Understanding the Contributions of the Treatment Action Campaign and Section27 to a Rights-Based Approach to HIV and AIDS in South Africa

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ABSTRACT

This thesis examines the link between social movements with the legal system to enforce human rights within the public health sector in regards to access to HIV and AIDS-related disease treatment. Research shows large scale incapacity for the provision of such essential medications within the public health sector; this is not merely an issue for those in the developing world. This thesis demonstrates that it is an issue that is faced by those using the public health sector services to access essential HIV and AIDS medications and it shows that certain people are unaware of their human rights to have fair and equal access to such essential medications. Although there is abundant research studies on HIV and AIDS in South Africa, there is a lack of studies that look into the impact that social movements have had in strong-arming, to a certain extent, the government in holding it accountable for infringing its constitutional promises to all citizens. This thesis is set against a backdrop where, the crisis of lack of access to essential medications in the public health sector which is closely intertwined with the collapsing health care system and it is combined with the issues of international patent policy for essential medication and developing countries like South Africa, who are trying to tackle this hurdle straight on. This thesis argues that the social injustices of rights violations integrated with the issues of international patent laws aggravate the access to essential medications in the public health sector in the country.

This thesis adopts the use of a Rights-Based Approach, which is built on the foundational understanding that at the centre the focus is on human rights. In using the rights-based approach the intention is to outline ways in which to improve and further develop the ability of individuals and communities to recognize their rights. The findings show that the important factor of using a Rights-Based Approach is that it puts the pressure on the state to legitimately fulfil its obligation to its people. Thus the thesis evaluates the use of combining the legal system to enforce human rights and the role of social movements to realize the right to health for South Africans that use the public health sector to access essential HIV and AIDS antiretroviral drugs.

This research paper shows that the Treatment Action Campaign and Section27 have contributed to the recent transformation of the public health sector in South Africa. They have achieved this through the implementation of rights-based education campaigns as well as HIV and AIDS education particularly geared for those that use the public health sector facilities, to attain access to essential medications; not only for HIV and AIDS but also for tuberculosis and other AIDS-related disease treatment. The thesis further highlights that the Treatment Action Campaign and Section27 have assisted in greatly improving the access to HIV and AIDS essential medications for prevention of Mother to Child Treatment Programs. The findings of the research paper outline that the main issue lies in the fact that even though essential medications for HIV and AIDS are now more available, the medical infrastructure is one of the main problems accounting for the lack of service delivery of these essential medications in the country's public health sector.

ACRONYOMS

ALP	Aids Law Project
ARV	Anti-Retro Viral
ASSEFA	Association of Sarva Seva Farms
GRO	Grass Roots Organisations
GMHC	Gay Men's Health Crisis
HIV	Human Immune Defiance Virus
MRC	Medical Research Council
OECD	Organisation for Economic Cooperation and Development
OHCR	The Office the United Nations High Commissioner for Human Rights
PCP	Pneumocystis Pneumonia
PMTCT	Protected Mother to Child Transmission
NAPWA	National Association of People living with AIDS
NGO	Non-Governmental Organisation
NSP	National Strategic Plan
SA	South Africa
SAMJ	South African Medical Journal
SCF	Save the Children Fund
TAC	Treatment Action Campaign
TRIPS	Trade-Related Intellectual Property
UN	United Nations
UNAIDS	United Nations AIDS
UNHCR	United Nations High Commissioner for Refugees
US	United States
WHO	World Health Organization

WTO	World Trade Organization

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CHAPTER 1:

INTRODUCTION

This conceptualization chapter will highlight the two-tier health system which reinforces the great divide in the country between the haves and the have-nots, which is reminiscent of the apartheid regime. Then the discussion will move onto discussing the reasons that international Non-Profit entities such as the WHO and the UN use a Rights-Based Approach to combat world-wide health issues. This chapter will also outline the backdrop of South Africa's health care system problem. This will be done through briefly discussing the historical background of HIV and AIDS in South Africa from the perspective of NGOs and later in the thesis this history will be more localised and discussed from a South African perspective. In closing this chapter will set out the goals of the thesis and through each chapter aspects of each goal will be tackled.

1.1 Conceptual Framework

The health care delivery service in South Africa before democratisation was categorised into a two-tier system of: private health care which was subsidized by medical schemes and covered up to 20% of the country's population, and the public sector which was characterized by fragmentation, poor working conditions and inadequate infrastructure (TAC, 2004: 10; Human, 2010:33). This two-tier system is still evident to this day where the private sector hospitals are tertiary care centres that predominantly deal in specialist services and, when contrasted to the public hospitals and clinics, the latter are restricted to moderate and primary care services (Human, 2010: 33). As a result of this, physicians and other medical staff prioritize the private sector for employment because they get to use modern efficiently equipped facilities and they are paid better wages. Therefore, the public sector is left to be handled by 'over-worked and undercompensated health care professionals' (Human, 2010: 32-33). This means when these factors are combined, they create a public health care system that is understaffed, poorly equipped and 'that does not – and cannot – provide the same quality of care as the private health care system' (Human, 2010:33 & Section27, 2013:5-10).

Access to healthcare and of course medicines is not equal for all citizens of South Africa because there continues to be a great divide between the haves and the have-nots which is reminiscent of the apartheid regime (Peters et al., 2008: 161; United Nations, 2013:8). This might no longer be based on race but it is based on the differential economic status that people hold. However, Heywood mentions that the political failures that have brought on the

crisis of the health system cannot be solely blamed on the apartheid legacy (Section27, 2013:2). This is because they are caused by democratic failures that are brought on by a crisis 'of mismanagement and political oversight' and this makes it a 'crisis of the Constitutional promise' (Section27, 2013: 2).

The constitution outlines in section 7(2):

> *"the state's responsibilities which remain unfulfilled promises, namely, that the state has to respect, protect, promote and fulfil the rights in the Bill of Rights"* (Section27, 2013: 2).

This means that there are people who will always be held accountable for the shortfall of not fulfilling the delivery of these constitutional rights to civil society (London, 2008; Section27 2013; TAC, 2004). In this case, the South African government can be held accountable for failure to deliver on the constitutional rights it has set out to provide for health care to its citizens. The constitutional rights set out in Section 27 require the proposed research project to take into account the duty that the government has to progressively realise this right on delivering quality health care to its people.

The rights-based approaches (RBAs) to health according to Gruskin et al (2010:129) include a wide range of ways in which the United Nations (UN), governments and non-governmental organizations (NGOs) integrate human rights into public health efforts. This was initiated by Kofi Annan who 'called for the United Nations to integrate human rights into all of its work' (Gruskin et al, 2010: 134). By incorporating the relationship between health and human rights into the public health policy it speaks to the demands of the people, policy makers and political leaders in addressing the outcomes that will meet public goals (Tarantola et al, 2012: 11). The World Health Organisation (WHO) uses the 'Common Understanding' which frames the right to health through stressing the importance of 'availability, accessibility, acceptability and quality of goods and services' (Gruskin et al, 2010: 134-135). The Pan American Health Organization believes the human rights based approaches are built on the foundation of the international human rights treaties. These organisations recognize health as a human right that empowers the vulnerable and marginalized groups while putting to the forefront government accountability' (Gruskin et al, 2010:135).

1.2 Context of the Study

1.2.1 Context of the Health Care Problem in South Africa

Inequalities between the public and private sectors in South Africa are highlighted by the fact that in 2001 there were about 7 million medical scheme recipients in the private sector who paid for private health care out of their own pockets, which is about 16% of the population, and approximately 38 million South Africans (over 86%) utilized the public health sector (Human, 2010:32; Schafheutle et al, 2002), with the balance of the people probably using traditional or other health-care means. The Millennium Development Goal Report of 2011 states that in the public sector, generic medicines were available in 38.1% of medical facilities and their cost in comparison to the international reference price was an average of 250% higher (WHO, 2012). The private sector had generic medicine availability in 63.3% of medical facilities and the cost on average was about 610% more than the international reference price (WHO, 2012). The high prices often make medicines unaffordable in particular with common treatment schedules (such as dialysis or chemotherapy) 'costing a low-paid government worker quite a few days' wages' (WHO, 2012; Coetzee, 2013; Human, 2002). This makes it difficult for the government to usher in a good health-care system (WHO, 2012). This has come to affect the availability of crucial medications to most people (WHO, 2012). Making pharmaceuticals cheaper goes hand-in-hand with making pharmaceuticals accessible in developing countries (Section27, 2010: 438). By accessible this means that the pharmaceuticals are both physically available in medical dispensary facilities and they must also be financially affordable.

The South African health care system in 2002, particularly for the public sector, was in crisis as illustrated by the various strikes that occurred that year. These strikes were bought on due to the reorganisation of the provisional departments of health all over the country. It did not appear as well that the South African government was living up to the Millennium Development Goal 8 (Target 8.E) which focuses on the need for states and pharmaceutical companies to increase the provision of (and access to) affordable essential medicines in developing countries (WHO, 2012). At the same time, the South African health-care system had to deal with issues of accessibility, supply and availability of medical staff, equipment and medications for those in the rural and urban areas (Human, 2010: 33).

1.2.2 Historical Background of the Study Area

In this context, this study examines the Treatment Action Campaign (TAC) and Section27, two NGOs involved in the HIV sector. The TAC was established on 10 December 1998 and

the key goal was to make sure that HIV positive people got access to safe and effective Anti-Retro-Viral (ARVs) medicines that were widely available in developed countries but were scarce in South Africa (TAC, 2010:9). TAC started as a social movement that campaigned within the National Association of People Living with AIDS (NAPWA). The TAC was deliberately launched on International Human Rights Day because it was addressing the need to avail treatment to the millions of South Africans who are HIV positive (TAC, 2010: 4; Pillay, 2003). The TAC cemented the pathway for the state to begin providing full health care services to HIV positive people (Willems, 2011). The lack of access to ARV treatment coupled with the high prices of drugs in South Africa and 'the lack of political leadership, starting from the top with ex-President Thabo Mbeki and the Ministry of Health under the late Minister of Health, Dr Manto Tshabalala-Msimang', contributed to the high incidence of HIV in provinces like the Eastern Cape, Mpumalanga and KwaZulu Natal' (TAC, 2010:9). There was no treatment plan implemented until 2004 and there was no ambitious strategic plan until 2007, when the Cabinet adopted the National Strategic Plan (NSP). The TAC used court cases and intense community mobilisation as the order of the day 'in dealing with a non-responsive and arrogant government' (TAC, 2010:9). Section27 was established in May 2010 and it integrated with the AIDS Law Project. Section27 'is a public litigation centre that uses and develops the law to protect, promote and advance human rights' and it draws its name from Section 27 of the South African Constitution which says 'that everyone has the right to have access to health care services' (South African Government, 1996: 1255).

Responding to the government inaction, in July 2002 the Constitutional Court passed judgement when the TAC constitutionally 'threw down the gauntlet' to government's policy of restricting the delivery of Nevirapine, 'the most effective drug on the market' (Cotlands Baby Sanctuary, 2002:3) for the purpose of preventing mother-to-child transmission (PMTCT) of HIV to a select number of 'pilot sites' (Heywood, 2003; Mitlin and Mogaladi, 2008) in the case of the Minister of Health and Others versus TAC and Others (Grootboom case) (Cotlands Baby Sanctuary, 2002). This case suggests that human rights disputes might increasingly revolve around socio-economic rights and demonstrates that skilful litigation can be exploited to realize constitutional promises. Finally, the outcome of the case validates the Constitution, and should confirm to those who still suffer marginalisation and deprivation that the Constitution can materially impact on and better their lives (Heywood, 2003:279). This case is the epitome of civil society organisations such as NGOs holding the state

accountable to the people and propelling it to act in accordance with the stipulations of the Constitution.

This thesis contributes to the prevailing literature on NGO engagement with the AIDS pandemic. In this regard, it notes that there remains a disparity between the lofty goals of Section 27 of the Constitution, and actual implementation of HIV policies and programmes in the public sector. This is despite significant work by HIV NGOs. As well, NGOs find themselves in a catch-22 space in which they are caught between the demands of donors (and upward accountability) and HIV-infected and -affected individuals and civil society more broadly (or downward accountability) (Helliker, 2012). This awkward space for instance has led to splits within the HIV NGOs in South Africa, which impacted on TAC (TAC 2010:8; Pillay, 2003). Hence, in examining the effectiveness of NGOs, it is necessary to consider their internal dynamics, processes and conflicts as well.

1.3 Goals of the Study

The principle objective of this study is to critically evaluate the changes that have occurred in the public health care system in South Africa when the Treatment Action Campaign and Section27 implemented a rights-based approach to HIV and AIDS in South Africa. The subsidiary goals of the thesis include:

- Strategies employed by NGOs in making rights-based constitutional rights a reality for poor people;
- Examining the effectiveness of NGOs, by considering their internal dynamics, processes and conflicts;
- Reasons for lack of government service delivery of pharmaceutical products in the public sector;
- The utilization of branded versus generic medicines and the attendant patent and manufacturing laws and impact on costs.

Conclusion

This chapter sets the scene, by introducing the conceptual framework which is rooted in the use of human rights being supported by a Rights Based approach to health. This first chapter further outlined the aims and objectives of the study which will be discussed throughout the thesis within the appropriate chapters. This following chapter will further discuss the rights-based approach which will be linked to human development.

CHAPTER 2: HUMAN RIGHTS

Introduction

As mentioned in chapter one the thesis will use a human-rights approach to tackling the subject at hand. In this theoretical framework chapter the aim will be to discuss how human-rights have come to the universal. This will then support the following building block of the historical accounts of Rights-Based Approaches. Once the historical continuum has been traced out the thesis will move onto explaining what the Rights-Based Approach is. Then the discussion will outline the link between the uses of Human Rights Based Approach to development.

2.1 Understanding Human Rights

What would the world be like without human rights? Most of the freedoms that we experience would not exist and the current ongoing world integration would not exist. Could that mean that the existence of a globalized world would not be fathomable? This indicates that we would not belong to a unified human race. Maybe that could be a far reaching statement, but having legitimized human rights has opened up many doors of opportunity for, firstly, and most importantly, freedom as a whole. Human rights have, secondly, allowed people to gain ownership in determining who they are and how they want to conduct themselves. Without human rights many states and nations would still be oppressed and many more people would continue to be marginalized all over the world. Human rights are universal and they are important in the 'definition' of who we are as humans and how we can conduct ourselves with one another. Human rights have brought forward many changes in society and this is because human rights have integrated many parts of our everyday rights and this has legitimized them.

Looking broadly at the changes that human rights have brought to the world, this chapter will discuss how human rights have come to be universal. Even though human rights, as it could be argued, are a western notion, they have come to be adopted by most nations around the world.

> *"The notion of human rights depends on universalism in order to have any meaning at all"* (Englund, 2006:26).

Englund (2006:25-26) notes that some scholars blame, for instance, Malawian culture for its slow pace in discussing the 'new talks' about human rights to make certain claims. This was because it was innate that culture instilled in the people to "suffer in silence". That is why

Englund disagrees. He puts the blame of claims being unheard on the very Malawian activists not wanting to engage with the people in Chichewa, the local Malawian language (Englund, 2006: 25-26). An issue of language translation and semantic translation seems to be an issue that needs to be dealt with so that human rights exist in most languages that are not European or have European rooting so they are acknowledged and understood (Englund, 2006:27). Ishay (2004:7) justifies this view through arguing that this is due to one of history's 'most consequential realities' where the impact of the West including the 'Western concept of universal rights… has prevailed'. This means that this proclamation builds on the exclusionary nuances and these form the foundation of a particular type of universalism. This is because the universalism has the fault of not being able to provide an explanation as to how the universal notion can be the privilege of the one specific civilization (Englund, 2006:26). This brings to question as mentioned by Anna Lowenhaupt Tsing (2005) who wrote about 'engaged universals' signifying that universality is an intellectual ideology and it remains a thing which is hoped for but it is illusionary or rather it is impossible to achieve. This means that human rights being written to be universal are ideologically appealing but they are a toll order. Then it is possible to argue that the Malawian scholars and activists whose refusals to use or consider Chichewa when discussing and understanding human rights stems from them taking Anna Lowenhaupt Tsing's perspective as mentioned above. That is why Alain Badiou (2001) has mentioned the importance of bearing in mind circumstances in which human rights are suggested as ineluctably 'political' (Englund, 2006:26-27). Englund (2006:27-28) brings this to the forefront because he makes the assumption that the human rights discourse adds to the ways of governance in its translational and subjective modalities.

It is important to understand that the under-development of social and economic rights will have an impact on civil and political rights continuing not to be fully recognised. This is based on the backdrop where the 'founding fathers' of independent Africa noted that the socioeconomic development is 'not a more' crucial matter than the creation of the nation's civil and political rights (Englund, 2006:26). This is because it is vital to ensure that any discussions that are spoken of on the level of moral absolutes or universal humanity are not only ineffective but ideologically destabilising of the interests of the African masses (Englund, 2006, 26-28). That is why Shivji (1989:69) notes that 'human rights talk should be historically situated and socially specific', for the purpose mentioned above. What is critical with this issue is the need to understand the degree to which the rights discourse allows subjects to claim entitlements (Englund, 2006:26). This is because the indication of

entitlements has the underlying tone of presupposing membership within the political society where the institutional provisions guarantee historically specific standards of life (Englund, 2006:28). This is where citizenship becomes the focus of various struggles and this is over rights; then the understanding and the meaning of 'human' in human rights starts to look less definite. These are concepts brought forward by scholars such as Chatterjee and Mamdani which will be discussed later when the paper looks deeper into the make-up of civil society.

The reason it is important to understand this is that human rights when placed against political identity they are often working in unison. This is because, according to Asad (2003:129), human rights are meant to be inherent in all persons and this is meant to be regardless of their cultural or political associations. It could be argued that is so because the understanding and protection of these rights is often highly dependent on judicial institutions belonging to nation-states and international organisations, many of which have rightfully continued to instil order and protection in their nations. However, these are the very same states that will advocate for the importance of adhering to international human rights in global discussion arenas but they do not practice what they preach back home.

The discussion will now lay the ground work of how the rights-based approaches came into being and were realised and legitimized on an international platform.

2.2 Historical Accounts of Rights-Based Approaches

It is important to locate the current rights through a historical discussion because there are many tensions. The historical account that brought about the rights discourse on the international platform of development agencies was the World War II , because of WW II the period of the early 1990s saw dramatic changes in society and needs to manage and or reduce the societal gaps more evident (Manji, 2004: 14). This was the time when the north (the United States and certain European countries) was drastically developing at higher rate than that of the south (African countries and parts of Asia). It could be argued that this was due to the historical accounts of colonialism which definitely created the societal gaps where the south remained dependant on the north. This continued through the colonial ages and for a while after the post-colonial era. Many countries in the south are still dependant on the north, maybe not in the formal distinctions of the colonial era but for a while a lot of the newly independent countries still looked to the north for 'guidance'.

The developments from the early 1990s continued to gain momentum in the build-up of the Copenhagen Summit on Social Development in 1995 (Musembi and Cornwall, 2004:6 and

Manji, 2004:13-14). This was where the societal gaps were seen to be distinct and there was a need to bridge the gap.

Discussing and trying to negotiate attaining social, economic and cultural, as well as civil and political rights has been a topic that has been on the political agenda for many developing countries (Musembi and Cornwall, 2004:6-7). This can be seen where in some cases the African countries were colonised. Manji (2004:15) mentions that during the colonial era government social services for Africans were nearly non-existent. Nationalist and anti-colonial movements laid their foundation for their need to be self-governed in relation to the various everyday constraints and injustices that colonial administrations forced on their livelihoods and that is why the discussions of rights are, according to Mamdani (1996) and Kabeer (2002), an important feature of the struggle and liberation movements in developing countries (Musembi and Cornwall, 2004:6-7).

Manji (2004:14) mentions that:

> *"The struggle for independence in Africa was thus informed, at the base, by the experience of struggles against oppression and brutal exploitation experienced in everyday life. These struggles constituted the emergence of a tradition of struggles for rights which was organic to and informed by the specific histories and experiences of those involved . . . The concept of rights was . . . forged in the fires of anti-imperialist struggles. It was informed by the need to overthrow all forms (not just colonial) of oppression and exploitation, not by constructs which had either been embodied in the UDHR or imported into Africa by those nationalist leaders who had spent periods in exile or study in the imperial homeland."*

This meant that the right to citizenship had to be fought for and won because it was not given by a 'benevolent nation state' as mentioned by Musembi and Cornwall (2004:7). This was based on the foundation of prejudice against the excluded majority of the population who could not participate in the decision making that could and would affect their lives due to the government not being a reliable state that would guarantee definite basic rights (Musembi and Cornwall, 2004:7). Through the *act of struggle* rights have the space to be articulated and this is where the first building blocks are found that have come to mould the basis for action to be taken for social justice (Mamdani, 1996 and Manji, 2004:15-16).

Therefore the need for human rights approach is one that came on the global arena because there were many social injustices that were creating the societal gap between the north and

the south because of the aftermath of World War II. Many people of the north had access to many rights politically and socially whilst the south was not experiencing the same access.

The next part of the discussion will go into briefly unpacking the definition of a rights-based approach so to better understand how it adds to the discussion of human rights which are found at the core of the rights-based approaches.

2.3 What is a Rights-Based Approach?

When discussing the use of rights-based approaches to development projects, what is critical is understanding that at the centre the focus is on human rights. This will shed light on the importance of understanding that this is the most constructive way to combating issues such as various social injustices, conflict, marginalisation and poverty. By using the rights-based approach the intention is to improve and further develop the ability of individuals and communities to recognize their rights. Another important factor of using a rights-based approach is that it puts the pressure on the state to legitimately fulfil its obligation to its people. By doing so the people hold the power in their hands to make the changes that they require in their communities instead of the charity based approach where there is giving towards people's needs.

The implementation of human rights in trying to achieve healthy goals and needs for people is coupled with trying to achieve set development goals. It is important to understand that it represents a set of interdependent set values, aspirations and disciplines (Tarantola et al, 2012:1). When working with this interdependent set of values the core aim is to improve human welfare which is grounded upon moral and instrumental values that have as their fundamental base concepts such as dignity, justice, equity, equality, wellbeing and progress (Tarantola et al, 2012:1).

The 19th century industrial revolution in Europe was a time when various cities and factories were mushrooming all over the continent. This was when there were visible health and social inequalities. This was followed by the emergence of both public health and medical discoveries and treatments and at the core was the scientific ingenuity would solve the complex issues that were faced at the time (Frank and Mustard and Tarantola et al, 2012:1).

This was also a time when the developed nations had set up various industries that thrived and competed with one another for economic and political influence (Tarantola et al, 2012:1). Several states in the world came to thrive on these influences through extensively exploiting poorer nations via colonial domination (Tarantola et al, 2012:1). The atrocities faced by

these colonized nations brought about the need for governments to set out the needed obligation that they have as the protectors of the state to the people (Tarantola et al, 2012:1).

That is why the human rights based approaches spoke on a legitimate base for governments to be held accountable to the promises that they made in their constitutional laws to their newly independent people. That is why it is important to understand that having human rights could be seen as the most constructive way of combating issues such as various social injustices, conflict, marginalisation and poverty. Human rights will then further assist in the development of various countries. The following section will discuss the ways in which human rights-based approaches are incorporated into development approaches.

2.4 Human Rights-Based Approach to Development

> "*Human rights are rights inherent to all human beings, whatever our nationality, place of residence, sex, national or ethnic origin, colour, religion, language, or any other status. We are all equally entitled to our human rights without discrimination. These rights are all interrelated, interdependent and indivisible*" (United Nations, 2008)

Human rights have been interwoven to apply to every aspect of our everyday lives for all human beings across the world since the aftermath of World War II. World War II was a world altering event where human rights seem to have gone over and above or rather they preceded the existence of individual state laws. They were formed through a collaborative effort on an international platform where the United Nations (UN) legitimized these human rights. The fundamental aim of human rights is that they exist to contest and better develop the social and economic injustices that are inflicted, particularly on marginalized groups such as women and children.

Various states around the world have adopted the international blue print of implementation of human rights into their constitutions and bill of rights. This is because they aim to combat and develop the social and economic injustices that are inflicted, particularly on marginalized groups such as women and children. The Universal Declaration of Human Rights, Article 55 of the United Nations Charter promises to promote environments of steadiness and security. These are needed elements that contribute to non-violent and responsive relations that are needed for nations to co-exist, which are all grounded on the foundation of the 'respect for the principle of equal rights and self-determination of peoples' (United Nations, 1945). This

is coupled with the intention that human rights were created to protect, defend and be defended on a universal platform because they are there to service mankind.

The signifying world event that propelled human rights to be recognised on the global scope is World War II (WWII) (Tarantola et al, 2012:2-4). WWII was 'ground zero' for world heads of states to redirect their politics and truly look out for their countries' people and hold each other accountable to some degree. The reality of the effects of WWII is that during the decolonisation of the 1960s it saw a rapid growth rate in the emergence of independent states and they were driven by the transformation of the economic globalisation (Lauren, 1998 cited in Tarantola et al, 2012:2-3). This transformation brought to the forefront visible global inequalities in health, wealth and the awareness of the need for human rights (Tarantola et al, 2008:2-4).

Various inequalities from wealth, social development and health could clearly be seen after WWII with the dived to the North having first world developed countries and the South and the East which had most the undeveloped and underdeveloped countries of the world. When the northern states decided to rebuild its infrastructures as well as the distribution of wealth was already unbalanced and rooted in the historical accounts of the colonial era. This created bigger developmental gaps where the north as the developed first world countries became the countries that gave a helping hand to the undeveloped and poorly developed southern countries.

This came through programmes such as the Structural Adjustment Development Programmes (SADP) that rippled through the newly independent African states that were in the transitional stages of rebuilding themselves in the post-colonial era. One of the many issues that the SADP brought about was that many African states had to cut the cost to social funding such as education, public services and health. Discussing the major effects of the SADPs is a topic that needs deeper analysis; however, for the purposes of this paper the focus will be on the remnants of the SAPs affecting the health care system mainly within African countries.

One of the major issues that arose in health during the transformative time of the early 1980s was the spread of HIV/AIDS. The global launch of the epidemic was in 1987. This advanced the understanding of the interdependence of health and human rights and this highlighted how those living in poverty experienced the highest number of people infected and affected by HIV/AIDS (Tarantola et al, 2012:2). These are the same people who are subjected to

discrimination and violations of various human rights on a daily basis by their governing states.

Lauren (1998) notes that governments were compelled to recognise that they have an obligation towards their citizens and towards other states (Tarantola et al, 2012:2-4). According to Maastricht (1997) there are three particular obligations that governments have in relation to all rights; governments have obligations to respect, protect and fulfil each right (Tarantola et al, 2012:3-5). The first obligation is that states have to respect the human rights, which means that they have to refrain from interfering directly with the enjoyment of human rights. The second is the obligation of governments to protect human rights, which means that governments need to take measures that prevent non-state actors from interfering with the enjoyment of human rights whilst providing legal and appropriate forms of redress. The third obligation is that the government has to fulfil human rights and this requires states to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards the full realisation of human rights. This means that there are certain conditions that need to be created so that all people can enjoy their rights fully in their everyday lives (Tarantola et al, 2012:4).

According to both the Vienna Declaration (1993) and Howard and Donnelly (1997:268) human rights are seen as an international normative. Even if human rights are adopted and are defended on a universal platform, not all countries are supportive nor do they defend these human rights. The issues lie within their conception, implementation and content of these human rights as they contain views and implementation strategies that are in conflict with political views and religious beliefs of other world states. This results in the mistreatment and neglect of human rights in constitutional rights and bills of rights, and what becomes evident is that 'exclusionary politics' take shape (Helliker, 2013). This means that those people who have access, usually the minority, to the relevant institutions are more prone to reaping the benefits of these rights that they 'rightfully' have access to, whilst the majority, usually the poor, tend to be the ones who have to lay claim to these same rights. They are often treated as second class citizens because they are either physically removed from these institutions or they do not have the knowledge and resources to access their rights. This is evident through the works of Mahmood Mamdani and Chatterjee in understanding civil society in Africa and India. This will be further discussed later in the paper.

The United Nations in the implementation of the Article 55 of the Human Rights promised to provide 1) higher standards of living, full employment, and conditions of economic and social progress and development; 2) solutions of international economic, social, health, and related problems, and international cultural and educational cooperation; and 3) universal respect for, and observance of, human rights and fundamental freedoms for all without distinction as to race, sex, language, or religion.

Chatterjee mentions that:

> *"In legal-political theory, the rights of the citizen were unrestricted by race, religion, ethnicity, or class (by the early twentieth century, the same rights would also be made available to women)"*(Chatterjee, 2004: 30).

The axis of human rights is that they are all inclusive of all people and the creation of these all inclusive rights is that that they were meant to protect, defend and bring about development.

In this part of the thesis I aim to discuss the progression of human rights through engaging with the brief historical origins of human rights so to understand the importance of the contextual meaning of the impact that human rights have.

Human rights have been portrayed as being held as a universal moral right because this has been reinforced by the belief that human rights originated from Europe and North America which are seen as the liberal humanist societies (Roodt, 2003:47). Europe and North America have access to these liberties because, according to Roodt (2003:48), these are culturally and history derived from liberal humanist societies. This indicates that Europe and North America see human rights as intrinsic to all human beings.

When trying to understand human rights it is important to briefly note that they have gone through three distinct generational changes from their time of conception. The first generation of rights are related to civil and political rights; these include freedom from arbitrary arrest, freedom to assemble and freedom of conscience and expression (Freedman, 2013:936 and Roodt, 2003:47-48). The second generation of rights is related to those rights that are meant to guarantee the economic and social rights of individuals; these would include the right to health, education, employment and housing (Freedman, 2013:937 and Roodt, 2003:47-48). The third generation of human rights is linked to the rights that were not directly included in the Universal Declaration; these rights are usually known as group or

people's rights. These rights include the rights to self-determination and development (Freedman, 2013:936-939).

For the purposes of this paper the focus will on the second generation of human rights which included health, education, employment and housing. The main focus will be on health and how making health a universal human right has given people the bargaining power to hold their governments accountable if they do not have access to essential medical treatment. Having health as a human right has developed the health policy and trade of pharmaceutical products all around the world.

2.5 Rights Talk Linked to Development

The value of rights have been incorporated into development through the three broad categories of normative, pragmatic and ethical. The normative reason states that rights add value and that politics are at the core of development practices (Musembi and Cornwall, 2004:2). When using a human rights approach to development, the way in which it works is that it sets out a vision for what is meant to be: that would be, that it sets the normative framework to orient development cooperation (Hausermann, 1998). Hausermann (1998) mentions that by using this approach it brings to the forefront the importance of ethical and moral dimensions that need to be incorporated into development. This would be based on the foundation of international law that is based upon internationally agreed set of norms. As a result it offers a firmer basis for the claims that citizens can make on their states and states can also be held responsible for their duties to improve the access of their citizens to the awareness of their rights (Musembi and Cornwall, 2004:2). Kabeer (2002) argues extensively whose normative we using when there are various perspectives that only to specific nations (Musembi and Cornwall, 2004:2-3). This is because as usual international laws are a Eurocentric ideal, this means it opens up doors of some values of 'enlightenment' which are culturally and historically rooted to undermine some claims to universality; because of the legacy that colonialism and imperialist ages left behind (Kabeer, 2002 cited in Musembi and Cornwall, 2004:2-5).

What is visible is that a rights based approach is to some extent very similar to the needs-based approach. Musembi and Cornwall (2004:2-6) mention that the difference is that the needs-based approach focuses on securing additional resources for delivery of services to marginalised groups of people and a rights-based approach demands that current resources be communal meaning that they would be more equally shared (Jonsson, 2003:20). The rights-based approach takes on a political process when it explicitly empowers the marginalised

people to affirm their rights to those resources (Jonsson, 2003:20-23). What motivates the differences is that the needs could be met through charitable intentions and the rights are based on the foundation of legal obligations (Musembi and Cornwall, 2004:3-6). Jonsson (2003) mentions the normative force of a rights-based approach and the use of utilitarian-driven methods such as "low cost high impact" project method and cost-benefit analysis. This means that the rights-based approach would focus more on gross type of rights violations even if they only affect a small number of children, for instance. The other approaches would, for instance, focus on less gross types of violations which would affect a greater number of people (Jonsson, 2003:20-23).

Then there is the pragmatic (practical) reasons for the incorporation of rights to development. Musembi and Cornwall (2004:3) argue that the present model of aid makes demands for ensuring that states as the recipients are held accountable (Ferguson, 1999:22). Ferguson (1999:23) mentions that by referring to rights is in itself a 'vehicle for increasing the accountability of government organisations to their citizens and consequently increasing the likelihood that policy measures will be implemented in practice'.

The Office of the United Nations High Commissioner for Human Rights stated the notion of accountability as:

> *Perhaps the most important source of added value in the human rights approach is the emphasis it places on the accountability of policymakers and other actors whose actions have an impact on the rights of people. Rights imply duties, and duties demand accountability.*
>
> (UN OHCHR 2002: paragraph 23)

> *Under international law, the State is the principal duty-bearer with respect to the human rights of the people living within its jurisdiction. However, the international community at large also has a responsibility to help realize universal human rights. Thus, monitoring and accountability procedures must not only extend to States, but also to global actors – such as the donor community, intergovernmental organizations, international NGOs and TNCs – whose actions bear upon the enjoyment of human rights in any country.*
>
> (UN OHCHR 2002: paragraph 230)

The above lays the foundation for the contrast of other views which have the intentions to define rights past the conventional boundaries placed on state accountability; the language of a rights-based-approach in the development context provides the element of opportunities that could broaden the concept of accountability for rights to non-state actors (Musembi and Cornwall, 2004:3).

Musembi and Cornwall (2004:3-4) highlight a vital broader issue of power dynamics that is inherent in the practice of international development and this affects the question of ethics. Eyben and Ramanathan (2002) note that by engaging in the discussion of rights it is important to note that the discussion is about power and it is about the responsibilities of those involved in supporting development.

This view implies that those involved in development have to understand that rights-based approaches have the potential to create a space for making critical linkages between participation, accountability and citizenship because they highlight the importance of having the assistance of the political scope of participation that filters into the mainstream (Kabeer 2002; Gaventa 2002 cited in Musembi and Cornwall, 2004:7-10). However what has come to light is that even if human rights are universal and intrinsic to all humans, due to the north and south divide, there are further divisions between people in the same country. As mentioned before, we all might be citizens but we are not all equally created. This is because there are different relations that the state has with the people that either lay claim to their rights and those that are granted their rights. This will be further discussed in the next chapter so to better understand how access to human rights differs for many people.

Conclusion

This chapter discussed the rights-based approach to human development. The chapter highlighted that the intention of using a rights-based approach is to improve and further develop the ability of individuals and communities to recognize their rights. Another important factor that came to light about using a rights-based approach is that it puts the pressure on the state to legitimately fulfil its obligation to its people. Thus the chapter shows that the rights-based approach takes on a political process and as a result it explicitly empowers the marginalised people to affirm their rights to resources. The chapter brought to light that the implementation of human rights in trying to achieve a healthy society and the needs for people are coupled with trying to achieve set development goals.

CHAPTER 3: STATE AND CIVIL SOCIETY RELATIONS

Introduction

As discussed in the previous chapter there is a link between human rights and development and to better understand this link, this chapter serves to discuss the relations between state and the civil society. As these relations serve to better reinforce the notion of the two-tiered health system in South Africa which was mentioned in chapter one. Later the thesis will into depth with this divide. This chapter will look at the state and the civil society, with the aim of highlighting how these relations have created a space where NGOs can serve their function both on an international scale and more specifically within the South African perspective. This chapter will then move onto discuss the historical background of HIV and AIDS in South Africa. This will be done through looking at the different waves of stigmas that were attached and continue to be attached to people who have HIV and AIDS. The chapter will then discuss the pseudo-scientific medical explanations of HIV and AIDS as proliferated in the media and by the state heads in the early 1990s. Then the chapter will close with the discussion by focussing on the 1990s antenatal survey outcomes which will set the backdrop as one of the goals set out by the TAC and Section 27 in later chapter 4.

3.1 State and Civil Society Terrain

The term 'civil society' is a contested subject regarding how it should be translated in reality. According to Keane (2009:1) civil society is an arena, an environment where citizens gather to accomplish a range of purposes; these are sometimes positive and peaceful, and others are seen as negative and violent. After reading into the works of Mamdani and Chatterjee and a few other scholars who have addressed civil society in their work, it could be argued that as a collective there is a consensus that civil society is made up of two components: civil society institutions and civil society organisations. Keane (2009:1) claims that civil society:

> *"Has included the observation that a civil society gives preferential treatment to individuals' daily freedom from violence and other incivilities; claims concerning the importance of enabling groups and individuals freely within the law to define and express their various social identities, as equals who have feelings for others and, thus, the capacity for trust and solidarity."*

This then creates a political space whereby:

> *Civil society is a political space where voluntary associations deliberately seek to shape the rules that govern aspects of social life. Civil society organisations target*

> *rules they seek to change and or impose social constructs or social order* (Keane, 2009:1)

That is why there are NGOs that exist within the civil society because there is preferential treatment that exists within civil society and they are trying to change these social contracts for those that are seen to be not part of the civil society.

The relations that exist between the state and civil society are meant to be co-dependent. The definition of civil society is one that has been contested as mentioned above much like the term 'sustainable development' due to the context in which it is applied. For the purposes of discussing the South African Civil Society it has to be noted that from the colonial era the settlers created societal segregation between them and the natives. After the colonial period ended the ruling reigns were taken over by the National Party who amplified the segregation and legitimized the racial segregation through apartheid laws. This then created a different civil society which, on the one hand, consisted of the white South Africans who had rights and were considered legal citizen of the country, whilst, on the other hand, there were the non-whites that belonged to the homelands and were not South African citizens. They were referred to as Mamdani (1996) coined the term 'subjects' as they were under a tribal chiefdom-ship rule. When the African National Congress came into power as the first democratic ruling party, the notion of civil society changed once again. Where there might not have been racial segregation and the constitutional law was now all inclusive of all races, this did not translate into the make-up of civil society. This will become evident in the following discussion as it lays down the foundation of how the apartheid era has left a legacy that is evident through the relation between the democratic state and the civil society.

It could be argued that membership of civil society appears more vital than simple humanity. Socially conditioned individuals are substituted by political subjects. Therefore it could be argued then why there are differences within civil society when civil society according to Chatterjee (2004:30):

> "*In legal-political theory, the rights of the citizen were unrestricted by race, religion, ethnicity, or class, these were universal rights that the citizen has (supposedly).*

The notion of civil society is therefore meant to be inclusive of all and non-discriminatory.

Taking this statement at face value it is simply to deduce that the notion of 'civil society' could seem like an inclusive title or maybe it is the overall general title we give to all the

citizens of a nation. These are meant to be the deserving beneficiaries of the state's services, the protection and promotion of rights, and civil liberties, all of which supposedly go hand in hand with the ideal of the nation state and its relation to democracy.

However, Partha Chartteree does not see 'civil society unfolding in reality as stated ideologically'. This could be the case because in reality the term 'civil society' is often at odds with the implications of the written definition. Due to a great degree of it not being representative of the will of the people in relation to democracy, it has been used by the nation state to exclude and seclude certain parts of the population, being more specific, the poor ('political society') in the urban areas, usually at the request of the middle class and the elites. The definition of civil society when merged with the notion of democracy on paper presents ideals such as equality, the rights of the individual, fairness and tolerance among other things (Elliot, 2004, cited in Gudavarthy and Vijay, 2007:3051). The church, the media, unions, non-governmental organisations (NGOs) and community forums are the institutions that are separate from the state, but they ensure that the ideals of civil society are promoted and protected (Gudavarthy and Vijay, 2007: 3051). Chatterjee (2004:4) notes that civil society in reality is an exclusive or closed off entity whose standards and aids can only be accessed by a few, the elite. This means the notion of 'civil society' includes people who are part of the elite class; these are the people who, according to the state, are the identifiable members of society who are rights bearing citizens. This is due to their actions which are different to those of the "population" who fall within the broader law.

This brings to the forefront the question of who are these people that are excluded within the South African context. In the South African context these would be the people that belong to the urban poor who live in the mushrooming informal settlements as well as those that live in government housing and in the rural poor areas.

The use of language alone insinuates the power relations that exists within the 'civil society'. This is because governments tend to rely on the support of the middle class and the elite; this means that the government 'cannot afford' to destabilize this support. This is because governments buckle from the pressure to 'get rid' of the squatters. An example of this was in West Bengal where:

> *"There was increasing pressure on the communist-led government to clean up Calcutta in order to attract foreign investment in growth sectors such as petro*

> *chemicals and electronics. The government's support among the urban middle classes was falling sharply" (Chatterjee, 2004:61).*

What followed was 'Operation Sunshine' which was in full motion and those that were considered to not be part of 'civil society', the street vendors and their stalls, were removed by the police and municipal officials who were tasked with clearing the streets, and in those areas where the squatters were removed, the roads were expanded and trees were planted (Chatterjee, 2004:61). This is a clear example of how the state treats the urban poor, as mentioned before, at the request of the middle classes and the elite. Their right to make a living in spaces 'reserved' for the urban middle class is stripped away. They have to lay claim to their rights and this is often done in an illegal manner, and the response of the state is to ill treat them. Shindo (2009: 219) refers to this civil society as 'monopolizing' civil rights.

Chatterjee (2004:35) notes that the role of the state has shifted from a political to a technocratic (administrative) one, this is evident through understanding the definition of 'population'. What can be noted is that according to the state's bureaucratic methods, the population is based on statistics, figures, and classifications. He further mentions that:

> *"All of this made governance a business for experts rather than for political representatives" (Chatterjee, 2004:35).*

This would explain to some extent the differential treatment that states give populations and citizens, where the citizens are allowed to engage with the state about their needs and preferences (Chatterjee, 2004:135). This means they do not need to lay claim to their rights like the urban poor, populations that are often pacified. Often you find that the state has to treat them in a particular way so to accommodate them, whilst they safeguard that they do not become a threat to others; being those that belong to the middle class and the elite (Chatterjee, 2004:135). This also evident in the Universal Declaration of Human Rights, for example where it acknowledges civil, political, social and economic rights but this occurs at the expense of others (Englund, 2006:47).

Linking the above to the 'development state', in the words of Chatterjee (2004:34), post-apartheid South African promises to provide and implement socio-economic policies that are meant to bring about reform which would end unemployment and poverty. However, after twenty years of democracy there are still a vast number of South Africans who are suffering the dire social injustices on a daily basis in trying to survive poverty when most of them fall under the unemployment line. As a result they resort to self-mobilisation (through means

such as service delivery strikes) because they have been let down by those who are meant to negotiate for them on their behalf for their needs. Organisations such as 'Abahlali BaseMjondolo' (ABM), a shack dwellers' movement founded in Durban and led by S'bu Zikode, have come into existence because of the state's relation with them as the urban poor. Their aim is to support one another through self-mobilization so that they can organize themselves to negotiate their needs with the state (Zikode, 2009:2).

The state still views them as a threat most of the time and tries to pacify them (Zikode, 2009). Zikode's article *Party Politics vs Living Politic* in Kennedy Road supports this. Zikode defines '*living politic*', as the reality that exists within the kind of democracy that South Africa has; it can be labelled as the sort that protects and promotes the interests of a particular few and this is at odds with there being a vast number of homeless people who are living in inhuman conditions (Zikode, 2009:1). He then defines the '*party politic*' as a top down approach where there a minority that makes the very decisions that affect the majority and this is often done without much consultation, which he sees as 'dirty politics', that is full of fear, threats and death (Zikode, 2009:1).

There is a clear differential treatment that is evident in the South African political space. The state is so self-consumed with the middle class agenda. This will become more evident when the discussion deals with the conditions of the hospitals in the urban and rural areas as well as the available skills in the public health sector. There are staggering differences that add to the poor healthcare that is often provided in the public health sector and worse in the rural clinics and this the work that the TAC and Section27 are trying to change whilst holding the government accountable.

Zikode through his article clearly sets a strong undertone that the power to emancipate the poor can best come from the bottom, from the very people who are suffering. They need to be actively involved in their own struggle. The poor need to self-organize and mobilize in trying to negotiate the very rights that the state is meant to provide for them as mentioned before. This is because they are coerced by the state and the political parties that have not lived up to their promises. The reason that the state, according to Chatterjee, does not focus on assisting the poor is because it has its focus on improving infrastructure that will attract foreign investment.

This part of the paper will now tackle the different ways in which civil society interacts with the state so that it can make its requests as well as the ways in which political society has to mediate with the state.

Englund (2006:28) argues that whatever the type of society in which persons can claim membership, it is vital to know there are as many variations in the kinds of citizenship as in the concept of rights. Marshall ([1950] 1977) recognized political, civil and socioeconomic elements in citizenship and he was mainly troubled with the exclusion of the working class in post war Britain from social rights to the kinds of education, health care, and social security, which, if provided, would have created a communal sense of equal citizenship (Englund, 2006:28-29). Thus the exclusion of a certain type of citizen is both in the first world and in the developing world such as India and South Africa.

These are exclusionary politics that are mentioned above, and they clearly show that the notion of civil society is one that is not all inclusive. Even though the Constitution is law that is all inclusive of the South African people, there are socio-economic divisions that now create an 'other' in society who could be viewed as a second class citizen. Like the subjects of the colonial and apartheid eras, such people still have to lay claim to their rights from the state whilst they still have to suffer, it could be argued, worse social injustices than those that were experienced during the apartheid era. This might be a sweeping statement where, even though there are major differences that the democratic nation is experiencing, there are many issues that the state is not tackling. Those that do not belong to the correct economic bracket to be noticed by the state and not be seen as a burden, they are the ones who are on the receiving end of the social injustices which they are not meant to be suffering due to the existence of the constitutional law of the country. This will be further discussed in the following chapter where the focus will be on the social injustices of health that those that have been seen as the 'other' by the state are suffering from since the time of the apartheid era and during post-apartheid period since 1994.

3.2 Historical Background of HIV/AIDS in South Africa

On 9 January 1983, the headline of South Africa's bestselling weekly newspaper, the *Sunday Times,* read 'Gay plague: more victims?' At the time, HIV/AIDS was a new disease many thought exclusive to the gay community. It was poorly understood by scientists, socially misapprehended, and its threat to public health was not yet fully appreciated. A combination of scientific ignorance, social prejudice, and structural inequality gave rise to discriminatory interpretations of HIV/AIDS and a failure to produce a constructive public health policy

appropriate to the scale of the disease. In a short time, within a decade or two, HIV/AIDS became a full-blown epidemic in South Africa.

Early detection of HIV/AIDS began in the late 1950s and was highly concentrated amongst gay white men (Geffen, 2010:14-15). There was very little literature written about these accounts during the time and early press accounts focused on gay white men. The first two cases published about South Africans that died from HIV/AIDS were two gay white male South African Airways stewards, Ralph Kretezen and Charles Steyn. Both men experienced high fevers, weight loss, and were diagnosed with low white blood cell counts. They were given various medications that briefly improved their symptoms. However, a few days later both men died, and Kretezen's autopsy showed he had pneumocystis pneumonia (PCP), a lung infection commonly contracted by AIDS patients (Geffen, 2010:16-17). The South African Medical Journal (SAMJ) published an article about Kretezen and Steyn in July 1983 under the headline, '*Homosexual" disease kills SAA stewards*'. *Time* magazine picked up on the story, referring to it as a 'mysterious and deadly epidemic'. The impression that HIV/AIDS is 'confined to male homosexuals' was quickly repeated throughout the world. However, within a space of three weeks, reports of people affected diversified: in the United States it spread to 'heterosexual drug-abusers', Haitians, hemophiliacs and children (Geffen, 2010:17).

Pseudo-scientific medical explanations of HIV/AIDS also proliferated in South African media, compounding misconceptions of the disease. One popular story held that HIV/AIDS could be treated through the use of long and 'intense' homeopathic remedies. The spokesman of the South African Homeopathic Society, who had never treated an HIV/AIDS patient, reported that the treatment worked through building the immune system (Geffen, 2010:17). This speculation about how to cure the disease was premature and lacked scientific rigor. The complexity of the disease was not yet understood medically, but a consistent truth lay in the breakdown of the immune system. It followed that building the immune system back up might help manage the disease.

The disease continued to ripple through like a dry summer season bush fire during the eighties where it continued to kill many people (Geffen, 2010:17). The number of deaths from the epidemic were not well detected and reported due to the lack of Aids testing. In the South African context there were only 166 Aids cases reported by December 14th of 1988 and the infected patients were mainly gay white South African males. This clearly shows how

there was an imbalance in the testing of both white and black men and women and children (Geffen, 2010:17). This was during the apartheid regime and being gay was illegal. Following late detection in the country what further tipped the scale of unbalanced reporting of HIV/AIDS cases in the country was the racial segregation which offered the white South Africans the best medical access for treatment at an unbalanced scale to that of the other racial groups in the country. As a result there were more reported cases of white gay men being affected by HIV/AIDS than of any other racial group in the country

There were very few cases detected within the black population (Geffen, 2010:16), mainly due to the low levels of access to information about health care and the disease amongst black people. The apartheid system ensured that a very low number of people were equipped to fight against the epidemic despite the high level of suffering it caused and this marginalized people (Geffen, 2010:16).

A few people contracted HIV through blood transfusions whilst the majority of the documented cases, 125 people, contracted it through homosexual sex, and the remaining 24 documented cases were transmissions through heterosexual sex and only three were children (Geffen, 2010:17). The number of people who had not contracted Aids but had the HIV infection was documented as 1857 and most of them were reported as being white male (Geffen, 2010:17). This was a time when the epidemic was still 'small' and this remained the case for a while; however, this was soon to change and the demographic enormously transformed (Geffen, 2010:18) to black men, women and children. Race has factored in to affect the disproportionate speculation on the spread of the disease and this occurred throughout the world due to popularized media influence. The HIV/AIDS went from it being a homosexual disease and its narrative then changed to having begun on the 'plagued' African continent and thus being a black man's disease. The various issues of speculation on the disease were hardly based on the foundations of scientific findings that informed how the disease replicates itself in the host and how, as we now know, it is transmitted through body fluids.

This was evident from the changes that can be seen through the first 1990 antenatal survey that anonymously tested thousands of pregnant women in public hospitals. The result was that there were less than one in 100 women who were infected (Geffen, 2010:18). Aids from the 1980s to the early 1990s seemed like a manageable disease outbreak. The HIV epidemic in South Africa until 1990 had a similar pattern to the European and American epidemics

(Venter, 2013:2). The second survey in 2005 saw the numbers had increased to 30 in 100 and the 2005 household survey results showed how over 10% of the population, mainly being above the age of two, were infected and they were mostly women (Geffen, 2010:18 and Venter, 2013). Media speculations of whom was the most prone to spreading the disease changed from gay white males to promiscuous black men and women. This became the 'black man's' disease for the next half a decade or so and then the media changed its speculation to reporting that more women than men were infected with the disease. It could be argued, though, that because more women were getting tested than men the reported numbers of women being infected would increase. This perspective would unbalance the media speculation that women were to 'blame' for being promiscuous and spreading the disease as many women, particularly those in the rural areas, had to endure this wrath. But every story has two sides. It could be argued that most women who underwent HIV/AIDS testing contracted the disease from their husbands who worked in the city in such places as mines and as construction worker.

As a result of more women being tested, about 60 000 infants were detected to have been infected with HIV either during labour or from being breastfed by an infected mother (Geffen, 2010:18 and Venter, 2013:2). These numbers to some degree supported the media speculation that promiscuous women were the main spreaders of the disease as mentioned above. This touches on South Africa's gender inequality issues. This perspective was highly influenced by 'strong' culturally patriarchal perspectives which came to influence the media speculations on the disease.

There was very little discussion on how, in less than a decade, HIV/AIDS became the world's largest epidemic (Venter, 2013:38 and Geffen, 2010:18). This could be attributed to lack of information on the disease, and lack of testing popularity amongst sexually active people regardless of their sexual orientation and age. Venter (2013:2) mentions that the increase was poorly understood due to several issues such as 'sexual and cultural behavioral issues, to peculiar characteristics of the local virus, to medical practices, to inherent susceptibility of the local population'. Venter (2013:38) further stated that the absence of clarity about the main reasons that are behind the 'increase' has resulted in the lack of prevention efforts which were 'unsuccessful'.

The apartheid government was notorious for being disinterested in the Aids discussion as it was viewed as being a 'homosexual disease' and it resulted in the issue being made a private

matter. This meant individuals resorted to privately running awareness programs during the early years of the epidemic being detected (Geffen, 2010:18). The government in October 1987 released a regulation banning the employment of HIV-positive foreign workers and the immigration police had the power to randomly test immigrants for HIV/AIDS and they could detain and deport non-South Africans who were HIV-positive (Geffen, 2010:18 and Venter, 2013). This further indicates the lack of access to knowledge about the disease on how it spreads and how best to manage it both on an international and national level. This shows that the government has poorly attempted to 'manage' the disease outbreak. The South Africa government's actions at the time further portrayed the nuances of being xenophobic to great extent.

To further add to the lack of much needed disease control, the introduction of condom awareness through public advertisements received much backlash and was opposed by the Cape Town City Council in 1992. This was a condom awareness campaign that was developed by the Medical Research Council (MRC) (Geffen, 2010:18). The South African Broadcasting Channel censored HIV/AIDS and condoms commercials during prime time television and they were limited to being broadcasted only after 9pm (Geffen, 2010:18-19). This was all during the time of Aids 'denialism', for lack of a better word, with the government taking 'the ostrich-in-the-sand-approach' (Geffen, 2010: 19). This was a time when the disease held a great stigma which meant that it had huge implications for the lives of those who were living with HIV/AIDS. This caused a lot of people to be fired from their places of employment and a large number were ostracized from not only their families but also other areas of their social lives. This was due to people being uniformed on the way HIV/AIDS could be contracted. This was also depicted through the early HIV/AIDS campaigns which focused on informing people on how the disease was not airborne and that it could not be passed on through merely touching an infected person. There was very little emphasis on unprotected sex with multiple partners and how mother-to-child infections can occur and be the highest cause of HIV/AIDS transmission.

ARVs during this time were highly unaffordable to many of those affected by HIV/AIDS and the AZT drug was not the most effective on the market, and it was not going to be until 1996 (Geffen, 2010:19). The AZT drug was the first issued HIV/AIDS drug that was made available to the public. It seemed to further break down the immune system and many people who were in the first few stages of being administered the drug kept getting sicker and very few survived taking this harsh medication with low white blood cell counts.

Former president Nelson Mandela expressed great regret that from 1994-1999 HIV/AIDS continued to be low on the radar of political discussion in the New Democratic South Africa (Geffen, 2010:19). This was explained by journalist Donald McNeil who said Nelson Mandela in 1991 endorsed safe sex in Mpumalanga to some parents and Nelson Mandela said that he read the parents' responses after his delivery of his speech and that it was like he had said something revolting. As a response one of the parents said 'How can you talk about this? You want to encourage prostitution among our children?' (Geffen, 2010:19). This negative response made him not speak of safe sex anymore. This of course affected why the government at the time did not have an effective HIV/AIDS prevention information campaign. This was because there was poor implementation of a 'useful document' that was developed by the National Aids Coordinating Committee of South Africa and endorsed by the Cabinet in 1994 (Geffen, 2010:19). This type of reaction from the parents was expected as the disease was portrayed as being one that infects promiscuous people, both male and females who were sexually active. The use of condoms to some parents meant that this would encourage their children to begin and or further continue being sexually active, as if the disease was heaven sent to reduce a teenager's sexual drive. It could be argued that this poor reaction should have not have hindered the government to stop taking action publicly for five years.

The era of government denialism continued after the first president into the presidential regime of Thabo Mbeki. This was based on the calculations made by the use of models where Venter (2013:38) said that they showed the increased infection rate with between 1.3% and 1.5% of South Africans, or approximately over 300 000 citizens, being currently infected annually. These numbers could have been much lower as five years without much government action allowed for the stigma to grow and this also filtered into the creation of 'cultural beliefs' escalating about the cure. One of the beliefs of a cure was for a HIV/AIDS infected man to have sexual intercourse with a virgin girl. This was one of the major beliefs that contributed to people not seeking researched medical assistance and taking needed precaution for prevention and disease management.

A large and complex HIV-positive pediatric population which has been projected to be 70 000 per year is part of the treatment challenge, but with the effective implementation of the mother-to-child transmission programs (PMTCT) has decreased the number of projected infected infants (Venter, 2013:38). The number of both adult and the pediatric epidemic has

placed South Africa as one the world's leading countries with the most HIV/AIDS infected people.

The HIV/AIDS numbers are certainly high where there are about 2.5 million people who are on ARV treatment and this includes men, women and children. It could be argued, though, that had the Mandela and the Mbeki regimes acted accordingly to dealing with the HIV/AIDS treatment in South Africa, the country's HIV/AIDS status might not be where it is right now. Even though South Africa has treatment the diversity of the treatment can be brought into question. This will be further discussed in the data analysis chapter. It is clear to see that the South African government with its history, both in the apartheid era and the post-apartheid era, definitely contributed to the increase of the HIV/AIDS epidemic. The South African health care system due to the apartheid era was, firstly, divided into the black and white. Then with the new democratic South Africa the health care system changed into the private and public divisions. This will be further discussed in the following section.

3.3 South African Health Sector Private and Public Divide

The South African health care system is one that is divided between private and the public health sectors. There is a massive division between the two health care sectors. The apartheid regime policies left the legacy where it contributed to the current inequality regarding the access of health care services in South Africa (Wadee et al., 2003:4). The fragmentation of the South African health care sector has continued to worsen due to other issues such as governance and the differing service delivery that is between different population groups in the country (Wadee et al., 2003:4). With the creation of the constitutional law and the bill of rights one of the aims of the democratic government was to standardize the fragmented policies and ways of life in the country. With that intent it has to be noted that the South African health care system has been shaped by the Growth, Employment and Redistribution (GEAR) policies which were put into place to deal with social inequality and also increasing economic growth (Wadee et al., 2003:10). As a result it allowed for private companies to invest in the health care system that was once state owned and this was the 'birth' of the private health sector and the government continued to fund the public health sector, which remains to a large degree stagnant (Wadee et al., 2003:27).

According to the document leased by Statistics South Africa, South African Statistics of the General Household Survey (2014:11) the use of public clinics as the first point of reference whenever a household member fell ill or was injured was put at seven in every ten

households that makes for about 69.9% of the South African population. With just looking at these numbers this is more than half of the population and this would mean that the public clinics are more accessible to the majority of the population. However, what needs to be further accessed are the conditions of these public clinics for as much as they may be more accessible than the private or larger private or public hospitals, this does not mean they are well equipped with the services and staff to deal with the cases that come through on a daily basis. There is a glaring difference between the facilities and infrastructure in the private and public sectors.

On the other end of the scale is that a quarter or 24.2% of the households indicated that they would go to private doctors and 4.7% said they specifically preferred private clinics and/or hospitals (Statistics South Africa, 2014:11). Statistics South Africa (2014:11) further indicates that most households which was put at 92.1% went to the nearest facility whether public or private. There are various factors that could contribute to these numbers and these would be availability of transport, access to money for medical care or access to medical aid schemes and the severity or the critical level of the person needing the medical attention that could contribute to the decision to go to either a public or a private hospital or clinic. Of those who did prefer to go to private clinics or hospitals, they had to often deal with driving very long distances to access health facilities and 15.7% reported to have to often deal with longer waiting periods. They opted for this option often because their normal 'catchment area' facilities are under-staffed, under-equipped and often do not provide the services that they require. Statistics South Africa (2014:11) further reports that only 'nearly a quarter' or 24.5% of South African households would have a minimum of one family member who was registered with a medical aid scheme. Those individuals who belong to medical aid schemes in South Africa constituted only 18.4% as recorded in 2013. The private sector in South Africa still predominantly serves the white population and high income groups (Wadee et al., 2003:10).

These numbers could be contested, though, as student medical aid schemes are not included and often most universities require that each student be on medical aid. What is definitely interesting with the findings of the South African Statistics (2014:11) is that their study indicated that 82.5% of the households that were using public health-care facilities were highly satisfied with the services that they received. In comparison to the households that used private health-care facilities, there was a staggering 98% who were just satisfied with these more expensive services. However, an Al Jazeera (2012) report indicated that South

Africa's public health sector is characterised by rundown buildings, broken equipment and widespread corruption, while the private health sector enjoys world-class hospitals with advanced equipment.

It could be argued that private health-care facilities are not at the same standard in service delivery as the public health-care facilities. This brings us to question the quality of services rendered by the health-care system. This is because they have caused the issue of access to medical treatment and this issue has contributed to households being highly satisfied or being merely satisfied with the health-care services regardless of location.

It is clear to see that there are major differences in the services that are accessible for those that use the public health services and those that use the private health sector. This is clearly a social injustice and this must infringe on the rights of those that can only afford to access the public health sector. Many of them are on social grants and they use that money to take care of their families and this could cause them to be caught between a rock and a hard place where they have to make life changing decisions between getting medical assistance and feeding their families. This is definitely a social injustice and the government has to be held accountable for infringing on the health rights of those that can only afford to use the public health care system. This is where the non-governmental organisations come into play as 'activists' for those that are in the public sector who are suffering these social injustices. The next part of the discussion will deal with the non-governmental organisations and the role that they have played in the South African political space as civil society organizations. As civil society organisations they are trying to hold the government accountable for the infringement of people's rights to health care through the use of legislative law.

Conclusion

This chapter examined the relevant state and civil society relations in South Africa. The chapter highlighted that civil society organisations are trying to hold the government accountable for the infringement of people's rights to health care through the use of legislative law. The chapter noted that the private health-care facilities have better service delivery and it is clear that there is a notable difference in the standard of service delivery that is offered in the public health-care facilities. The chapter further discussed the contextual material on the public health sector, and interventions regarding HIV and Aids in South Africa. The social injustices suffered by the people who use the public health care system are evident in this chapter, this lays the foundation for the next chapter which will discuss reason that NGOs exist as civil society organisations that aim to tackle these social injustices.

CHAPTER 4: NON-GOVERNMETNAL ORGANISATIONS

Introduction

This chapter expands on the discussion of NGOs which was mentioned in the previous chapter. In this chapter the focus will be on characterises, definitions and the space in which NGOs can exist within the civil society realm discussed in the previous chapter. This will be further discussed through looking at how NGOs align their goals with the development theory. This discussion will move onto discussing how this alignment brought the rise of NGOs in the development world. This chapter will then look into discussing the NGOs context in South Africa from the apartheid regime to post-apartheid regime. This will be done through unpacking the contributing factors that existed within the space of state and civil society as discussed in chapter three, which altered and regulated the relationship between NGOs and the government as well as the relationship that NGOs had with the communities they are helping out. This chapter will then discuss the human rights movements of the TAC and Section 27, this will be done through the discussion of how they are civil society organisations that can internationally locate their activities within the international human rights framework. This histories and goals of the TAC and Section 27 will be discussed to highlight the space in which they exist in the South African context of the health crisis. In closing this chapter the discussion will focus on the link between health and human rights and this aspect of the discussion will come full circle in the following chapter.

4.1 What are Non-governmental Organizations?

The definition of what actually constitutes a non-governmental organization (NGO) varies because there are a multitude all around the world and they work in various specialized roles (Lewis & Kanji, 2009:2). NGOs have come to be recognized on the local, national and international levels for various work that they do in the world of development (Lewis & Kanji, 2009:1). NGOs have come to be the lead players in the scene of development because they have taken the route to express themselves either through 'the delivery of services to people in need and organizing policy advocacy and public campaigns for change' or they are extremely active in a varied range of specialized roles like emergency response, democracy building, conflict resolution, human rights work, cultural preservation, environmental activism, policy analysis, research and information provision (Lewis & Kanji, 2009:1). NGOs have attained their acceptability through them being:

> *"Highly legitimated because they embody highly legitimated world-cultural principles. NGOs have legitimacy because they promote the rights and welfare of the*

> *poor, the oppressed, the victims of violence and their selfless commitment to work on behalf of others in need" (Beiri, 2010:100).*

The role of NGOs as 'legitimators' for both the funders and the people on the ground comes from the values taken from global cultural principles. This is because they can assist as 'highly legitimating forces' for any of the developments in which they are involved (Beiri, 2010:100). NGOs have created a space of authority where they play the part of being ethical guardians that have tasked themselves with keeping states and trans-national cooperation's (TNCs) truthful and this stems from global scripts (Beiri, 2010:100).

As of 2008-2009 the United Nations estimated that there are approximately 35 000 large established NGOs and there is even a greater number of these NGOs that are receiving international aid (Hulme & Edwards, 1997:3-5 and Lewis & Kanji, 2009:2). There has been a significant increase in the number of NGOs since the 1980s; their numbers have grown exponentially as the size of some of these NGOs has made them noteworthy players in social welfare and employment markets on national platforms (Hulme & Edwards, 1997:3 and Hilhorst, 2003:3). The increasing acceptance of NGOs with governments and official aid agencies is linked to the response to progresses in both economic and political thinking (Hulme & Edwards, 1997:5 and Eade & Pearce, 2002:119-120). This increase of NGOs on the world platform is an important phenomenon because it has repercussions on the development projections for poor people as well as the future of the organizations themselves and the broader political economy of which is growing and they belong to (Hulme & Edwards, 1997:5). This makes them attract more funding where they even have the influential power to affect policy-making forums, the media and the views of the general public which has never been highly influenced to this degree before (Hulme & Edwards, 1997:3).

The significant change has also brought about the change in which international aid funds channeled their money. For example, foreign aid in the case of channeling funds to tackle problems such as illiteracy in sub-Saharan Africa has chosen to use NGOs as the principle channels. This is because:

> "*while any aid program will experience a level of waste and corruption, funds send straight to the field, often in relatively small amounts via NGOs, are far more likely to be better spent than those flowing into the treasuries of countries... where any effective government has ceased to exist" (Clad, 1993).*

Even if NGOs have a long history as the providers of welfare services to poor people, particularly in countries where the governments were short on resources to guarantee universal coverage in health and education, the differences are now seen when the funders have chosen the favoured channel for service-provision to be through NGOs in the deliberate exchange for the state providing these welfare services to the poor (Hulme & Edwards, 1997:6).

This reason for this channelling of foreign funds being handled by the NGOs is because they work more directly with the poor people and this is the most effective strategy that they apply in trying to implement and carry out projects that will bring about lasting development, like alleviating poverty. NGOs tend to stand by the ideologies of 'sustainability and participation', integrating these elements into all the facets of development programmes, so to attain the desired change that the NGO and the funders are supporting (Collier, 1996 cited by Eade & Pearce, 2002:115). This intricate relationship between NGOs and their donors will be discussed later in the paper.

The abbreviation 'NGO' continues to make an impression on the daily language for professionals, activists and regular citizens where various images, representations and the work of NGOs has become normal (Lewis & Kanji, 2009:2). We see various NGO advertisements on social media networks such as Facebook, blogs, and YouTube and we see various billboards and newspaper adverts that inform us of the work that NGOs do. NGOs are also highlighted blatantly in cultural life such as movies and books (Lewis & Kanji, 2009:2). Take for instance the Hollywood film *Beyond Borders* staring Angelina Jolie where the epic tale of the turbulent romance between two star-crossed lovers is set against the backdrop of the world's most dangerous hot spots and they bring to the forefront the issue of refugees and issues of food insecurity in Africa and Cambodia. Through the promotion of the film the actress becomes a goodwill ambassador (a high profile for celebrity representatives) where she ends up working for the United Nations High Commissioner for Refugees (UNHCR). At the end of the film the UNHCR is highly advertised through the real life documentaries of the work they do and they encourage the viewers to support the donation effort geared towards the alleviation of hunger in Africa.

When films and celebrities are highly involved with NGOs, we often see more traction in the social media around the world on the World Wide Web; this gives the publicity for the film and the NGO. There still remains an unexpectedly difficult task of understanding the

phenomenon of NGOs even if they seem to be everywhere (Lewis & Kanji, 2009:2). This is due to NGOs being diverse groups of organizations and as an analytical category they are complex where they are often unclear and difficult to grasp (Lewis & Kanji, 2009:2).

NGOs need to be understood according to Hilhorst as 'open-ended processes' because they do not have static limitations and they generally do no function in isolation (Hilhorst, 2003). NGOs are organizational structures which are usually non-membership based and are sites of employment, which imply that they are bureaucratic and have hierarchical structures that help to assist them run efficiently. NGOs can be termed as organizations that are non-state groups and are engaged in issues that generally mirror the range of concerns articulated by global justice movements (Borras, 2009:205). This could be because NGOs are seen as one of the channels that create the opportunity for operationalizing the new policy agenda's economic and political goals (Hilhorst, 2003:1997). According to Moore (1993) this is because NGOs are viewed under the lens which portrays them as 'vehicles for democratization' and they are vital mechanisms that will ensure a thriving 'civil society' (Hulme & Edwards, 1997:6). This will be seen through the work of the TAC and Section27.

4.2 Understanding the Historical Context of the Development of NGOs

As mentioned above, from the late 1980s onwards NGOs have gained a far larger role and profile on the site of development than they had previously. NGOs were highly celebrated by donors because they brought to the forefront new solutions to complex and long-standing development problems (Lewis & Kanji, 2009:24). They brought about new concepts to altering development thinking and practices where different concepts of participation, empowerment, gender, and the introduction of making person-centred approaches to development became more important (Robison, 1993 and Lewis & Kanji, 2009:24). This raised the level of expectation of NGOs particularly as they were seen as what Vivian (1994) called a 'magic bullet' because to donors NGOs were a 'quick fix' since they could clear the dissatisfaction, disappointment and standstill that had come to brand the development world (Lewis & Kanji, 2009:24). Due to NGOs being put on the pedestal to deliver on change evidence proved that many of the NGOs in the late 1990s failed to deliver on their promises of improvement.

The history and origins of NGOs are definitely assorted and they are rooted as in a range of complex historical, cultural and political factors from various corners of the world (Lewis & Kanji, 2009:34), meaning that NGOs cannot be neatly categorized under one umbrella or be generalized due to their varying histories. Carroll said that:

> *"All NGOs operate within a contextual matrix derive from specific locational and historic circumstances that change over time" (Carroll, 1992: 38 cited in Lewis & Kanji, 2009:34).*

This can be seen through the context of South Asia, where NGOs in India highlight distinctive factors such as them being influenced by Christian missionaries which was due to the growing reformist classes in various locations of the country. Whilst Mahatma Gandhi was at the forefront of advocating for the notion of voluntary action through his campaign for villages to utilize self-reliance which was the epicentre of his vision for development in India (Sen, 1992 and Thomas, 1992). His notions later birthed organizations such as Association of Sarva Seva Farms (ASSEFA).

In the context of Latin America NGOs were also influenced by the commitment that churches had to the poor and this was linked to some degree to the growth of the popularity of Protestantism (Escobar, 1997) all based in the existence of the Catholic Church and this was in the midst of the rise of the liberation theology of the 1960s (Lewis & Kanji, 2009:35). The radical ideas about 'education for critical consciousness' and organized community action, a philosophy of Brazilian educator Paulo Freire, was highly influential (Blackburn, 2000). Freire argued that the uneducated poor usually possess a 'culture of silence' that could be challenged by radical education which could motivate the poor to be more critical of the status quo and shape new liberating structures and developments for change (Lewis & Kanji, 2009:34). Freire's notions stirred and informed existing NGO tactics where 'participatory budgeting processes' are being used in cities such as Port Alegre, Brazil (Guareschi and Jovchelovitch, 2004 cited in Lewis & Kanji, 2009:35).

In the Middle East and Jordan factors such as the political repression, especially the political reforms that occurred during 1989, meant that NGOs were initially involved in apolitical activities like welfare provisions such as healthcare, education and orphanage support. The increasing Islamic NGOs which opposed the regime predominately channelled their activities to provide services that centred on healthcare, scholarships and religious cultural work (Lewis & Kanji, 2009:37). There is also a strong presence of the 'royal' NGO (RONGOs) sector being run by the members of the Hashemite family and they demonstrate concern for the welfare of its people through the activities that they do (Witkorowicz, 2002 cited in Lewis & Kanji, 2009:37).

Another type of organization is the formation of the grassroots organization Take. The landless labourers could see opportunities in the arable land surrounding them and, through government connections to attain resources, they could use the land for collective purposes which could outweigh the individual risks of taking over huge pieces of land (Lewis & Kanji, 2009:38).

These examples above portray that NGOs take on various forms due to the contexts from which they come because people organize in response to perceived opportunities. NGOs can then be grounded on a three-level structure of organization within a society, 1) new development NGOs which have been created by outside ideas and resources meaning that these are NGOs usually built from scratch; 2) development of NGOs which have emerged out of pre-existing associations and groups; and 3) the diverse range of pre-existing, informal grassroots associations in a society (Lewis & Kanji, 2009:38-39).

4.3 NGOs and Development Theory

To briefly understand the world of NGOs this paper will be taking the understanding of NGOs as local voluntary private non-profit organizations that are involved in carrying out projects and programs that provide relief, rehabilitation and development and who achieve their goals by utilizing finances that they raise through voluntary, private sources, and donor agencies, and these NGOs that the paper will refer to are those NGOs that manage themselves to some degree autonomously at local, national and/or international levels (Kuruluşlar et al, 2003:299). By NGOs managing themselves autonomously to some degree I mean that they lay out their own aims and go after funding that will support their aims and not necessary be driven by the donors' aims. This is because NGOs can be categorized in various sectors as they can either be considered as 'non-state bodies', they are sometimes seen to be part of civil-society and they are sometimes organizations that are funded by the private sector but are still not-for-profit (Helliker, 2006:7). Korten (1990:115) refers to NGOs which are involved in projects or programs that deal with 'care and welfare' inherited from the 19th century to today through the generous work or charity that thrived in industrial countries (Kuruluşlar et al, 2003: 299-304). This type of work was usually carried out in rural areas where the national governments did not or could not reach (Kuruluşlar et al, 2003:299-304).

In the development industry NGOs gain their prominence in the 1980s because of the drive of a combination of four clusters of interrelated factors. According to Booth (1994) the first was the 'theoretical impasse' within the development theory when the main stream theories of 'modernization' and dependency theory lost their appeal over a period of two decades, so

NGOs were seen as the source of alternative ideas where useful organizational actors could come to the forefront and possibly open up new theory and practice (Lewis & Kanji, 2009 and Edwards & Hulme, 1995). The second was shift away from 'government to government aid' and donor funding from the northern and southern NGOs increased and this was because development agencies decided that governments had accomplished very little in the fight against poverty and they were against how the government had contributed to growing levels of bureaucracy and corruption (Lewis & Kanji, 2009:40). According to Bordhead (1987) the new policy interest in NGOs was driven by disillusionment that NGOs could solve development issues and often this was fuelled by donors who overstated the potential of NGOs (Lewis & Kanji, 2009: 40). Third, NGOs had experience of issues such as the environment, gender and social development and they contributed to development through bringing forward new ideas to development and this made them move closer to the aid system (Lewis & Kanji, 2009:40). Fourth, when the Cold War ended in 1989 it opened up the doors for a new private space to exist and this reconstructed and shaped the former socialist societies and economies and these were becoming transitioned into Western-type liberal capitalist countries (Lewis & Kanji, 2009:40).

4.4 The Rise of NGOs in Development

According to Anheier (2005) what existed at the periphery of governments and development agencies have been a range of local organizations and initiatives which have operated for generations in the form of religious organizations, community groups and organized self-help ventures in villages and towns (Lewis & Kanji, 2009:31). Then during the colonial era European countries that powered a large area of the less developed world brought along the use of missionaries which often used typical NGO initiatives which tried to improve the fields of education, health service provision, women's rights and agricultural development (Lewis & Kanji, 2009:31). Fernado and Heston (1997) further build on to say that this resulted in the NGOs stressing welfare approaches, charity and empowerment approaches which resulted in the attraction of development that was community organizing and was from the bottom-up (Lewis & Kanji, 209:31).

Looking at a brief historical formation of the a few NGOs will give perspective to how many of them began before they became world renowned. Charnovitz (1997) traced the seven evolutionary stages of NGOs in the West from 1775 to 1992. This can be seen in the table below (**The seven historical stages of Western international NGOs,** Lewis & Kanji, 2009:32):

Stage	Example
• Emergence (1775-1918)	Anti-Corn Law League founded in 1838 in Britain to campaign against unfair tariffs
• Engagement (1918-1935)	International associations given representation in the newly established League of Nations
• Disengagement (1935-1945)	The League of Nations falls into decline as Europe falls into authoritarianism and war
• Formalization (1945-1950)	Article 71 codifies selected NGO observer status at the new United Nations under ECOSOC
• Nuisance Value (1950-1972)	NGOs generally marginalized as UN processes dominated by governments and Cold War tensions
• Intensification (1972-1992)	NGOs play ever higher profile roles in succession of UN conferences from Stockholm 1972 onwards
• Empowerment (1992-?)	The Rio Environment Conference marks the new ascendancy of NGOs in development and international affairs

As Carroll (1992:38) points out:

> *"All NGOs operate within a contextual matrix derived from specific locational and historic circumstances that change over time."*

The above point can be made through looking at the following examples where in the United Kingdom the larger internationally known NGOs existed for many years prior to the boom of the rise of NGOs in the 1980s forwards and their main focus was relief work in Europe (Lewis & Kanji, 2009:31). The now world renowned NGO, Save the Children Fund (SCF), was founded in 1919 by Eglantyne Jebb and it was created after the First World War and after the Second World War the US agency CARE was formed to send food packages to Europe in 1946 (Lewis & Kanji, 2009:31).

NGOs became highly associated with the world of international aid over the duration of the last decade in the twentieth century and NGOs have been birthed from self-help communities and the longer-term traditions of various forms of philanthropy across a multitude of cultures throughout history and it can be defined as 'the ethical notions of giving and serving to those beyond one's immediate family' and this has been frequently driven by religious tradition (Ilchman et al. 1998 cited in Lewis & Kanji, 2009:30-31).

Various literature has proved that NGOs are not new to the world of development. They have received so much credit both reputable and bad. They are documented as 'high-profile actors' in the arena of international development where they have played a dual role of being providers of services, mainly to those that are part of the vulnerable sector of a particular community. NGOs have also played the role of being campaigning policy advocates (Lewis & Kanji, 2009). NGOs and Grass Roots Organizations (GRO) are meant to perform as a counterbalance to state authority by introducing and implementing channels of communication and participation whilst also providing training grounds for activists endorsing diversity and by defending human rights (Hulme & Edwards, 1997:6).

Development NGOs registered in the Organization for Economic Cooperation and Development (OECD) countries of the industrialized north have increased in number. The total spending in 1980 with 1600 NGOs was US$ 2.8 billion but in 1993 the number of NGOs had risen to 2970 and the spending rose to US$ 5.7 billion (OCED, 1994 and Smillie and Helmich, 1993 cited in Hulme & Edwards, 1997:4). From the Emergence (1775-1918) stage of NGOs according to the Commission of Global Governance (1995) the number of international NGOs rose from 176 in 1909 to 28 900 in 1993 (Hulme & Edwards, 1997:4). This rise in the number of NGOs was occurring all over the world and this was also evident in Tunisia where there were 5186 NGOs registered in 1991 and the growth from then on was slow as in 1998 there only 1886 NGOs that registered with the OCED (Hulme & Edwards, 1997:4). The growth of NGOs to being decision-makers in both the north and the south has greatly increased due to their advocacy role where they are involved in debates over policy and practice which is on a continuing expansion rate (Hulme & Edwards, 1997:5). After the year of 1992 and the UN Earth Summit in Rio the number of NGOs continued to amplify and in 1995 in Beijing NGOs received greater news coverage than the official UN Women's conference (Hulme & Edwards, 1997: 5). The rise of NGOs can be explained by the increasing acceptance that they had with governments and official aid agencies and this

speaks to the response to the new developments within the world economic and political thinking (Hulme & Edwards, 1997:5).

It is important to note this significant rise in the number of NGOs because this has implications for the way in which the development prospects of the poor are handled as well as the future of these organizations and how they have the influential power to affect and be impacted by the political and economic thinking of which they form a growing part (Hulme & Edwards, 1997:5).

From the early 1990s NGOs had gained much prominence in the world of development as literature on NGOs was more available in the mainstream position particularly in development policy (Lewis & Edwards, 2009:38). NGOs according to Brodhead (1987:1) were 'catapulted into international respectability' and governments and multilateral institutions saw them as important actors in development (Lewis & Edwards, 2009:38). This is because NGOs attracted the interests of both activists and people who were interested in discovering and implementing alternative development strategies within the general global trends in international development (Hulme & Edwards, 1997; Hilhorst, 2003 and Lewis & Kanji, 2009:35-39). It could be argued that due to industrialization and globalization NGOs gained international recognition. According to Chrnovitz (1997) NGOs gained recognition due to a combination of these factors: "growth of intergovernmental negotiation around domestic policy brought about by increasing integration of the world economy; the end of the Cold War, which removed the polarization of global politics around the two superpowers; the emergence of a global media system which provides a platform for NGOs to express their views; and the spread of democratic norms which may have increased public expectations about participation and transparency in decision-making" Lewis & Kanji (2009:39).

4.5 NGO Context in South Africa

Non-governmental Organizations (NGOs) are organizational structures which are usually non-membership based and are sites of employment, which implies that they are bureaucratic and have hierarchical structures that help to assist them run efficiently.

The first NGOs that emerged in South Africa were those that were forged out of the historical struggle against the apartheid (Wallace et al, 2006:83). The NGOs that existed during the 1950s were closely linked to welfare activities and these were predominately linked to urban poverty and those that emerged in great numbers during the 1980s onwards particularly focused on addressing the needs of the marginalized blacks that lived in Bantustans and

townships (Wallace et al, 2006:83). Their main focus of these NGOs was to provide non-racial social service delivery and this provided a type of shadow welfare system in support of the mass-based movements and the poor (Habib & Taylor, 1999:75). The organizations that came during and after the 1980s during the apartheid era took their identity as the opposition to the oppressive regime and this attracted donor funding both secretly and openly particularly from solidarity organization that were based outside the country (Habib & Taylor, 1999:74). This laid a good foundation for the NGOs that came to exist after the struggle because they could draw international staff with greater knowledge and who have a better understanding with donors and their constituents, who are willing to take a stand and challenge and question policy and practices that they do not agree with (Habib & Taylor, 1999; Wallace et al, 2006:83). There were a few NGOs during the 1990s that were linked to international funders and many of them relied upon the local and non-grant sources of funding (Wallace et al, 2006:83). Many of the donors shifted their funding from anti-apartheid struggle towards development through the government and this occurred once President Nelson Mandela was elected into office (Wallace et al, 2006:83 and Habib & Taylor, 1999:75). Many of those that were employed by NGOs filtered to work in government and they acted as liaisons between the government and the NGOs which were involved in debates that surrounded issues of policy, land, housing, literacy and gender inequalities (Wallace et al, 2006:83). In the midst of the transition NGOs became insecurely positioned when policy was defined and adopted: government became increasingly resilient to external criticism and as a result some NGOs struggled to find entry points and forms of working with the official government departments that are meant to provide official services, whilst other NGOs found themselves 'caught between their role as contracted agents to implement programs and their accountability to their constituents and local beneficiaries' (Wallace et al, 2009:83). It could be argued that the change in government, like the transition from the apartheid regime to the post-apartheid regime, can be a contributing factor that has power to alter and regulate the relationship between NGOs and the government as well as NGOs and the communities they are helping out.

This is further supported by Helliker (2006:2) when he mentions that NGOs represent inconsistent relations where there are contradictions between 'the global' and 'the local'. This is affect by the NGOs finding themselves in a catch-22 space in which they wrestle between their upward accountability that they have towards their donors and also their downward accountability towards the communities in which they are working.

NGOs can also be referred to, according to Helliker (2006:8) and Helliker (2013:318), as 'intermediary' and this brings to the forefront how NGOs have been labelled as 'problematic organizations' because they are located within an unclear social space as they are part of a 'complicated web of social relations as part victim and part maker'. This is because they have to negotiate their existence in the communities that they are in as 'agents' of the work that they do and as 'intermediaries' (Helliker, 2006: 8). NGOs can be intermediary because they create links between the beneficiaries, donors or financial institutions and links to 'often' remote levels of government (Caroll, 1992:11 cited in Helliker, 2006:7-8). Because NGOs are generally seen as protective, defensive and resilient to disapproval, they are involved in 'turf struggles' and they sometimes 'fall back into narrow self-justification' which means that that NGOs involve themselves in balancing practices; which make up their work and world, that make their work more manageable (Helliker, 2013:318).

This is where the Vangaurdist politics of NGOs emerge. When speaking of Vangaurdist politics here, the argument that needs to be understood is that there is an issue of NGOs being stuck in the catch-22 position that was spoken about earlier. Where the issue then becomes about how NGOs are exist in a situation that blurs the lines as to whether they are either more downward accountable or upward accountable, this has the power to determine their existence when it comes to donor funding (Helliker, 2013:321 and Lewis & Kanji, 2009:18). As they tend to go in search of funding, they find that donors have their own requirements that need to be met, like report writing and carrying out the donor' stipulations for the NGO to do certain projects or programs so that they can continue to be funded. This then determines what projects the NGOs can carry out and which donors these NGOs decide to associate themselves with. These power relations highlight the way in which NGOs then tend to be seen as forces that undermine progressive social movements which constitutes the existence of the domination that some NGOs have over social movements. This is where NGOs are seen as "imposing their own agendas and becoming self-interested actors at the expense of the people they are in theory supporting" (Lewis & Kanji, 2009:18). That is why to some extent the NGO will experience a shortcoming, particularly because of the dual relationship of being both "facilitator and mediator" (Andrews, 2007:203). This is a position that is difficult to uphold when the NGO has its own agenda that it needs to meet to ensure its own survival and, because it is a site of employment, it uses a top down approach to some degree when working with the rural movements. This will be further unpacked when

discussing the Treatment Action Campaign and Section 27 to further understand their contributions, strategies and effectiveness as NGOs.

From about 1996 NGOs working in development could access international funding with virtual effortlessness and this was when donors were searching for local partners and funds were obtainable to NGOs (Wallace et al, 2006:83). Then the time period post-1996 funders selected to back the new government's programs, seemingly with a share reserved for feeding into local NGOs (Wallace et al, 2006:84). The conditions placed on funding increased as did the diversity of programs and donors. As an effect of this back donors such as the Department of International Development (DFID) stiffened restrictions on aid distribution (Wallace et al, 2006:84). South Africa can serve as principal example of a country which, due to its past practices of conflict and activism, is entwined with the problem of financial vulnerability and dependency (Wallace et al, 2006: 84).

The NGOs in South Africa, that act as national efforts to accelerate delivery of crucial services, also serve to democratize government and they also stimulate the government by backing the ANCs growing development programs, but then this created pressures over likely roles that NGOs played as civil society organizations (Wallace et al, 2006:86). Post-apartheid 1994 NGOs had great difficulty not only in creating new identities for themselves that were apart from being anti-apartheid organizations as they were no longer relevant once the struggle was won but they also struggled to create a relationship with the new democratic government at both a national and a local level as well, as redefining their relationships with broader communities (Wallace et al, 2006:86). There was the expectation that NGOs would act as advocates for marginalized peoples, as government watchdogs, as agents of delivery and training, among others (Wallace et al, 2006:86). Broader literature on NGOs in South Africa proposes that these possible roles are often mismatched and, as result of the transition and redefining themselves, many of the NGOs are becoming either more commercial in their dealings with the government and beneficiaries or more confrontational towards the ANC government (Wallace et al, 2006:86-87). There were some NGOs that had favour with the government and this gave them an advantage when it came to their dealings with donors and the government due to the legacies of the struggle (Wallace et al, 2006:87). The NGO sector is large and varied, with leaders from a diverse range of racial, ethnic and national backgrounds and some of the NGO leaders have moved in and out of ANC leadership positions (Wallace et al, 2006:87). Unions are strong, and local activism has brought

important changes to government policy and international relations, especially around HIV/AIDS and peace and justice work (Wallace et al, 2006:87).

4.5.1 Human Rights Movements

TAC and Section27 are grounded in the use of the tools of human rights movements in trying to materialize their vision and mission statements. This is because they are civil society organizations that can internationally locate their activities within the international human rights framework. Heywood (2009:16) highlights that this can be the case if these organizations are working within the vision of the Universal Declaration of Human Rights.

The publication of the International Guidelines on HIV/AIDS and Human Rights by the United Nation's Joint Program on AIDS (UNAIDS) and the UN Office of the High Commissioner for Human Rights (OHCR) in 1998 has assisted to expose governments who are violating the standards set out in the document and the document can be merged into advocacy. As a result the value of emphasizing human rights to claim a normative international standard has amplified in 'currency' in the field of HIV/AIDS from the early 2000s (Heywood, 2009:16). NGOs re-articulate political and social issues as human rights problems and to some degree this has contributed towards what Reich (2002) calls 'reshaping' the state because new technologies 'have created new sources of power: through the flow of ideas, information, alliances, strategies and money' (Heywood, 2009:17). Heywood (2009:17) argues that many NGOs have not focused their day to day workings on promoting and being involved with social movements where the poor for whom 'human rights are a personal need' regardless of the NGOs' existence, are their advocates because most these organizations have created a foundation where they advocate ideas through an 'apparatus and a handful of professionals, gaining their strength from their media reach and modern communications'. He further argues how the TAC has implemented a different approach where it will follow human rights claims particularly directed against the poor whilst also catalyzing a political movement for health (Heywood, 2009:17).

4.5.2 The Treatment Action Campaign and Section27

The Treatment Action Campaign (TAC) and Section27 are two civil society organizations involved in the HIV and AIDS sector. The TAC was established on 10 December 1998 and the key goal was to make sure that HIV positive people in particular received access to safe and effective Anti-Retro-Viral (ARVs) medicines that were widely available in developed countries but were scarce in South Africa (TAC, 2010:9; Heywood, 2009:15 and Geffen, 2010:48). This has largely contributed to the cost of ARVs being too high and as a result

only a few of the richer South Africans can afford the medication (TAC, 2010:9 and Geffen, 2010:49). The majority of the poor South Africans, however, who are living with HIV have a higher morbidity rate as they cannot access the needed medication to regulate the disease (TAC, 2010:9). The leaders of the TAC acknowledged that HIV, although a virus, is indicative of being part of the deeper social and political catastrophe that is faced by the poor people, and that the escalation of HIV to pandemic proportions is because HIV transmission is frequently through social fault lines produced by poverty, inequality, and social injustice (Heywood, 2009 and Heywood, 2009:15). That is why the founders of the TAC are trying, through popularizing and enforcing using a combination of protests, mobilization and legal action, to attain what they described as 'the right to access to treatment' (Heywood, 2009:15 and Geffen, 2010:49). That is why the fight against HIV and access to treatment was fought on the streets in March 1999 when activists in Braamfontein and Soweto attained 13 000 signatures from people in clinics, hospitals, schools, shopping centres and bars. Heywood mentions that this mass mobilization was done "in support of the demand for a prevention of mother-to-child transmission program"; they further won the fight in the courtroom, where the organization influenced the government to begin providing all-inclusive health care services particular for the poor South Africans (TAC, 2010:9 and Geffen, 2010:49). Heywood further mentions that the TAC staged demonstrations with its first being held on the 21st of March 1999 at the Chris Hani Baragwaneth Hospital where approximately 250 people consisting of doctors, traditional healers, church leaders and those infected and affected by HIV as well as branches of the South African Communist Party and members of the Congress of South African Trade Union (Cosatu) and various other AIDS organizations in Johannesburg were part of the staged 'lie-down' that was demanding a prevention of mother-to-child transmission programme (TAC, 2010:7). This mass-mobilization and demonstration gained traction for the organization and this attracted volunteers who formed various groups that drove the campaign into their communities.

To begin with the TAC focused on its main obstacle to increasing the awareness of the existence of the right to health which can also be found within the context of HIV where privately owned pharmaceutical companies had to be informed that the aim of reaching the bottom line by excessively pricing of crucial ARV drugs has resulted in these medications being put out of reach of the poor, particularly in developing countries (Cameron and Berger, 2005 cited in Heywood, 2009:16).

It is clear that the price of HIV drugs was one of the first driving elements that contributed to the lack of access to treatment and this is part of the foundation upon which the TAC was built.

TAC started as a campaign within the National Association of People Living with AIDS (NAPWA). NAPWA South Africa is a 'non-political, non-discriminatory, non-governmental, not for profit, membership-based organization that does not discriminate based on race, age, creed, sex and sexual orientation.' NAPWA South Africa is widely spread out through the country and it has nine (9) provincial offices, with more than 500 branches with a membership base of approximately 300 000 and an innumerable number of ever cumulating support groups throughout the country (NAPWA, 2010:2 and Geffen, 2010:49). NAPWA's vision is that it is a society which is all-inclusive and it 'cares for, supports, empowers and defends the rights of people living with HIV and AIDS' to ensure that they are not ostracized by their community members and they can continue 'to live as humans with full potential in South Africa' (NAPWA, 2010:1). NAPWA's mission as a 'non-political, non-discriminatory, non-governmental membership based organization' aims to enable and 'advocate for the social-economic development of people infected and affected by HIV/AIDS' and they aim to develop social structures that will have at their core the discourse aimed at issues of 'care, support and prevention' of HIV/AIDS and they aim to be in 'partnership with relevant organizations and the broader community' (NAPWA, 2010:1-2). The vision and the mission statements of NAPWA lay the cornerstone for the TAC. The Aids Consortium during the early years of the 1990s brought together organizations such as NAPWA and the Aids Law Project (ALP) and through sharing various resources about HIV and human rights available to each entity they planned campaigns (TAC, 2010:7), with the mission of making their mission statement a reality. This partnership is best explained through how Heywood (2009:15) describes TAC's aims as being to:

> "*Challenge by means of litigation, lobbying, advocacy and all forms of legitimate social mobilization, any barrier or obstacle, including unfair discrimination, that limits access to treatment for HIV/AIDS in the private and public sector.*"

The TAC was deliberately launched on International Human Rights Day because it was addressing the need to avail treatment to the millions of South Africans who are HIV positive (TAC, 2010:4 and Pillay, 2003). The TAC cemented the pathway for the state to begin providing full health care services to HIV positive people (Willems, 2011). The lack of

access to ARV treatment coupled with the high prices of drugs in South Africa and 'the lack of political leadership, starting from the top with ex-President Thabo Mbeki and the Ministry of Health under the late Minister of Health, Dr Manto Tshabalala-Msimang', contributed to the high incidence of HIV in provinces like the Eastern Cape, Mpumalanga and Kwa-Zulu Natal' (TAC, 2010:9). This has been discussed above in how the apartheid regime had some influence on the HIV/AIDS epidemic in South Africa post 1994, including the mismanagement of the constitutional rights and lopsided information given to the public by the former head of state, President Thabo Mbeki, supported by the now late Minister of Health, Dr Manto Tshabalala-Msimang. This would serve to be an element to explain how there was no treatment plan implemented until 2004 and there was no ambitious strategic plan until 2007, when the Cabinet adopted the National Strategic Plan (NSP). The TAC used court cases and intense community mobilization as the order of the day 'in dealing with a non-responsive and arrogant government' (TAC, 2010:9).

The TAC as an NGO acts as a site of employment and a space which people like the TAC chairperson, Nonkosi Khumalo, refer to as an organization that served as a learning and leading centre, where people 'learned about politics, leadership, democracy, law and social mobilization' (TAC, 2010:9). Here the organization not only focused on HIV issues but it also branched out to form one of its core elements which looks into issues about 'access to health care' and this is where Section 27 of the Constitution became highlighted (TAC, 2010:9).

According to Deena Bosch, one of the founding members of the TAC, the 'TAC is an extension of the work started in the Bellville Community Health Project with Zackie Achmat, Jack Lewis and others who joined the Marxist Workers', tendency of the ANC in the mid-1980s,' (TAC, 2010:4). This was an organization that was launched through 10 members who fasted on the steps of Cape Town's St George's Cathedral, where they launched the first TAC statement that read:

> "*The National Association of People Living with AIDS (NAPWA) has initiated the Treatment Action Campaign to draw attention to the unnecessary suffering and AIDS related deaths of thousands of people in Africa, Asia and South America. These human rights violations are the result of poverty and the unaffordability of HIV/AIDS treatment. The Treatment Action Campaign calls on the minister of health, Dr Zuma, and Trevor Manuel, the minister of finance, to meet immediately with NAPWA and*

> *HIV/AIDS organizations to plan for resources to introduce free AZT [an antiretroviral drug] for pregnant mothers with HIV/AIDS..TAC also calls on government to develop a comprehensive and affordable treatment plan for all people living with HIV/AIDS*" (TAC, 2010: 6).

These were the early days of the TAC and the above clearly states the core aims of the organization and at the time they were fighting for access to the basic treatment medication for HIV/AIDS to be made not only more available, particularly for the HIV positive pregnant women, but also free. The TAC even 10 years after its development still holds at its core the importance of preventing mother to child transmission of HIV.

The TAC acquired moral and legal strength from the South African Constitution, which entrenches rights to equality, life, dignity and it says:

> *Everyone has the right to have access to-*
>
> *Health care services, including reproductive health care (SA Constitution, Section 27).*

The founders of the TAC were not highly knowledgeable in the understanding of the South African public health or its politics. That is why, according to London:

> *"The Treatment Action Campaign (TAC)... has shifted the debate firmly to one of fundamental human rights and utilized the human rights machinery established by the same government to force its hand on the ARV issue" (London, 2006: 12).*

When the TAC began it made it its mission to focus on the reduction of the excessive pricing of crucial medications as mentioned above; through doing this they highlighted the key players such as multi-national pharmaceutical companies, who according to them had clearly dishonored a variety of the human rights issues which, since 1996, had been engrained in the South African Constitution (Heywood, 2009:16). This is where the organization was strengthen through the legal expertise of Section27 as the founders of the TAC were not highly knowledgeable in the understanding the South African public health or its politics. Section27 was established in May 2010 and it integrated with the then AIDS Law Project. Section27 'is a public litigation center that uses and develops the law to protect, promote and advance human rights' and it draws its name from Section 27 of the South African Constitution which says 'that everyone has the right to have access to health care services' (South African Government, 1996:1255). Through the use of its own resources and the

TACs it contended that intellectual property and patents were protected by the law and this was further strengthened under the World Trade Organization's 1995 TRIPS agreement. Heywood (2009:16) argues that 'this was not an inherent human right, but a device granted by the state for a public purpose'. It could be argued that there are suggestive causal relations that are between the states and these pharmaceutical companies where reaching the bottom line is done at the expense of the violation of human rights as well as having constitutional injustices being suffered by the poor.

The TAC and Section27 have bestowed upon themselves the duty to 'protect and promote human rights' particularly in South Africa because it has made health rights subject to trial in the court of law and this has inferences for the conduct of government (Heywood, 2009:16).

Myburgh (2007) mentions that the TAC went through the learning curve of being aware that in developing countries there is a higher risk of the government being negligent of public health this is evident through the 'democratic pro-poor governments such as the African National Congress (ANC) in South Africa' (Heywood, 2009:16). He further notes that this can serve as an obstacle to the poor gaining access to the right to health as much as it is a 'profiteering' by pharmaceutical companies (Heywood, 2009:16). This it could be argued is rooted within the progression of the modernization theory and thus it could be viewed as one of the 'consequences' of economic globalization.

It is important to note that there are interrelated relationships that exist between, for instance, the 'rights to dignity and equality' because they influence both a positive and/or a negative scope on nearly every aspect of social life and political control. The reason that the TAC took up this rationale was because there was a 'distrust of the professional AIDS and human rights movement' and this frequently appeared to be an element of the global industry reproduced by the epidemic. Heywood claimed that this approach was 'articulate but ineffective' (Heywood, 2009:17).

This means that there is a need for community-based activists to be knowledgeable in the various ways in which they can articulate and know how best to apply their human rights so as to tackle issues related to particular social and political problems (Heywood, 2009:17). The right to health cannot be pursued effectively if it is not connected to issues of law, politics or governance (Heywood, 2009:17). This is because the right to health is recognized in international covenants, national constitutions and jurisprudence. That is why the TAC saw the need to build this capability from the bottom with the support of the law, human

rights and the Constitution but, most importantly, they saw the need for the health movement to be led by people who are HIV positive. The TAC took on this model from the United States AIDS activists who established the idea of 'treatment literacy'; which thrived on the belief that to 'fight for rights effectively, people also are required to understand the science of HIV, what it was doing to their body, the medicines that might work against it, the research that was needed' especially amongst people with HIV (Heywood, 2009:17). The TAC was the first organization that implemented this model in a developing country and in doing so it partnered with treatment literacy activists such as Gay Men's Health Crisis (GMHC) and ACT-UP (Heywood, 2009:17). Treatment literacy for the TAC is the largest apparatus and it has the potential to be used to increase the means of mobilization and local organizations because it has been ongoing behind both TAC's campaigns and court cases (Heywood, 2009:18). Treatment literacy provides the basis for 'self-help and social mobilization' as this empowers people with the appropriate knowledge about HIV, and poor people can gain power by being their own advocates on both a personal and a social level (Heywood, 2009:18). With the access to correct data about health and linking the information to 'rights empowered marginalized people' resulted in both a public voice and greater visibility (Heywood, 2009:18).

In conclusion in many villages and townships TAC activists, empowered by treatment literacy, are highly confident that by having both the law and human rights at the centre of their course assists them to continue fighting for the right to health care and this further legitimizes their work. The model used by the TAC has helped to create a 'national social mobilization capable of unifying people to demand the right to health from government and pharmaceutical companies'. In addition, on the local level it shaped an 'empowered citizenry' and this has aided by demanding the government deliver on promised healthcare services, particularly within poor communities, through rights stipulated in constitutional law. The following discussion will deal with understanding the link between health and human rights.

4.6 Health and Human Rights

Health has been narrowly defined as:

> *"The physical and mental well-being of individuals"* (Armaline et al., 2011:91).

That is why Ratcliff (2002) notes that Americans have usually looked at the state of the country's national health through an individualistic lens and that is why a narrow definition

of health exists (Armaline et al., 2011:91). Ratcliff argues that the general assumption which is used to measure public health is reduced to the extent to:

> *"Which individual's experience diseases, physical and mental maladies are viewed as the result of viruses, bacteria, injuries, lifestyle choices, diet and genetic factors"* (Armaline et al., 2011:91).

He notes that is important to take into account that they are richly linked to social structural variables where at times they occur due to the consequences of public policy implementation (Armaline et al., 2011: 91-92). This is why the maintenance or the improvement of health becomes reliant on a person's own actions and those of doctors, other health care providers and the health care system rather than the way society is structured and organized (Armaline et al, 2011: 91). This is why there is a need to analyse health as a social structural issue and this will allow the conversation to develop into being about health as a human right rather than it being about health as a personal issue (Armaline et al., 2011: 91-92). Michael Moore portrays through his documentary *Sicko* (2009), the same view as Armaline et al (2011) and he does this through tackling the various reasons why the United States health care system is failing so many people who are not only unemployed but are also part of the lower working class.

Michael Moore does a comparison of costs for health care services in first world countries such as France, Canada and the United Sates. There are great disparities which become evident. At the root of the American health care system the multinational pharmaceutical companies are the ones that are in control of determining the role out of medication and also the access to health care services. This is legitimized through the use of medical health schemes where individuals are responsible for paying for part of their medical procedure or the use of medical facilities for a fixed monthly payment.

This is the similar case in the South African health care system where there are people who rely on the public health care sector that is mainly funded by the state and the services are usually rendered poorly or they are non-existent at all. The South African government has poorly funded many clinics in the rural areas and by doing so the government is infringing on people's rights to health care, because in the public health sector people cannot gain access to the needed medical services and care. This will become more evident in the data analysis chapter where the differences are described between people who use the private health care sector and those who use the public health care sector.

Conclusion

This chapter considered the international and national landscape for NGO work, with particular focus on the TAC and Section 27 working in the rights and health landscape. The chapter further discussed the historical background of the TAC and the current strategies and calculations of its activities were explored. This chapter brought to the forefront that there was a need to analyse health as a social structural issue because this will allow the conversation to develop into being about health as a human right rather than it being about health as a personal issue. This brings the discussion to the next chapter of the thesis which will discuss the South African constitutional law that states the South Africans right to health which are rooted in both the TAC and Section 27s goals as mentioned in this chapter.

CHAPTER 5: CONSTITUTIONAL LAW

Introduction

This chapter will now move on from the human rights discussed in the previous chapter to the discussion of the South African Constitutional law. This will be done through noting the laws that are relevant to both the TAC and Section 27 in setting their goals. This will then lead the discussion to the Medicines Act which will show the actions that the government carry out on patent holders to grant the necessary licence to the state or general public. Then this chapter will discuss the Grootboom case which will highlight the social injustice and service delivery problem in the country and it will tie the constitutional law with the goals and aims of the TAC and Section 27.

5.1 South African Constitutional Laws for Health

The Bill of Rights recognizes in the South African Constitution the right to health and what is determined by this is that there is also access to education, food, clean water and housing and these are measurable and justiciable (Heywood, 2009:21). From sections 24 to section 27 these are:

- Section 24 says people have a right 'to have the environment protected';
- Section 25 mentions that 'the state must take reasonable legislative and other measures, within its available resources, to foster conditions which enable citizens to gain access to land on an equitable basis';
- Section 26 notes that 'the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of . . . the right to have access to adequate housing';
- Section 27 mentions that 'the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of . . . the rights to access to health care services, sufficient food and water, and social security'.

For the purposes of this thesis the focus will mostly be on Section 27; however, the other stated rights, as will be noted, are highly interdependent as they determine the realization of Section 27.

The TAC model took it upon itself to inform themselves of the law and they worked in partnership with progressive lawyers and this was because the TAC claimed that the

Constitution had stated that the government has a legal obligation to fulfil the promises that it has made about the provision of human rights to the South African people (Heywood, 2009:19). When looking at the focus of the TAC on the right of access to health care services, the organization claimed that the government had to take the necessary steps needed to deal with tackling the issue of 'unaffordability of medicines, particularly when the law holds them accountable' (Heywood, 2009:21).

The South African government has tried to strong-arm against the legal measures that have proven to be threats to compulsory licensing and this has been built into the Medicine Act. The Medicines Act had written into law that it would assist the price reduction of drugs on the market and this was a course that the TAC was highly supportive of (Geffen, 2010:49). This put the government in a position of realizing the power to influence the laws of patent medications where the government had put pressure on patent holders to grant the necessary license to the state or to the general public (Heywood, 2009:21). On the other hand it is also important to note that there are issues of having to deal with patented medications that are imported from a country where it is priced lower and this is often done without the legal permission of the patent holder (Heywood, 20009:21).

5.2 South African Service Delivery

It is no news that the South African government has had issues with services delivery across the board. There have been many strikes driven by disgruntled South Africans who have had to be on the receiving end of the government not providing them with the services that they are not meant to lay claim to through striking. Take for instance the case in Queenstown, a small town in the Eastern Cape. Here the TAC held a march where they occupied the local hospital with the aim of demanding the hospital to speed up its ARV programme. As a result of this peaceful protest, the police opened fire with rubber bullets on TAC marchers (Heywood, 2009:19).

The TAC, as a campaign that advocates for the 'right to health and social justice', has chosen to focus on the 'supposedly narrow demands' to pressure the government to provide better access to ARVs because the organization is built on the foundation of the reality of the AIDS epidemic in South Africa(Heywood, 2009:19). There was an ever increasing number of HIV positive pregnant women who needed ARV drugs to reduce the high probability risk of infecting their unborn children during the duration of the pregnancy (Heywood, 2009:19). The medication is not only crucial for survival and the provision of the medication was the organization's key task as these were the very people who would act as the activists who led

the movement that was grounded on dealing with HIV which either affected them or they were infected by it (Heywood, 2009:19).

The work of the TAC and Section27 has changed the social awareness of HIV/AIDS in South Africa through its many educational campaigns as mentioned above. The work that they have done can be seen through the court cases that the TAC and Section27 won, firstly, for the right to access to information and then the case following below will discuss the victory of the TAC and Section27 for holding the government accountable for the role out of ARVs in the public health sector.

5.2 Grootboom Court Case

Due to the lack of access to essential medications in the public health care sector the TAC and Section27 took the government to court so that it could better provide the needed essential medications for those that use the public health care sector. The main concern was the drug that prevented mother to child infection of HIV/AIDS as most of those who were infected with HIV/AIDS were mainly from poor backgrounds and used the public health care sector in South Africa. They not only do not have the money to access the best medical facilities but they also have to deal with not getting the access to the medications that they need from poorly equipped health facilities.

Responding to the government inaction, in July 2002 the Constitutional Court passed judgment when the TAC constitutionally 'threw down the gauntlet' to government's policy of restricting the delivery of Nevirapine, 'the most effective drug on the market' (Cotlands Baby Sanctuary, 2002:3) for the purpose of preventing mother-to-child transmission (PMTCT) of HIV to a select number of 'pilot sites' (Heywood, 2003; Mitlin and Mogaladi, 2008) in the case of Minister of Health and Others versus TAC and Others (Grootboom case) (Cotlands Baby Sanctuary, 2002). This case suggests that human rights disputes might increasingly revolve around socio-economic rights and demonstrates that skillful litigation can be exploited to realize constitutional promises.

Finally, the outcome of the case validates the Constitution, and should confirm to those who still suffer marginalization and deprivation that the Constitution can materially impact on and better their lives (Heywood, 2003:279). This case is the epitome of civil society organizations such as NGOs holding the state accountable to the people and propelling it to act in accordance with the stipulations of the Constitution.

Now that access to needed essential medications was won, it assisted in the government roll-out of these medications. What comes to the forefront is the ways in which these essential medications from the pharmaceutical markets become available in the South African market. There is red tape that surrounds the provision of essential medication to the public health care sector and the South African government is not the only party to blame for the lack of access to essential medications.

Conclusion

This chapter mainly focused on the significance and provisions of the South African Constitution in regard to human rights. The Grootboom case involving the TAC and Section 27 versus the state was discussed, and the national and international dimensions of pharmaceutical patent policies being leased came to light. The discussion touched on the Medicines Act which highlighted the states violation of the people's rights to the access of essential medications. The next chapter will discuss pharmaceuticals crisis which is the next key player in bringing the discussion full-circle and this will be done through looking at the global perspective and then the local perspective.

CHAPTER 6: PHARMACEUTICAL CRISIS

Introduction

This chapter builds on from the outcomes of the Grootboom case discussed in the previous chapter this will be done through focusing on the aspect of the pharmaceutical crisis noted in the previous chapter from a global perspective of the developing world. Then the discussion will expand where the South African perspective is taking into account where the focus will be on the TACs fight for patent laws on essential medicines.

6.1 Global Perspective

"*Economic and political advances in developing countries on the African continent and South East Asia are threatened by the rising death and morbidity rates of HIV/AIDS"*
Schuklenk & Ashcroft (2002:179).

There is a clear lack of access to medication for most developing nations around the world not only in Africa. This has become an epidemic where the lack of access to affordable medications impacted socioeconomic developments (Schuklenk & Ashcroft, 2002:180). There is a large number of HIV positive and AIDS affected people who are part of a low income working class or are unemployed and cannot gain access to essential affordable medications. This is because the medication is expensive and also patent laws restrict the availability to essential medications being readily accessible for all people infected with HIV/AIDS. Edwin Cameron (2000), an openly HIV positive South African Appellate Court judge, summed up the problem by saying that:

> *"Nearly 34 million people in our world are at this moment dying [of AIDS]. And they are dying because they don't have the privilege that I have, of purchasing my health and life. . . . Now why should I have the privilege of purchasing my life and health when 34 million people in the resource poor world are falling ill, feeling sick to death, and are dying? That to me . . . seems a moral inequity of such fundamental proportions that no one can look at it and fail to be spurred to thought and action about it. That is something which we in Africa cannot accept. It is something that the developed world also cannot accept."*

In Malawi there was a reported number of 30 out of 1 million Malawians who were infected with HIV/AIDS and could not afford essential AIDS medication. In the case of Uganda an estimated 1.2% of 820,000 Ugandans were living with AIDS and could not afford a variety of

the medications used to manage the illness (Schuklenk & Ashcroft, 2002:180). Similar brush strokes were repeated throughout the developing world, but this was not the case in the countries like Brazil as they do not have restrictive patent laws on pharmaceutical production of these essential medications (Schuklenk & Ashcroft, 2002:180). Brazil began manufacturing generic reproductions of essential AIDS medications from the mid-1990s. This resulted in the country's AIDS mortality rate declining by approximately 50% (Chequer, Sudo, & Vitfria, 2000). The latter suggests that one of the key issues to decreasing the mortality rate of HIV/AIDS is the pricing of essential HIV/AIDS medications. This has to be coupled with a well-functioning healthcare delivery service that is supported by the pharmaceutical industry's lobby organization, International Federation of Pharmaceutical Manufacturers Associations (IFPMA) (Schuklenk & Ashcroft, 2002:180). This section of the thesis will discuss factors such as economic and patient licencing that contributes to the lack to access of essential AIDS medications in developing countries.

Access of essential medications like any other product on the consumer market is determined by the supply and demand chain. This means that if there is a high demand for a particular product then there needs to be a manufacturer prepared to produce the desired product (Schuklenk & Ashcroft, 2002:181). In the case of most developing countries that there is a high demand rate for essential AIDS medications; however, two principle features determine the supply of HIV/AIDS medications in developing countries. These are the price of HIV/AIDS medications in developing world markets and the upkeep of barriers to entry that go into the manufacture of such medications (Schuklenk & Ashcroft, 2002:181). The supply and demand chain is often highly influenced by there being manufacturing competitions for one product. This then would normally result in the regulation of pricing where there is the willingness of the suppliers to supply goods at variable price levels (Schuklenk & Ashcroft, 2002:181). This means that the consumer has purchasing power and thus has influence on the price setting by the manufacturer. This would then create a fair trading where both parties can achieve a win-win. However, this is not the case in most developing countries. They often have ‘non-competitive’ markets and as a result the suppliers have the power to decide the level of profit that they want to make and they set their prices according to the desired bottom line (Schuklenk & Ashcroft, 2002:181). In such cases the purchasers and/or consumers have very little influence on the price setting of manufacturers because there are limited, or only one, supplier(s) of a good. Thus they have further diminished economic power because often ‘essential' goods are purchased by the state, who is the middle-man for a

group of consumers that are interested in buying the good 'if at all possible' (Schuklenk & Ashcroft, 2002:181). The selected level of profit of the drug companies and the 'barriers to entry to drug manufacture' are the most vital factors that influence the price and purchase of medication on the market (Schuklenk & Ashcroft, 2002:181). Most developing countries such as Brazil and India have to adhere to international regulatory standards for the quality and purity of manufacture and they also have to adhere to enforcement of intellectual property rights.

The latter issue is the most difficult hurdle to adhere to, particularly for developing countries. This, according to Schuklenk & Ashcroft (2002:182), can be to linked to three factors, the first being that "even if companies' intellectual property rights are honoured and enforced, this does not address whether the price they charge is fair, and what their responsibilities to set a fair price might be". Secondly, there is the inconsistency where there is a lack of recognized exceptions or limits to intellectual property rights. Thirdly, Schuklenk & Ashcroft (2002:182) argue that if recognized exceptions and limits to intellectual property rights existed they would be standardized and enforced legitimately however they are not 'applied in the current international arena' by the World Trade Organisation's (WTO) division on Trade-Related Aspects of Intellectual Property Rights (TRIPS). It is tasked to manage the national patent laws of the WTO national member nations. The European Commission (2000) noted that:

> "*In the trade area, I am committed to do whatever is necessary in order to shape the right conditions so that the poorest of the poor will have access to the medicines they deserve at affordable prices. . . . In the area of intellectual property rights, it is acknowledged that TRIPS provides for the necessary flexibility to address public health concerns and emergency situations*" (Schuklenk & Ashcroft, 2002:182-183).

There is a clear recognition of exceptions to intellectual property rights particularly for state of emergency situations. However, what comes to the forefront is the question Schuklenk & Ashcroft (2002:183) bring forward: 'Why do developing countries not make use of the TRIPS provision to issue compulsory local licences of essential AIDS drugs, and begin local production?'

6.1.1 South African Perspective

> "*The dread of hospitals probably still survives among the very poor, and in all of us it has only recently disappeared. It is a dark patch not far beneath the surface of our minds.*" (George Orwell)

There are a few factors that contribute to the pharmaceutical crisis in Africa. These are rooted in the interconnected relationships that are visible between the social, economic and political factors that affect the social well-being of all South Africans. The main issues that were arising are also rooted in the information that is given to those who are HIV positive. This was highlighted when Dr Manto Tshabalala-Msimang was the Minister of Health when she advocated that there is link between nutrition and Aids (Geffen, 2010:102). She then decided to recommend garlic, lemons and an olive diet that she claimed she had tested and had positive results to strengthening the broken down immune system (Geffen, 2010:102). This diet was published in the Drum magazine where Ruth and Nozipho Bhengu advocated the use of the diet and this put a regular face to the name of HIV. This was done, of course, by a prominent member of South Africa's ruling elite (Geffen, 2010:102). This assisted in 'pushing back on the stigma' of the disease in that this was a young well educated woman who had contracted the disease and was embracing it in that she was taking responsibility to take care of herself and she went public with her diagnosis. Edwin Cameron, one of South Africa's best-known judges, also came forward and revealed his HIV status to the public but, unlike Nozipho Bhengu, he took ARVs and he also stressed the importance of a balanced nutritional diet (Geffen, 2010:103). The ARV medication was very strong at the time and many people who were on the medication went off it like Nozipho Bhengu who said it made her much sicker (Geffen, 2010:103). These two contrasting ideologies marked the 'main battle line' in South Africa about the response to managing HIV and AIDS (Geffen, 2010:103).

The media was now becoming more aware of publishing stories that portrayed people who, through their stories of living with HIV/AIDS, were claiming that there was a correlation between the combination of a good nutritional diet being coupled with a healthy sexual lifestyle which would result in people living longer and coming to terms with the fact that medical research was nowhere near finding a cure.

It could be argued that whilst former president Thabo Mbeki was in office the South African government can be held at great fault for not admitting fully that HIV if untreated leads to AIDS. The South African government took such a long time to release the roll out of ARVS

on the health market. This could have been a preventative measure taken to reduce the numbers of those who became infected with HIV and particularly mother-to-child transmission. People during Mbeki presidency were conflicted as to which method was best to use to treat the disease and the government continued to hold information away from the public during this critical time. South Africa was four years behind the rest of the world when it came to informing the public about the disease.

The research will look further into the contributions of the TAC in the light of this matter through the data analysis chapters where it will reveal more about the work of the TAC and Section27. However, before the discussion gets there, there is a need to understand the non-governmental organisations from a global and localized South African perspective.

6.2 TACs Fight for Patent Laws on Essential Medicines

This brings the discussion to the topic of understanding the implication of the use of branded and generic medications. This section of the paper will look at the issue of patent and licensed medications. As briefly stated above, the South African government has tried to enforce regulations that affect the imported medications in the South African market. The thesis will discuss the ways in which the TAC has been involved with the government to try and reduce the price of drugs and its attempt to get patent licensing will also be addressed. This will unveil the ways in which the international pharmaceutical laws and the prices stipulated by the pharmaceutical companies come to affect the South African pharmaceutical laws and the prices of these drugs and thus affects their accessibility.

The TAC was highly focused in its foundational two years in the fight against the pharmaceutical industry where approximately 40 drug companies that were led by the Pharmaceutical Manufacturers' Association (PMA) were funded by the American government. They joined forces with the agenda of taking the South African government to court, with the aim of trying to get it to stop changes to be made to the Medicines Act which were geared to reduce the prices of drugs (Geffen, 2010:49). The AIDS treatment court challenge brought to the forefront the shameful approach of the drug companies who were working to block the new stipulations of the Medicines Act which would make access to cheaper drugs more available (Geffen, 2010:50 and Gabriel, 2001:1).

There was an introduction of an amendment in 1997 to the Medicines and Related Substance Control Act by Dr Nkosazana Zuma, the former Minister of Health. This amendment was

signed into effect by former President Nelson Mandela. The amendment stated three new provisions:

> *Firstly, a transparent pricing mechanism for Aids drugs would be established, as is the case in other countries. Secondly, it would be compulsory for health professionals to prescribe cheaper generic substitutes instead of expensive brand-name medicines, once the brand's patent had expired (i.e. compulsory generic substitution). Thirdly, patented medicines could be imported from other countries where the same medicine is sold much cheaper than in South Africa (i.e. parallel importing)* (Di Blasi et al, 2001:1).

The expected result of the introduction of the new amendment by the Zuma was that there would be a drastic reduction in the cost of AIDS medications in South Africa. This was because the same model was used in Brazil and this reduced the average cost of medication by 80% (Di Blasi et al, 2001:2).

By the pharmaceutical companies taking the South African (SA) government to court, what came to the forefront was that they were disagreeing with the SA government by saying that the new law breaks the World Trade Organization (WTO) international agreement on Trade-Related Intellectual Property (TRIPs) (Di Blasi et al, 2001:2). These pharmaceutical companies further argued that the new laws were in violation of their constitutional property rights. Di Blasi et al (2001:2), however, mentions that the SA Constitution, Section 231, clearly states that international agreements like TRIPs are 'subject to the scrutiny of parliament'. The support of Section 27 'obliges the state to take measures to ensure progressive access to health care by all citizens'. The TRIPs agreement in article 6 allows for parallel importing and it also allows for compulsory production or that the importation of cheap generic drugs that are licensed can be distributed particularly in a serious public health crisis as supported by article 31 (Di Blasi et al, 2001:2). The World Health Organization (WHO) has taken the stance to support this move in an unprecedented manner, where it too is going against the pharmaceutical companies and is insisting that South Africa is not breaking the TRIPs agreement (Di Blasi et al, 2001:2).

As a result the Al Gore and the Bill Clinton administrations came under fire by the protesters and only during the George W Bush administration were pharmaceutical companies backed by the government, but then George W Bush called for the drug companies to drop the case (Di Blasi et al, 2001:2). The Bush administration supported the pharmaceutical companies

because the state stood a great chance to reap the financial gains as well. This could be because the Bush administration was built on the foundation of neo-conservatism which is in support of the state also attaining a piece of the bottom line that would be gained by pharmaceutical companies. According to Di Blasi et al (2001:2-3) the TRIPs argument is being viewed as a 'smokescreen'; this is because what was at the core of the pharmaceuticals' court challenge was the bottom line which they were defending because the pharmaceutical companies were also trying to gain power internationally.

One of the first campaigns that the TAC implemented was one that went head to head with trying to get the drug company Pfizer to reduce its prices for its patented medication Fluconazole, a drug that was exorbitantly priced. This drug was used to treat fatally opportunistic infections, systemic thrush and crypotoccal meningitis (Geffen, 2010:50). Various South Africans came to the stand to testify to the Parliamentary Portfolio Committee on Health as representatives who used the medication in trying to compel the company to reduce the prices of the medication and they tried to further convince them to sell the generic version of the product because this would drop the price of the medication by the competing companies (Geffen, 2010:50).

Geffen being a member of the TAC researched the types of generic medications that could be imported into the country from Thailand and India. The importation of the cheap WHO-approved generic brand of Fluconazole called Biozole was further researched to meet the requirements of an effective and cheap generic drug, but the problem was that this drug from Thailand was in violation of the Pfizer's patent (Geffen, 2010:50).

The generic pharmaceutical drug that was found in Thailand by the TAC confronted the state to acknowledge that there is a need for pharmaceutical companies to get involved in the fight to try to attain a healthy society. It would not make sense to have the essential medications available to the people yet it costs the state an arm and a leg to purchase these medications. This could evidently contribute to the issues of the state not being able to provide the needed medications due to costs. The bottom-line could be the cause to the millions dying and the stringent laws of patency and intellectual property rights also add to cause of morbidity.

Conclusion

This chapter focused on discussing the political economy of the pharmaceutical corporations and the implications for the delivery of HIV and AIDS treatment. The chapter highlighted this through showing how the AIDS treatment court challenge brought to the forefront the

shameful approach of the drug companies who were working to block the new stipulations of the Medicines Act, which would make access to cheaper drugs more available. This chapter also brought to light that the introduction of the new amendment in 1997 to the Medicines and Related Substance Control Act expected to see a drastic reduction in the cost of AIDS medications in South Africa. The chapter closed on the discussion where by the TAC confronted the state to acknowledge that there is a need for pharmaceutical companies to get involved in the fight to try to attain not only a healthy society but also address the social injustice that people were suffering.

CHAPTER 7: RESEARCH DESIGN AND METHODOLOGY

Introduction

This chapter will deal discuss the research design and methodology. This will be done through unpacking why the particular design and qualitative methodology where chosen and how they were implement throughout the study to attain the findings that will be discussed in the following chapter.

7.1 Qualitative Methodology

An interpretivist paradigm was used for the study because it best suited the qualitative data capturing. This paradigm was suited to the study because people in society perceive their surroundings from a subjective point of view and this creates the way that they come to define and view the social reality that they are a part of (Sarantakos, 2005:29).

Qualitative researchers require that the data obtained should be mostly beneficial when the participants give rich descriptions of their social world which is valuable. This type of data is attainable through detailed interviews (Denzin and Lincoln, 1994:16). By using a qualitative research approach this allowed for the study to obtain a substantial amount of descriptive data from the participants.

The goal of qualitative research is to describe and understand human behaviour which is better than just explaining the underlying relationships like quantitative research aims (Babbie and Mouton, 1998:270). The qualitative research approach uses a naturalistic approach that emphasizes the understanding of phenomena in context-specific settings. This then allows the researcher to avoid manipulation of the phenomenon of interest (Denzin and Lincoln, 1998:600). On paper qualitative research is meant to be conducted in the natural setting of the participant and the phenomena of interest instead of controlling the environment so to get a preconceived reaction from the social actors (Babbie and Mouton, 1998:270).

For the purposes of this study using a qualitative research approach was the best way to attain the needed data. Interviews best suited the data collection method, as a set of questions were prepared prior to the interview and they were all catered to suit the participants of the study. The interview schedule used was more of a guideline to keep on topic. The flexibility of the semi-structured questions allowed for other follow up questions to be asked at the comfort level of the participant. This allowed for the interview to flow and be more of a conversation than an intense structured interview that went point by point.

Some of the participants in the qualitative research were sent the interview schedule prior to the scheduled interview time. During the preparation period leading up to the interview, I attained as much information as possible about the research participant like their job descriptions within the public and private health care sector in South Africa. This approach was taken so to further influence the possible alterations that could be made to the open-ended questions to suite the interview participants. For the participants who were asked to participate in the study at the local clinics and hospitals, they were informed by the nurse and in two cases their personal doctors about the study. They were asked if they would voluntarily be research participants and those that agreed were also informed that their confidentiality was going to be protected. They were informed of the disclaimer that they could withdraw from the study at any time. This was to ensure their comfort levels during the study as participants who are HIV positive accessing their medical health care services.

The open-ended questions allowed the interview participants to express their own opinions in their own words. The questions also allowed the interview participants to specifically indicate their involvement in the South African health care sector. Participants were also asked about their level of interaction with South Africa's health departments in the Eastern Cape and in Pretoria. The participants were informed that a digital recorder was being used during the in-depth interviews and that the recordings would be the property of the research study. It was important to use a recorder because it allowed me to focus on the conversations and further ask other questions that were not part of the interview schedule. The interviews were later transcribed onto a text document; however, the informal discussions that took place about the research topic were not recorded.

From the transcribed text qualitative researchers analyse and interpret the data collected. This is the reason that the research adopted an interpretvist paradigm because it allowed for the exploration of various issues that surround the factors that are influencing the way in which the public health sector is functioning. From management to the use of the health care sector, the aim of the study was to understand the phenomena from the participants' perspectives. This allowed for the participants to give their subjective views and insights. Knowledge of the social world can also be enhanced by using empirical principles which require the use of senses and scientific methods in order to observe and study the social world (Neuman, 2001:8). A systematic observation was used to verify what was said by the participants and what was observed by the researcher, in terms of the ways that they interacted particularly with those that used the public health care system and those that were

employed by the health care system, as opposed to relying solely on the descriptions given by the participants.

7.2 Population and Sampling

The chosen population for the study was made up of people from two civil society organisations, the TAC and Section27, as well doctors that worked in the public and in the private hospitals and clinics, and people who used public and private health care systems in South Africa.

Various decisions were made in the sampling of the group of people chosen for the study (Blanche and Durrheim, 1999:45). The employees and members of the TAC and Section27 as well as the doctors could be the portion of the population of the research that could be transferable to a similar project or context. The staff from the TAC, Section27 and the doctors and nurses were participants who had been involved in the work that they do in the public and the private health care sector from five years to a decade. The sampled staff also included nurses and volunteers who worked at different levels in the hierarchy of the TAC, clinics and hospitals. The people chosen for the study were knowledgeable about the inner workings of the research topic. Snowball sampling; where the participants of the study referred me to other suitable people for the study, was used to deduce the most suitable participants as advised by those in the TAC and the doctors because they had more insight into the type of people to interview based on their role with working in South Africa's health care sector.

A total of 10 participants were sampled. These included two TAC employees/members, one Section27 employee, three doctors (a doctor from the public health care system at Settlers Hospital, a doctor from the public health care system in Cape Town and a doctor from the private health care sector), two nurse from the Settlers public health care sector and two HIV positive people, one who used the public and the other who used the private health care sector.

Additional data on the public health care sector was obtained through informal discussions about the public health care sector.

7.3 Data Collection

The whole country underwent the restructuring of the provisional municipalities in 1994. This impacted on the changes that occurred in the organisation of the health system which was restructured from 1994-2000. The Eastern Cape Provisional Department of Health, for

example, was created and under it were five health regions and under that were 21 health districts. Then another change occurred in December 2000: the government did away with the health regions and created six district municipalities and 1 metropole in the case of the Eastern Cape Province the government did away with the 21 health districts completely and it created the 38 local municipalities. The new organisation of the health system saw further changes in the district municipalities and the metro remained and 24 local service areas were created. In the case of locating Settlers Hospital which belongs to the Eastern Cape Municipality of Makana, with the main town being Grahamstown, its district municipality is DC10 which is in the western part of the province.

7.3.1 Grahamstown Settlers Hospital

Settlers Hospital public health sector reports most of its issues of supply for medical resources to the local Makana health centre and it makes its supply orders from to Bisho which is where the department of health office is located. Sometimes Settlers Hospital obtains its medical resources from the Nelson Mandela Metro. The issues in the health sector in this district go to the head office in Bhisho. The private health care sector uses a different resource centre because it is 'a partnership between the department of health and a private consortium' consisting of Nalithemba hospitals, Netcare and a group of local businesses (Medical Chronicle, 2007:13). There are distinct differences between the private and public health care services provided by Settlers Hospital. The public sector relies on the municipality health office to take care of most of its needs whilst the private sector is affiliated with Netcare and other businesses and it is Netcare that handles most of the medical equipment and supplies to the private sector only.

In order to obtain the needed information from Settlers Hospital staff and patients I had to formally apply to the National Health Research Database by sending off my approved proposal from Rhodes University's Higher Degrees Committee which adheres to the stipulated ethical guidelines of the university. After the approval from the National Health Research Database it was meant to be sent to Settlers Hospital CEO then that would be filtered down to the appropriate Settlers Hospital staff who would be suitable for my study. Due to the high traffic on the National Health Research Database I did not get any indication that my work was received or approved. After continuously attempting to directly contact the National Health Research Database, I still did not attain the needed response to carry out my research in time. The Settlers Hospital administration and management were reluctant to participate in the interviews without the approval letters from the National Health Research

Database and the CEO of the hospital. As a result I opted to go directly to the head nursing staff at the hospital and formally presented my approved proposal and informed them further of my study. One of the nurses then took me aside and gave me her personal contact details and informed me that she would be a willing research participant only if she remained anonymous and she agreed to connect me to a few people if they too remained anonymous. She instructed I call her after hours and that is what I proceed to do and we arranged a place for the interview. Some of the other nurses from the public sector to whom I was referred by the head nurse requested that the interview be informal and not recorded because they feared to share information that might get them into trouble with the hospital. I had to resort to taking down notes as they spoke about their accounts of working for Settlers Public hospital with HIV and AIDS patients on a daily basis. Some of these nurses who were interviewed even showed some discomfort at being interviewed with the recorder; however, as they got more comfortable with the questions, they showed much more confidence in the daily workings in the Public Health Care Sector of Settlers Hospital, particularly with the HIV and AIDS patients. This could have also been because they have worked for Settlers Hospital for over 5-6 years and they had also worked in other clinics in the province doing the same type of work. Most of the nurses did inform me that the doctors would be reluctant to speak on the topic because they were more focused on prescribing the medication and not talking to the patients. The nurses also expressed that the doctors were not well informed on the suppliers of the medications as well as alternative places where people had to resort to finding this prescribed medications so that the patient stayed on the regime. Despite the nurses advice I did attain an interview with one of the doctors from Settlers Hospital public sector through a lecturer from Rhodes University. The doctor also wanted to remain anonymous for the study and the interview took place away from the hospital after office hours.

7.3.2 My Sexual Health Private Clinic

My Sexual Health Private clinic is a specialized clinic that offers Sexual Health Services with a multi-disciplinary team. It consists of a sexual health nurse, a sexual health doctor and a therapist but the patient goes through his/her first check-up and tests with the clinic. It does not focus only on patients with HIV and AIDS, as they deal with sexual health as a whole. After finding their contact details a formally drafted email was sent to the clinic's administrator and it stipulated the purpose of the study and it requested interviews with doctors and nurses who were willing to participate in the study. In a matter of a few hours I

received a phone call where I was directed to email a particular doctor who would be willing to be a participant in the study. After such a speedy response I sent the sexual health doctor an email briefly describing what I hoped to speak to him about and what the goals of my study were. After a business day I received an email with a possible time schedule for the interview and the doctor informed me that there would patients who would be willing to be part of my study if I was interested in interviewing them as well. I kindly accepted the scheduled times for the telephonic interviews with the sexual health doctor, a nurse and two patients, and these all went smoothly.

7.3.3 Treatment Action Campaign and Section27

Through a contact of a colleague I received a contact for a person who worked at the TAC who could immediately connect me to people he worked with. After emailing back and forth about the possible participants for my study, I was informed that in late September they would be available. Upon waiting for the interviews to be confirmed, I attained necessary information about the participants and an interview schedule was drafted. As the end of the month came and I went back to confirming if the interviews were arranged and there was no response to the email for the next three months. When the end of the year was approaching, I resorted to calling and further sending emails asking if the participants had changed their minds about being part of the study. Still there was no response until the New Year when I received an email informing me that the research participants were willing to be part of the study. After the telephonic interviews were arranged, I ended up having interviews with the TAC National General Secretary and the Eastern Cape provincial chairperson of the TAC who is also the coordinator of the Eastern Cape Health Crisis. I also spoke to a research fellow for Section27. The aim of the questions that I asked the research participants from these organisations was to attain an understanding of how the organisations have contributed to the current changes that had occurred in the South Africa health care system. My questions were also aimed at unpacking the views on the workings of the health care system in South Africa, particularly because they work very closely on the very ground as well as on a district, provincial and national level.

7.4 Credibility and Trustworthiness of Data

This study used a qualitative research approach. Qualitative researchers pride themselves more on issues of credibility, trustworthiness and transferability (Neuman, 2001:214). Some scientists have viewed the research done by qualitative researchers with scepticism, claiming that their findings are not trustworthy because they do not pay attention to issues of reliability

and validity (Golafshani, 2003:599). That is why Guba and Lincoln (1985) saw it fit to substitute reliability and validity with the parallel concept of 'trustworthiness', containing four aspects: credibility, transferability, dependability, and confirmability. Credibility is an assessment of whether or not the research findings embody a reliable conceptual interpretation of the data that is taken from the participants' original raw data (Guba and Lincoln, 1985). Transferability refers to the idea that the findings of the study have the probability to be applied beyond the project (Guba and Lincoln, 1985). Dependability looks into the value of the combined processes such as data collection, data analysis and theory generation (Guba and Lincoln, 1985). Qualitative researchers seek for illumination, understanding and extrapolation, which differs from the quantitative researchers who seek causal determination, prediction and the generalisation of their findings (Golafshani, 2003:600). It has to be noted that reliability and validity are often dealt with separately in quantitative studies. In qualitative research they almost have a symbiotic relationship. That is why the best terminology that encapsulates both are credibility, transferability and trustworthiness.

Qualitative researchers pride themselves more on issues of credibility, trustworthiness and transferability (Neuman, 2001:214). The researcher in qualitative research uses the "self" as the main instrument in the research process, which quantitative researchers view as research bias because the presence of the researcher interferes with the research process adding to the level of error (Babbie and Mouton, 1998:270). Qualitative researchers argue that it is impossible for a researcher to remain objective and unbiased as every research undertaking will have a significant level of error or irrelevant information (Babbie and Mouton, 1998:270). Qualitative researchers, unlike quantitative researchers, do not see themselves as the experts on the subject but, rather, they value the insights of the subject on the issue (Neuman, 2001:332). Research in the qualitative approach is done in natural settings. The world is described according to the view of the subjects. It offers thick, rich description of the subject's perception and life story which is what is required in this study as we need thick rich and detailed descriptions of the health care system in South Africa.

With qualitative research credibility is developed through the researcher's rapports and the verification steps used all through the research process (Creswell, 1994:157). To ensure the credibility and trustworthiness of this study, a digital recorder was used when allowed to ensure that the participants' responses were not altered. Field notes were also taken

throughout the study, especially noting down what was being said during informal discussions.

This data was interpreted in relation to the context of the whole study to strengthen the credibility of the study. The study used snowball sampling so as to attain suitable and useful sampled participants who are actually experts or involved in the public health sector and those that used the public health sector services which was important to ensure transferability of the results to different contexts.

7.5 Problems/Challenges

Due to the nature of the study dealing with the delicate issue of HIV/AIDS, I encountered a number of challenges. There was a lack of data and statistics on the topic dealing with the distribution of medications to the public health care sector. A breakthrough occurred when I was able to do the interviews with the TAC and the Section27 employees/members. They further instructed me on the type of people that would best suite my study. Gaining access to Settlers Hospital as mentioned before was by far the biggest challenge, as I followed protocol but there was no response in the time that I needed it from the National Health Research Institution. Some of the doctors from the public side of Settlers Hospital even if I had personally called them were also very reluctant to share information on the topic of the study and one of administrators pointed out to me that they were definitely reluctant to allow a researcher to do such a study without approval. I was given the run around in the public sector trying to gain access to the head nurse to talk to me but then I was advised by alumni Rhodes University researchers that it was best to go directly to the hospital and ask for the head nurse or administrational head of the public side of Settlers Hospital.

7.6 Ethical Considerations

The research study adhered to Rhodes University's stipulated guidelines on the ethical requirements for carrying out the research. All the participants when sent the interview schedule prior to the scheduled interview time were required to read the disclaimer which included maintaining confidentiality, informed consent and stating that participation was all on a voluntary basis. They were informed that they could choose to remain anonymous and withdraw from the study whenever they felt uncomfortable with the study. They were also informed that the interview was being recorded and that the recording would be the property of the study.

Conclusion

This chapter outlined the methodology and highlighted the techniques used to conduct the study at hand. The research design outlined the paradigm used, the type of study, the target population and the sampling used. The data collection from the main hospital was done in person, while the organisations and the clinic were done telephonically. Each participant of the study personally consented to be participants. The data analysis forms the foundation for the discussion and interpretation of the findings in the next chapter.

CHAPTER 8: ANALYSIS AND FINDINGS

Introduction

The data presented in this chapter is due to the application of the methodology that is presented in the previous chapter. Each participant was interviewed and individually recorded as they answered the questions relating to the health care sector of South Africa. Due to the sensitivity of the research topic, some of the research participants were more comfortable to speak openly when they were not located in their place of work and they also required that their identity be concealed. A notebook was kept to take down the key issues that stood out from all the interviews as possible themes and after analysing the data various themes were highlighted. Themes were generated based on the findings. Findings from the hospital, organisations and the clinic are highlighted and a job description of the participant is provided so to give better clarity to the analysed data discussion. The themes that have come from the data analysis are linked to the relation of the existing constitutional structures, process and practices used in South Africa's health care system.

South Africa's health care system is confronted with widespread issues of the HIV and AIDS pandemic and lack of medication mixing methods and there is a lack of improved tuberculosis (TB) treatment which is an opportunistic disease and it is an AIDS-related one. This study attempts to examine the complex interplay between the health care system, including those that use it and work for it, and the governments' issues of mismanagement in trying to deal with this lack of essential medications, particularly to those in the public health care sector. More importantly, this study uncovers the inequalities that existent within the health care sector because the government has various vested interests with those that belong to a particular economic bracket which grants them a more holistic notion of citizenship and this encompasses greater access to medical health facilities. This exclusive interplay between the state and those that have the best access to governmental services has caused a niche within civil society where there is a need to address the main issue of the lack of certain government sectors infringing on people's constitutional rights. This is the foundation upon which the social mobilization of the TAC began. The following discussion will unpack theme by theme the fundamental areas that the study showcased in trying to fulfil the topic of the study.

8.1 Lack of Information about Access to Rights

The make-up of the South African society is stratified. This creates different levels based on how the state interacts with people who come from different economic backgrounds. One of

the major issues that has come out of this stratification within the civil society of South Africa is that the educational levels in South Africa differ. There are those who seem to be 'second-class-citizens' and this, to a degree, is a social injustice that the government has placed on its people. The Bill of Rights number 20 states that:

'*No citizen may be deprived of citizenship'.*

Even though the 'second-class-citizens' do have citizenship, they do not experience the same level of equality in their interactions with the state. It is clear that these 'second-class-citizens' still have to lay claim to their rights. It is no secret that there are differences within the South African civil society. There are two worlds that exist side-by-side (Seeking, 2003:1). Take a look at Alexander Township and Sandton City which are a stone's throw away from each other. There is a clear distinction between the two places, where most of the people who live in Alexander Township are part of the working class that lives under great social injustices. For example, they have to deal with issues of unsafety because they are living in an over-crowded space where some sections of the township are still using the bucket system for sanitary purposes. They are also a staggering number of people who are not part of the working class where they are unable to find jobs because they are either old, disabled or are uneducated (Seeking, 2003:10). This group of unemployed people form most of the population that is uneducated, thus they are mostly illiterate and this can be attributed to the apartheid legacy (Seeking, 2003:7-10). These two factors contribute to them being in a position where they are unable to educate themselves and move out of their economic bracket, whilst the people who live in Sandton's town houses or estates with first world security systems and they are mostly tertiary educated and have well-paying jobs that allow them to spend on life's luxuries like traveling and spending the near equivalent of their domestics monthly salary in a mere night out or on the weekend. This is the reality of how South African society is structured in terms of social groups other than race (Seeking, 2003:2), a shifted created by the de-racialization of the country.

Based on the interviews done with members of the TAC when questioned on issues of inequalities that exist in the civil society of South African, it was clearly stipulated that there are inequalities when it comes to the notion of being a South African citizen because of the various backgrounds that exist within the South Africa's civil society.

The National General Secretary of the TAC, Anele Yawa, supported the above in saying:

> *"There are clear differences between those that live in the Suburbs who have big homes, cars and 2.5 children they are educated and working, then there are the people that live in the township you know you have seen these people live under the worst living spaces that are crammed, no clean running water in their homes and some live with their extended families no mother, father no breadwinner with a proper job only e-Social grant feeds everyone and maybe one person is going to school not all the children because they have to work and support their families"*[1].

Provincial Chairperson of TAC Eastern Cape and coordinator of the Eastern Cape Health Crisis Coalition, Fikile Boyce, said:

> *"Now that is where the true, the real issue lies in our country we are still not all seen the same way by the government in practice of real-life because our history has placed us in different economic backgrounds and unequal education has a lot to do with it uneducated people do not know their rights sis-Nomalanga they know the basics"*[2].

It is clear to see that from these two responses that there are differences within the civil society of South Africa. By working with the TAC and South Africa public health system for more than 10 years combined they have seen the changes that have occurred in the health system from the ground where their work began and still continues to this day. They are well informed about the different societies that exist because they have been personally seen the differences between the two worlds that exist within the country. This is something that truly exists in our society because, as mentioned in the chapter that deals with state and civil society, there are clear differences. This is evident through the work of Partha Chatterjee. As mentioned before the reality is that he does not see 'civil society unfolding in reality as stated *ideologically*'. This could be the case because in reality the term 'civil society' is often at odds with the implications of the written definition. This supports both Yawa and Boyce's words, where we can clearly see that there are different state relationships that exist between the state and the people who come from different economic backgrounds. This also sheds light on how there are discrepancies in the translation of Bill of Rights in reality.

The constitutional rights Section 25 mentions that 'the state must take reasonable legislative and other measures, within its available resources, to foster conditions which enable citizens

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[1] Yawa, A. Telephonic interview. 20/01/2015
[2] Boyce, F. Telephonic interview. 19/01/2015

to gain access to land on an equitable basis'. This is not the case for the people who are living in townships and particularly in informal settlement housing. That is why one can so often see the mushrooming of informal settlements all over the country and often near places of employment. However, this is also because people are forcibly removed from their homes as seen in the case of the people described by the S'bu Zikode of the ABM. This is because the state is so self-consumed with the middle class agenda that it:

> *"Does not speak about the dead people. It doesn't talk anything about the people who have been displaced. It doesn't talk anything about the people who had their homes destroyed. It doesn't talk anything about the whereabouts of our children, many of whom are not schooling. It doesn't talk anything about the people who are threatened with death for speaking the truth about their lives* (Zikode, 2009:2).

The state as mentioned before is clearly more consumed with issues of those who belong to a particular economic background and who belong to the middle and upper class. They have a different relationship with the state than that of those who are from the lower class. As mentioned before the reason that the state, according to Chatterjee (2004), does not have its focus on assisting the poor is because they have their focus on improving infrastructure that will attract foreign investment. In the case of India:

> *"Thus manufacturing industries are being moved out beyond the city limits; squatters and encroachers are being evicted..."* (Chatterjee, 2004:144).

Whilst the state might have the economic interests in mind it then treats those that are part of the lower classes differently as mentioned by Zikode:

> *"Apart from being pacified by the state, they often criminalise activities by movements by the poor."*(Zikode, 2009:2).

This makes one realise that the people have to lay claim to their rights and that is why they socially mobilize so to try to get the government to hear them out and grant them their rights. This will be further discussed under the theme that deals with the shortages that are in the public health sector.

Section 26 of the Constitution notes that 'the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of . . . the right to have access to adequate housing'. When looking at the response from Yawa and Boyce they both mention that the living conditions of the people that would live in the township is

certainly different and this is a social injustice that they are suffering, as they might be living in informal settlement housing. Even though there are people who live in the state housing, they still have to belong to a certain economic bracket to attain the housing benefit. There are many shortages in the provision of housing that the state can offer. Those that haven't attained state housing either by not qualifying, or they might be still waiting for the housing to be allocated. In the meantime they continue to live in a crowed household and on land that they cannot lay claim to. Often they are using the municipal facilities illegally and they continue to suffer social injustice because they cannot afford the high prices of the services.

The right to health as stipulated in Section 27 of the Constitution states that 'the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of the rights to access to health care services, sufficient food and water, and social security'. This is the most important right that is linked to the fundamental basis of this thesis in discussing issues of health care. People that suffer the social injustice of inadequate health care and those that have a lack of access to it once again prove that the government cannot realize in practice its promises that it has made to its people. This injustice to the right to health will be discussed in the next section.

Patient A, one of the HIV positive patients, stated that:

> *"The hard part of being sick is when you come from a house with a low income you the medication is expensive because it is not only the ARVs that you need*[3]*"*

Yawa reiterated that:

> *"You know people are suffering out there because they need to feed their families, also pay for school fees and worse when they are sick they need to decide on sometimes to not take the medication and use it to household needs"*[4].

These are issues where the governments and the pharmaceutical companies need to see that there is a link between the health care that they provide and the exorbitant rates which are charged as this can affect people. This then becomes a life or death type of situation. This was mentioned in the section that discussed the issues of medications being too expensive when Heywood said that the country cannot attain a health care system that is functional when the prices for medication and other health care services are expensive. Particularly for

[3] Patient A. Grahamstown. 10/01/2015
[4] Yawa, A. Telephonic interview. 20/01/2015

the people that are already unemployed with the social government grant the only income they get. These are the major disparities that exist within the notion of civil society in South Africa.

8.2 Lack of Skills and Regular Training

It is important to note that the nurses and doctors that are meant to deal with HIV and AIDS infected patients are meant to be highly trained and well educated in the disease, and they need to be able to know how to handle themselves on a personal base. This is because the workload of nurses that work with HIV and AIDS patients, according to Hall (2010:2), has dramatically increased because the numbers of HIV patients and those who have AIDS-related diseases have increased in number over the past few years. The work they do as nurses is a very time-consuming type of care and this is much needed by a number of these patients and there is an absence of this critical support that should be available to them. According to Hall (2010:2) the nurses as health care givers make up 155484 which is 86% of the South African corps and they are primarily involved in taking care of the infected. There is, therefore, a need to educate the nurses so that they can handle the workload and the type of people that they deal with on a daily basis. According to Hall (2010:2) HIV and AIDS is a major contribution to the work that impacts the nurses in South African health facilities, there are also political and economic fluctuations which add to their work stresses. There is also a greater demand for health services and this has contributed to the shrinking nursing corps and that is why they face unsatisfactory working situations that add to the challenges they encounter on a daily basis (Hall, 2010:2).

The nurse A from Settlers Public Sector explained the work challenges of working with people who have HIV and AIDS-related diseases:

> *"This is not the first time I work in the public health sector I have worked for the South African public health for more 5years now I used to work in public clinic before getting work at a hospital I did training in the Johannesburg but then I moved here after getting married it is not easy working with people with HIV and AIDS because they get very sick and we have to do more than give them medication"*[5].

A follow up question was asked if she could explain the things that they do that are more than their job description.

Nurse A responded to say:

[5] Nurse A. Grahamstown Settlers Hospital. 11/01/2015.

> *"We do the normal things like take blood give them medications but then we also play the role of counselling them and sometimes this takes a very long time to do because people do not know how to deal with the disease and there are many other stresses that they complain about like ama-medications because the regime they are on is making them get sicker and we have tell them what other medication they need to get. Other people do not know how to speak English and we have to in the office with the doctor during their consultation and tell them what the doctor is saying but when other nurses are not on shift it is hard to do this job when there are complications in explaining what the medication is for and whey they need to stick to the medication and not change it. Sometimes the patient's comeback and say that the nurse said they should take other medication and we get into trouble with the administration"*[6].

These nurses' primary duty is to take care of their ill patients and provide patient care and they also have to deal with the death of patients on a daily basis and this causes psychological challenges where human suffering and the death of patients is involved in their daily jobs (Hall, 2010:3). This was a new discovery in the study because on a one on one basis the nurses confirmed that their jobs do not take into consideration that there is a lot more to the job than just patient care.

Nurse B from Settlers Public Sector when asked the same question said:

> *"Working the public health system is a real job you never leave the job at work, it comes home with you even after your shift is over you are sometimes very tired from working double shift sometimes because people are on leave and sometimes people often die if they are too far along and when they do die we have to deal with their families also who come and get the body later. This is what we take home and the other places I have worked you can't say are the cleanest places for people to call a hospital or clinic. We are not meant to be in charge of cleaning the hospital except to dispose of the medial waste correctly but they don't use the best cleaning materials because the hospital sometimes smells of sick people and old blood. We have to breathe this in everyday and we are expected to do our jobs like hospital is clean"*[7].

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[6] Nurse A. Grahamstown Settlers Hospital. 11/01/2015.
[7] Nurse B. Grahamstown Settlers Hospital. 10/01/2015

Nurse A at Settlers confirmed that the working environment is sometimes not conducive because:

> *"I have to deal with staff shortages and the only way I can do this is to get people to do a double shift and that means the patients that come the next shift will not be as productive and the nurses are not very happy when this happens because they are not always guaranteed over time as much they are paid they are paid very late. This does not create a good working environment between me and them and then there are other staffing issues I have with the cleaning staff which are not meant to be mine to handle like it like I do every day making sure they clean the hospital and dispose of the medical waste and use the correct cleaning things that actually do their job not the cheap detergent they use sometimes"*[8].

It is clear to see that the government definitely has issues in providing adequate staffing to deal with the issues such as nursing shortages and supplying efficient cleaning services for hospitals. Hospitals are meant to adhere to environmental health laws in making sure that disease and infection do not spread due to the environment not being cleaned. This being a controllable disease, this control measure is one that seems to be violated by many public hospitals that also have to deal with staff shortages as well as having poor infrastructure, including poor ventilation and the use of cheaper cleaning materials. Walking into public hospitals and clinics both in the Eastern Cape and the Gauteng province, I was meet with the distinct smell of unclean air, old blood and the smell of wounds, vomit and faecal-matter and cheap cleaning detergent that poorly masks the smell of sick people. In one of the clinics I walked into the smell was so pungent that I felt nauseous whilst walking around trying to get interviews. I assessed the environment and it was not one that represented wellness. I even started to question the ventilation in the hospital and I doubt that it is sufficient. I will not go any deeper into discussing this topic because it deals with issues of medical waste management and environmental health issues which might be interesting to the topic but this would be diverging from the study.

Getting back on topic with the issues of skills in the public health system, a medical student who went to UCT and who is now a doctor in the Cape Town private sector, did her residency at a public hospital in Cape Town. When asked to explain her experience and comment on the working conditions and skills found in the public health sector, she said,

[8] Nurse A. Grahamstown Settlers Hospital. 10/01/2015

Medical Doctor A:

> *"Nurses and doctors in the public health sector are great. They are well educated and they taught us very well as students but the main issue is that there isn't a lack of education of nurses as there are also many medical innovations and medicine changes. The issue lies in them resisting change to implementing the new methods where they are comfortable in the way they have been doing things for the past 10years if they had been taught by someone who has been using the same old method to do things. How are they meant to progress? And use new methods*[9]*?"*

This made me realise that this might be a ripple effect that needs to be addressed at nursing schools and as well as in the training programmes that occur throughout the year for some hospitals and clinics. The reason that this resistance occurs is also due to the gap in the type of training that the older nurses have been given. They might have learnt being nurses during the apartheid era and may not have been shifted due to lack of skills to being employed in the private health care system. This was reiterated by the doctor from the private health care sector who works for My Sexual Health Clinic in Pretoria and she mentioned that:

> *"Some of the nursing staff under the public health care sector are excellent! My feeling is that more than 50% of them are overworked and are undereducated, in that they did not go through the proper training in what they are meant to be dealing with and often they get frustrated and then the patients are the ones that initially suffer from that and the other thing is that the community doctors. There just aren't enough doctors actually, and you find the sisters at the end of the day are working and they are left trying to manage HIV, TB and all those AIDS-related diseases because there are just not enough doctors to support them"*[10].

It is evident to see that the nurses have to assume other roles that are beyond their job descriptions and this is where their work challenges lie on a daily basis. This is also based on the foundation that is due to a lack of qualified specialist doctors who are in the public health care sector. Even though they exist, there are not nearly enough where they are needed. This is supported by Boyce and Yawa (2015) from the TAC when they both agreed that there was a lack of specialized doctors in the public health care sector.

Boyce then went on to further state that:

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[9] Medical Doctor A. Johannesburg. 12/12/2014.
[10] Dr. J. Serfontein. My Sexual Health Clinic. 13/12/2014

> *"the problem you see is that the state is not willing to pay the specialised doctor more money that is why after working their residency or community service year(s) in the public health sector and they have specialized in HIV treatment and the treatment of AIDS-related disease they are poached by the private health care sector because they will pay them that bigger salary"*[11].

When learning doctors and nurses have finished doing their community service years or residency and if they have particularly specialized, they are often poached by the businesses that fund the private health care system. It could be argued that this is where the internal brain drain occurs. After your studies you look for employment that will pay a higher salary and people are often not guided to work in areas where their qualifications are needed.

8.3 Poor Medical Infrastructure

Kuroiwa et al. (2008:366) highlighted the disparity between the hospitals and clinics found in urban areas and the medical infrastructure that affects various areas where the emphasis is on rural hospitals because they suffer a lack of technology, administrative services and finances, to a great degree. According to Vumase (2009:6) a major issue that rural hospitals are further faced with are issues concerning the poor communication systems at provincial or even local government levels, where they suffer inherent delays when it comes to technological development. When comparing rural hospitals and clinics to those in urban areas, there are slight differences in some cases and in other cases you find that the hospitals in the urban areas are worse off that are very large and which mainly cater to patients that are using the public health care system. This is mainly due to poor resources and infrastructure as well as lack of technology, expertise and knowledge.

Human (2011:1) discovered the existence of the two-tiered system within the medical health sector in South Africa and from her study this division came to uncover the class existence of inequality that lingers in the system even after the 'demise' of the apartheid regime. The great inequality that exists has caused staggering differences in the accessibility and quality of care that is provided by the South Africa's medical system (Human, 2011:1). It should be noted that South African's health care sector is based on universal health care. This means that the public health care sector is a branch that provides free basic health care particularly to every citizen who cannot afford to pay for the services of a medical aid - also known as health insurance - and it also covers people who do not receive medical aid through

[11] Boyce, F. Telephonic Interview. 19/01/2015.

employment (Human, 2011:1). The public health care system also covers government employees such as nurses and government-related groups are also served by the public health system. According to Human's findings, an astounding 80% (about 35 million people) of the population use the public health sector and this is mainly through accessing clinics in townships and at public hospitals (Human, 2011:1). There is further division of the two-tiered system where the hospitals or clinics are located either in the rural or urban space. Their location affects the quality of services depending on the location of the hospital or clinic and whether it is privately funded or if it is government funded making it a public hospital. The findings of this study indicate that and this has been reiterated by Human's study of South Africa's health care system. When looking at public teaching hospitals in the major cities like Johannesburg and Cape Town, Human (2011:1) notes that they offer good services; however, they struggle with the overwhelming demand.

This is reiterated by Dr Serfontein when she claimed that:

> *"The nurses and doctors that are in public hospitals are really good at providing their services and they are not short of skills but they have to deal with a lot of patients in one day where you find that a doctor cannot find the doctors are so overwhelmed with the workload that the nurses have to take over that workload"*[12].

This is further reiterated by the doctor A when she said that:

> *"The work that is done in public hospitals is great, I learnt a lot as a medical student when I was doing my first and second year of medical school but there are some hospitals where there are staffing problems because they have to work overtime because there is a lack of doctors and there are a lot of sick people who have been referred to the main hospital in the city because there aren't enough resources to treat the patients that comes from the township, rural area or smaller clinics that do not have specialists*"[13].

According to Sheps (1981 8) the government is facing the inability to fully equip rural hospitals, and this causes a ripple effect in the functionality of particular services like it comes to affect the rural communities' ability to have well equipped and fully functional hospitals or clinics. Often rural hospitals struggle with poor building conditions, with broken

[12] Dr J. Serfontein. My Sexual Health Clinic ./12/2014.

[13] Doctor A. Johannesburg. 12/12/2014.

equipment, and often with scarce resources of essential medications and this adds to the poor service (Human, 2011:1). This is evident through the many articles that can be found in various publications of Equal Treatment that are written by people affiliated with the TAC and Section27. Some of these real life accounts are very horrific as they describe some of the deaths that have occurred or the increased medical complications from experiencing a lack of health care equipment, space and resources.

Patient B is HIV positive and he uses the public health sector to attain medical care and services. When talking to patient B he was very open to share his status but not his name because I met him through one of the nurses who directed me to an HIV-support group. The interview was not recorded because there had been a group session prior to us meeting and a few group members were still around. I took some notes and patient B spoke a lot about the challenges that are faced in the public health care sector when it comes to the lack of education and also the lack of treatment variation. The notion of treatment variation will be dealt with in the pharmaceutical crisis section of the discussion.

Patient B noted that even trying to get people to come to the support group is very difficult because people are afraid to disclose their status to their communities and loved ones, let alone strangers. What came to the forefront was that the public health sector on days when people come and refill their medications they have to wait in long queues and often all day long. The patient went on to tell me of various scenarios where people often in the rural areas are suffering the most because often their local hospitals or clinics have run out of medication to dispense to them. This is a great challenge because these people had either walked a long distance or paid for bus fare and arrived to not get any medications because they were not delivered. They are often referred to hospitals that are further away and have longer queues where they are unfamiliar with the overworked nurses and doctors who, he aid, are often not the most patient nor are they highly concerned about their other personal aliments if they do not usually get their medication from the public health facility. When the participants were asked to respond about their view of the public health sector, this is what they had to say:

Boyce:

> *"It is in total collapse because the people who are bestowed with the responsibility of giving the services to the people especially those who are dependent upon the public health care sector they are sort of non-touchable because they do not want to account*

for their actions as a result that is why we find there is a collapse in the South African health system[14]*."*

Yawa's response was as follows:

"Honestly speaking the public health care system of South Africa is falling apart, we have got a good minister of health, what I mean is that he is good at presenting good reports whenever there are problems the minister of health is nowhere to be found and the MPCs in other provinces that do not have the political will to deliver on the poor and the marginalised people. In South Africa we have "iHealth" system that is failing the poorest of the poor. If you go to any clinic in South Africa you find that there are human resource problems there is a shortage of doctors, nurses, pharmacists and all that stuff. You will also find out in these clinics that space is very small as a result of that they cannot deliver on all the services where the place has shortages and is not well equipped. You also find that the nurses most the time in these clinics have an attitude against health leaders which makes it difficult for health users to be able to continue with their appointments and medications because particular nurses have an attitude and sometimes the nurses break the patient confidentiality"[15].

Bheki Dlamini, a Section27 research fellow, described the South African health care system as:

"Living in two different worlds and its quite interesting between the private and public. So our work challenges is making sure the public health care system is in a better state because we are catering for a large number of people, But unfortunately it is not of the right quality so currently we have to bridge the gap between the two which is private and public. So if we get to bridge the gap between the two it means that we would have quality health care services to all people and not just to a particular sector of our society which happens to be affluent people"[16].

Therefore, when asked to describe South Africa's health care system, there was a general consensus that there was gap in the system that needed to be bridged between the private and the public health care system. The type of patient care that is given as described above is

[14] Boyce, F. Telephonic Interview. 19/01/2015.
[15] Yawa, A. Telephonic Interview. 20/01/2015.
[16] Dlamini, B. Telephonic Interview. 19/01/2015.

definitely unacceptable and it violates the rights of the patients who are there to seek assistance.

There are added issues of infrastructural problems that greatly affect the running of public clinics, particularly in the rural areas of South Africa. Yawa further stated that:

> *"Most of the provinces in South Africa we have deep rural areas like in the Eastern Cape you have OR Tambo or Lusikisiki around Umtata. Most if the time it is difficult for an ambulance to fetch an ill person in those rural areas particularly if the road is not even cleared and in the deep rural areas some nurses work without electricity and use oil lamps and there is no running water and it makes things difficult for doctors to be able to render services adequately to health users"*[17].

The added challenges that are part of the public health system are those that, at the national level of service providers, affect the working of the public health system. As described by Yawa:

> *"On top of other key players that add to the challenges in the public health sector is the service providers currently look at the National Health Laboratory (NHL) service it is unable to render services. People's blood samples are sitting there because the National Health Department is unable to pay the NHL so that they can be able to render services particularly to the poor"*[18].

The reason that the public health sector is dysfunctional or is in total collapse is due to a number of reasons that are caused by the ripple effect of interdependent sectors of the public health system that are not run very well. This can come from the very top and this is how the trickle down of mismanagement occurs and it has caused drastic problems that have created the 'total collapse' of the public health sector.

This is not to say, though, that there is nothing good about the public health care system. The participants were also asked to describe the good aspects of the public health care system and this was Boyce's response:

> *"What is good about the public health care system is that there are services that are rendered free to the poor and the vulnerable"*[19].

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[17] Yawa, A. Telephonic Interview. 20/01/2015.
[18] Yawa, A. Telephonic Interview. 20/01/2015.
[19] Boyce, F. Telephonic Interview. 19/01/2015.

Yawa mentioned that:

> *"Even though I might be contradicting myself. However the only thing that I will tell you is that in South African health care sector from our point of view as TAC what is good, is that through the public health system of South Africa we have managed to save lives of people. Who are more than 2.5 million who were on the death row due to the issue of accessibility of ARVs that is something good".*[20]

So far the accounts discussed above about the public health care sector show the one end of the health care sector in South Africa. At the other end of the spectrum of the South African health care sector are the private clinics like My Sexual Health, which provides a place where patients can get their counselling and attend therapy about their sexual health, where they can get tested and treated at the clinic where they also get their medication dispensed. This clinic is for families which means there are fertility specialists, sexologists, gynaecologists, doctors and nurses that specialize in HIV and AIDS as well as AIDS-related diseases.

When asked the reason that the doctor decided to work in the private health care sector after studying in the public health care sector, Dr Serfontein stated that:

> *"the private health care sector appealed to me initially was the financial reasons where I thought I would make more money in the private health sector and there is the convenience of it where there is the possibility of doing your own thing, you are in control and I like the patient profile, the education the consultations and it's just much cleaner and much more comfortable situation and there is so much more a your disposal"*[21].

This clinic is equipped to achieve a good family health care service where, as mentioned, there are many specialist doctors on the staff and trying to get pregnant is never an issue for their patients because they offer In Vitro Fertilization (IVF). This is an assisted reproductive technology commonly referred to as IVF, where the fertilization is done through manually combining an egg and sperm in a laboratory dish and then the doctor transfers the embryo to the uterus, a service that is not readily available in the public health care sector.

One of the patients interviewed was a young lady age 27 who is a regular patient of this private clinic. She was very open to share her status and be part of the study. She mentioned

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[20] Yawa, A. Telephonic Interview. 20/01/2015.
[21] Dr. J. Serfontein. My Sexual Health. 13/12/2014.

that she was very satisfied with the services and care that she received from the private health care sector. When asked to share her experience of using the private health care sector, this is what she had to say:

Patient A:

"I am HIV-positive and I have been for the past 7 years, I contracted the disease from my first boyfriend and I thought I would never be able to have kids if he ever left me. The day came and oohh my God everything fell apart for a sometime, until I started going to My Sexual Health Clinic to get help, through therapy and trying to get on the best medication possible. I was confident that I could continue to manage this disease and that I can still live a full life, without much worry about my health because of my status. Long story short, I meet my fiancé two years after I found out I had contracted the disease and he was there when I decide to tell my family at the therapy session. My family was very understanding and supportive and so was he…We (her fiancé and herself) knew our best option to get pregnant was through IVF and on our first try we were successful. We were very happy about this news[22]*".*

Dr Serfontein mentioned that she noticed that the patients that came to her clinic were more educated and open about their HIV-statuses. She mentioned that this helps in patients keeping to their medication regimes and they better understand the importance of managing their health through regular check-ups, sticking to their daily medications, and eating healthy diets with a regular exercise schedule. It is evident that the private health sector hospitals and clinics can have more of a 'combined' medical health system where a patient is more likely to receive better health care services and usually from one place as evident with the My Sexual Health clinic used by Patient A. Often in the public health care sector they do not have enough specialists under one roof so mother and children go to separate hospitals or clinics and those with different AIDS-related diseases also have to go to different hospitals and clinics to attain the medical assistance that they need. These are added costs to travelling to these hospitals and clinics and this could work against the patients' ability to stick to taking all their needed medications.

8.4 Discrepancies with Delivery of Constitutional Rights

When it comes to the South African Constitution it has been praised all over the world as one of the best written constitutions, and particularly for an African country. The South African

[22] Patient A. My Sexual Health. 13/12/2014.

constitution has rights that protect everyone and almost every sphere of life for the South African citizens. It is definitely a ground-breaking piece of legislation that, during the colonial and apartheid era in South Africa, would have been unfathomable to some people. The three main constitutional rights that will be dealt here are the right to citizenship which is stated in the constitution as follows:

Citizenship 3. (1) There is a common South African citizenship. (2) All citizens are - (a) equally entitled to the rights, privileges and benefits of citizenship; and (b) equally subject to the duties and responsibilities of citizenship. (3) National legislation must provide for the acquisition, loss and restoration of citizenship.

The Bill of Rights addresses citizenship under Section 20 as follows:

> *"No citizen may be deprived of citizenship".*

This right states that all citizens are meant to be equal in the eyes of the South African law.

The second right that will be discussed is the right to education and the South African Bill of Rights mentions in Section 29 that:

> *" (1) Everyone has the right –*
>
> *(a) to a basic education, including adult basic education; and*
>
> *(b) to further education, which the state, through reasonable measures, must make progressively available and accessible.*
>
> *(2) Everyone has the right to receive education in the official language or languages of their choice in public educational institutions where that education is reasonably practicable. In order to ensure the effective access to, and implementation of, this right, the state must consider all reasonable educational alternatives, including single medium institutions, taking into account - (a) equity; (b) practicability; and (c) the need to redress the results of past racially discriminatory laws and practices".*

The third and most important right that will be dealt with is the right to health. In the Bill of Rights Section 27 deals with rights to health care, food, water and social security. The Bill states that:

> *"(1) Everyone has the right to have access to - (a) health care services, including reproductive health care; (b) sufficient food and water; and (c) social security,*

including, if they are unable to support themselves and their dependants, appropriate social assistance.

(2) The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.

(3) No one may be refused emergency medical treatment".

The chapter that dealt with the South African Constitution showed that there are some discrepancies when it comes to the government materialising the promises of the South African constitutional rights. The rights to citizenship, education and health have been definitely infringed by the government. The data from the interviews clearly shows that the state is unable to fulfil these needs for its people as promised in its legislation.

Yawa mentioned that:

"There are big issues when it comes to the state not delivering on its promises because it is clear that ama-rights of the people are being infringed"[23].

Boyce also shared the same sentiments with Yawa when he said that:

"It is not that the legislation is wrong it is about the mismanagement that is going on, you know it is the way that the government heads have handled trying to materialise these rights"[24].

Fikile went on to to mention that the South African people know that they have rights but they know their very basic rights. This is where the work of the TAC and Section27 comes in because the people's rights were being infringed and they did not know that they could take the government to court and hold them accountable for this social injustice. By using the rights-based approach as previously mentioned the intention is to improve and further develop the ability of individuals and communities to recognize their rights because it is important to understand that it represents a set of interdependent set values, aspirations and disciplines (Tarantola et al, 2008:1). The implementation of human rights to health care is all aimed at trying to achieve desired health goals and where the needs for people are coupled with trying to achieve set development goals.

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[23] Yawa, A. Telephonic Interview. 20/01/2015.
[24] Boyce, F. Telephonic Interview.19/01/2015.

Tying in the global perspective into the local work that the TAC is doing is based on the foundation of the publication of the International Guidelines on HIV/AIDS and human rights by the United Nation's Joint Program on AIDS (UNAIDS) and the UN Office of the High Commissioner for Human Rights (OHCR) in 1998. The document has assisted in the expose of governments who were violating the standards set out in the document and the document can be merged into advocacy. The result of emphasizing human rights to claim a normative international standard has amplified the 'currency' in the field of HIV/AIDS from the early 2000s (Heywood, 2009:16).

South Africa has legitimate institutions that are like watchdogs for human rights. Take for instance the South African Human Rights Commission (SAHRC) its duty is dedicated to the ensuring that it monitors the exercise and enjoyment of the right to health care when "health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest standard of health conducive to living a life in dignity" this is under Article 12 of the International Covenant of Economic, Social and Cultural Rights (2000).

As mentioned by Boyce the work of the TAC activists is based on the notion that:

> *"We also have our constitutional rights as the South African people within the bill of rights if people cannot enjoy such rights in the health system like this because it is in total collapse and the rights are being infringed even though there is the good legislation like the constitution especially for the unemployed and the pensioners. There is law that states that the unemployed and the pensioners should have access to free health care and children up to the age of 7years.This is the provision found in the National Health Act during the time of Mandela"*[25].

This is where it all comes together. As mentioned before in the history of the TAC, it began as a social movement and it helped to educate at a grassroots level the people about their rights. As stated previously NGOs re-articulate political and social issues as human rights problems and to some degree this has contributed towards what Reich (2002) calls 'reshaping' the state because new technologies 'have created new sources of power: through the flow of ideas, information, alliances, strategies and money' (Heywood, 2009:17). Here is the rights-based-approach beginning to become evident to the people. With the help of Section27, the TAC partnered up with a much needed legal force which allowed them to be

[25] Boyce, F. Telephonic Interview. 19/01/2015.

further educated about the law and the various ways to use the most appropriate type of law that suited each case. With this joint effort we have seen the materialisation of the rights-based-approach where the people have taken action on their own to mobilize and, through the use of the legal legislation, they could reinforce their cases that applied to the government. As mentioned by Heywood (2009:17), the TAC has implemented a different approach where it has fostered the capability to follow human rights claims particularly directed to the poor whilst also catalyzing a political movement for health (Heywood, 2009:17). This has been evident through the mission statement of the TAC and they have materialized their efforts through their work that has been done in various provinces in the country.

What does come to the forefront, though, is that even though the TAC has partnered with Section27 for a legal foundation, it is a clear indication of the ways in which certain citizens have to appeal to the government for their rights. This shows that the government has to a degree infringed on the rights to citizenship, the rights of being equal and treated equally in the eyes of the law. It has been discussed in the section where there are clear differences in the division of health care in the South Africa, where the division is not only between the public and private sectors but it goes further where there is a divide between the rural and the urban hospitals. When such divisions exist within a democratic state, it brings to question that notion of civil society and access to equal rights and services provided by the government.

As previously mentioned, Lauren (1998) notes that governments were compelled to recognise that they have an obligation towards their citizens and towards other states (Tarantola et al, 2008:2-4). In the case of South Africa even though the state recognises their obligations, they have not made sufficient changes to making sure that the people's rights are not infringed. If the government had met the provision of equal services to all its people, there would not be a need for people to form social movements such as the TAC. The issues lie within their conception, implementation and content of these human rights as they contain views and implementation strategies that are in conflict with political views and religious beliefs of other world states. This results in the mistreatment and neglect of human rights in Constitutional Rights and Bills of Rights, and what becomes evident is that 'exclusionary politics' take shape (Helliker, 2013); where those that use the public health sector find that their rights are being infringed. The issues the TAC and Section27 are lobbying for are issues that began in the colonial era and they were amplified during the apartheid era. However, as mentioned in the history of HIV and AIDS in South Africa, had the Mandela

and the Mbeki regimes not acted accordingly in dealing with the HIV/AIDS treatment in South Africa, the country's HIV/AIDS status might not be where it is right now. Now there are over 2.5million people who have to be on ARV treatment and this includes men, women and children. This is because the democratic heads of states restricted access to HIV and AIDS education in the country. As mentioned before the South African Broadcasting Corporation censored HIV/AIDS and condoms commercials during prime time television and they were limited to being broadcasted only after 9pm (Geffen, 2010:18-19). This was all during the time of Aids 'denialism', for want of a better word, when the government took 'the ostrich-in-the-sand-approach' (Geffen, 2010:19). In the TAC documentary *Fire in the Blood,* Peter Mugyenyi, MD describes the government denialism by saying:

> "Let me put it this way -- there is not a world country which would have tolerated the loss of millions of their citizens while life-saving drugs were available."

This is the foundation upon which the TAC saw that there was a lack of HIV and AIDS education. As Boyce mentions:

> *"Our work with educating people started with dealing with educating the men about the disease first because here we were dealing with issues of patriarchy and there are a lot of gender issues that came into play during the beginning stages of HIV and it also a time when the stigma had to be dealt with"*[26].

As mentioned before the HIV and AIDS stigma was one that was transferred onto particular societal individuals. As mentioned previously HIV and AIDS began as a homosexual disease and then it was attached to those that were deemed sexually promiscuous, all because the disease was not understood nor was it well research at the time. 30 years ago HIV and AIDS were one and the same thing and due to research and further HIV and AIDS education people understood the difference. The HIV and AIDS education campaigns that the TAC did dealt with such issues and it came to also debunk the stigma in communities because it was all about knowing the importance of how people could contract it through various ways and not only through unprotected sex with a HIV-positive person.

So much work has been done by the TAC and Section27 when it comes to using a rights-based-approach to health. The most successful case pertaining to this study was the Grootboom case that dealt with PTMTC, Dr Serfontein said:

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[26] Boyce, F. Telephonic Interview. 19/01/2015.

> *"I think the PTMTC guideline has been one of the most successful because it has been well implemented and it deals with the wide range of issues, it changed issues from if the baby is born HIV-positive or it acquired the HIV through breastfeeding it definitely has dropped the HIV rate significantly from 30years back to now and the good thing that has changed about the PTMTC guideline is that the mother can be started on treatment earlier to start ARVs and diagnosis and I think that is an excellent thing in that, that works well and in terms of it being used in the public health sector is really very good"*[27].

As mentioned previously in the section that dealt with understanding what a rights-based approach is, through looking at the work that the TAC and Seciton27 have done, it has shed light on the importance of understanding that this is the most constructive way to combat issues such as social injustices, conflict, marginalisation and poverty.

As mentioned in the opening statement in the human rights movement section, the TAC and Section27 are grounded in the use of the tools of the human rights movements in trying to materialize their vision and mission statements. This has been supported through the data provided in this discussion about the efforts of the TAC and Section27. This is because they are civil society organizations that can internationally locate their activities within the international human rights framework. Heywood (2009:16) highlights that this can be the case if these organizations are working within the vision of the Universal Declaration of Human Rights.

8.5 NGOs

Understanding the workings of the TAC it is important to know that it began as an AIDS activist movement before they became the more organized NGO that it is today. As mentioned before, this NGO started because there were needs that needed to be met and this was because particular citizen rights were being infringed as discussed above. As previously mentioned in the NGO chapter, NGOs tend to stand by the ideologies of 'sustainability and participation' when integrating these elements into all the facets of development programmes, so as to attain the desired change that the NGO and the funders are supporting (Collier, 1996 cited by Eade & Pearce, 2002:115). NGOs need to be understood according to Hilhorst as 'open-ended processes' because they do not have static limitations and they generally do not function in isolation (Hilhorst, 2003). The TAC encompasses this definition of what NGOs

[27] Dr.J. Serfontein. My Sexual Health Clinic. 13/12/2014.

are because its initially began as an HIV and AIDS social movement campaign and now it has partnered with Section27 which encompasses the use of the law to support its cases it has to make in court to attain their desired goals. NGOs can be termed as organizations that are non-state groups engaged in issues that generally mirror the range of concerns articulated by global justice movements (Borras, 2009:205). This has been the work of the TAC which has now become an award winning South African social movement campaign because:

> "*In the 12 years since it was established TAC has helped to save and better millions of people's lives in South Africa. It has also contributed to the deepening of democracy in South Africa, through its use of the courts, advocacy and promotion of human rights constitutionalism*" (TAC, 2011:1).

This could be because NGOs are seen as one of the channels that create the opportunity for operationalizing the New Policy Agenda's economic and political goals (Hilhorst, 2003). According to Moore (1993) this is because NGOs are viewed under the lens which portrays them as 'vehicles for democratization' and they are vital mechanisms that will ensure a thriving 'civil society' which is seen as crucial to the success of the New Policy Agenda's economic dimension (Hulme & Edwards, 1997:6).

With the TAC working with the legal aid of Section27, it could be argued that as an NGO it has brought about new concepts to alter development thinking and practices including different concepts of participation, empowerment, gender, and the introduction of making person-centred approaches to development more important (Robison, 1993 and Lewis & Kanji, 2009:24).

NGOs can be categorized in various sectors as they can either be considered as 'non-state bodies' or they are sometimes seen to be part of civil-society or they are sometimes seen as organizations that are funded by the private sector but are still not-for-profit (Helliker, 2006:7).

A few NGOs during the 1990s were linked to international funders and many of them relied on the local and non-grant sources of funding (Wallace et al, 2006:83).

Helliker (2006:2) believes that NGOs represent inconsistent relations where there are contradictions between 'the global' and 'the local'. This is affect by the NGOs finding themselves in a catch-22 space in which they wrestle between their upward accountability

that they have towards their donors and also their downward accountability towards the communities in which they are working.

NGOs have also played the role of being campaigning policy advocates (Lewis & Kanji, 2009). NGOs and grassroots organizations (GRO) are meant to perform as a counterbalance to state authority by introducing and implementing channels of communication and participation whilst also providing training grounds for activists endorsing diversity and by defending human rights (Hulme & Edwards, 1997:6). This can be seen through the work of the TAC where it has branched out further in not just socially mobilizing on the ground. The TAC in 2011 over a couple of months has assisted in the development of the new National Strategic Plan on HIV, TB and STIs for the years 2012-2016. This has assisted to resolve the shortage of essential medicines used to treat various opportunistic infections; their work also brought about the organization of clinicians, government and civil society organisations with the aim to take action and collectively combat the TB epidemic (TAC, 2011:1).

Yawa mentioned that NGOs such as the TAC and other advocacy groups can be seen as the key players in the South African health care system. This is because:

> *"The TAC and other advocacy groups are there to speak out when certain services are not rendered to the health users and these organisations also assist to educate, rally people to get tested and also to change the South African health care system both at the bottom and at the top with all the key players of the South African health care system to be involved. Like the health users, providers of the health care services in those particular facilities, the clinic comity who assist here and there with governance of that particular institution and also we have politicians who are decision makers either at a district level, provincial level or at a national level"*[28].

It is evident that the TAC does not work alone in trying to attain their goals. This shows how they play the role of being intermediaries in the South African health care system. They have noted the importance of working with all the health care players because they are interdependent on each other to create a functional and equal health care system. The volunteers of the TAC work in various communities all over the country and they have distribute over five million condoms a year and the treatment literacy practitioners assist in the provision of information about HIV treatment to the patients in the clinics all over the country (TAC, 2011:1). There are 130 branches and they are all geared to recognize problems

[28] Yawa, A. Telephonic Interview. 20/01/2015.

that are found in the clinics and they attempt to get local health authorities to work effectively (TAC, 2011:1) because they are part of the web of the health care systems in South Africa. The TAC has also worked to expose the Tara Klamp disaster and they have won many complaints at the Advertising Standards Authority against impostor health practitioners (TAC, 2011:1). The TAC has been a very outspoken civil society voice that has been advocating for diverse issues within the health care system. With the help of Section27 these organisations have from the Medicines Control Council won the recent court case against Adcock Ingram denouncing the Protection of State Information Bill (TAC, 2011:1). The TAC and Section27 have done a lot more than these projects mentioned above over the past 10 years in the South African health care system.

According to Helliker (2006:8) and Helliker (2013:318), NGOs can also be referred to as 'intermediaries' and this brings to the forefront how NGOs have been labelled as 'problematic organizations' because they are located within an unclear social space as they are part of a 'complicated web of social relations as part victim and part maker'. This is because they have to negotiate their existence in the communities that they are in as 'agents' of the work that they do and as 'intermediaries' (Helliker, 2006:8). NGOs can be intermediary because they create links between the beneficiaries, donors or financial institutions and links to 'often' remote levels of government (Caroll, 1992:11 cited in Helliker, 2006:7-8).

This is where the vanguardist politics of NGOs emerge. When speaking of vanguardist politics here, the argument that needs to be understood is that there is the issue of NGOs being stuck in the catch-22 position that was spoken about earlier. Here the issues become about how NGOs are torn between existing in a situation that blurs the lines as to whether they are either more downward accountable or more upward accountable and this has the power to determine their existence when it comes to donor funding (Helliker, 2013:321 and Lewis & Kanji, 2009:18).

When one looks at where the TAC got most of its funding in 2011, it was from the five year grant that comes from the Global Fund to Fight AIDS, TB and Malaria (GFATM). This is where the TAC received a large sum of money to cover most of its work (TAC, 2011:1). Due to the National Department of Health delaying the payment of R6.5 million tranche in 2011 this has caused an acute cash flow crisis for the TAC (TAC, 2011:1). As of 2014 last year the TAC was facing major financial challenges and they have to face tough decisions of

downscaling or closer as of February this year if they have not attained the needed funding (Rutter, 2014:1). The reason the TAC is facing such major funding issues is because there have been quite a few foreign donors that have withdrawn their funding for AIDS and are no longer providing funding to the TAC as well as other civil society organisations that they used to fund in the past as well (Rutter, 2014:1). These donors that have withdrawn their funding include one of the key funders of the TAC, the United Kingdom's Department for International Development (DFID). This is because they are withdrawing from South Africa because they now see South Africa as belonging to the middle-income status (Rutter, 2014:1). These are funders that would require NGOs to be accountable to them as donors that have chosen to fund them and as a result:

> "Most of the time when donors give you money it is required that TAC must deliver on this and that and TAC is a campaign where we respond to issues as they present themselves on the ground. So at times if there is a problem on the ground and if the problem is not part of the funding aims then it becomes a problem for TAC to intervene. That is why it is important for people to understand that as much as we get funds from the donors but most of the time it should not be restrictive funding we should be able to be given a leeway of managing money that is not restrictive"[29].

The TAC has lost funders towards their cause despite there being about 400 000 new HIV infections that occur every year in South Africa, 170 000 AIDS-related deaths and there are about 88 000 deaths per year of people who have been living with HIV due to TB alone (Rutter, 2014:1).

This is because, according to Boyce and Anele Yawa, the treatment of TB is very out dated and it needs to be addressed because it is a HIV and AIDS-related disease and it is the most opportunistic disease that affects the sick. Without the necessary treatment the AIDS response in the South Africa is defiantly 'in peril' as mentioned by the *New York Times* (Rutter, 2014:1).

The TAC activists are still continuing to do serious work when it comes to holding the government as well as the private sector responsible for being active to lessen the co-epidemics of HIV and TB that are found in the communities (Rutter, 2014:1). According to Rutter (2014:1) 'without the training, mobilisation and organisational infrastructure of the TAC, users of the healthcare system will find it challenging to demand better health services

[29] Yawa, A. Telephonic Interview. 20/01/2015.

and to respond effectively to mismanagement, inefficiency and corruption in provincial healthcare systems'. The study's data discussion has shown that the TAC has certainly done a lot to change the health care sector in South Africa. What come to the forefront now is how the TAC is planning on attaining the funding goals even if there are still funders that have not backed out. There is still much needed funding to attain their goal of R30-million operating budget for this current year.

The TAC to a degree is not caught in the mentioned caught-22, where they have to question where their accountability lies as they are not torn between their donors and the people for whom they are trying to change the public health system. This is because they have changed the funding strategy maybe not out of choice but they have had to re-evaluate their funding strategy. The participants from the TAC were asked if their funders asked them to alter their programs to satisfy their agenda as funders and these were their responses.

Boyce explained the new approach to funding that the TAC has adopted:

> *"Last year we have taken a bold decision after some confrontations both on the national and the board of director's level who have agreed on the funding of our own campaign in terms of starting our own funding campaign. If you remember that towards the end of the year the funds of the TAC were depleted and we are not yet sure if we will get funding for 2015-2016 financial year but it is one of the reasons we came up with such a campaign whereby we are using all our resources and available avenues in terms of making sure the TAC stays afloat in the next financial year. We ask volunteers and staff to contribute towards the funding of the organization as well as that everyone can take it upon themselves to go out and embark on a fundraising campaign locally and nationally"*[30].

Yawa supported Boyce statement by adding that:

> *"Most of the TAC funding is coming from the donor community but after the funding crisis the TAC is going to be using a global funding campaign where we have made the plea to the people of South Africa to the people of the world and to the individuals and to other donor organizations to come forward to contribute to TAC so that we can be able to save lives so many people in South Africa and across the world as*

[30] Boyce, F. Telephonic Interview. 19/01/2015.

> *individuals have contributed a lot of money to TAC that is why we have managed to raise more than R1.5-million and this funding is not restrictive funding"*[31].

The TAC has certainly attained the some funds and has managed to stay afloat so far even though, as Rutter (2014:1) notes, that this was done in the "difficult funding climate", and so far as Yawa has mentioned, 'the TAC has managed to raise less than 30% of our budget for the 2015/2016 financial year' (Rutter, 2014:1).

As claimed by Boyce:

> *"So long as people see the work of the TAC as important to trying to prolong people's lives and they realize that the TAC and Section27 is the voice of the voiceless, this will make sure that the TAC continues its work. We are also hoping that the donations will continue to flow in and the work will continue. This will further help the TAC to continue doing work that is much determined by what is going on the ground in the public health sector"*[32].

8.6 Pharmaceutical Crisis

Millions die of AIDS while giant pharmaceutical corporations block access to the low-cost medicine which could have saved their lives.

The pharmaceutics crisis is present both in the first world countries like the United States of America and in the developing world countries like South Africa. There is a higher prevalence of the pharmaceutical crisis in the developing world than there is in the developed world. The film *Fire in the Blood* clearly portrays the HIV and AIDS pandemic in South Africa where:

"In 1996, everything changed for people like Justice Cameron when a combination of three anti-retroviral drugs, or ARVs, proved successful in fighting HIV. Suddenly the most feared and destructive disease of the age was no longer a death sentence. The drugs he was taking were sold internationally at over $15,000 per patient per year, far beyond the reach of 10s of millions of people living with HIV/AIDS." (+). Zackie Achmat, founder of the TAC: "The only reason we are dying is because we are poor."

The narrator in the film *Fire in the Blood* said:

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[31] Yawa, A. Telephonic Interview. 20/01/2015.
[32] Boyce. F. Telephonic Interview. 19/01/2015.

> *"The problem Zackie and other South Africans faced was both simple and brutal: the drugs they needed were made under patent by multinational pharmaceutical companies, and the patent made it illegal for others to make, sell, or import unpatented generic drugs, which typically cost less."*

Achmat explains his cousin, who had AIDS, extended her life for 6 months by smuggling in drugs.

A very similar pharmaceuticals situation as being experienced in South Africa was also evident in the American health care system. This is evident in the documentary by Michael Moore called *Sicko.* In this film Moore was interested in trying to understand why the US nation is the 'sickest' nation in the world when the US is the leading country in the world with the best medical research and supply of pharmaceutical medicines. Through his portrayal of the US health care system you can see that those that tend to go for the generic medicine belonged to the lower income financial bracket which is similar to that of the South African people who qualify to use the public health care system. As mentioned before the majority of South African's who are purchasing generic medicines are not on a medical aid scheme and they cannot afford private health care. This is a similar case to those Americans who have to use the public health care services as well. Many of the Americans in the documentary had to leave the US to attain medical attention outside the country because the medicines were cheaper and this is where one of the major issue lies - the expense of medicines and their availability.

The narrator in the film *Fire in the Blood* stated that:

> *"The only way Zackie Achmat could help his cousin was by breaking the law. Pfizer had a patent on Fluconazole (sold under brand name Diflucan)which could alleviate extreme pain in those suffering from AIDS-related infections....its patent gave it a monopoly in South Africa, enabling the company to charge astronomical prices. A generic version was available at a tiny fraction of the cost, but that was in Thailand."*

In Thailand, the generic cost less than $0.05 per capsule and in SA $30/capsule. Pfizer's patent made importing it a criminal offence.

Various people do the same thing in America where they would rather seek medical treatment in other countries like France and Canada because health care expenses are much cheaper to access in those countries than in the US.

Achmat's reason for trying to attain drugs in other countries in the film *Fire in the Blood* contains no malicious intent of stealing but he declared that:

> *"We don't have the intention of breaking the law. What we will be doing is breaking Pfizer's patent. We will be showing you that Pfizer and other companies are abusing their patent. We have no criminal intention. Our only intention is to defend people's lives."*

This screen cap in the film *Fire in the Blood* read:

> *"In 2000, Pfizer's sales of Fluconazole were $1 billion per year, with prices of up to $40 per tablet. The average weekly wage in South Africa, the continent's richest country, was $68."*

This clearly shows how pharmaceutical companies have the main intention of meeting the bottom line and not realizing that by over pricing their medications they are affecting the health of millions of ill people. Rost from the film *Fire in the Blood* said this is because:

> *"The drug industry, like any other private corporation, is there to make money. It is there to make money for its shareholders. The concept is to set the price at the level when you will maximize revenues. That means you gonna lose some patients because it is so high but you making up for it because the others are forced to pay that very high price."*

The legal restrictions called patent laws are the very laws that protect intellectual property rights. However, these also cause the issue of drugs being scarce on the market because of their high prices that are solely determined by the pharmaceutical production companies. This is where the discussion deals with understanding what generic and branded medicines are which, according to the CDER, are:

> *"drug (s) products that are comparable to a branded/reference listed drug product in dosage form, strength, route of administration, quality and performance characteristicsand intended use"* (Sherwood, 2008:7).

The requirements that the generic drug needs to meet are that it has to have the same active ingredient as the branded drug and it has to have the same strength. It can differ in colour and shape and the inactive ingredients have to be already approved by the FDA and they should also have huge similarity to the branded drug's inactive ingredients (Sherwood, 2008:10).

The altering differences to the branded product is the packing, shape of dosage (if not liquid), the different name they give the generic drug and usually the colour will differ and this is what the inactive ingredient would be meaning that it does not alter the effectiveness of the drug. This definition is the basic foundation upon which various researchers and writers have come to define their understanding of what generic medicines are.

The narrator of the film *Fire in the Blood* noted that:

> *"Branded pharmaceuticals had been for decades the most profitable business on earth. Even though the industry made almost all its money in rich Western countries [see awesome pic, shows 90% of sales in Western world (plus Japan)], with half of all revenue coming from the United States alone, the continent of Africa as a whole accounted for just 1% of sales. While Africa was only of marginal interest as a market, the drug industry feared that relaxing its patent monopolies in the poorest countries could set a bad precedent - one which might threaten future profit margins in major emerging markets like China and India."*

However during the past 10 years and counting generic drugs are increasingly in demand in the market and this is at a higher rate than the branded drugs and in particular within developing countries. It is clearly noted by the 2012 Mediscor Medicines Review (MMR), an organisation that has geared its focus to following the medicine practices of South African residents who mainly use medical schemes; the report notes that the available medical schemes in South Africa offer its members a generic consumption rate that is currently sitting at 53.4%. It can be further noted that this is somewhat higher than the generic drug consumption rate reported by 27 countries of the European Union, which are presently positioned at 50% (Health24, 2013:1). This is mainly because the generic drugs in developing countries are much cheaper than the branded equivalent. This also could be influenced by more people in developing countries being able to mostly afford public health care where the government funded hospitals opt for the cheapest medication that they can afford.

The narrator added that:

> *"Although low-cost generic ARVs were now being made in a few more developed countries like Thailand and Brazil, quietly acting to curb their own epidemics, governments in the poorest and hardest-hit countries backed away from challenging*

> *Western patents on AIDS drugs, having been repeatedly warned by the United States and others, that doing so would lead to severe consequences."*

Peter Rost, MD (former VP, Pfizer Inc., Pharmacia and Wyeth Pharmaceuticals) explained the reason that intellectual property (IP) was going to be protected even by the US government is because:

> *"The US gov't and the industry work hand-in-hand. Aid from the US is rarely given without straits -- it's given to further American interests. Those interests are aligned with the companies because, quite frankly, at the end, the companies are running the US gov't. I mean, they're pulling the strings."*

The lack of availability of generic drugs in developing countries was contested even by intellectual property (IP) rights activist in the US. IP activist James Love who featured in the film *Fire in the Blood* was noted by the narrator as saying:

> *"Desperate to build awareness among Americans about the fact that millions of people were dying of HIV/AIDS, even though there were drugs which could save them, intellectual property activist James Love found few people in Washington willing to so much as discuss the issue, and faced hostility from unexpected quarters."*

Love then mentioned how:

> *"A lot of American AIDS activists were opposed to this. They didn't really care. They felt like they had drugs; if they had cheap drugs in Africa they thought it might discourage R&D for them, they had insurance, you know, they didn't see the pricing problem."*

Besides pharmaceutical companies doing all they can do in courts to justify their pricing of their medications, some IP activists in the film even argued HIV strains would build resistance to the drugs in Africa and come back to infect Americans. This is one of the major issues that had stalled the roll-out of generic drugs to developing continent like Africa for a very long time.

By having the generic drugs be more available we need to deal with the issues of IP particularly in developing countries where there are major out of stock issues and it is clear that generic drugs are needed. Yawa reiterated this by saying that:

> *"When you talk about the shortages of drugs and all what have you, you cannot isolate the Department of Trade and Industry because in South Africa we are saying if there is a draft IP (intellectual property) policy our government is too slow to pass or act on the draft IP policy because should our government pass that draft policy it will mean that we will be able to access cheap generic drugs and effective"*[33].

Generic medicines tend to come at a more affordable rate than the originator pharmaceutical medicines. This has resulted in substantial savings for the consumer, as co-payments are either substantially lower or in many cases even eliminated. It has also brought about welcome and much needed savings for medical schemes (Health24, 2013:1). This then sheds light on how there is a growing use for generic medicines in the South African context. In South Africa, pharmacists can be found at the core of the recommendation and dispensary of generic drugs; thus they are playing a progressively significant role in the more widespread usage of generics. Khan mentions that:

> *"If generic alternatives to original patented drugs are available, it is mandatory by law for a pharmacist to suggest such alternatives to healthcare consumers. This is all part of the pharmacist's role to educate, inform and ensure that consumers do not pay more than they have to for medicines"* (Health24, 2013:2).

Therefore it is the role of Department of Trade and Industry, the South African government and pharmaceutical companies, doctors and pharmacists to work together in trying increase the generic drugs in the South African market so that issues of unaffordable drugs and out of stock issues are combated for the benefit of health users.

One of the foundations of the Grootboom case was that it was based on the high cost of good medications which put them out of the reach of many South Africans who used the public health care system to attain essential HIV and AIDS medications. The reality of the pharmaceutical crisis in South Africa could be summed up by the words of Edward Cameron when he was at a rally as seen in the film *Fire in the Blood* when he said:

> *"Why should I have the privilege of purchasing my life and health when 34 million people in the resource-poor world are falling ill, feeling sick to death, and are dying? We need to change the facts that are going to lead to the deaths of 25 million people*

[33] Yawa, A. Telephonic Interview. 20/01/2015.

> *in Africa. We will change that fact, we will challenge the future, and we will intervene in it."*

During an interview, Cameron passionately stated that this was a social injustice when he said:

> *"You (the government and pharmaceutical companies) may not do this. You may not leave 10 or 20 or 30 million Africans to die unnecessarily from a disease that can be medically treated. That was the turning point that Durban represented."*

Yawa further added to the importance for the need of generic drugs in the public health sector:

> *"In South Africa there are more than 6million people who are living with HIV and AIDS and there are more than 5million people that are in need of ARVs. If it means then the generic drugs from Pfizer are expensive our government needs to be given a leeway to bring in generic drugs that are cheap and effective because it is not about profit it is about saving lives"*[34].

Even though the roll-out of PMTCT was approved by the government the issue lies in accessing this medication in the rural public clinics where the infection rate of mother-to-child is still high. All three doctors who were interviewed agreed that the PMTCT guideline has definitely changed the projection of infection rates for new born children particularly in the urban areas where medication does not frequently run out in the hospitals and clinics.

This was reiterated by one of the HIV positive patients who seek medical assistance from My Sexual Health Private Clinic. This young woman was 27 years old and she was pregnant with her first child. Patient A shared that the PMTCT treatment was the answer she and her fiancé were looking for when they decided to get pregnant. They used the IVF procedure to get pregnant. After the first IVF treatment they were successful. The mother to be Patient A said:

> *"IVF coupled with the PMTCT treatment I am in good health and working with my doctors has helped me to better understand and trust that my baby will be HIV-free when they are born"*[35].

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[34] Yawa, A. Telephonic Interview. 20/01/2015.
[35] Patient A. My Sexual Health Clinic. 13/12/2014.

This young lady did not seem to have any concerns about infecting her unborn baby because she was on the best medical treatment she could afford on her medical aid. She did mention, though, that most of her stresses come when she is told that she has to change the brand of medication every so often. This also brings up further issues of inconsistency of generic medications that can be prescribed to patients.

Dr. Serfontein stated that:

> "One of the major problems are that we face in the private health care sector is the issue we have with pharmaceutical companies who do not have a consistent flow of their medications. They often discontinue their medication brands in trying to cut costs and this can be a problem sometimes. That is why you certainly see stock out in the private health sector as well, but maybe not to the extent of the public sector"[36].

Yawa further mentioned that:

> *"You also find that patients that go to these public health clinics go with the hope that they will get medication and assistance but they will be turned away because there are shortages of drugs due to a number of reasons. You have got pharmaceutical companies that have got to take the responsibility and be committed because one of the things we say as the TAC is that these pharmaceutical companies are charging very high prices on the expense of the poor. I strongly believe that even though we can get a health system that is running well as long as the pharmaceutical companies are not there, there will be no medication. So it is very important that pharmaceutical companies understand that life or health services is not all about profit it is about saving lives especially in the public health sector"*[37].

When pharmaceutical companies have the power to influence the change within the health care system, it is important that they are not the only ones determining their costs in pricing their medications. This has a great influence on causing ripple effects of the disease and infection rates increasing. This is due to what Yawa refers to as the patients defaulting on their medication when he said:

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[36] Dr. J. Serfontein. My sexual Health Clinic. 13/12/2014.
[37] Yawa, A. Telephonic Interview. 20/01/2015.

> *"On top of having access to ARVs increase we have a challenge in terms of short comings in the Public health sector, this is that people are defaulting on their treatment. Why are people defaulting on their treatment? It is based on the thing I have raised to you issues of drug stock out because of high prices of pharmaceutical medication, the nurses attitude and issues that are HR (human relations) related"*[38].

One of the other issues that affect the default of medication is that the pharmaceutical companies change their products so often. This was confirmed by Dr. Serfontein when she said:

> *"One of the challenges that we definitely face in the private sector and much more in the public sector is when the inconstancy of the generic medications because they often change and prescriptions have to change and it is a challenge for pharmacists to continuously find other generic brands with the same active ingredients. This is something that needs to change so that people can stick to their medication and this can cause possible drug resistance and that is the worst thing that happen to an HIV-positive patient"*[39].

This was reiterated by Yawa:

> *"Because drugs change all the time people can become resistant to medication and they often do not have the option to change to another regiment because it's not available in South Africa. The medication mix for HIV and AIDS and AIDS-related disease medications we have to oldest TB treatment for instance"*[40].

This issue of medication mix not being broad enough is a serious medical issue because the current HIV and AIDS medication available is not suited for everyone because some people are resistant to it. This means there are medication mixes that are not available in the public sector there is no other option for these people.

Conclusion

From the findings it was gathered that the public health care facilities are definitely struggling with infrastructural problems. As a result the general public health care is in a state of collapse all over the country for both hospitals and clinics in the urban areas and the most affected are the poorest that use the rural clinics. This is due to the government not being

[38] Yawa, A. Telephonic Interview. 20/01/2015
[39] Dr. J. Serfontein. My Sexual Health Clinic. 13/12/2014
[40] Yawa, A. Telephonic Interview. 20/01/2015.

able to pool enough resources towards rural development because they do favour clinics more in the urban areas. They are bigger hospitals but this does not the solve the problem because there are more people closer to urban areas that use the public health care services but hospitals cannot handle capacity when there are shortages of staff and medications in the rural areas and there is an influx of people seeking medical assistance there. This poses high health risks for all. The TAC has definitely done a notable job that has brought about various changes in the health care sector in South Africa. The findings have shown that most of the work of the TAC is geared towards the public health care sector and its users. The TAC and Section 27 have become key players in the South African health care system alongside the government and other NGOs in the country geared towards the same cause with different specialities.

Every institution should be able to handle the number of people that come to access medical services. This research has shown that public health care facilities funded by government are often experiencing a lack of staffing. They also experience issues of human resources and there are issues of being out of stock of affordable essential medications, often generic medications. Hence there is a need for legislation that will assist to combat the IP policy that hinders the provision of generic medications. Stringent patient care practices need to be implemented within healthcare facilities from the point of hiring and also at furthered education seminars. There are a large number of people who are accessing public health care facilities daily, for maternity, children's clinics and immunisations, TB, HIV/AIDS testing, AIDS-related diseases and other chronic illnesses that need to be treated. Often they cannot be treated under one roof in the public health care sector and this contributes to patients defaulting from their medication treatment. Therefore, there is a need for the government to look into better funding the public health sector so that the major issues that the findings have shown can be dealt with to resolve the 'collapsed' public health system.

The data and literature have shown that mismanagement of the service delivery within the health care system is one that starts from the top with the government at the epi-centre, especially when government is disorganised and does not have a unified communication line between the ministers and the sectors that they are the heads of as well as the pharmaceutical companies that have the potential to provide cheaper generic medications. This creates the ripple effects that cause the health care sector to collapse and at the end of the day the people who are affected are the most poor who solely rely on the public health sector and if it not functional it is a great disservice to them. This infringers on their rights as South Africans

who are meant to be protected by the constitution and the bill of rights. The people who solely rely on the public health sector belong to the periphery of civil society and this has been evident through the data. This is because their need and right for good health care services cannot be matched by the health care services found in the private health care sector. Therefore by the TAC and Section 27 using a rights-based approach to the right to health has given these people a voice that makes them stand on solid ground in laying claim to their rights.

CHAPTER 9: CONCLUSION

9.1 Conclusion

The principle objective of this study is to critically evaluate the changes that have occurred in the public health care system in South Africa when the Treatment Action Campaign and Section27 implemented a rights-based approach to HIV and AIDS in South Africa. The subsidiary goals of the thesis include:

- Strategies employed by NGOs in making rights-based constitutional rights a reality for poor people;

- Examining the effectiveness of NGOs by considering their internal dynamics, processes and conflicts;
- The reasons for the lack of government service delivery of pharmaceutical products in the public sector;
- The utilization of branded versus generic medicines and the attendant patent and manufacturing laws and impact on costs.

The Health Act of 2003 stipulates that national health services across the nation are meant to regulated and provided in a uniform basis and this is meant to be attained by 'establishing a national health system which encompasses public and private providers of health care services and provides in an equitable manner to the population of the Republic the best possible health services that available resources can afford' (South African government, 2003: 10). In order for the Health Act of 2003 to be realized there is a need for the South African health care system to be more of an integrated system involving both the private and public sectors. What is meant by 'integrated' is that people in the public and like the private health care sector will go to clinics or hospitals with all the needed specialists under one roof. This has been shown in the findings where there are clear infrastructural problems in the rural health care services like lighting, clean running water and sufficient space for treatment of the health users. The National Health Act of 2003 states that the objectives of the Act are setting out the rights and duties of health care providers, health workers and establishments and users (South African government, 2003:10). This is meant to police against medical malpractice as the findings have showed that the TAC has worked in calling out fraudulent medical practitioners. This means that there are standardization and policing issues regarding the selection process that are involved when hiring medical staff. This is a very crucial issue that needs to be dealt with because this is recklessly putting the lives at high risk of those that rely on the free public health system to take care of them. This means that health care facilities are meant to adhere to the National Health Act of 2003 as stated above. Since there are no policing facilities in place that will deal with issue of policing, the TAC has stepped in to deal with such issues. This is because every public health institution should have a well-educated and skilled administrative board that does the proper hiring of medical staff that meets the requirements of the job skill set. The findings showed this comparison through nurses in the public and private sector. The nurses in the public sector also had issues of having attitudes towards the patients. This is probably due to being over worked and sometimes unpaid for

their hard work and their working conditions as the findings have shown are not the best. Due to lack of medical infrastructure in the rural areas of the Eastern Cape, like OR Tambo, the data has shown that medical infrastructure in the rural areas are not a major feature in the government's National Health's plans. These rural clinics often have a lack of space and so this is where so often the patient confidentiality is broken as there are no rooms to talk privately with. This would discourage people from coming to get tested if their medical progress cannot be kept confidential because the HIV and AIDS stigma still exists. The National Health sector needs to look into funding the public health care sector both in the rural and in the urban areas.

The National Health Act of 2003 also stipulates that its objective is protecting, respecting and fulfilling the rights of-

i) The people of South Africa to the progressive realisation of the constitutional right to access to health care services, including reproductive health care (South African government, 2003:11).

This shows that the National Health Act is linked to the Constitution of South Africa as it does stipulate the very same right in Section 27 with the right to health. Thus the government is meant to be held accountable for delivering on this right to health; because, it clear that it is infringing on this health right for those that rely on the public health sector.

The government heads are meant to be ones that are held accountable for the fulfilment of this right to health. However, it has been evident that the government has not been able to deal with the delivery of this right due to many issues that relate to mismanagement of the health care system and there have been restrictions of funding to clinics and hospitals as mentioned above and most importantly the restrictions that IP policy has caused for the roll-out of essential medications. The TAC and Section27 have acted as the voice for the voiceless and they have increased the roll-out of essential medications and fought against various patient laws. The TAC and Section 27 have also brought forward the access to generic drugs and have been part and parcel in the creation of the PTMTC treatment guidelines. The PTMTC as a result has been the most successful treatment that has been created for the whole health care system.

However the main problem when it comes to the access to medications is in the combat of generic drugs. Where the reality is that it is difficult to get them into the country when there is the inconsistency of pharmaceutical companies sticking to particular generic drug brands.

The issue then adds to the patent law battles that resurface when pharmaceutical companies use other suppliers that have different patent laws on their drugs. This issue of inconsistency also affects the patients both in the public and the private health sector as it is a one of the causes that makes patients default from their medication and this will increase their probability of being infected by AIDS-related diseases. They could also become resistant to the available drugs on the market for HIV and AIDS treatment. This then further-adds to the untreated HIV and AIDS patients in the country.

There is a clear gap between the private and the public health care sector in South Africa and this gap needs to be bridged. The TAC and Section27 have created a space within the public health sector and they have been acting as intermediaries between the people they work for and with on the ground and the South African government as well as their funders. By the TACs changing its funding strategy it makes them more of an autonomous organisation as they are more at liberty to decide on the projects that they want to tackle, without having funding restrict their actions. The TAC and Section27 has been the voice of the voiceless in the public health sector by using a rights-based approach to materialising the right to health and holding the government accountable for not materializing not only the constitutional right to health but also to education and citizenship. The TAC has taken strides in improving the roll-out of HIV and AIDS drugs as well as improving access to medications that are much needed to deal with AIDS-related diseases. This shows that the TAC has taken a holistic approach to tackling the HIV and AIDS pandemic in the South Africa's health care system.

This study found that the TAC is deeply involved in the HIV and AIDS community from the ground level and it has access to the government offices that the people on the ground usually do not have access to. The TAC and Section27 have used the foundation of the Constitution to tackle the various issues within the health care sector and this has made significant changes. The increased access of generic drugs that are affordable and treatment guidelines have decreased the infection rate of young infants in the country with HIV positive mothers.

In explaining the lack of access to knowledge about HIV/AIDS and later to the essential medications crisis that the country was in, this thesis adopts the use of the human rights approaches to development perspective which is based on the premise that through the use of intrinsic legitimized human rights and social mobilization this will create a generation of informed people, who can also legitimately hold the government accountable for violating their constitutional rights. Certain democratic governments view themselves as superior and

separate from the very people they are governing, this has to a degree been the South African government, whereas need to note that they cannot separate governing tactics for further developing the country from their constitutional promises as well as international human rights because they are interlinked. As the South African government is part of the global civil society, it cannot be concerned solely to meet the goals of economic development at the cost of violating constitutional rights, because this would be contradictory to them being a democratic state. The thesis emphasises that the integration of human rights with health rights is a socio-political problem as much as it is a governance problem. Hence the need to focus on the role that social movements, which birthed non-governmental organisations such as the TAC and Section27, have played in materialising the need for the government to be held accountable to constitutional rights, including how these NGOs have come to address the restrictive international patent policies for essential pharmaceuticals not only in South Africa but also in other developing nations.

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