cites, "In 2005, spending per private medical scheme member was nine-fold higher than public sector expenditure, and one specialist doctor served fewer than 500 people in the private sector but around 11,000 in the public sector" (Harris *et al.* 103). Unfortunately, in 2012, *The Lancet* reported that this inequality continued to broaden in recent years due to rising costs and the concentration of skilled health professionals in the private sector (Mayosi *et al.* 2036).

National Health Insurance

The persistent inequality of the health system set the stage for the rollout of NHI, which follows the United Nation General Assembly's call for a global movement of governments towards universal health coverage. NHI aims to diminish the division between socioeconomic lines, and:

- create a unified health system by improving equity in financing, reducing fragmentation in funding pools, and making health care delivery more affordable and accessible for the population.
- NHI will eliminate out-of-pocket payments when the population needs to access health care

services. In the long run, households will also benefit from increased disposable income as a result of a significantly lower mandatory prepayment (DoH 1).

The Department of Health proposed that this be done in three stages over a fourteen-year period, from 2012 to 2025. In the first phase, from 2012 to 2017, the government established eleven pilot sites and formed a transitional NHI fund. In phase two, from 2017 to 2021, the NHI fund will begin to buy health services from providers, the Health Patient Registration Fund (HPRS) is initiated, and the public begins to get NHI cards. In the third and final phase, from 2021 to 2025, the government will integrate public and private health services and restrict medical aid to offer only top-up cover. NHI will be paid in taxes, and the fund will buy health services from public and private providers (McCann 2016).

One of the key tenets NHI is the strengthening of the public health sector. This will be done by strengthening primary healthcare services, which are the ‘backbone’ of the health system. This emerges from the historic World Health Organization (WHO) Alma Ata Declaration, which explains:

primary health care is essential health care...made universally accessible to individuals and families in the community...at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work (WHO 1978).

The primary healthcare platform reforms the sector in three key areas: re-training community health workers, establishing mobile clinics to serve the most disadvantaged schools, and creating district specialist teams focusing on maternal and child health. (Matsoso *et al.* 156). However,

Caldwell *et al.* (2017) argue that primary health models must be used in conjunction with specialist care, and tertiary services must not fall to the sidelines (39). The 2016 NHI White Paper only provides for 'district specialists' in pediatrics, obstetrics, anesthetics and family medicines. Caldwell warns, "if excluded from formal policy in the NHI, long-established multifaceted specialist outreach programs of proven ability to 'deliver the goods' might come to an end, denying the sustainability that is a prerequisite for the full benefit of such outreach" (Caldwell *et al.* 40).

The shift to NHI has also required the establishment of the Office of Health Standards Compliance, which has developed a set of norms and standards and audits the country's public health facilities. Audits have revealed that few facilities currently comply with these standards, and many are still plagued with long wait times and drug stock-outs (Mayosi *et al.* 2036). The subpar state of the public sector raises significant criticisms from stakeholders of the feasibility of the shift to NHI as is currently outlined by in the White Paper. While both private and public sector stakeholders admit that resources are unfairly skewed to the private sector, the private sector notes that poor working conditions in the public sector contributes to the inequity (Ramjee *et al.* 186). Indeed, Harris (2011) found that fewer health care users in the public sector felt that they were treated with respect than in the private sector, which led patients, even low income patients, to choose to use the private sector despite the high cost of service (Harris *et al.* 118). This leads to fears that the state does not have the capacity to provide health coverage without significantly compromising quality of service. As Harris warns, NHI reform that addresses only financial barriers will be insufficient to bridge the gaps in the current health system.

The Mental Health Gap in South Africa

Mental healthcare in South Africa, like the rest of the system, is fraught with inequality.

Historically, determinants such as race, class, and gender have impacted who received mental health treatment and who did not. For instance, in 1880, the Natal Government Asylum was built in what is now KwaZulu-Natal—the first mental asylum built expressly for that purpose in southern Africa. In 1927, overcrowding led the Natal government to convert old army barracks to a second facility. While the majority of patients in the asylum were poor and black, there was the greatest number of white men per capita. However, across racial categories, the majority of patients were men (Parle 2). Historian Julie Parle argues that this was because even while suffering from a mental disorder, women could still contribute to households by performing domestic tasks, which were often crucial to family survival. Institutionalization was not an economically viable option in many households, even though families were not required to pay until 1920. Thus, it was only when it was clear that family members could no longer contribute to the family economy, or when they were so unstable that their presence was severely disrupting or endangering the family, that institutionalization became a viable option (Parle 9).

Unfortunately, class, race, and gender continue to affect access to treatment in the present day. Socioeconomic status not only affects access to treatment, but even the nature of illness itself. The relationship between poverty and mental illness has been described by Schneider et al. (2016) as a “vicious cycle”. People living in poverty face greater stress, social exclusion, and increased risk of violence, and thus are at increased risk for developing mental disorders. People suffering from mental disorders are at greater risk of becoming impoverished because of stigma, the cost of treatment, and loss of employment due to diminished productivity (154).

Commenting on the 'vicious cycle' of mental health and poverty, Cooper *et al.*, assert, "Although improving mental health status in Africa ultimately requires global structural economic interventions aimed at eradicating poverty, the self-perpetuating negative cycle of poverty and

mental ill-health can be lessened through cost effective clinical, economic, and social interventions" (309). These include direct interventions such as low-cost medications, psychotherapy, and rehabilitation. Further, welfare and education has also been shown to reduce rates of medical disorders in low and middle income countries (Cooper *et al.* 310).

The relationship between poverty and mental disorders compounds with the high rates of poverty and unemployment in South Africa to contribute to the mental health treatment. This gap is not unique to South Africa. In low resource countries, especially in Africa, mental health continues to be a neglected issue despite the growing global burden of mental disorders. In 2000, mental health conditions were estimated to contribute to 12% of the global burden of disease, and the WHO estimates this will rise to 15% by 2020 (Cooper *et al.* 309). The percentage of the total healthcare budget spent on mental health is unknown in South Africa, but in most African countries it is less than 1% of the healthcare budget. In a 2011 study of mental health systems in Ghana, Uganda, South Africa and Zambia, Cooper *et al.* found, "The low priority and commitment given to mental healthcare was attributed primarily to the widespread stigma surrounding mental health; insufficient political will, advocacy and leadership; limited information on the burden of neuropsychiatric disorders; and prevailing perceptions that productivity will not be enhanced as a result of better mental health outcomes" (312).

The 2011 study spoke to the prevalence and nature of stigma against the mentally ill in all four countries, calling this stigma "ubiquitous and insidious across society". The researchers continue to describe how stigma prevails "within the general community, among relatives of patients, amid general and mental healthcare providers, and at the level of government. Such stigma was found to be all embracing, being directed not only at those labeled as mentally-ill but also extended to their family members, across generations, and even to the mental hospitals

themselves" (Cooper *et al.* 312). Furthermore, the study found that in African societies, many believe that mental illness is caused by “spiritual possessions, witchcraft, substance abuse, and/or sins committed by afflicted individuals or their relatives” (Cooper *et al.* 313). Additionally, there is a widespread belief that mental afflictions have no cure, which is a significant barrier to seeking treatment, and can lead to alienation, abuse, or abandonment of the ill person by their family and community.

A Path Forward: South African Mental Health Care Policy in the Age of NHI

In light of growing awareness of the neglected status of mental health, leaders of global organizations have publically called for the issue to be prioritized. Mental healthcare was notably included in the United Nations’ 2015 Sustainable Development Goals, a marked shift from the 1990 Millennium Goals where the issue was omitted (UN 2015). In 2013, South Africa committed to integrating mental health into the South African health system in the publication of its Mental Health Policy Framework and Strategy Plan (Schneider 154). In the years since, the country has been lauded for its establishment of a 72-hour referral service for psychiatric emergencies, introduction of a minimum of one medicine per psychiatric therapeutic category on the essential drug list, management of psychiatric patients by primary health clinic (PHC) nurses, and the assignment of disability grants to individuals with severe psychiatric disorders.

Unfortunately, rural areas continue to be under-resourced, with inadequate support given to PHC nurses for management of psychiatric emergencies, and "inconsistent and irregular identification and treatment of more common mental disorders such as depression and anxiety" (“Integrating Mental Health into Chronic Care” 43). However, Cooper *et al.* (2011) comment, "In South Africa, there has been little advancement in mental health services beyond de-hospitalization, which entailed the downsizing of hospital based care without the development of adequate

community based services" (318). While downsizing hospital-based care does reduce costs and move towards a more effective treatment model, this does more harm than good if the infrastructure and resources to provide community-based treatment are not provided. As Cooper argues, "deinstitutionalization has to be in synchrony with comprehensive and integrated primary mental healthcare" (Cooper *et al.* 318).

Researchers suggest that the introduction of NHI in South Africa is an opportune moment to leverage additional attention to the needs of the mental health care sector. However, Schneider argues that though NHI and mental health policies in recent years have been admirable, it is lack of political will, managerial skills, and adequate financing that has continued to prevent the treatment gap from narrowing. For instance, the National Department of Health established multidisciplinary mental health teams at NHI pilot sites using the principle of ‘task-shifting’, which is defined as “the training of non-specialist health workers in the provision of health care services under the supervision of scarce specialist health personnel as a mechanism to compensate for the shortage of specialists in Low and Middle Income Countries (LMICs) and facilitate scaling up of health services at a minimal cost" (“Integrating Mental Health into Chronic Care” 34). Unfortunately, Schneider reports that the team’s efficacy was stymied by lack of money and qualified staff, a limited number of evidence-based treatment protocols other than medication, lack of awareness and stigma, and a “low-level of health-systems readiness to integrate mental healthcare” (Schneider 155). To mitigate this, Schneider suggests “the content of the comprehensive package for insurance-holders should be redefined to incorporate mental health, as well as substance abuse. Indeed, although the White Paper includes mental health services and health counselling services as part of the comprehensive package, it does not acknowledge the wide-ranging nature of mental disorders” (Schneider 156). Despite criticism,

there is a growing body of research that highlights a path forward for deinstitutionalization and integration of mental healthcare into primary healthcare facilities. Indeed, Swartz *et al.* (2014) assert that task-shifting, if done correctly, can be even more effective than work done by professionals at the tertiary level because, “community members trained to deliver mental health services are more likely to share cultural, linguistic, and social backgrounds with those receiving care than are professionals” (Swartz *et al.* 2).

Concluding Thoughts

Inequality in the South African health system is deeply entrenched, and thus, although difficult, the shift to NHI is an important step in the direction of equality. However, mental health faces unique challenges due to stigma, lack of research, and the multiplicitous nature of mental disorders. The authors I have sampled raise critical concerns about the efficacy of NHI with specific regard to mental health, and more broadly, the barriers that the policy has and will continue to face during implementation. Further scholarship is necessary to determine actions that can be taken to repair or supplement gaps in the White Paper, and to integrate a plurality of perspectives from the private and public sector, academia, and patients and their families. In order for mental health treatment to be moved from the ‘back-burner’ and for mental disorders be prioritized as serious health conditions, there must be a vocal civil sector calling for change.

Methodology

The data for this project is grounded in qualitative research. I conducted six semi-structured interviews with key stakeholders in the mental healthcare system. I found my interview subjects using the snowball sampling technique, drawing upon the personal networks of my program director and advisor as well as the interview subjects themselves. As the direction of the project greatly differed based on who I chose to interview, I selected my interviewees in order to amplify voices which approached the issue from differing backgrounds. I was able to include individuals working in both the private and public sector, urban and rural settings, different levels of care, and different professions, including participants from academia, medicine, and the healthcare business. My final six subjects consisted of a psychiatrist at an urban public hospital in KwaZulu Natal (KZN), a private sector psychologist in KZN, two employees at a healthcare consulting company, Professor Arvin Bhana of the University of KZN (UKZN), a co-investigator at the PRogramme for Improving Mental Health CareE (PRIME) South Africa (see p. 25), and One Selohilwe, a program coordinator at PRIME working in a rural clinic in the Dr. Kenneth Kaunda (DKK) district, which is also a NHI pilot site. Although four out of the six of my participants chose to remain anonymous, Bhana and Selohilwe have agreed to have their names used much of our interviews consisted of discussions about their work at PRIME due to its relevancy to my topic.

The interviews were approximately one hour in length. Although I hoped for them all to be conducted in person, three were conducted via phone because of logistical constraints. Originally, I intended to record all of my interviews and transcribe them. Unfortunately, two of my participants requested that I not record them due to the sensitive nature of the topic. For those interviews, I took detailed handwritten notes, which I revisited the same day of the interview and

typed up. Although the data was not as rich as it would have been had I been able to record the interviews, I believe that the honest and candid testimonies I received from these participants brought up themes that would not have been addressed otherwise, and thus still proved fruitful. For Ms. Selohilwe's interview, my computer crashed the first time we spoke and I lost the recording of our conversation. Thankfully, I was able to record and transcribe a second conversation that I had with her the following week. The remaining three interviews I recorded and transcribed as anticipated. All participants were briefed on what my project would be used for and where it would be shared before the interviews took place, and submitted informed consent, either written or via email.

Although I used the same set of questions for each interview (see Appendix A), the interviews' semi-structured nature and the varied areas of expertise of my interview subjects led our conversations to dwell on different themes. The questions served as a guide, rather than instructions, and I asked different probing questions in each interview. Additionally, as many of my subjects were much more knowledgeable than I, the interviews often took on an instructive tone. The interview subjects themselves at times directed me to further literature and new themes to explore on my topic, which has helped the project to be as thorough as possible.

Limitations of the Study

The first, and most significant limitation of the study was the short five-week time constraint, which constricted the amount and the nature of the interviews I was able to conduct. Based upon slightly more than six hours of interviews, my methodology inevitably highlights certain perspectives while leaving others out. Due to ethical concerns, I will not be able to interview any mental health care users or their families, a crucial group of stakeholders whose ideas must be taken into account in any policy decision or reform of the mental healthcare sector.

Additionally, because many of my subjects hold multiple advanced degrees and are all employed, they represent a privileged section of the population who is not likely to be seriously disadvantaged by the current healthcare system. Despite this, I believe that most participants were conscious of their own biases when responding to my questions. I was further limited by reservations that participants may have felt about discussing their frustrations or criticisms within their own field of study, place of work, and indeed at times even their government. However, the steps that I have taken to protect participant identities, including anonymizing interviews upon request and not recording the interviews in some instances, have to some degree accounted for this hurdle. Finally, I was also limited by my own personal bias and ignorance. I have only been in South Africa for four short months, and as an undergraduate student in Neuroscience, I am certainly no expert in healthcare policy nor mental health in South Africa. I have attempted to acknowledge and fill in my own gaps in understanding as best as possible given the short time frame, but I undoubtedly have still more to learn. Despite these limitations, I have attempted to present my data largely through the voice of my participants in a manner which represents their viewpoints in an unbiased and accurate way.

Participant Biographies

Consultant A works at a healthcare consulting firm but was formerly a doctor in the public sector.

Consultant B works at a healthcare consulting firm and came to South Africa from the United Kingdom.

The Psychologist is a recent graduate and is working in a private practice in UKZN. Before graduating she completed two years of required community service in the public sector.

The Psychiatrist works at a public hospital in an urban setting in UKZN and previously worked for several years in a rural clinic.

Arvin Bhana is a professor at the UKZN school of public health and a clinical psychologist. He is also a co-investigator for PRIME South Africa (see below).

One Selohilwe is a project coordinator at PRIME South Africa, and a researcher at the UKZN school of psychology.

A Note on PRIME South Africa

For this project, I was honored to be given the opportunity to interview two members of the PRogramme for Improving Mental hEalth care (PRIME) South Africa team: Arvin Bhana and One Selohilwe. Below, I have included a brief overview of the PRIME program, as much of my interviews with Bhana and Selohilwe consisted of discussions of their work due to its relevance to my topic. These discussions greatly informed my project, as PRIME is at the forefront of mental health research in the country and may be a model piloted nationwide.

PRIME is a “consortium of research institutions and Ministries of Health” (PRIME 2011) in Ethiopia, India, Nepal, South Africa, and Uganda. PRIME also receives support from the United Kingdom (UK) and the WHO. It is a six-year program which launched in 2011, and aims to correct the mental health treatment gap in Low and Middle Income Countries (LMICs) through the generation of “world-class research evidence on the implementation and scaling-up of treatment programs for priority mental disorders in primary and maternal healthcare contexts in low resource settings” (PRIME 2011).

In 2013, PRIME South Africa developed a mental healthcare plan (MHCP) for district and community level reform that was piloted from August to November 2013 in a semi-rural clinic in the Dr. Kenneth Kaunda (DKK) District. The reforms were designed in synchrony with NHI’s aim of improved Integrated Chronic Disease Management (ICDM) which is the coordination of treatment for patients with multiple chronic level diseases. In April 2017,

PRIME began phase two of the project in South Africa and began their expansion into all of the community health centers in DKK (personal communication, April 18th, 2017).

The work that is done by PRIME is groundbreaking, because as knowledge of the important role of mental health in ICDM increases, mental health is positioned to become a national health priority. As Petersen *et. al* explain, "it is increasingly understood to be integral to the delivery of chronic care given that depression and alcohol misuse compromise prevention efforts and adherence to treatment" ("A task shifting approach to primary mental health care" 1-2). However, there is currently no specific budget for mental healthcare in ICDM and thus mental health care providers must compete with other areas of care for resources ("A task shifting approach to primary mental health" 10).

Primary Research: Findings and Discussion

Part One. Understanding the Mental Health Gap and Existing Barriers to Treatment.

During the interviews, participants disclosed a myriad of factors that contribute to the mental health treatment gap. Despite considerable disagreement, three barriers came across in all interviews. The first was the lack of government investment in mental healthcare, the second was absence of knowledge and understanding of mental illness, and the third was the difficulties of the healthcare sector in general. While issues of inequality and lack of resources in the healthcare sector as a whole undoubtedly have a large effect on access to mental healthcare, they have been extensively researched and reported on in other scholarship (Coovadia 2009; Emmerich 2016; Harris 2011; Mayosi 2009) and are beyond the scope of this study. In the following section, I have outlined participant views on the unique challenges of the mental healthcare sector. Their testimonies make clear that there must be a change in public understanding of the nature and severity of mental illness if the treatment gap is to diminish in the coming years.

Policy versus Practice: “Mental Health has never been allocated the budget or attention it deserves”

When asked about government prioritization of mental health, all participants said it was a low priority. Indeed, the psychologist remarked, “I do not think that it is the number one priority, or even in the top ten” (personal communication, April 13th, 2017), and the psychiatrist concurred, saying “mental health has never been allocated the budget or attention it deserves” (personal communication, April 19th, 2017). A major complaint cited by the participants was the disjunction between what was promised by the government in their policies and the reality

experienced while working in the mental health sector. Selohilwe gave several examples to support this from her time at the clinic:

“The South African Mental Health Policy Framework for 2013 to 2020 says that the government is going to provide mental healthcare through task sharing because there is an acknowledgement of not having enough people on the ground to provide these services. But this is not ordinarily taking place in their facilities [...] the government has come up with a plan to have district mental health teams... but it has been very difficult to get that going. In DKK, for example, one of the task teams did everything, they had the mental healthcare plan ready to be put in place [...] but when it came to appointing the [review board] there was no budget so the team was never put in place. There is now a healthcare plan in the area which does not include the mental healthcare plan [they wrote]” (personal communication, April 25th, 2017).

The psychiatrist also discussed the mental health review boards and said that although doctors are required to submit paperwork to be reviewed by the board, she often does not ever hear back (personal communication, April 19th, 2017). The psychologist complained of neglect, and noted that despite the fact that the “country really needs psychologists [...] because the mental health budget [is so low] [...] [the government] can’t afford to hire more psychologists, so as soon as someone leaves, instead of hiring someone else to replace them [...] they are freezing the position” (personal communication, April 13th, 2017). This indicates that the budget for mental health is shrinking, and certainly does not speak to a government commitment to improve mental healthcare.

The number one reason participants cited for the neglect of the mental healthcare sector was competing healthcare priorities, especially the HIV/AIDS and tuberculosis (TB) pandemics. Consultant A posited that a contributing factor to the neglect of mental health may be that it is more difficult to quantify the return on investment with mental health than it is for a disease like

diabetes. This is because the impact of mental disorders is felt on a personal level, unlike how a disease like TB is spread and detected (personal communication, March 30th, 2017). This was supported by Consultant B, who argued that the only sphere where mental health could be considered a national priority is the extent to which it relates to HIV (personal communication, April 6th, 2017). This is underscored by the existence of the PRIME project, as it aims to integrate mental health counseling into the treatment of patients with other chronic conditions. Bhana spoke to the government's support of the project, noting that the government is "now beginning to recognize that [...] [there is] a growing number of [...] people being treated for TB, HIV, but that also have comorbid conditions beginning to emerge [...] and mental health is an essential part of it. They recognize that you need to integrate, that it must be part of the approach" (personal communication, April 10th, 2017). Work on integrating mental healthcare with other comorbid conditions was the only area where participants cited that the government actualized the commitment to improving mental healthcare it made in the 2013 policy.

Bhana had one of the most positive opinions of not only the government's commitment to improving mental healthcare but also of his experience working with them. When asked about the input and involvement he felt he had in Department of Health decisions, Bhana answered "In all our projects we work closely with them, they have an advisory function, and it is a complete feedback loop" (personal communication, April 10th, 2017). Consultant B also reported open communication remarking, "they try to include us in the process and [...] fairly regularly interact with people in the private sector" (personal communication, April 6th, 2017). Although the participants certainly raised notable concerns about the government's monetary and political commitment, a strong and open line of communication bodes well for the possibility of future change.

However, not all participants felt this line of communication existed—the psychologist, for instance, argued that “at the psychologist’s level and therapists point of view [...] [there is a] lack of communication about how [policy change] is going to work and how it is going to effect us” (personal communication, April 13th, 2017). Additionally, Selohilwe complained extensively of government neglect, despite working in a clinic of the same project Bhana researches at (personal communication, April 18th, 2017). While the sample size of my study does not lend itself to generalizable findings, such discordant views suggest that there may be an uneven level of input between stakeholders. Both Consultant B and Bhana felt that the government was receptive to their feedback, while the psychologist, psychiatrist, and Selohilwe expressed neglect and lack of communication. The voices that are featured and those left out in the policymaking process effect the direction that mental healthcare will travel in the future. Psychologist, psychiatrist, and counselor buy-in is essential for the success of any mental health policy in the country.

Public Awareness of Mental Health

Knowledge of mental health was a common theme bridged across all six interviews. As put by Consultant B, “mental health is something that you really have to learn exists” (personal communication, April 6th, 2017). Unfortunately, the participants concurred that the public has extremely limited knowledge of mental health. What little is known is often riddled with stigma and falsehoods. In fact, Selohilwe argued that the number one barrier to treatment she witnessed at the DKK clinic was that many patients did not recognize their experience as symptomatic of an illness, and thus saw no reason to talk to a medical professional (personal communication, April 18th, 2017). The psychiatrist reinforced Selohilwe’s statement, remarking that it is not when people experience internal stress that they are recognized as ill and brought in for

treatment, but only once the illness has progressed to the point that they are causing distress to those around them (personal communication, April 19th, 2017). Unfortunately, Selohilwe, the psychologist, and the psychiatrist agreed: the majority of their patients have reached a stage of illness where it is much more difficult to manage than it would have been had they come in for counselling months, or even years, earlier. Furthermore, participants spoke not only of the lack of knowledge of the symptoms of mental disorders, but also of widespread misunderstanding of the variation of mental disorders experienced by the population. Bhana explains, “mental health has been seen as [...] only for people with severe mental disorders which is the case for less than 1% [of the population]. Most people have common mental disorders: depression, anxiety, stress, post-traumatic stress disorder (PTSD)” (personal communication, April 10th, 2017). It is these common mental disorders, not the severe disorders, which make up the bulk of the treatment gap.

When discussing public understanding of mental health, the issue of *sangoma*, or traditional healers, came up in nearly every interview. The psychiatrist raised concerns that patients visiting *sangoma* instead of or prior to seeking help from mental health professionals contributed to the delay in patients coming in for treatment (personal communication, April 19th, 2017). The psychologist underscored this sentiment in her interview, noting that while “in some instances [seeing a *sangoma*] might be exactly what [patients] require to get better, sometimes [...] they have undergone so many other processes that by the time the patient gets to us they are really desperate or really ill and its hard then to try and fix them” (personal communication, April 13th, 2017). Surprisingly, both Selohilwe and Bhana disagreed, instead citing “very little crossover” with *sangoma* in their experience, and that traditional medicine has not seemed to alter the health-seeking behavior of the patients seen at the DKK clinic (personal communication, April 10th and 18th, 2017). Furthermore, Selohilwe noted that the clinic has actually had some patients

seek treatment for mental disorders seen to be part of their ‘calling’ from the ancestors to be a *sangoma* (personal communication, April 18th, 2017). The tensions between participant’s answers raise the question of to what extent *sangoma* influence public understanding of mental disorders. While the differences in the interviews may have resulted from different cultural understandings of *sangoma* or a difference of experience between urban and rural healthcare settings, conclusions about this interaction is beyond the scope of this study. However, these findings certainly beg further investigation into the role of traditional healing in mental healthcare.

Stigmatization of Mental Illness

Perhaps one of the most significant barriers to treatment cited by participants was widespread stigma. Mental illness is seen as separate and different than physical illness, and is treated as less serious and more shameful. As the psychologist explained it, “if you [...] have a broken arm, you would probably go to a hospital [...] but if you need an antidepressant, [patients] are not willing to go [to a doctor for treatment] because they might think, ‘what if someone sees me there, what if someone walks in while I am taking the medicine, what do I tell them, I do not want them to think that I am crazy!’ ” (personal communication, April 13th, 2017). This aspect of stigmatization of mental illness was described by Selohilwe as “internalized stigma” (personal communication, April 18th, 2017). As Bhana noted, this type of stigma is particularly insidious and deeply entrenched because it is “not simply other people thinking negatively about the person [who is experiencing mental health issues], it is about their own experiences” (personal communication, April 10th, 2017). This can lead to patients refusing to acknowledge and seek treatment for their illness.

Unfortunately, the stigma described by participants existed not just within mental healthcare users, but also in the healthcare sector itself. The psychiatrist described how medical professionals see psychiatrists, psychologists, and their patients as somehow different from, for instance, a diabetes patient, although both illnesses result from a combination of lifestyle factors and chemical imbalances. The psychiatrist remembered an incident in medical school when another member of their class remarked, “How can you be doing psychiatry, you were one of the level-headed ones” suggesting that psychiatry was a lesser field (participant communication, April 19th, 2017). Selohilwe also spoke of stigma within the medical profession, explaining that PRIME had to develop additional trainings on stigma for social workers treating schizophrenic patients because so many feared that the patients would be violent and dangerous (personal communication, April 18th, 2017). The testimonies of my participants echo the findings of previous research, such as a 2011 study of Ghana, Zambia, Uganda, and South Africa which found that the, “the low priority and commitment given to mental healthcare was attributed primarily to the widespread stigma surrounding mental health” (Cooper *et al.* 312). This data was perhaps best summarized by Bhana’s statement that, “There is stigma. It exists in patients, it exists in healthcare workers, it exists in the general public, it exists everywhere” (personal communication, April 10th, 2017).

Media and Mental Health: The Life Esidimeni Tragedy

One cannot discuss public awareness of mental health without discussing the Life Esidimeni tragedy that occurred last fall, which has garnered intense media scrutiny and discussion. However, there was considerable disagreement between participants concerning the possible effect that the media attention may have on the nation’s understanding of mental health. All three participants who interact directly with patients—Selohilwe, the psychologist, and the

psychiatrist—said that they felt that the tragedy might lead to greater public awareness of mental health issues. For instance, the psychologist called the incident “quite a wake-up call” and said that “people realized how important it is to have these types of centers [and] that mental healthcare is not a small thing” (personal communication, April 13th, 2017). She felt that it demonstrated the seriousness of mental disorders and the importance of long term treatment facilities, such as the ones in Gauteng formerly operated by Life Esidimeni. Selohilwe took a more critical interpretation, and argued that the incident displayed that the government has not yet determined how to best keep psychiatric patients alive, let alone identified the best way to reintegrate them into society (personal communication, April 18th, 2017). Despite this, she remained hopeful that the incident might lead to change and might highlight the importance of mental health.

However, other participants raised concerns that the attention that comes from the tragedy may not lend itself to improvements in the mental health sector. Both consultants felt that, rather than highlighting “how serious and how life- threatening mental health can be” (personal communication, April 6th, 2017) the tragedy would underscore the problem of corruption and gaps in management in the government and non-profit sector. Bhana’s concerns were slightly different, although he too did not feel that conversations around the tragedy reduced stigmatization of mental disorders. In his view, while the tragedy has raised awareness of the seriousness of care required by some institutionalized patients, it has perpetuated the perception held by much of the public that “these are the only type of people that have [mental disorders]”, rather than broadening the discussion to include the majority of individuals who suffer from common mental disorders, and require a very different level of care (personal communication, April 10th, 2017). All participants agreed that the tragedy had garnered great national attention

and has featured prominently in the media. Whether their predictions about any effect it might have on the mental health sector are true remains to be seen and may be a fruitful course for further study.

Part Two. National Health Insurance and Mental Health

The country's shift to National Health Insurance will lead to large changes in the healthcare sector, however, nearly all participants disclosed doubts about the policy's prospect of success. In this section, I will discuss participant understanding of the policy's provisions for mental health, barriers to its successful implementation, and predictions for its impact on access to mental healthcare.

Thoughts on NHI

Participant discussions of NHI were riddled with uncertainty about not only how the policy will change in coming years, but even its status today. The psychologist observed, “the back and forth at the policy level seems like the biggest barrier [to the success of NHI] [...] and lack of communication [...] there is the White Paper but it would be great if they had seminars explaining how it is going to work [...] so that we could all be on the same page” (personal communication, April 13th, 2017). This confusion is troubling considering that, as the psychologist herself expressed, “the moment that NHI comes in things are going to change quite a lot” (personal communication, April 13th, 2017). NHI will greatly effect her day-to-day work and that of her peers.

Participants also expressed particular confusion about the provisions made for mental health by the White Paper. As Consultant B voiced, “the problem with the White Paper is that it has not been specific on what kinds of illnesses it is going to cover. It does [...] include mental

health services under their comprehensive packages service, but they haven't said what they are going to cover with regards to mental health, so they haven't said 'we'll cover five psychologists visits per year' or 'we'll cover all psychiatric problems' ” (personal communication, April 6th, 2017). While this lack of specificity may seem pedantic, the provision made for mental health will have tangible impacts on patient health outcomes. For instance, the psychiatrist explained that currently, the essential drug list requires that clinics stock a limited number of psychiatric medications: usually one antidepressant and one antipsychotic. If a mental healthcare user is not prescribed these drugs then they must travel to a facility that stocks the drug they need; typically, a hospital in an urban setting, rendering the clinic close to home obsolete (personal communication, April 19th, 2017). As illustrated by this anecdote, in the limited resource environment of the public healthcare sector, many patients are hardly able to access services and drugs included on the 'essential' list. Their chances of obtaining anything not on the list is unlikely.

The clinic where Selohilwe works is a pilot site for both PRIME and NHI and therefore she was able to offer insight into the reception of the pilot thus far. She noted, “For people who have received mental healthcare services through our program there is gratitude [...] about being able to get help when they did not think they would be able to” (personal communication, April 25th, 2017). This raises a crucial aspect of NHI's mission—bringing care to patients who would not otherwise have access to it. However, NHI's prospects are darkened when one considers the perspective of the private healthcare system and patients who are currently on medical aid. These patients already have access to care. Given the current state of the public sector, unifying public and private into a single system would likely mean that their quality of care would take a nosedive. It is buy-in from these patients that will be a great challenge. For, as the psychiatrist

explained it “Which private patient on medical aid would come to my ward? I am on medical aid and I would not come to this facility” (personal communication, April 19th, 2017). This is a critical issue, because although the portion of the country on medical aid that might suffer under NHI is only a fraction of size of the population that would be gaining access to new services, the resources—money, doctors, drugs, equipment—which are needed for the health system to remain operational, are concentrated in the hands of the private sector. Bhana articulated this, saying, “We are less concerned with what NHI [...] looks like when it is on paper right now, [that] probably will never work. It will look very different, but we will be stuck with the issue of how we get the resources to make this happen” (personal communication, April 10th, 2017). In Bhana’s view, the particularities of the policy document are arbitrary, the essential issue is, and will continue to be, the reallocation of resources.

The Impact of NHI on Mental Health

Despite the uncertainty and doubt shrouding NHI, participants spoke to the possible effect that the policy could have on the nation’s mental healthcare. Consultant B argued that, “The best thing for mental health would be if the health system overall were improved because then that would essentially open up capacity for providers, for money to be focused on mental health” (personal communication, April 6th, 2017). In his view, in order to address the nation’s mental health crisis, other health crises that currently dominate the resources must be taken care of first. However, Bhana disagreed, instead favoring integration and immediate action. As he explained it,

[Mental Health] can’t stand off on its own. The NHI is [...] promising to make quality, affordable help available to the majority of the population, it is within that context that [mental healthcare] has to work. Whether it should be part of NHI is irrelevant, it is the health system [...] All you have to do is

to start changing how you deliver better healthcare that includes mental health. Better management of diabetic patients, hypertensive patients, HIV patients, TB patients, all of that is the same thing.

You cannot try to deal with all of those things without trying to deal with the struggles that the person has in trying to manage themselves (personal communication, April 10th, 2017).

As Bhana has argued, mental healthcare cannot be considered a separate crisis, or something to deal with only once other more ‘pressing’ health issues have been managed. It must be dealt with in tangent with care for other chronic conditions such as HIV and TB. This is the concept of comorbidity: each condition impacts the other—a depressed patient is more likely to default on their medicine. Thus, if you are a nurse at a community health center and want a patient to take their ARV’s, their depression must also be addressed. An individual’s health does not occur in a vacuum, it is holistic.

Part Three. Where do we go from here? Participant reflection on the Capacity of the Mental Healthcare Sector and Suggestions for Future Improvements

There was overwhelming consensus that a greater number of patients must be seen by mental healthcare professionals, however participants disagreed on whether the mental health sector had the capacity to handle this increased burden. Despite acknowledging the existence of significant challenges in the sector, participants were able to identify tangible changes which could be made to improve access to care. Many of the solutions in the following section need not wait on policy changes made at the national level, but rather necessitate management and culture change. Participants stressed the importance of education campaigns, improved management, and investment in community based care in the interim years of the NHI rollout.

Closing the Mental Health Gap: The Capacity of the Mental Health Sector

Participant views splintered in the extent to which they believe the sector will be able to handle an increased burden of patients in coming years. For instance, Consultant B hypothesized “if you start telling everyone that they have issues, [that] everyone needs to talk to a psychologist at some point in their lives, [and] probably 30% of people need to go on medication at some point, then people start trying to access mental health services but the services aren’t there” (personal communication, April 6th, 2017). This view is supported by concerns raised by South African academics that the country lacks the human resources necessary to provide universal health coverage. The mental health sector is identified as being even more ill-equipped. Currently, it is estimated that there are only 0.28 psychiatrists per 100,000 South Africans, and the vast majority practice in the private sector (Cooper *et al.* 317). As cited by Ramjee and McLeod in the *South African Health Review*, Econex has calculated that “NHI would require approximately 10,000 more GPs and 17,000 more specialists, and could bring up to 2 million more people into private hospitals” (Ramjee *et al.* 187). The psychologist gave an account that supported these concerns, describing the current public mental healthcare system as overburdened and inefficient. She reported how, “when I was in government we would see nine or ten patients a day and we weren’t even getting through all the patients, unfortunately there just weren’t enough of us to get through everyone who needed the care, and a lot of it was being done by us, the interns” (personal communication, April 13th, 2017). If the current healthcare system is overwhelmed by treating only a quarter of the nation’s mentally ill—even with care provided by medical students that have yet to graduate—it seems unlikely that the sector will be able to serve more patients in the future.

However, other participants had more hope for the sector’s capabilities. Selohilwe in

particular pointed to the work that she and Bhana have done with PRIME as a model which could feasibly be expanded nationwide. In her analysis of the expansion she predicted:

The infrastructure shouldn't be overburdened when it comes to meeting the needs of the community [...] for example we have [counselors] who are assigned for HIV counseling and they are seeing part of their target population for mental health care services so even though there is I guess [...] an added role providing mental health services it is also helping to relieve the burden of getting, like, the 'revolving door syndrome', where patients keep coming back [...] when you look at the comorbidity of mental illnesses with other illnesses, that interaction, patients will have worse health outcomes if mental illness is not treated. So even though on the surface it may look like it is giving a particular cadre of workers more or additional work, at the end of the day, patient outcomes, health system outcomes will outweigh what is termed as an 'increased burden of work' (personal communication, April 25th 2017).

If Selohilwe's prediction is true, then integrating mental health care into existing chronic care services would be possible because it does not require more workers but instead retrains an existing cadre of healthcare workers—the community health workers currently administering medications such as ARVs—to also screen for mental illness. Through the model of integrated care, PRIME aims to stop the 'revolving door' phenomenon where patients continue to return back to the clinic because they are not being treated effectively. Therefore, mental healthcare could be expanded to treat a larger portion of the population without a huge budgetary expansion. However, this assumes all of the primary care workers are effectively able to carry out the screening, which Selohilwe herself has acknowledged will be the program's biggest challenge. Bhana too spoke to the efficacy of the PRIME model of care, but was less optimistic of its probability of success nationally, instead arguing:

The issue is, the better the identification, the more people that you need to treat [...] even in our

model [...] they cannot cope with the numbers that might emerge [...] That is why I am saying that [...] self care must be the primary outcome that you are looking for [...] shifting the burden of care back to the individuals. So that what you are left with is people who are in serious need of care, who need a higher level and deeper level of care. In a simplistic way, to deal with two-thirds of the sort of general problems that people have we are offering a general approach to. There is a top third that will never be receptive to this type of intervention [...] It's an ideal of trying to shift care but we do not know if it is actually going to happen. The point is you have to move in the right direction (personal communication, April 10th, 2017).

As Bhana points out, what is promising about the PRIME model is not only that it relies upon a cadre of workers that already exists, but also that it emphasizes self-care. This means incorporating teaching into treatment, so that patients will be enabled to eventually be relatively independent of the health system, although their condition may not have been cured. Unlike Selohilwe's analysis, Bhana feels that success at a national level is only a fragile hope at this point. Although it is probably true that the expansion of the PRIME program will not happen smoothly, or indeed perhaps at all, the current state of the mental healthcare sector should not stun the country into paralysis, but rather, demands change.

Proposed Solutions: Education Campaigns

Given that participants identified lack of mental health knowledge as a major barrier to treatment, it is no surprise that education campaigns were widely proposed as a solution. Bhana cited the reduction of stigma as a key goal for any education campaign, asserting:

People don't think about [mental health] too much until they actually experience it. But there are people that have actually experienced it, and [...] the more celebrities and people who are actually going through it that talk about it [the better]. People like me who talk about it? No effect. But people will say 'oh this, person, I thought this person was such a well put together person, and he suffers

serious depression’, that is useful. It is reducing the stigma associated with it (personal communication, April 10th, 2017).

Here, he makes the important point that personal experience, either of highly visible people such as celebrities, or of someone from a person’s own community, is a more powerful teaching mechanism than a government campaign or scientific facts and figures will ever be. These feelings were corroborated by Selohilwe, who remarked, “Overall, the patients’ experience of their own disorder must be understood. When patients learn and are helped with these issues, they take that back to their communities and families” (personal communication, April 18th, 2017). Meaningful and lasting change in the ways that communities experience and understand mental disorders must, to some degree, come about organically. However, to make this happen, the voices of individuals experiencing and recovering from mental disorders must be amplified.

Currently, PRIME has begun holding psycho-education talks about common mental disorders in the clinic waiting room. Selohilwe described, “the psycho-education talk that takes place in our system, helps [...] people identify that they need the service, that the symptoms that we have talked about can be treated, and enables them to demand that healthcare be available” (personal communication, April 18th, 2017). However, she warned against putting too much faith into education campaigns alone. They are effective in the setting of the PRIME clinic, she argued, because they are coupled with available services, but these clinics are the exception, not the rule. She explained, “if we are to get education campaigns it will be a matter of, how does that feed into helping people get to their facilities, how will [mental disorders] be identified, are [MHCU] going to self report? Are [MHCU] going to approach the facility, telling the [clinicians] what they have?” (personal communication, April 18th, 2017). Education must be coupled with infrastructure that will support action, knowledge alone is not useful unless it enables patients to change their circumstances.

Proposed Solutions: Integrating Care at the Community Level

In order to create infrastructure that can support the needs of the mental healthcare sector, further work to improve integration of mental health with the primary healthcare sector via task-sharing was suggested by all participants, not only by Selohilwe and Bhana in the context of the PRIME program. The psychiatrist described the health system as an ‘upside-down pyramid’ (see Appendix D) with the hospitals monopolizing the majority of the resources while the community clinics, which should serve the greatest number of people, taking on the least. She spoke to the cost-effectiveness of primary healthcare, explaining that while it costs only R80-90 per day on average to manage a patient at the primary health care level it can cost R1100-1500 per day to manage a patient at the district hospitals and anywhere from R3000-5000 per day to manage a patient at the tertiary level (personal communication, April 19th, 2017). Although she agreed that this model was more cost effective, the psychologist stressed the importance of good management, remarking “there isn’t the budget to have psychologists, so [...] [task-sharing] would more effectively reach more people [...] if it is implemented correctly [...] but if you try to do it on a very minimal budget using non-qualified people then it could also end up hurting or harming people in the long run” (personal communication, April 13th, 2017). Indeed, Selohilwe echoed this in her own work at the clinic, imploring,

All levels of managers need support. For instance, we have recognized that the program requires a lot of emotional labor from the nurses. In the PRIME model, nurses identify patients who are experiencing poor mental health, and refer them to counselors. These counselors will treat the patients for eight sessions, six of which focus on the triggers for depression. However, nurses have their own issues, and if they are not able to adequately perform their job the model breaks down. Nurses are often not supported by their managers in doing this work, it is seen as ‘extra’ and does not feature on their performance indicators. Managers must support this as being part of their jobs.

Things that seem easy or obvious end up being issues, [mental healthcare at the clinic] is so new, upper managers are not planning for it (personal communication, April 18th, 2017).

As Selohilwe illustrates in this quote, the health system requires quality of care at multiple levels—community health worker, counsellor, and supervisor—to be able to provide effective treatment. Each player must be given the resources that they need to succeed in order for such a decentralized model to work.

Bhana underscored this, and argued that improving the quality of care provided at primary health clinics through good management and training would make strides in diminishing the treatment gap. He explains, “you can have a facility that is poorly resourced but if the quality of care is good that changes everything. You then get fewer returns, better health, which is what you are looking for. It is not only about how much equipment you have, how much stuff you have” (personal communication, April 10th, 2017). This was echoed by Consultant B, who said, “It’s management and culture change. And that doesn’t need regulatory change. You just have to start focusing on systems management and making people care. And these are all things that a good leader can fix in their organization” (personal communication, April 6th, 2017). Amid the ineffectiveness of many aspects of the mental health sector, these suggestions bring hope for improvements that can, and indeed should be made sooner rather than later. NHI should not be used as an excuse for inaction, but rather, a springboard for change.

Conclusion

As with South Africa's healthcare in general, participants identified a myriad of issues which plague the mental healthcare sector. Systemic inequity from the apartheid regime has left the system two-tiered, with very different care being administered between the public and private sectors. The public sector is challenged by a lack of qualified personnel, drug stock-outs, and long waiting lists. Treatment is too concentrated in urban settings and poor, rural patients are often left isolated and without the means to access care. However, through their experiences, explanations, and predictions, participants made clear that it is fundamentally incorrect to see mental healthcare as simply a microcosm of the larger healthcare system in South Africa. Instead, the mental healthcare sector must be given its own attention and research, for it experiences unique problems not seen in other areas of medicine. These problems act as barriers to treatment, and contribute to the mental health treatment gap. To understand why the treatment gap exists, it is crucial to highlight the factors which bar 75% of patients in South Africa from receiving the care they deserve. This project comes at an opportune moment to leverage the needs of the mental healthcare sector because the NHI rollout promises to bring significant change to the health sector.

Participants across careers, geographical contexts, and levels of care highlighted barriers to care. Despite not always agreeing, certain barriers were consistently brought up in the interviews. For instance, South Africa's mental health policy, as outlined by the 2013 Policy Framework and Strategy Plan, is in line with the WHO guidelines for mental healthcare and puts forth the importance of mental health. However, all participants said they felt that mental health was not a government priority in practice. The neglect of mental health is fueled by stigma,

which Bhana remarked, “exists everywhere” (personal communication, April 10th, 2017).

Indeed, mental illness is stigmatized not only in the general public, patients themselves, and their families, but also within the medical community itself. Stigma has led mental health to be seen as separate, different, and less serious than physical health, and was identified as a significant barrier to treatment.

This stigma is fueled by a lack of knowledge and understanding of mental illness by the general public. Participants said that because patients do not know that their experiences are symptomatic of illness, they do not seek treatment and thus only see a healthcare professional when they have progressed to a state where they are causing distress to those around them. Participants also argued that the general public lacks nuance in their understanding of mental disorders. The public is fairly familiar with severe mental disorders—such as those experienced by the patients who passed away in the Life Esidimeni tragedy last year. However, the vast majority of the mentally disordered population has what are termed ‘common mental disorders’—such as depression, anxiety, and trauma. These disorders manifest very differently than the severe disorders and require much different kinds of care.

Participants expressed concern that the neglect of mental healthcare would not be corrected by NHI. The White Paper does name mental health as a priority, but lacks specificity in the extent it will be included in the list of essential treatments and drugs. Furthermore, the success of NHI was doubted by nearly all participants. While Selohilwe, who works in an NHI pilot clinic, did note that patients were happy to receive treatment that they would not otherwise have access to, the psychiatrist said that she did not think any private sector patient would be content coming to her public hospital. Private sector buy-in continues to be the central problem

with NHI, as resources are concentrated in this sector, and NHI is almost certain to result in reduced quality of care for these patients.

With the success of NHI so uncertain, participants called for changes to the mental healthcare sector which could be made immediately, regardless of policy change and government action. A key solution was the continuance of the work done by PRIME South Africa to integrate mental healthcare with chronic care administered at the community level. However, in order for this to be scaled-up beyond the fourteen pilot clinics, improved management and culture change will be necessary in facilities nationwide. This must be accompanied by education campaigns, both for communities and health professionals, to increase awareness and reduce stigma. Participants stressed that such campaigns must be accompanied by service provisions—with such a vast population currently without treatment and given the limited capacity of the mental health sector, the medical community should be weary of giving information without action steps that patients can take to get better.

Although participant's views aligned for many issues, they did disagree about the prioritization that mental health can and should expect to take in future years. Consultant B argued that mental health is never going to take priority over pandemics such as HIV/AIDS or TB. Therefore, the best thing for mental health would be if the health system in general improved. Bhana argues that the health system in general will never improve if mental healthcare is not also improved. This is because of the concept of comorbidity. When a patient has multiple conditions, each condition effects the other. To improve their health, these conditions cannot be treated individually but must be cared for in tandem. Mental healthcare has been neglected from such treatments, and its continued neglect will only worsen the quadruple burden of disease that South Africa faces. The mental health treatment gap is not a problem that

can wait. If the Life Esidimeni tragedy has shown anything, it is that mental illness does take lives. However, mental illness is a problem that has a solution. Finding that solution requires the investment of time, effort, and resources but can and must be done.

Recommendations for Further Study

This study has illuminated several areas where further scholarship is necessary. Firstly, it would be fruitful to continue this research by interviewing a larger sample size of health professionals. In future studies, representatives from the local, provincial, and national Departments of Health should be included in the study as well. Additionally, the voices of mental healthcare users and their families are absent from this study and their views on the sector currently and suggestions for further improvements should carefully considered. The study also points to the need for scholarship on the relationship between *sangoma* and community understanding of mental health, as well as on the impact that the Life Esidimeni tragedy will have on national conversations on mental health. Finally, as the NHI rollout progresses and the policy continues to evolve, researchers must continue to monitor the policy's impact on access to mental health treatment in the country and the input of mental health professionals in the policymaking process.

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Appendix A: Preliminary Interview Questions

- What is your job role and responsibilities? How long have you been working in this job, and what led you to choose this career? –or- What is the current nature of your research? To what extent have you researched about mental health?
- What is the best part of your job? What is the most difficult part?
- How familiar are you with the government’s White Paper on National Health Insurance, or NHI? To what extent do you feel that mental health has been incorporated into the White Paper?
- To what extent do you feel that mental health is a national priority?
- How familiar are you with the 2013 Mental Health Policy and Strategic Plan? Do you think that it had any effect on your job?
- How familiar are you with the national effort to integrate mental health care at the primary healthcare level? Do you think that this is a good idea? What do you believe is the best way to go about this?
- In 2016, the South African Medical Journal reported that 75% of South Africans suffering from mental disorders do not receive treatment. Does this statistic ring true in your experience?
- What do you think are **barriers** that prevent access to mental health treatment in this country?
- What do you think can be done to improve access to mental health treatment in the country?
- Do you think that the NHI rollout thus far has had any impact on access to mental health treatment, especially on those who are economically disadvantaged?
- Do you anticipate that NHI will improve access to mental healthcare in the coming years?
- What do you think will be the greatest barriers to the successful implementation of NHI?
- How do you think the public feels about the public healthcare system? How do you think the public feels about mental health care?
- What do you think is the best way to improve opinion of the public mental healthcare system?
- How familiar are you with the recent tragedy in the Gauteng province? Do you think that this has changed national conversations around mental health? If so, how?

Appendix B: Informed Consent Form

SIT Study Abroad

a program of World Learning



CONSENT FORM

1. Brief description of the purpose of this study

The purpose of this study is to examine the impact of the NHI rollout on access to quality mental healthcare and to investigate solutions to the so-called “mental health treatment gap”.

2. Rights Notice

In an endeavor to uphold the ethical standards of all SIT ISP proposals, this study has been reviewed and approved by a Local Review Board or SIT Institutional Review Board. If at any time, you feel that you are at risk or exposed to unreasonable harm, you may terminate and stop the interview. Please take some time to carefully read the statements provided below.

- a. **Privacy** - all information you present in this interview may be recorded and safeguarded. If you do not want the information recorded, you need to let the interviewer know.
- b. **Anonymity** - all names in this study will be kept anonymous unless the participant chooses otherwise.
- c. **Confidentiality** - all names will remain completely confidential and fully protected by the interviewer. By signing below, you give the interviewer full responsibility to uphold this contract and its contents. The interviewer will also sign a copy of this contract and give it to the participant.

Participant’s name printed

Participant’s signature and date

Interviewer’s name printed

Interviewer’s signature and date

Date

Student Signature

Appendix C: Commonly Used Terms & Acronyms

DoH: South African National Department of Health

DKK: Dr. Kenneth Kaunda District, a district in the Northwest Province

ICDM: Integrated Chronic Disease Management

MEC: Member of the Executive Council

MHCU: Mental Health Care User

MHCP: Mental Health Care Plan

NCS: National Core Standards

NGO: Non-Governmental Organization

NHI: National Health Insurance

PRIME: Programme for Improving Mental Healthcare

WHO: World Health Organization

Appendix D: 'The Upside-down Pyramid'

Below is a model of the 'upside-down' pyramid described by the psychiatrist and referenced on page 43.

