MORAL JUSTIFICATION OF CONTINUED EXCEPTIONALISM OF HIV CARE IN SOUTH AFRICA

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Medicine in Bioethics and Health Law

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Declaration

I Letjie Charmain Maserumule declare that this Research Report is my own, unaided work. It is being submitted for the Degree of Master of Science in Medicine in Bioethics and Health Law at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

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(Signature of candidate)

23rd day of October 2022 in Pretoria

I dedicate this work to my ever-supportive husband, Gontse Mathibedi and our loving children, Masego and Morongwa.

Abstract

South Africa has the largest population of people living with HIV (PLWHIV) in the world, and specialized HIV clinics to treat them are unsustainable. Decentralisation of care to primary health care (PHC) facilities reduces the burden on HIV clinics, but the PHC facilities are already overburdened with limited human and infrastructure resources. My aim is to defend that it is morally and legally justified to temporarily continue exceptionalism of HIV care in South Africa while strengthening health systems. My arguments are based on patients' right to healthcare, the bioethical principles of beneficence and non-maleficence, and deontological moral theory. I contend that the complete abandonment of HIV clinics would burden PHC facilities even more, thus affect rendered care negatively, and violate patients' intrinsic dignity. The complete decentralization of HIV care will be morally and legally justified when PHC facilities are improved for the progressive realisation of access to quality healthcare for all.

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List of Acronyms

Acronym	Explanation
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
CHC	community Health Centre
CME	Continuing Medical Education
COVID-19	Coronavirus disease (SARS-CoV-2)
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
ICDM	Integrated Chronic Disease Management Model
ICESCR	International Covenant on Economic, Social and Cultural Rights
NDoH	South Africa's National Department of Health
NHI	National Health Insurance
NIMART	Nurse-Initiated Management of Antiretroviral Therapy
NGO	Non-governmental organisation
PHC	Primary Health Care
PLWHIV	People Living With HIV
PMTCT	Prevention of Mother-To-Child Transmission
SANC	South African Nursing Council
UNAIDS	The Joint United Nations Programme on HIV and AIDS
UNICEF	The United Nations Children's Fund
WHO	World Health Organization

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Chapter One: Introduction

1.1 Background Literature Analysis and Critique

The human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) epidemic is one of the most important public health issues in South Africa. The Joint United Nations Programme on HIV and AIDS (UNAIDS) states that South Africa has the largest epidemic in the world (1). In 2021 it was estimated that 8.2 million people, comprising over 19% of the adult population were living with HIV in South Africa (2). Furthermore, 20% of the global population on antiretroviral therapy (ART) live in South Africa, making it the largest HIV treatment program in the world since 2015 (1).

Following a period of lack of political will and AIDS denialism, South Africa's National Department of Health (NDoH) started the national rollout of ART in 2004 (3). The initial national strategy for HIV treatment involved selected clinics that had gone through stringent approval processes to be able to give patients HIV treatment (3). International funding and government commitment led to the establishment of the successful HIV programme that South Africa has today. At inception, the HIV treatment programme was seen as an international emergency warranting specialized funding (4,5). This kind of approach to a health problem is often termed a 'vertical approach'. It is so called as it is, "Directed, supervised and executed, either wholly or to a great extent, by a specialised service using dedicated health workers" (6). This approach is opposed to a horizontal approach that aims to strengthen health systems (7). The vertical approach to HIV has resulted in specialized clinics with some health professionals more equipped than others to care for people living with HIV (PLWHIV). As the HIV programme grew, the burden on these clinics presented a need for a more integrated strategy to be adopted. As a result, it became necessary to develop strategies that ensure sustainable delivery of quality healthcare to PLWHIV and to make HIV care more accessible to individuals in need (8–10). One such strategy is to fully integrate HIV care into primary health care (PHC) and shift tasks from doctors and professional nurses to trained lay personnel to increase patient access (8,11,12). The revival of well-functioning PHC has been

on the political agenda in South Africa since the end of the Apartheid era, but due to many factors, PHC still fails to provide comprehensive care to those in need (13).

Chu and Selwyn described three eras of the HIV epidemic in the United States in the three decades between 1981 and 2011 (14). The first decade was characterised by opportunistic infections with no effective therapy against HIV and palliation was the aim of treatment (14). During this time, primary care was paramount (14). In the second decade, life-saving ART changed the natural history of HIV to a chronic manageable illness. Individuals living with HIV were treated in specialised clinics often attached to academic centres (14). Naturally, when patients start to live longer, the next era is that of HIV as a chronic disease in long-surviving patients with other comorbidities (14). Chu and Selwyn suggest that in this period, it is important to reincorporate primary care into the care of PLWHIV (14). Although the South African timeline is behind that of the United States in terms of the ART initiation as a national strategy, South Africans are living longer on ART, requiring new strategies to ensure the continued success of HIV care.

Research has shown that with the increasing burden of HIV disease in South Africa, there has been no reciprocal improvement of increasing the capacity of the health system's human and infrastructure resources (9,15,16). An integration strategy coupled with the background of an ill-functioning PHC system may result in poor care provided to the patients. An example of a relatively recent legal case illustrating poor health infrastructure was the scandal surrounding South African health authorities rushing the integration of mental healthcare into PHC (17). This process led to many patient deaths due to poor healthcare after transfer from Life Esidimeni facilities to non-profit organisations that were ill-equipped to care for mental health patients (17). In Life Esidimeni facilities, patients were in hospital-level care and the non-governmental organisations (NGOs) were situated in the community as part of PHC (17). The arbitration between the families of the mental health patients affected by this project and the National Minister of Health of South Africa and others documented violations of the inviolable rights to life, dignity, and to freedom from torture, and to the economic rights to access to healthcare, food, and social security (18). This tragic incident has demonstrated how a poorly planned decentralisation strategy can violate the rights of already marginalised communities.

Section 27(1a) of the South African Constitution calls for the right to access healthcare services (19). Section 27(2) of the Constitution further states that: “The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights” (19). This section of the Constitution requires that any future strategies employed by the South African government seek to further improve the quality of healthcare services provided. The current healthcare literature advocates for developing countries to abandon specialized physician-run HIV services in favour of community-based healthcare services (7,11,14,20). Proponents of community-based HIV care cite the benefits of integrated health services to all involved. The patients receive care closer to their community, peer support is encouraged, and in some areas, it has been shown to decrease chances of treatment default (21,22). The physicians’ workload for stable patients decreases, and they have increased time to focus on complex patients needing specialized care (20). From a health-system perspective, it is postulated that community approaches will save governments money, as less skilled personnel are trained to deliver health services (23). Considering all these reasons, such an approach is attractive for resource-limited settings such as South Africa. However, the success of such a system requires adequately trained human resources to be retained in the public sector.

In 2012, George et al. wrote that some of the factors that lead to poor PHC are the lack of continued human resource development, the migration of professionals to urban areas, and the move of skilled personnel to the private sector (24). The success of an integrated HIV service also depends on a well-functioning referral system. Unfortunately, the referral system in South Africa does not function well, with patients often bypassing PHC facilities and overburdening hospitals (25). It is therefore necessary that these factors are addressed to improve healthcare delivery.

At the time of writing this research report, no literature was found arguing against the integration of HIV services into PHC. It is not the aim of this report to deny that integration is essential. My research report documents that even the current status of healthcare delivery with the vertical approach is inadequate to meet the comprehensive healthcare needs of PLWHIV. I argue that factors put forward in the previous paragraphs, which are essential for integration, are lacking in South Africa.

Health systems problems must be addressed to progressively realize the population's right to access healthcare services. Therefore, the purpose of my research report is to argue for the temporary continued use of the vertical approach towards HIV treatment, while strengthening PHC to ensure continued access to quality healthcare for all. Furthermore, I do not imply that PHC should not take care of PLWHIV at all, but rather, the ongoing vertical programmes should continue to support the PHC facilities and not be abandoned until PHC is well-equipped to support the range of needs of PLWHIV. The question that this normative report seeks to answer is: "Is it morally and legally justified for the South African government to continue supporting specialised HIV clinics in South Africa?"

1.2 Rationale of Study

HIV is a relatively new disease with the first cases of AIDS being identified in the early 1980s (26,27). The first sustainable treatment changing the natural history of the disease from a deadly disease to a chronic, manageable infectious viral illness was introduced in 1996 (26). Currently, the first generation of people born with HIV are in care. Furthermore, due to research, HIV-positive patients on treatment have access to multiple regimens of ART when they fail on first-line treatment (28). As a result of these successful treatment options, the first aging population of PLWHIV is emerging (29–31). Due to the existing problems of the elderly population, such as chronic diseases of lifestyle and malignancies, HIV care will pose special challenges in this population. It has been shown that the immunological response in patients over 50 is poorer than in younger patients, and they are more likely to die prematurely within 4 years of starting ART (32). Considering HIV in this manner demonstrates that special attention still needs to be paid to the illness in some populations. The strategies employed to curb the epidemic now will determine continued success in the long term. Public health proponents encourage that in resource-limited settings such as South Africa, a vertical response to HIV should be abandoned for a fully integrated, horizontal model of care for HIV (7,33,34). This approach is accessible to a greater number of people (7). However, a well-functioning PHC system must be in place to ensure a continued quality level of care. The Alma-Ata Declaration of 1978 on PHC expressed the importance of a healthy community as an important contributor to a better quality of life and world peace (35).

An important feature of a well-functioning PHC as stated in the Alma-Ata declaration is that it:

> "Should be sustained by integrated, functional and mutually supportive referral systems, leading to the progressive improvement of comprehensive health care for all, and giving priority to those most in need" (35).

Currently, studies show that South Africa has a poorly functioning PHC system (9,13,36). Recent research confirms that skilled health care workers such as doctors and midwives are concentrated in more affluent parts of the country and urban areas, whereas some rural clinics in impoverished communities may not even have a visiting doctor (15,16). Furthermore, it has been shown that, in general, HIV clinics are better staffed and equipped than PHC clinics (9). The National Health Insurance (NHI) White Paper towards universal health coverage recognises the inequities in PHC; one of its aims is to re-engineer PHC to improve the services delivered (37). The paper states that the NHI needs to realize the "Constitutional right of citizens to have access to quality healthcare services that are delivered equitably, affordably, efficiently, effectively" (37). When PHC cannot guarantee continued delivery of quality healthcare and the referral system is still poor, it cannot be expected that HIV care will be fully integrated without potentially risking patients' lives. As an example, it was seen in the Life Esidimeni incident that rushed, poorly planned down-referrals of mental health patients resulted in mortality of over 140 patients (17). Although this example is not HIV-related, it illustrates that long-term planning is essential for healthcare delivery strategies.

Another important factor to consider is the training of health professionals in HIV care at the PHC level. At the inception of the HIV programme and over the years, multiple clinical education courses have been developed to equip both nurses and doctors with the skills to manage HIV-related problems. Some examples of these programs include nurse-initiated management of antiretroviral therapy (NIMART) for nurses and a postgraduate diploma in HIV management for doctors offered by the South African College of Medicine (38,39). Furthermore, many non-profit organizations offer continuing medical education (CME) in the field each year. However, research conducted in South Africa indicates that these CMEs are often

inaccessible to health professionals who deliver patient care, and often attended by personnel in managerial positions (40). These kinds of training must be massively scaled up and delivered to appropriate target groups to ensure continued quality care at all levels.

Having demonstrated some of the gaps in the South African health system, my research report will show that burdening the already strained PHC system will not only violate the patient's right to healthcare, but is also morally unacceptable, as it may result in the harm of PLWHIV. The thesis statement of this report is that it would be ethically and legally wrong for South Africa to abandon vertical approaches to HIV care for a service delivery model that is ill-equipped and is likely to cause harm to PLWHIV.

1.3 Aim and Research Objectives

The aim of the report is to defend that it is morally and legally justified to temporarily continue exceptionalism of HIV care in South Africa while strengthening health systems based on the South African Constitutional right to healthcare services and the ethical principles of beneficence, non-maleficence, and justice.

The following are the main objectives of my normative ethico-legal study:

1. To explain the health needs of PLWHIV in South Africa.
2. To demonstrate the current inadequacies of PHC in South Africa that make it difficult to justify full integration of care of PLWHIV for continued successful outcomes.
3. To identify criteria to be met in South Africa before it becomes justifiable to integrate care of PLWHIV into PHC.
4. To defend criteria that support temporarily continuing vertical care for certain groups of HIV-positive patients.
5. To address possible counterarguments that may arise from advocates of integration.

1.4 Summary of Argumentative Strategy

To answer whether it is morally and legally justifiable to continue exceptionalism of HIV care, I first identify criteria that I believe are necessary to meet to support discontinuing exceptionalism. Then I document how in South Africa those criteria are not yet met. I mainly use deontology with a focus on human rights, drawing on Kant's humanity formulation of the categorical imperative. It states that, "We should never act in such a way that we treat humanity, whether in ourselves or in others, as a means only but always as an end in itself" (41). This defence of my thesis aims to defend the rights of PLWHIV to life and quality healthcare. In Article 12, the International Covenant on Economic, Social and Cultural Rights (ICESCR) recognises everyone's right to enjoy the highest level of physical and mental health (42). Furthermore, Chapter 2 of the Constitution of South Africa includes the rights to life, dignity, and not to be discriminated against (19). The State has a responsibility to protect, promote and respect all the rights stipulated in Chapter 2 of the Constitution (19). The United Nations 2016 Political Declaration on HIV and AIDS reaffirms the importance of protecting the rights of PLWHIV in the fight to end the AIDS epidemic by 2030 (43). I illustrate how rushing to decentralise all HIV services can result in a violation of the rights of vulnerable PLWHIV.

I also defend my thesis drawing from principlism as described by Beauchamp and Childress (44) who provide a principle-based framework for biomedical ethics guided by four principles: respect for autonomy, beneficence, non-maleficence and justice (44). The application of these principles to ethical dilemmas is called principlism and is used in healthcare to provide a framework for resolving ethical dilemmas. Ethical dilemmas occur when an action causes conflict between two or more principles. In this report, I demonstrate that beneficence and non-maleficence towards PLWHIV conflict with distributive justice towards the rest of the people in South Africa. South Africa has an enormous PLWHIV population, and any harm to them may result in public health catastrophe. The last part of my argumentative strategy addresses possible counterarguments including, but not limited to, the cost-effectiveness of integration, the fuelling of stigma and discrimination, and the prioritization of one health condition over others.

Chapter 2 describes the history of HIV and its care in South Africa, defines essential services at PHC facilities and describes the needs of PLWHIV. Furthermore, I focus on the needs of specific populations of PLWHIV. In Chapter 3, I focus on legal and ethical argument for continued HIV care exceptionalism in South Africa. The following chapter is dedicated to dealing with possible counter-arguments to my arguments, and in the last chapter I offer my recommendations.

Chapter Two: Health Needs of PLWHIV and Inadequacies of PHC in South Africa

2.1 Introduction and History of Human Immunodeficiency Virus

AIDS was first described in North America in 1981 when young gay men fell ill with opportunistic infections and Kaposi sarcoma, followed by premature death (45). The first case of AIDS in South Africa was detected in 1982 in a homosexual man, and the first deaths occurred in 1985 (46). In 1982, the aetiology of AIDS remained unknown, but it was discovered in haemophiliacs who had received blood transfusions and in intravenous drug users. This epidemiological information suggested an infectious agent transmitted through contaminated body fluids and blood was the cause (47). Immunological investigations showed a rapid drop in circulating CD4 T-cells in patients with AIDS resulting in severe illness when CD4 T-cells decreased below 200 cells/mm^3 (26). It was not until 1983 that the disease was seen in heterosexual Central African immigrants, and further investigation showed that more than 80% of new infections worldwide were from heterosexual transmissions (26). In 1983, the retrovirus suspected to cause AIDS was identified by electron microscope, and a causal link between the virus and AIDS was established in 1984 (48,49). It was only in 1986 that the virus was named ‘human immunodeficiency virus’ (50). The discovery of the virus enabled the ability to develop the first blood test in 1984 for serological detection of HIV-infected individuals (51).

The first drug used in the management of HIV/AIDS patients was Zidovudine in 1987 (26). Its effectiveness was short-lived, with the discovery of a fast mutation rate and the development of drug-resistant HIV mutants (52). Drug development continued through the early nineties. The first use of triple drugs in the form of highly active antiretroviral therapy (HAART) with dramatic clinical improvements was seen in 1996, transforming AIDS from an acutely lethal to a chronic, manageable disease (26,53). The use of HAART resulted in multiple toxicities, with the most obvious appearing as disfiguring fat loss and redistribution (26). A sharp decline in mortality in patients with AIDS was seen in the developed countries. The access to therapy in developing countries was limited by exorbitant prices of the drugs, resulting in continued increasing AIDS-related mortality in sub-Saharan Africa (54,55). The XIII

International AIDS Conference in July 2000, hosted by South Africa in Durban, served as a turning point for the developing world, with international commitments to fund HAART availability emanating after the conference (56). The exorbitant prices of HAART continued to limit access of badly affected countries. In a landmark case of *Aids Access Foundation v. Bristol Myers-Squib* (2002), the Plaintiff (an NGO protecting the rights and welfare of PLWHIV in Thailand) argued that the Defendant's (a United States-based multinational pharmaceutical company) patent protection would severely restrict access to HIV medicines in Thailand, as Didanosine was unaffordable to many people and could not be replaced. The Defendant maintained that the Plaintiffs were not injured or interested parties, and thus not entitled under the Patent Act to request that the patent be revoked. The Court ruled in favour of the Plaintiff, stating that injured parties were not limited to manufacturers of patent protected medicines, but included patients and organizations of PLWHIV (57). In response to the Judgement, the Thailand state-owned pharmaceutical company started to produce Didanosine at a fraction of the original cost, improving patient access.

In South Africa, the prevalence of HIV increased exponentially from 1990 to 2000 with minimal attention by the government, and the causal link of HIV and AIDS was denied by the President, Thabo Mbeki (58). During this period HIV-associated mortality increased exponentially, and hospices were overwhelmed with the care of terminally ill patients, resulting in the demand for palliative care services outstripping availability (59,60). When pressures from civil society increased on developing a national programme to tackle HIV, the South African government identified two sites per province to participate in a pilot study of Nevirapine to prevent mother-to-child transmission (PMTCT) of HIV. The limited sites hampered access to the HIV preventative program for pregnant women significantly. In *Treatment Action Campaign (TAC) v. Minister of Health* (2002), the Applicant put forth an application for a court order for the Respondent to ensure widespread national availability of Nevirapine to reduce intrapartum transmission and develop a comprehensive plan for nationwide rollout of ART. The Respondent was found to have violated the constitutional rights to healthcare and children's rights and the court ordered the development of a comprehensive country program and Nevirapine availability in public health facilities (61). The Respondent appealed the judgement in the

Constitutional Court. The court ruled that the government was to devise and implement, within its available resources, a comprehensive program for progressive realization of pregnant women and their children access to healthcare services for PMTCT (62). The South African government, with assistance from international donors, progressively developed a comprehensive plan, and in November 2003 the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa was approved by Cabinet (63). The ART roll-out finally started in April 2004 in a few accredited facilities nationwide (3). Additionally, from 2004, the South African government began collaborating with the United States President's Emergency Plan for AIDS Relief (PEPFAR) to increase access to ART and HIV prevention services (5). PEPFAR funding and support helped with the development of policies and guidelines and the provision of training, drugs, laboratory services, staff, equipment and technical assistance (5). The stringent accreditation processes resulted in limited facilities able to treat PLWHIV and the verticalization of the program. All nine South African provinces started providing ART by March 2005, although largely through hospitals. Over the years, the program grew with progressive expansion of treatment. Currently, all patients who test HIV-positive are eligible to start therapy regardless of their CD4 count (64). The increasing population of PLWHIV requiring healthcare services need to be taken care of in a well-functioning, integrated PHC system.

2.2 What is a Well-Functioning PHC system?

The Alma-Ata Declaration of 1978 on PHC expressed the importance of a healthy community as an important contributor to a better quality of life and world peace (35). An important feature of a well-functioning PHC as stated in the Alma-Ata declaration is that it:

> "Should be sustained by integrated, functional and mutually supportive referral systems, leading to the progressive improvement of comprehensive health care for all, and giving priority to those most in need" (35).

The availability of HAART initially benefited only the first world countries due to high costs and the lack of generic drugs, such that most low- and middle-income

countries could not afford public health programs to care for PLWHIV. The inequities caused outrage in civil society with demands for generic drug manufacturing which would only start in 2001 (65). The U.S. Central Intelligence Agency also advocated for the availability of ART in the developing world, arguing that AIDS epidemic was a threat to national security in the United States. The agency argued that the pandemic would add to political instability and slow democratic development, while increasing political tensions (26). Such outcomes would disturb world peace.

The initial response to the AIDS pandemic in South Africa resulted in the verticalization of HIV care, and with the subsequent increase in demand for HIV healthcare services, an integrated approach with use of PHC facilities became necessary (9). A cross-sectional study by Crowley and Stellenberg (2014) provided evidence that, although basic HIV treatment services were provided in PHC clinics, they were not equipped adequately to render integrated HIV care services due to the lack of clinical capacity and deficiencies in health systems resulting in poor support systems (9). In the following paragraphs, I discuss the state of PHC and the referral system in South Africa.

2.3 The State of PHC in South Africa

As mentioned in Chapter 1, South Africa has a poorly functioning PHC system and research confirms that skilled healthcare professionals are concentrated in more affluent urban parts of the country, whereas some rural clinics in impoverished communities may not even have a visiting doctor (9,13,15,16,36). Furthermore, it has been shown that HIV clinics are generally better staffed and equipped than PHC clinics (9). The NHI White Paper towards universal health coverage released in 2017 recognises the inequities in PHC, and one of its aims is to re-engineer PHC to improve the services delivered (37). The paper recognises that the NHI needs to realize the “Constitutional right of citizens to have access to quality healthcare services that are delivered equitably, affordably, efficiently, effectively” (37).

2.3.1 The Ideal Clinic in South Africa

The Ideal Clinic is defined by the South African National Department of Health as:

> “A clinic with good infrastructure, adequate staff, adequate medicine and supplies, good administrative processes and adequate bulk supplies that use applicable clinical policies, protocols, guidelines as well as partner and stakeholder support, to ensure the provision of quality health services to the community” (66).

Based on the definition, such a clinic would be able to provide comprehensive care to its end-users. Between 2012 and 2013, a Baseline Audit of every public healthcare facility in the South Africa was performed, and its findings led to the Ideal Clinic initiative (67). Among its findings, the following were the most damning of PHC facilities:

- Almost half (47%) of all clinics and 205 community health centres (CHCs) had no visit from doctors.
- Eighty-four percent of clinics and 40% of CHCs had no pharmacist / pharmacy assistant post-basic.
- Over half of clinics had no administrative support, thus increasing the workload of nursing staff.
- Rehabilitation and therapeutic services (physiotherapists, occupational therapists, psychologists, speech therapists and social workers) were not available in over 70% of CHCs.
- Over half of PHC facilities had no security guards.
- There was unavailability of essential medicines in over 40% of clinics and CHCs.
- Twenty-three percent of PHC facilities had inadequate space for private patient consultations that ensured privacy (67).

The findings illustrate not only human resource deficiencies, but also unavailability of infrastructure and essential medicine supply. As described earlier, the initial verticalization of HIV care resulted in select clinicians, nursing personnel and lay counsellors being equipped with knowledge and skills to care for HIV-positive patients. In 2002, Sherer et al. proved a strong and consistent relationship between a patient receiving ancillary support services, including mental healthcare, and retention in HIV primary care (68). The absence of social workers and psychologists

at PHC facilities will limit patients' access to mental healthcare, and the increasing burden of patients with limited mental healthcare personnel means less time spent with patients to notice their mental health needs and make appropriate referrals. In addition, the limited availability of private consulting rooms makes it difficult for patients to address all their concerns in the time they have with healthcare professionals.

Pharmacists form an essential part of health care service provision. Pharmacists employed in the public sector generally work in hospitals and some CHCs and not in clinics (69). Primary care nurse specialists' core competencies, as stipulated by the South African Nursing Council (SANC), include prescribing medication for health care users, with the support of other health professionals, such as pharmacists (70). Despite their competencies allowing primary care nurse specialists to prescribe, their workload without support is likely to lead to mistakes. In particular, paediatric ART regimens are complex, with regular adjustments based on growing weight. Underdosing increases the risk of treatment failure, whereas overdosing may cause toxicity. The need for available HIV care support to primary care nurse specialists, specifically for the paediatric population, is very important.

Many studies have proven that HIV-infected children and adolescents have worse developmental outcomes in domains of working memory, executive function and processing speed (71,72). More support is therefore needed in the provision of psychological and physical therapy services for this population. Lastly, safety of patients, health professionals, infrastructure and medical supplies are essential for continued care at all health facilities. Absence of security in facilities may limit the willingness of professionals to work at such facilities, and patients may feel unsafe coming to them.

I have shown that each healthcare team member has a crucial role in the care of PLWHIV. The adoption of a multidisciplinary model at the PHC level will uphold the bioethical principle of beneficence. A beneficent action is described by Beauchamp and Childress (2012) as an action intended to benefit other persons (44). They further explain that beneficence has two components; positive beneficence (the moral obligation to act for the benefit of others) and utility (the moral obligation to

balance benefits, risks and costs so as to produce overall best results) (44). Beneficence supports rules of obligation to defend others' rights and to prevent harm to others. A multidisciplinary, integrated team approach will benefit PLWHIV and ensure progressive realization of their right to healthcare. In addition, such services, when available, benefit all patients attending the health care facilities, and thus result in utility to all patients. It likely will take some time before such a comprehensive care package can be provided in PHC facilities across South Africa.

Despite the deficiencies described in previous paragraphs, the use of PHC facilities continues to increase, and thus addressing these challenges, including long waiting times and space for pleasant and private consultations, remains unfilled, leading to negative experiences by patients (73). To this effect, in 2016 a report by South Africa's Office of Health Standard Compliance stated that patients were not treated with respect and privacy at some clinics, with incidents of HIV testing and consultations occurring in open areas and not behind closed doors (74). The future of the NHI depends on a strong PHC model and thus the Ideal Clinic initiative. The Ideal Clinic Model is a horizontal approach to solving the problems in PHC facilities, aiming to strengthen systems and deliver integrated health care in a patient-centred manner. A report on the progress on the implementation of The Ideal Clinic in 2017 reiterated the problems of staffing, infrastructure and supply chain management in many PHC facilities (73). When PHC cannot guarantee the continued delivery of quality healthcare and the referral system remains poor, it cannot be expected that HIV care will be fully integrated without potentially risking patients' lives.

2.4 Special Populations of PLWHIV

Health is defined by the World Health Organization (WHO) as: "A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (75). All stakeholders involved in the management of PLWHIV should strive to achieve this level of health. In the following sections, I discuss barriers to achieving optimal health in various sub-populations of PLWHIV.

2.4.1 Paediatric population

Southern and Eastern Africa are home to two-thirds of the global paediatric population (0-14 years) living with HIV; and, with good PMTCT strategies, new infections have declined by over 70% in the last decade in South Africa (76,77). Minimal progress has, however, been realised in virologic suppression in this population. UNAIDS set a target of eradicating HIV infection globally by 2030. Their strategy required that 90% of PLWHIV will know their HIV status, 90% will be on ART, and 90% will be virally supressed by 2020, and it was adopted by South Africa in December 2014 (78,79). As of the year 2020, in South Africa, only 75% of children living with HIV are diagnosed, 47% are on treatment, and 33% are virally suppressed (76,78). Many factors, including poor access to care, poor social circumstances, complex formulation of the paediatric ART regimens, unpleasant taste of medication, drug stock-outs and, most recently, coronavirus disease (SARS-CoV-2) via the COVID-19 pandemic, contribute to the failure to reach these targets in South Africa (80,81). Unfortunately, with over 65% of patients not achieving virologic suppression, the incidence of treatment failure will increase, resulting in limited available regimens as the children grow to be adults (82,83).

In the initial phases of the ART roll-out, children were initiated only by doctors, but with the start of NIMART in 2010, many professional nurses are now trained to initiate and manage HIV patients on therapy. This decentralisation strategy has been shown to improve access and the uptake of ART. However, studies have shown that nurses require continuous mentoring to develop confidence for paediatric HIV care (39,84,85). A multidisciplinary team approach becomes vital, with support to the local clinics provided by experienced clinicians, social workers, psychologists and other rehabilitation-oriented health professionals. Audiology, dietetics, occupational therapy, physiotherapy, psychology, and social work services have been shown to be available in less than a quarter of PHC facilities in the country, and when available, they are offered mostly by visiting staff from referral hospitals (67). This limited availability of services may contribute to poor outcomes in the paediatric population. No data could be found on viral suppression in children being cared for at specialised HIV clinics by doctors, compared to children in the local PHC clinic.

Another important aspect of paediatric HIV services is disclosure of HIV status, which parents and most health professionals find difficult to do. It is vital that children are supported by capable psychologists and social workers in the process of disclosure. As described above, disclosure of HIV status becomes almost impossible in the PHC setting if these professionals are not available. Professional nurses and lay counsellors may not be skilled enough or have time to fully assist children going through the transition of knowing their HIV status and dealing with the issues of becoming an adolescent (86–88).

2.4.2 Adolescent population

Adolescents represent a growing population of PLWHIV. The United Nations Children's Fund (UNICEF) reported that in 2020 alone, 150,000 new infections occurred in adolescents aged 10 to 19 years old, even though HIV testing is limited in this population (89). There is also a growing population of perinatally infected PLWHIV population members becoming adolescents. Puberty is a difficult period for most individuals, and HIV adds a significant burden of stress to HIV-infected teenagers. Among the many issues that may affect this population is HIV status disclosure, which may have been deferred in childhood, and social isolation, perceived or enacted stigma, and the death of family members from AIDS-related illness. All these factors are likely to have a detrimental effect on mental wellbeing (90). It has been shown that poor mental health is higher in HIV-infected adolescents, with diagnoses including major depressive disorder and neurocognitive disorders (91,92). Without appropriate psychological support, adolescents living with HIV are at risk of being lost to follow-up and thus HIV-related mortality. It has been reported that AIDS-related mortality has declined by 68% in all age groups globally since 2004 (93), but only by 21% in adolescents since 2002 (94). These findings suggest the need for intensified interventions on the prevention of HIV transmission, adherence to ART to ensure viral suppression, high-risk sexual behaviour modification, and HIV testing.

Adolescence is a transitional phase from dependency on caregivers towards autonomous decision-making, which may result in individuals being involved in high-risk behaviours like alcohol and drug use and engaging in unprotected sex (95). In a

systematic review, Zgambo et al. showed that adherence to ART among adolescents was suboptimal. Most sexually active adolescents did not disclose their HIV status to their partner(s) due to fear of stigma, and some did not use condoms during intercourse (96). It is essential at this point in their care to have a space that is supportive and caters for the adolescents' biopsychosocial needs. Adolescent-friendly clinics are essential to form support structures outside the home for these patients. The unavailability of allied health services, such as psychologists at the PHC level, results in suboptimal care to these patients and may be a contributing factor to poor adherence and virologic failure. In a qualitative study of intensive interviews by Woollett et al., adolescent participants advocated for specialised adolescent-friendly clinics with support groups and widespread availability of counselling facilities to cater to their mental health needs (97).

2.4.3 Adult population with co-morbid illnesses

The elderly population is already burdened with chronic diseases of lifestyle and malignancies, and HIV care poses special challenges in this population. It has been shown that the immunological response in patients over 50 is poorer than in younger patients, and they are more likely to die prematurely within 4 years of starting HIV treatment (32). As the first aging population of HIV-positive patients is being cared for, there are many uncertainties regarding the effect of HIV on chronic illnesses of lifestyle and malignancies. Careful attention must be paid to screening patients for HIV-related malignancies. Although significant strides have been made in cervical cancer screening and prevention, patients still present with advanced disease, and the COVID-19 pandemic has had a negative impact on the screening programmes (98–100). Furthermore, some ART drugs have cardiovascular side effects, and knowledge of important screening needs and awareness of such effects is essential to provide better strategies of therapy in the future (101). Unfortunately, some of these issues may not be adequately addressed by professional nurses or untrained clinicians. Thus, until our clinics are equipped with the necessary human resources, progressive realisation of better healthcare services is not possible.

In conclusion, PLWHIV have many needs that require strategies to ensure progressive realisation of holistic healthcare. It is essential that in planning future

strategies for healthcare provision, they are taken into consideration. In the next chapter, I present my arguments for continued exceptionalism of HIV care.

Chapter Three: Ethical and Legal Arguments for Continued HIV Care Exceptionalism in South Africa

3.1 Introduction

In this chapter, I mainly use deontology with a focus on human rights, drawing on Kant's humanity formulation of the categorical imperative to defend my thesis statement that it would be ethically and legally wrong for South Africa to abandon vertical approaches to HIV care for a service delivery model that is ill-equipped and is likely to cause harm to PLWHIV. Kant describes the categorical imperative as follows: "Act only according to that maxim by which you can at the same time will that it should become universal law" (102). This defence of my thesis aims to defend the rights of PLWHIV to life and quality healthcare. Article 12 in the ICESCR ratified by South Africa in 2015 recognises everyone's right to enjoy the highest level of physical and mental health (42). Furthermore, the Bill of Rights (Chapter 2) in the Constitution of the Republic of South Africa (Act No. 108 of 1996) demands protection by the state of the following rights:

- Right to inherent human dignity (section 10)
- Right to life (section 11)
- Right to healthcare services (section 27.1a) (19).

The State has a responsibility to protect, promote and respect all the rights stipulated in Chapter 2 of the Constitution (19). The United Nations 2016 Political Declaration on HIV and AIDS reaffirms the importance of protecting the rights of PLWHIV in the endeavour to end the AIDS epidemic by 2030 (43). I illustrate how rushing to decentralise all HIV services can result in a violation of the rights of vulnerable PLWHIV.

I also defend my thesis statement by drawing from principlism as described by Beauchamp and Childress (44). They provide a principle-based framework for biomedical ethics guided by four bioethical principles: respect for autonomy, beneficence, non-maleficence and justice (44). Ethical dilemmas occur when an action causes conflict between two or more bioethical principles. In this report, I demonstrate that beneficence and non-maleficence towards PLWHIV conflict with distributive justice towards the rest of the people in South Africa. As noted in Chapter

1, South Africa has an enormous population of PLWHIV, accounting for 19% of the adult population (2).

3.2 Deontology as a Moral Theory

Deontology is derived from the Greek words for duty (*deon*) and study of (*logos*) (103). As a moral theory, deontology is non-consequentialist in that an action's morality is determined by whether it is right or wrong in itself, regardless of its consequences (104). A deontologist believes that an action is judged according to its conformity to universal moral rules, such as the obligations not to kill, steal or lie (103). Deontologists refer to negative duties (not to kill), and positive duties (help the needy), and personal duties (105). Personal duties arise from relationships one has with others, such as an obligation of a mother to her child, and obligations to complete tasks in the workplace. Another aspect of deontology is contractarian deontology of which Thomas Hobbes' (1588-1679) social contract theory is an example. Hobbes considered morality as the solution to a practical problem that arises for self-interested human beings in a shared world (102). The social contract morality was summarized by Rachels and Rachels (2015) as follows: "Morality consists in the set of rules, governing behaviour, that rational people will accept, on condition that others accept them as well" (102).

The best-known deontologist is Immanuel Kant (1724-1804), who is considered to be the most influential concerning deontological theories. Kant maintained that the highest moral good is having good will (103). He stated that humans should treat each other as ends and not mere means (102). Rational agents are autonomous, and each one is obligated to make and obey moral laws (103). The right moral rules are those which rational agents will freely choose to govern them, and they should be universalized without using others as means or compromising autonomy (106). Kant called this the Categorical Imperative, and one of the formulations he used was: "Act so that you treat humanity, whether in your own person or in that of another, always as an end and never as a means only" (102).

3.3 Argument For Continued Exceptionalism of HIV Care

In Chapter 2, I demonstrated the characteristics of an Ideal Clinic and the special needs of various populations of PLWHIV. I further provided evidence of non-compliance with an Ideal Clinic in PHC facilities across South Africa exhibiting limitations of human resources and infrastructure, causing patient dissatisfaction and sub-optimal clinical care. Despite all the problems faced in PHC facilities, their patient numbers increase every year, including an increasing number of PLWHIV. There are still many specialized HIV clinics typically called, 'Wellness Clinics,' which are usually situated adjacent to or in hospitals. These clinics were the initial sites for ART initiation when the roll-out started, and they are typically well-staffed with trained and experienced health practitioners. In view of the large population of PLWHIV and distance of the Wellness Clinics from many communities, the need for ART roll-out and patient care in PHC facilities soon became evident, and these duties were transferred to professional nurses and lay counsellors at local clinics. The NIMART training of nursing staff has been vital in establishing HIV care in PHC facilities in South Africa. Due to many factors, including funding, the developing world is moving towards care of HIV exclusively in the PHC clinics and the extinction of the centralised Wellness Clinics. In the next section, I show how this transition may be detrimental to the wellbeing of PLWHIV.

3.4 Argument Based on Deontology

South Africa's Constitution Section 27(1a) calls for the right to access healthcare services (19). Section 27(2) of the Constitution further states that: "The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights" (19). This section of the Constitution requires that any future strategies employed by the South African government must seek to further improve the quality of health care services provided. Progressive realisation of the right to access health care requires improvement on all the limitations present in PHC facilities. Complete decentralisation of HIV care and closure of the Wellness Clinics without infrastructural and human resources improvements will burden the already overworked staff at the PHC facilities, increase the patient waiting times, cause patient dissatisfaction, and likely have a negative impact on treatment adherence

and retention in care of some patients. Such consequences affect health care worker morale and will impact negatively on patient outcomes of virologic control and reduced morbidity and mortality from HIV.

A decision by the State to completely decentralise HIV care services can be argued to be treating patients and health care workers as a means to an end rather than as an end in themselves. To expand, health care services provided by hospitals will move to clinics, and duties performed by more skilled professionals will be delegated to trained, but less skilled, lay personnel. This transition will be more cost-effective than the current model of care, and the end would be beneficial to the State. However, without improvements in current PHC facilities, the patients and health care workers will not benefit. Thus, they are treated as a means. Kant states that human beings have an intrinsic worth and dignity and are thus valuable in themselves (102). A poorly planned decentralisation strategy will likely victimize PLWHIV by overburdening the PHC facilities with limited human resources, limited support of health care workers and inadequate infrastructure, and thus reduce the quality of care provided. Such actions would undermine the dignity of PLWHIV.

3.5 Argument based on Principlism

Beneficence as a bioethical principle refers to the obligation to act to benefit others and not merely to avoid harm; non-maleficence demands that a moral agent not intentionally harm others through either acts of omission or commission (44). Actions that support the principle of beneficence for PLWHIV include improving access to trained and skilled professionals to ensure access to healthcare at their local PHC facility to achieve the best possible level of health. The WHO definition of health includes physical, mental and social well-being (75). As discussed in Chapter 2, health services provided in most PHC facilities are provided by nursing staff with minimal access to other therapeutic disciplines. Thus, patients' mental and social well-being are likely not attended to as well as their physical ailments. The service status is better in many Wellness Clinics due to better staffing (9). To act on the moral principle of beneficence, implementation of these services in PHC facilities is paramount prior to disassembling Wellness Clinics.

Maleficence has been demonstrated in the recent past in the Life Esidimeni incident, when rushed, poorly planned down-referrals of mental health patients resulted in the mortality of over 140 patients (17). Patients who were previously in hospital-level care were transferred to NGOs situated in the community as part of PHC (17). The arbitration between the families of the mental health patients affected by this project and the National Minister of Health of South Africa and others documented violations of the inviolable rights to life, dignity, and freedom from torture, and the economic rights to access to health care, food, and social security (18). This tragic incident demonstrated how poorly planned decentralisation strategies with the background of an ill-functioning PHC system can violate the rights of already marginalised communities. The example illustrates that long-term planning is essential for the success healthcare delivery strategies. A hastily executed decentralisation plan may cause unnecessary harm to PLWHIV in that the quality of care received may decline and therapy outcomes may be affected. Poor management of HIV would not only affect PLWHIV, but is also a public health matter because reduction of infectivity depends on adequate management that causes virologic suppression in individual patients. Thus, to overcome the epidemic, and avoid maleficence, the quality of healthcare provided should improve and not decline.

In my experience as an HIV healthcare physician based in a hospital-based Wellness Clinic and supporting several PHC facilities, patients diagnosed in WHO stage 1 and 2 (asymptomatic and mild symptomatic stages) (107) with no co-morbid illnesses do well at PHC facilities with minimal need for physician intervention. Patients in these stages are increasingly starting treatment early, with the South African guidelines mandating the universal ‘test and treat’ approach (64). Patients with WHO stage 3 and 4 disease associated with opportunistic infections and AIDS-defining malignancies (107) generally need hospital-based therapy initially and delayed initiation of ART. My experience, for example, with patients presenting with cryptococcal meningitis taught me to not down-refer early. These patients require prolonged prophylaxis with antifungal medication, which were more frequently out of stock at the PHC facilities, increasing the risk of relapse of the meningitis. Cryptococcal meningitis is responsible for 15% of AIDS-related deaths globally and sub-Saharan Africa accounts for 75% of the deaths (108). Although most deaths happen during hospitalization, relapse is a major cause of death because of not

taking secondary prophylaxis (109). The example from my experience shows that the inability to provide essential medicines at PHC facilities is detrimental to patient care and underscores the importance of the availability of resources needed for integrated HIV care. Furthermore, cervical cancer is the most common cancer in South African women and presents earlier in HIV-positive women (98,110). Late presentation in patients, particularly PLWHIV, with multiple opportunities for screening and early management during clinic visits, in my opinion, is an attestation of failure of the screening program. Preventative care is a major pillar of PHC and is clearly not optimal in cervical cancer screening. My postulated reasons for this are the lack of adequate human resources at PHC facilities, poor uptake of screening by patients, and poor linkage to oncology services once malignant or pre-malignant lesions are detected. These problems will not be solved by continued HIV care exceptionalism, but through strengthening care at PHC facilities. The continued increased burden without interventions to improve care will harm health professionals by causing burnout and harm patients with the resultant suboptimal service delivery. Continuing healthcare services in this manner can be argued to be maleficent, as it causes potential harm to patients. The improvement of the PHC facilities in areas elaborated in this report will prevent suffering of PLWHIV and ensure that the principle of non-maleficence is upheld.

To conclude this chapter, upholding PLWHIV's rights to healthcare services that are progressively improving is in line with treating them as ends in themselves according to the deontological stance. Decentralization with inadequate PHC facilities is treating others as means and thus not respecting their inherent dignity. It is essential that actions taken to decentralize HIV care protect PLWHIV's rights and avoid causing harm to ensure the principles of beneficence and non-maleficence are upheld. To achieve these objectives, proper planning is essential. In the next chapter I address possible counterarguments that are mainly based on consequentialist moral approaches.

Chapter Four: Counterarguments to HIV Care Exceptionalism in South Africa

4.1 Introduction

Current health care literature advocates for developing countries to abandon specialized physician-run HIV services in favour of community-based health care services (7,11,14,20). As alluded to earlier, proponents of community-based HIV care cite the benefits of integrated health services to all involved. The patients receive care closer to their community, peer support is encouraged, and in some areas it has been shown to decrease chances of treatment default (21,22). The physicians' workload for stable patients decreases, and they have increased time to focus on complex patients needing specialized care (20). The following section focuses on possible arguments by proponents of decentralisation.

4.2 Cost-saving Argument

From a health-system perspective, it is postulated that community approaches will save governments money, as less skilled personnel get trained to deliver health services (23). It can be argued that skilled personnel who are based in the community are also likely to identify with patients' circumstances and understand the available solutions. This circumstance would possibly improve retention in care and acceptability of care to many patients.

I respond to such an argument by demonstrating that in South Africa the recent events of mental health patients, whose rights to life, dignity, freedom from torture, and economic rights to access to healthcare, food, and social security, were violated due to the neglect of due processes prior to community-based care implementation (18). An elaborate plan with clear strategies of implementation, referral procedures to higher levels of care, and involvement of PLWHIV in planning is essential prior to the full implementation of decentralised care for them. Involvement of end-users in policy making and healthcare planning has been shown to better define their needs, improve sustainability and shared responsibility, and mobilize resources available in the community (111,112).

4.3 Wellness Clinics as a Contributor to Perceived and Real Stigma

Stigma was defined by Goffman as being disqualified from full social acceptance (113). In this context, HIV is seen as a significantly discrediting attribute that serves to reduce the stature of people living with the virus in the eyes of society (113). Three levels of stigma have been described: enacted, anticipated, and internalized (114). Enacted stigma is when PLWHIV overtly experience discrimination; anticipated stigma is the expectation that others will discriminate against them; and, internalized stigma is endorsing the negative beliefs associated with HIV/AIDS (115–117). The perception and experience of stigma and discrimination has been shown to have devastating effects on PLWHIV. It has been shown that patients who feel discriminated against are less likely to use testing and prevention services and, if infected, will delay enrolment in care until they are very sick and, moreover, are unlikely to disclose their HIV status to their sexual partners (118–120). Disclosure of HIV status to one's sexual partner has been shown to promote voluntary testing and safer sexual practices and improve adherence to ART; however, disclosure of women to their male partners has also been shown to be limited by the possibility of domestic violence (121,122). Non-disclosure has a negative impact on the reduction of new HIV infections in the public health domain and may impact adherence to ART and the mental health of patients (119). Furthermore, internalized stigma has been associated with mental health disorders such as major depression and alcohol abuse (123).

In 2011, the NDoH introduced an Integrated Chronic Disease Management Model (ICDM) aimed to reduce stigmatisation and improve patient outcomes, and leverage on HIV vertical programs to scale up services for non-communicable diseases (124,125). This model becomes a one-stop-shop for all the patients' needs. It has been shown that service integration can boost HIV care sustainability while supporting progress towards universal health coverage (126).

Proponents of decentralisation argue that ICDM clinics reduce stigma and discrimination and thus improve treatment outcomes of patients. Support for this argument has been documented by Ameh et al., who showed that ICDM reduced anticipated stigma in health facilities (114). In the same study, it was found that nursing personnel discriminated against young women coming for contraceptives

and pregnant women on ART. Patients coming for contraceptive consultation either had to test for HIV infection or be denied contraceptives, and pregnant women on ART were explicitly told that they should not reproduce (114). The findings of this study show that enacted stigma is still experienced by PLWHIV, and more concerning is the discrimination by healthcare professionals. The behaviour of healthcare professionals in this study suggests that there is still limited knowledge among healthcare professionals requiring systemic solutions, including education to improve their attitudes.

I agree that the stand-alone clinics may increase the perception of perceived stigma by the community and integration models would reduce it. However, it has been documented that patients in stand-alone clinics do not want decentralisation, and some of the reasons include mutual support of other PLWHIV, friendly health care workers and the availability of ancillary services (127,128). In one study on patients' views on decentralisation, the patients expressed that they would be comfortable with going to their local clinics if the nursing personnel had training and adequate health systems were in place (127).

Confidentiality is also one of the predicted benefits of the ICDM model, as everyone is meant to be in the same line with no separation based on medical condition. The benefit of confidentiality in integrated clinics has been shown to not be universal, though, with some aspects of service organization, such as room labelling, specific patient cards for PLWHIV, and drug dispensing systems, breeching confidentiality (128). I submit that decentralisation in some centres may lead to maleficence and the breach of confidentiality for PLWHIV. If patients feel stigmatised by healthcare professionals, retention in care and the achievement of the newer UNAIDS 95-95-95 goals, continuing from the 2020 90-90-90 goals to eradicate HIV (95% of PLWHIV know their status, 95% on treatment and 95% virally suppressed by 2030), could be jeopardized (129). Although the decentralisation strategy would save the government money, proper planning is essential for implementation. Staff training needs to be intensified, guidelines and policies must be in place, the reliable availability of essential medicines must be ensured, and the availability of ancillary services in PHC facilities must be improved (130). If services are decentralised without these

measures, it would result in PLWHIV used as cost-saving strategies and not as ends in themselves.

4.4 Burden on Hospitals

South Africa's public health sector is divided into primary, secondary and tertiary services provided through various facilities (131). Clinics and community health care centres are the backbone of primary care, whilst hospitals are mostly secondary or tertiary depending on the services provided. Clinics are typically located in the community and easily accessible, whereas hospitals are usually far away, requiring patients to spend money on transport to access healthcare. In the initial phases of the ART roll-out, therapy was initiated in hospitals and specialised HIV clinics were typically attached to the hospitals. As HIV is becoming a chronic illness with most patients being stable and needing less frequent follow-up, care in primary level care makes sense to reduce burden on hospitals and improve geographical access for patients (132). This HIV care approach improves waiting times and allows specialised clinics to focus on patients with complex presentations. It has been shown that trained nursing personnel and physician assistants with experience in HIV care focused solely on managing PLWHIV provided care of similar quality to physician HIV experts and was superior to physician non-HIV experts (133,134). South Africa has significant experience with NIMART-trained professional nurses, which has proven to increase the uptake of ART in communities (39). The validity of these arguments depends on adequate and continuous training and mentorship that is necessary to ensure good quality care by the available human resources at PHC facilities.

I argue that the NDoH is found wanting on continued staff development and training and thus quality care cannot be ensured. Jones et al. demonstrated that five years into the NIMART program, there were low completion rates of the NDoH NIMART training process at 12%, and a lack of ongoing mentoring for those who completed the course as the HIV programs evolve (135). Furthermore, it has been shown that adherence to guidelines among NIMART-trained nurses is suboptimal. Some reasons include lack of continuous training and mentorship from experts, continuously evolving guidelines, and limited trained personnel at facilities with

increasing workloads, resulting in patients being cared for by untrained staff (84,136,137). It is clear from the available evidence that there is a need to continue nurse-initiated and monitored HIV care. It is also clear that there are limited trained human resources and limited continual support. Complete decentralisation at this time will relieve burden on hospital personnel. However, without measures to strengthen human resources at the clinics, complete decentralisation will purely shift the burden to the already burdened PHC facilities. Thus, I propose that the NDoH must find sustainable measures to improve human resources training and retention for patients to receive quality care at all levels of health service provision. Zachariah et al. made a salient point that task-shifting should not undermine the important objectives to improve patients' benefit and public health outcomes (138).

4.5 Prioritization of HIV Over Other Illnesses

Proponents of decentralization may suggest that the continued existence of Wellness Clinics prioritises HIV over other illnesses. The argument would draw from Beauchamp and Childress's principle of distributive justice, defined as "fair, equitable, and appropriate distribution determined by justified norms that structure the terms of social cooperation" (44). The principle of distributive justice can also be supported by consequentialist moral theory of act utilitarianism that states that a good action produces an overall balance of happiness against unhappiness (102). Act utilitarianism is a theory under the umbrella of consequentialism. Consequentialism states that the right action is one that maximizes good consequences (102). Historically, utilitarianism is classified into act and rule utilitarianism (139). Rule utilitarianism considers the utility of an action if it was made a rule. Rule utilitarianism considers human behaviour and applies laws that would lead to greater welfare compared to other rules (102). Act utilitarianism looks at individual actions and evaluates them individually. It states that a good action produces overall balance of happiness against unhappiness (102). In both versions of utilitarianism, consequences are measured by the amount of welfare or happiness they produce and each person's happiness is equal (102). A major component of the utilitarian perspective is that when one calculates the utility of an action, it must be done from an impartial perspective and everyone's utility counts equally (102). Proponents of complete decentralisation can argue that decentralization will result in

greater healthcare access to all patients due to easier geographic access to PHC facilities.

Considering that South Africa has the largest population of PLWHIV in the world, which constitutes almost 20% of the entire population, I argue that HIV care requires prioritization. Furthermore, HIV is an infectious disease, and not giving it enough attention risks increasing its incidence nationwide and much is still to be learnt on the needs of PLWHIV. In South Africa, the first generation of perinatally infected children are becoming adults and the first aging population of HIV-infected adults are in care. The long-term effects of ART and the effect of HIV on other illnesses, including malignancies and diseases of lifestyle, are being monitored. Without experts in the HIV field and continued research, patients may not receive optimal care due to the absence of mentoring and expert management of complex cases.

As mentioned above, act utilitarianism as a moral theory demands that the utility of an action must be done from an impartial perspective and everyone's utility counts equally (139). Given the overburdening of health workers at PHC facilities and the infrastructural issues, the utility of decentralisation cannot be seen to result in overall good consequences for all involved. Consequently, I propose that in the current state of the PHC facilities, the greatest utility would not be achieved by decentralisation, and careful strategies must be applied to avoid outcomes similar to the Life Esidimeni scandal.

In the last chapter of my research report, I conclude by summarizing my argument and making recommendations for a model of care that I believe would be morally and legally acceptable for the care of PLWHIV.

Chapter Five: Conclusions and Recommendations

Limited human and structural resources remain the reality of South Africa's health system, and HIV is a major public health concern with the country having the largest ART programme worldwide. Decentralization and the abandonment of the vertical system of HIV care is clearly necessary for continued sustainability. Achievement of the UNAIDS 95-95-95 2030 targets depends, among other things, on good quality health care provision (129). I have shown systemic deficiencies in South Africa's health systems that make continual improvement of care received by patients unpredictable. I have demonstrated that abandoning vertical approaches without systemic reforms can cause maleficence to patients and violate their constitutional rights. Section 27(2) of the Constitution of South Africa states that there must be progressive realisation of the right to healthcare within the State's available resources (19). Regression in the quality of healthcare patients receive would violate their rights. The following section outlines my recommendations before HIV exceptionalism is abandoned in South Africa.

5.1 Improvement of Infrastructure

Investment in health infrastructure will increase the capacity of facilities to provide services for the increasing population needing PHC facilities. The PHC infrastructure will provide the necessary foundation for all public health services from child healthcare to the management of chronic illnesses. There is evidence of insufficient space in some facilities to ensure confidential consultations amidst the increasing number of patients using PHC facilities (67,73). Better infrastructure will improve patients' comfort at PHC facilities, attract professionals to work in these facilities and, in the long-term, improve the quality of all the services provided. In addition to the PHC infrastructure, ease of geographical access to referral facilities is essential to ensure the continuity of care for patients with complex clinical presentations requiring specialist referrals. Furthermore, in the long term, adequate infrastructure will improve preparedness for possible future pandemics. The COVID-19 pandemic revealed major infrastructure and human resource limits with a lack of sufficient hospital beds and staff (140). For the provision of quality healthcare that allows the

progressive realisation of the highest attainable level of health in PLWHIV, the existing PHC facilities must be upgraded and new facilities built.

5.2 Increase Human Resources in Primary Health Care Facilities

An essential foundation of strong health systems to improve service coverage and realize the right to enjoy one's highest attainable standard of health is the availability of capable health workers (141). Availability alone is, however, insufficient. It is essential that healthcare workers are distributed equitably throughout the entire population. South Africa has a significant shortage of doctors with the doctor to patients ratio being persistently under 1 per 1,000 between 1992 (0.6) and 2019 (0.8) (142). In 2013, Uys et al. suggested that an ideal registered nurse to patient ratio in PHC should be 5:1, and in 2020 the SANC reported a ratio of 387:1 (143,144). Furthermore, a 2019 study showed that most of South African medical school graduates work in urban rather than rural hospitals (145). Already available solutions to improve the attraction of young professionals to rural settings include monetary compensation in the form of a rural allowance and the provision of accommodation. The available solutions may not be sufficient for young professionals raising families, as they may want to be closer to schools and other amenities. Although expensive, long-term solutions to develop rural parts of the country's infrastructure and ensure access to quality education may improve the retention of young professionals in these areas. Such solutions will help retain professionals in rural areas and create employment in these areas.

5.3 Continued Education of Human Resources in Primary Health Care Facilities

Decentralisation requires the delegation of tasks from physicians to nursing and skilled lay personnel. The delegation of tasks should be accompanied by comparable quality of care and not degrade the quality of care patients receive. In Chapter 1, I alluded to the availability of opportunities for continued education for professionals in HIV care. However, research indicates that these continuing medical education opportunities are often inaccessible to health professionals who deliver patient care, and often attended by personnel in managerial positions (40). The reasons for non-attendance by the professionals delivering services include shortages of staff and

the lack of communication of the medical education information. I propose that it becomes mandatory that health professionals in HIV care receive updated training every time the NDoH updates national guidelines. Furthermore, biennial refresher courses should be scheduled to ensure that practitioners are still following guidelines. One can argue that the guidelines are published online and available at health facilities for professionals to read. However, these professionals are usually overwhelmed with many patients and have limited time to update their knowledge at work. Thus, scheduled courses for the health workers seeing the patients will assist them to keep their practice up to date. In my experience in the Wellness Clinic, when guidelines changed and my prescriptions changed accordingly, I often found myself having to convince my pharmacy colleagues that I was prescribing what was recommended. This was because they were not receiving any communication about the changes in guidelines and, as essential members of the team, they must be aware of all the changes related to HIV care medication. Furthermore, I have alluded to the paucity of mentorship received by clinic professionals in caring for PLWHIV. Confidence to take care of patients with multiple comorbid illnesses and children takes time, and mentorship programs must be significantly improved. A resource I found useful as a clinician without much support in rural hospital HIV care was the Medicines Information Centre HIV and TB health care worker hotline (146). When I had patients that I found difficult to manage, upon calling, I was answered by a pharmacist with extensive knowledge of HIV care, and when the question needed a physician, my query would be forwarded and within 48 hours I would receive expert advice. I recommend that a network of HIV physicians and experienced NIMART trained nurses be established in each province for telephonic support to PHC facility staff. In addition, regular visits to PHC facilities with random audits of patient records will be a powerful tool to assess whether guidelines are followed and identify areas that need to be supported.

5.4 Outline Clear Referral Paths for Patients

Quality health care provision requires patients to be treated at appropriate levels for their ailments and be promptly referred when they need higher levels of care. A well-functioning PHC facility is sustained by a supportive referral system ensuring access to comprehensive healthcare (35). In my experience in a district hospital which is

part of PHC, it was sometimes difficult to refer patients to specialist clinics in regional or tertiary hospitals with significant resistance from the receiving doctors. Having now worked in a tertiary hospital setting, I realized that the specialists resist because they are overworked and attempt to screen who they accept. The repercussion I have seen in this system is that doctors and nurses at PHC centres are reluctant to refer patients. I believe the root of this problem is the lack of human resources and improving that aspect will improve working conditions for all and ultimately improve patient care. After the initiation of ART, patients need support for retention in care. Community health workers and lay counsellors have the skills for this task, however, it is my experience and belief that there are not enough of them. I recommend increasing their capacity, specifically with people based in the community they serve, as they are likely to understand the community culture and dynamics better.

5.5 Conclusions

In conclusion, the health care system in South Africa needs significant improvement for progressive realisation of access to quality health care. Decentralisation of HIV care is essential to ensure patients receive care closer to their homes, for the reduction of costs, and for decongestion in hospitals. The implementation of decentralised HIV care should not reduce the quality of healthcare patients receive. The human resource paucity and lack of adequate infrastructure in many PHC facilities are major threats to the provision of quality healthcare. Furthermore, continued education of healthcare workers is essential for continued quality care provision and the reduction of enacted stigma. The progressive realisation of access to healthcare requires improvement of all these factors. Without interventions to improve the state of the PHC system, decentralisation may have detrimental effects on PLWHIV.

In conclusion, I have argued for continued HIV exceptionalism while improving and strengthening health systems in South Africa to protect the rights to life, dignity and access to healthcare, and uphold the bioethical principles of beneficence and non-maleficence for PLWHIV. Upholding the rights of PLWHIV is in line with treating them as ends in themselves, and poorly planned decentralization treats them only as a means with the potential for violating their inherent dignity.

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