



UNIVERSITAT DE
BARCELONA

**South Africa: The Diseased Nation?
An Analysis of HIV/AIDS Sufferers' Critique
of the Redemptive Discourse of Nation-Building
and the (Dis)Closure of National Traumas in Post-
Apartheid South African HIV/AIDS Life-Writing**

Óscar Ortega Montero

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Departament de Llengües i Literatures Modernes i d'Estudis Anglesos

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THE (DIS)CLOSURE OF NATIONAL TRAUMAS IN POST-
APARTHEID SOUTH AFRICAN HIV/AIDS LIFE-WRITING**

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Resumen

Esta tesis analiza el proceso transformativo y vivencial asociado con la contracción del VIH/SIDA en la Sudáfrica del post-apartheid, en particular bajo el mandato de Thabo Mbeki (1999-2008) durante la era negacionista. A través de una selección de auto/biografías y memorias de personas seropositivas, esta tesis explora, por un lado, el papel fundamental que desempeña la mediación discursiva en la composición de la enfermedad como narrativa y, por otro, los aspectos que favorecen la reinterpretación de un hecho o diagnóstico traumático a la hora de reescribir la historia vital de personas cuyas vidas se vieron truncadas por el VIH/SIDA. La presente tesis, además, representa una contribución novedosa en tanto que, tradicionalmente, la cuestión del VIH/SIDA se ha venido abordando desde una perspectiva centrada en la experiencia individual de las personas infectadas con y afectadas por el virus. Sin embargo, esta tesis desarrolla una visión colectiva a nivel nacional de la cuestión del trauma y, en particular, el tratamiento del trauma a través del valor terapéutico de la escritura. Así, esta tesis profundiza en el valor de la memoria como repositorio de conocimiento accesible y reformula el concepto ‘discapacidad’ desde una visión capacitadora, empoderadora y liberadora tras romper el silencio que rodea a esta condición médica en Sudáfrica. En la actualidad, Sudáfrica sigue siendo un país duramente golpeado por el demoledor impacto del virus entre su población, tanto adulta como joven, y que afecta a ámbitos tan sensibles y determinantes en la vida de las personas seropositivas como son, entre otros, el socio-sanitario, socio-económico, socio-afectivo o psico-emocional. Los diferentes testimonios recogidos en esta tesis son, además de una metanarrativa del sida, la constatación del profundo sentimiento de ‘otredad’, estigma y discriminación desde el cual surge una crítica amplia e incontestable, y a su vez necesaria, que pone en relieve los retos pendientes de la democracia sudafricana. Esta crítica de las personas seropositivas sirve como termómetro para medir el alcance real del cambio social, político y cultural promovido por la elaboración de la Constitución de 1996, de marcado acento progresista aunque con lagunas en su aplicación real, y el proceso de consolidación de la paz y de la convivencia surgido a raíz de la creación de la Comisión de Verdad y Reconciliación también en 1996. El surgimiento de movimientos robustos de ciudadanos y organizaciones de la sociedad civil confirma el compromiso de la ciudadanía con el largo historial de luchas y conquistas sociales y políticas que son seña de identidad del país.

Abstract

This Ph.D. dissertation explores the transformative potential of the HIV/AIDS experience in post-apartheid South Africa during the age of denialism under Thabo Mbeki's mandate (1999-2008). To that end, the selection of auto/biographies and memoirs has helped me to illustrate the process by which HIV/AIDS sufferers, with the support of narrative mediators, compose illness. In so doing, I pay particular attention to how HIV/AIDS sufferers reinterpret a series of past traumatic events associated with the disease in their bid to heal the wounds of stigma and discrimination in light of their personal experiences with the virus. Traditionally, the HIV/AIDS experience has been tackled from the perspective of the individuals infected with and affected by the virus. However, in this dissertation I approach the various HIV/AIDS experiences as stand-ins for national and collective trauma through the analysis of the therapeutic benefits of life writing. Thus, this Ph.D. dissertation places value on the construction of an accessible repository of knowledge to highlight the importance of the memorialization of the HIV/AIDS epidemic in South Africa. Likewise, I also engage with the concept of disability in a way that promotes an ableist vision of HIV/AIDS sufferers, thus meeting the twofold objective of breaking the silence around the virus and empowering sufferers in their reinterpretation of the HIV/AIDS experience. HIV/AIDS continues to be a major problem, and South Africa is the country in the world hardest hit by the spread of the disease, affecting areas as sensitive for the protection and well-being of sufferers as are the fields of social health, socio-economics, social and affective interaction, and psycho-emotional health. HIV/AIDS testimonial writing, as an example of metanarrative, proves there exists a profound feeling of 'otherness', stigma, and discrimination from which arises the HIV/AIDS sufferers' critique of South Africa's nation-building policies in the post-apartheid era. This critique is fundamental to measure the real extent of the social, political, and cultural change promoted by the workings of the drafting of the country's forward-looking Constitution and the Truth and Reconciliation Commission, both in 1996. The emergence of strong social and civil movements around the issue of treatment and visibility of HIV/AIDS sufferers comes to confirm the long history of social struggles –and gains– in the fields of human rights and activism, thus confirming the strong commitment of South African society to progress and the consolidation of a long-lasting peaceful conviviality.

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Introduction

Aspiring for a more just and inclusive society, South African struggles have mirrored the relentless work of activism in a significant number of terrains consistently over the past decades. South Africa has both flagged up the conquest of civil rights and inspired worldwide admiration, recognition and respect due to its genuine anti-racist and forward-looking spirit. Incorporating the seductive power of its past in the present has been articulated through the equally seductive power of life-writing so as to heal the psychic scars and emotional wounds of individual tragic stories that, likewise, operate as stand-ins for stories of collective trauma. The HIV/AIDS crisis conjures up emotions of regret, desperation, and isolation, but also of hope and determination to counterbalance the effects of stigma, discrimination, and trauma. HIV/AIDS have infected and affected large segments of the South African population, thus prolonging the trauma of a nation that certain segments of society still see as being both metaphorically and literally diseased.

The end of apartheid in the early 1990s offered a breath of fresh air for the future of hundreds of thousands of South Africans. During that blemish chapter in the history of the country, the bulk of population had to face (racial) discrimination, punishment and countless harmful practices on a daily basis before they could witness the first faltering steps of the then yet-to-be-constructed democratic South Africa. Borne out of the strong desire to create a nation teeming with possibilities, and in dire need of showing the international community the welcoming spirit of a fast-changing society, the “new” South Africa expected to trek the long path of democracy and heal the wounds of its very traumatic recent past. Thus, post-1994 South Africa, longing for freedom and opportunities to thrive in life, gradually began to engage in the (re)construction of a nation that has been so long dominated by hatred and the sheer

senseless of racism, reinforcing racial difference as a strong identity marker and as the nation's *raison d'être*. However, it was precisely in its purposefully neglected diversity that lie the country's full strength and potential to look ahead to the future with confidence, and a sense of pride of the cultural legacy that makes up present South Africa after decades of relentless violence, political tensions and perpetual suffering.

Thirst for life and, to some extent, an unconsciously empowerment by the then newly written Constitution of the Republic of South Africa, black South Africans advanced from not being considered citizens of the nation to having rights and enjoying the benefits of acquiring citizenship. In this improved context, old generations began to shrug off the shackles of the past, paving the way for the youngsters not only to live life to the full, but also to re-build the foundations of a nation ready to take the leap towards democratic values such as equality or freedom, to name but a few. Mandela's sweeping into office relocated South Africa on the world map, and more importantly, in the international arena, reaching its peak when South Africa became the up to now first African country in approving same sex marriage, a clear nod towards minority rights.

Furthermore, another golden moment saw light when the African power-house hosted the renowned FIFA World Cup in 2010. As South African institutions attempted to restore dignity to the people, modernize the nation, address social inequalities or come to terms with its troubled history through the Truth and Reconciliation Commission (1996), another concealed crisis, the AIDS epidemic, began to gain ground substantially. Over the last few decades, its devastating effects may well have reached the category of national emergency, and yet it is a cultural taboo in a society that while on the surface may seem at peace but, on the contrary, hides different layers of fear, stress and anxiety underneath.

These layers merit further attention in order to understand the complexities surrounding the HIV/AIDS epidemic in a society where the well-founded fear of social rejection on the grounds of difference persists in the national memory. Writing the unspeakable helps release emotional tensions and the creation of narratives around harmful experiences constitutes a way to both document and testify to it. In connection to how to testify to this fast-growing social and public health problem in post-apartheid South Africa, Rosemary Jolly observes:

I claim that the creative and critical realm of narrative is privileged in its potential to proffer ways of registering what has become deniable, and therefore unspeakable within a given cultural context. Narrative analysis can enable us to understand harm done that exceeds the limitation of the verifiable in legal terms and the limitation of the accountable in terms of that which is socially sanctioned. Further, narrative has the potential to accommodate a dynamic of reciprocity that frames stories of wrongdoing as offering possibilities, for their narrators and listeners, of complicity and transformation. (2010: 5)

This puts the spotlight on the vulnerability of individual subjectivities, whose bleak realities often clash with the still very much persistent anger and disagreement of some segments of the nation with the untimely tragedies that abound in South Africa's blurred collective memory. In this regard, life-writing provides an alternative arena in the form of personal historiographic accounts, and whose function is that of documenting certain historical passages and ideological blindspots within nation discourses. These passages are embedded in individual experiences of isolation that enable silent –and silenced– episodes of repressed emotions, containment, solitude and spiritual bypass to emerge on the social scene and within the public debate. In so doing, narrators and readers create hybrid spaces in/of (the) public domain where narrators and readers share their intimacies. I coincide with Rosemary Jolly who affirms that offering possibilities are opportunities for the transformation of South Africa's social fabric and for the yet to come generations to be aware of the importance of an all-inclusive, truly progressive society regardless of race, gender and class-based concerns. Therefore, this

assumption raises some relevant questions, namely what role do auto/biographies play in reasserting human agency; in what ways do collective imaginaries benefit from personal experiences and why; for what purpose and when does private grief become public?

Given the dimension of HIV/AIDS in South Africa, a big question mark hangs over the possibility of whether or not living with the disease in a country, where former policies of “separate development” and the aforementioned endorsement of difference, helps construct some sort of sameness, even at the cost of risking the lives of the affected by the disease. Is HIV/AIDS a social leveler to some extent? The case of HIV/AIDS narratives conceals aspects that bear an intimate relation with the diversity and inequality of existing social realities at all levels within South Africa. The textual enactment of these types of narratives, though hard and sometimes discomforting, mirrors larger society and its anxieties when it comes to dealing with feelings of failure and/or displacement; hence the therapeutic value of memoirs. According to Camilla Asplund Ingemark, “the act of disclosing trauma is seen to have beneficial effects, in the form of both health benefits and peace of mind” (2013: 8). Additionally, those narratives of fragmented selves provide an overall picture of the multifaceted experiences of living with the disease. It is important, then, to pinpoint shared experiences for the sake of determining what aspects give shape to a community on the one hand, and on the other hand to explore perceived differences among members of the community to understand the diverse contexts in which trauma plays itself out.

“Storying” the mind-numbing statistics of AIDS in contemporary South Africa is, in fact, an invitation to explore the far-reaching impact of this chronic disease, especially at community and gender levels. These two spheres are of the utmost importance in the analysis of these accounts for two main reasons, the first one being

the need to find out more about what aspects constitute a community, whereas the second one explores gender-based constraints through the influence of a multi-ethnic environment on individuals and social groups. Thus, literary representations of experiences with HIV/AIDS provide reading communities with a glimpse of different ways of living and coping with social disgrace. Fear, mistrust and deep distress take centre stage in the lives of those AIDS sufferers who have to live with the disease in silence. Breaking the silence and, thus, the on-going suffering and isolation of people from all walks of life in the so-called rainbow nation is in itself an act of resistance as well as the coming-together of individual voices, often misunderstood and stigmatized, in their bid to embrace human agency and bring all those experiences together in a polyphonic voice.

A road filled with difficulties lies ahead, and this also entails the exploration of what experiences sufferers embrace and/or reject when accounting for traumatic experiences in their re-interpretations of the past. This is an overriding factor considering the fact that in the process of writing on and about the self the unconscious takes the form of readable stories out of which the generation of knowledge can significantly operate, later on, as a role model for (young) South Africans to deal with the challenge of HIV/AIDS more effectively. All the more so taking into account the great temporary vacuum left by the almost god-like figure of Nelson Mandela, whose son, Makgatho Mandela, died of HIV/AIDS in 2005. As a sign of Mandela's family's greatness they became vulnerable in the public eye when they went on to say the cause of death openly, thereby opening the way to the normalization of HIV/AIDS and its subsequent debate in the media. Mandela's act finds shelter in, at least, one of the ideas explored in H el ene Cixous' *Rootprints: Memory and Life-writing*, where the same

author comments on the connections between suffering and nobility as a distinctive feature of human beings when death looms on the horizon. As she notes:

And then, in the most cruel moments of existence, basically we will be inclined to search out the noble form: perhaps by a sort of need to aid ourselves narcissistically. That is to say, to see ourselves from a point of view that raises us up at the moment we are debased. Perhaps, also, because it *is* noble; because suffering is a nobility of the human being. So we are ill-at-ease because everyday life, which is not at all noble, irrupts onto our high stage: and we do not quite know what costume we are wearing, or with what handkerchief we blow our nose. (1997: 20)

Hélène Cixous' insightful remarks on suffering and nobility provide an entry point for further exploration of those "cruel moments" in the selection of the auto/biographies and memoirs under analysis in this dissertation. Cruel moments abound either when facing death or when fighting against all odds to stay alive. Furthermore, the cruelest moments have as travel companion loneliness and discouragement. In relation to this, the great American novelist Carson McCullers referred to loneliness as the basic condition of human existence. The process of writing neutralizes those moments of solitude and contributes to feeding the core idea that the recovery of dignity through the understanding and textualization of personal pathos is within reach. If the study of auto/biographies and memoirs centered on HIV/AIDS can teach us anything, it is fundamentally that what is often regarded as a social stigma, when closely examined, turns out to be the driving force for change.

With great shrewdness, autobiographers, biographers, and memoirists alike reflect on the core aspects that render individuals who already belong to a specific community into (textual) agents of power, thus subverting social constructs on disability. These manifestations of power take different shapes, each of which walks the reader through diverse realities of and, perhaps, even competing discourses in South Africa. The cast of characters provides a representative stance of the complexities surrounding the lives of HIV-positive people in contemporary South Africa.

Liz McGregor's *Khabzela* accounts for the rise (and decline) of a South African celebrity, promoter of the so-called *kwaito* generation that gave artistic expression to the dreams of young Sowetans, whilst filling the streets of the most popular townships of Johannesburg with life, color and musicality. McGregor's work on Fana Khaba (also known as Khabzela) gives the reader a taste of Khabzela's complex upbringing which was constricted by his mother's strict religious beliefs and the tight social structures of his environment. Stephanie Nolen's collection of short-stories *28: Stories of AIDS in Africa* provides a full sweep of the disease on the continent. In the case of the stories set in South Africa, Nolen provides an interesting comparative analysis of how social class determines access to anti-retroviral drugs and, consequently, who lives or dies. Edwin Cameron's autobiography *Witness to AIDS* focuses the attention on activism and on the inconsistencies of a young democratic system as well as the hypocrisy of professional elites, thus exploring the issue of double-standards. As for rural South Africa, Jonny Steinberg's *The Three Letter Plague* takes a stance on this burning issue in rural remote locations of South Africa where conservative, monolithic and tolerance to traditional healing practices spread the disease. Jim Wooten's *We Are All the Same* puts a unique human face to AIDS: that of Nkosi Johnson. The heart-wrenching story of this courageous boy, who died of AIDS at age 12, invites us to reconsider and to reformulate our priorities when it comes to the implementation of social and health policies. This body of literature sheds light on cultural entanglements, specific gender problems, the relationship between sexuality and culture, and the emergence of new forms of oppression and vulnerability. These outpouring accounts of grief are, nonetheless, conducive to constructing collective stories of hope, confidence and visibility through which diverse social healing processes turn into a tangible reality, which is most laudable.

Interestingly, as a proof of the importance of community building strategies to gain visibility, the interconnectedness of these narratives in terms of cross-referencing in one way or another largely contributes to drawing a detailed portrait of the HIV/AIDS epidemic in South Africa. AIDS life-writing operate as metanarratives that build on the significance of core human values. Therefore, this research of inclusive nature seeks to provide an entry point for understanding and supporting the HIV/AIDS condition, as well as the rhetoric of AIDS denialism, through the testimonies of blacks and whites, the poor and the rich, gays and straights, urban and rural citizens, and female and male voices who despite remarkable differences of class, gender, race and ethnicity have a shared history of abuse, alienation, “otherness” and displacement. No matter what background they may belong to because, in the end, the disease makes them all equal in the face of vulnerability.

The exploration of AIDS narratives is a window into the complex social realities of a country marked by huge contrasts. These narratives enable us to articulate a social response seeking to neutralize the burden of emotional and psychological byproducts and to create very much needed spaces for dialogue, comprehension and social justice out of the narration of individual struggles facing adversity and violence in post-apartheid South Africa. Thus, this doctoral dissertation pays tribute to the disenfranchised and neglected individuals, whose stories deserve their place in our history and our hearts.

Chapter One: Theory and Key Concepts in HIV/AIDS Narratives

1.1 Introduction

The study of HIV/AIDS life narratives in twenty-first century South Africa encounters the challenge of a shifting social, cultural, economic and political paradigm. After the first multi-racial elections in South Africa in 1994 the country has initiated the daunting task of rebuilding its institutions and social bonds in their bid to restore their domestic and international credibility. The democratization of South Africa has led South African society to question its obligations to others after decades of racist policies that compromised the future of the country. One point of entry into the local scene in which this sense of national responsibility and commitment to others is played out is through the examination of the HIV/AIDS epidemic. South Africa is, to this date, the world capital of HIV/AIDS¹, and this situation puts an additional strain on the reconstruction of the nation and the accomplishment of its national targets in various terrains.

As a result, life expectancy in South Africa has generally been revised downward due to the epidemic². This information has largely contributed to the stigmatization of HIV/AIDS sufferers, as testing positive has become synonymous with a death sentence in the collective imaginary of South Africans. For many HIV/AIDS sufferers the consequences of testing positive are rather punitive as they feel inferior to others or can lose their jobs and, consequently, their livelihood. This form of punishment, whether social or economic, often gives rise to the temptation to conceal their medical status to live up their lives to the expectations that society demands of them. In this context, life-writing is a genre that captures this anxiety. Particularly, life-writing shows the socio-political structures and circumstances that shape the production

¹ Source: <https://www.kff.org/global-health-policy/fact-sheet/the-global-hivaids-epidemic/> Accessed: April 15th 2021

² Source: <https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001418> Accessed: April 15th 2021

of the different types of HIV life narratives, namely memoirs and auto/biographies. The storylines of sufferers provide accurate and nuanced information on the different critical processes of individuals from diverse socioeconomic backgrounds whose lives are felt to be institutionally (mis)managed. These voices, mediated or not, make personal experiences of illness visible. Indeed, the accounts and struggles of sufferers are made visible through attention to their long legal battles with the South African administrations during and after apartheid³. These struggles thus reveal the interior voice and determination of individuals whose representations of emotional distress and suffering constitute a valuable repository of knowledge.

The development of this archive of personal narratives of illness, besides reflecting the therapeutic benefits of telling and empowerment, builds up and strengthens the robust and resilient capacity of the AIDS community in South Africa. By feeling valued, tellers and narrators perform the role of inspiring the constitution of “new” communities which also include the support of readers and listeners. The formulation of new possibilities for living with HIV/AIDS in the South African society renders the actions of sufferers meaningful. In this way, HIV/AIDS sufferers gather relevant information on institutional discourses and practices that prevent them from living a life to their fullest. In this sense, the reconceptualization of HIV/AIDS and the promotion of alternative responses to the disease are essential in informing about public health programming and to develop resilience. It is also a fundamental contribution to lay the foundations for a revised version of the services provided at public care institutions from within the collective of sufferers. Although the impact of HIV/AIDS in South Africa is of major concern for all the parties involved⁴, the efforts made to

³ Source: <https://www.sahistory.org.za/article/history-official-government-hivaids-policy-south-africa>
Accessed: April 15th 2021

⁴ Source: <https://www.un.org/en/chronicle/article/impact-hivaids-education-and-poverty> Accessed: April 15th 2021

prevent the epidemic evince the existence of, at least, two types of communities: the epistemic and the counter-epistemic. These categories shall be discussed in more depth in chapter two. For the moment, suffice to say that these two models offer the disparate views on the modalities for providing assistance to affected individuals, and thus making room for the positions laid down by mainstream science and dissident voices, respectively.

Of particular interest in my research is the analysis of what I believe to be a substantial difference between these two knowledge-based communities in contemporary South African history. One major perceived difference between them lies in their understanding and perception of disability. The construction of HIV/AIDS disability offers an insightful view into the realities of a social problem that defines sufferers as individuals who lose their value in society. This loss of value is discussed within the ideological parameters of a liberal and capitalist mind-set. Closer observations of these two communities reveal that the epistemic group –largely formed by afflicted individuals, members of their innermost social circles, activists, and NGOs and other social organizations– advocates for an ableist vision of HIV/AIDS sufferers. On the contrary, the counter-epistemic group –led by former president Thabo Mbeki and dissident scientists– promotes the theory of conspiracy. These uphold the belief that HIV/AIDS is nothing more than a political disease⁵ seeking to undermine all the efforts and progress black South Africans have made to gain sovereignty over South African soil. This assumption revives the most tragic moments of the recent history of South Africa: outbreaks of white-on-black violence, oppressive home-rule, and close surveillance of the black population. The cast of writers and characters reflect the

⁵ Thabo Mbeki rejects the credibility of scientific evidence due to the high prevalence of HIV/AIDS only in specific populations across sub-Saharan Africa. In his view, the HIV/AIDS epidemic in (South) Africa reveals the prevalence of certain narratives on black lifestyles exclusively promoted by major economic powers to perpetuate the subjugation of blacks to white interests.

influence of power and privilege in the HIV/AIDS life narratives. The diverse and extensive influence of international governments and organizations also evince the attribution of international responsibility for the outbreak of the epidemic to the pervasive effects of colonization in Africa. The terrific impact of these socioeconomic factors has increased black South Africans' vulnerability and has also distorted their self-perception. The long shadows of colonization and apartheid's segregationist policies have both undermined black population's sense of self-esteem and self-dignity.

A trend in writing on life narratives of HIV/AIDS sufferers is to endow with value the representations of the selves. These selves are prompted to talk not only about their past sexual experiences but also about the on-going processes of "otherization" they suffer. Disclosures to intimate friends, relatives and partners are a solid attempt to normalize the HIV/AIDS condition while it also seeks the enforcement of human rights. By identifying the nature of the various social barriers that result in oppression and exclusion sufferers feel able to propel change in their communities. Literature is, in this regard, the tool that brings about this transformation in South African society, all the more so considering that sufferers feel empowered to participate in society through the constitution of specific pressure groups such as the Treatment Action Campaign. The formation of this new social fabric encourages the memorialization of the epidemic, seeing civil society development in post-apartheid South Africa as a necessity for the recovery of dignity. The strong presence of the Treatment Action Campaign acts as a unifying principle of all sufferers.

Jim Wooten's *We Are All The Same* (2005), Edwin Cameron's *Witness to AIDS* (2005), Liz MacGregor's *Khabzela* (2005), Stephanie Nolen's *28: Stories of AIDS in Africa* (2007), and Jonny Steinberg's *Three Letter Plague: A Young Man's Journey Through a Great Epidemic* (2008) constitute the literary corpus under analysis in this

Ph.D. dissertation. These narratives open a huge window into an epidemic that cannot be vanished from popular consciousness. It is through the exploration of these human experiences that I engage with the processes of how writers compose illness and the various meanings of the experiences of living at risk and as politicized individuals. HIV/AIDS life narratives represent an opportunity to redefine the self, relations with power structures and the body of the sufferer.

Through the memorialization of HIV/AIDS I intend to demonstrate that in post-apartheid South Africa illness operates as a common denominator against which all citizens are truly equal in the democratic age, especially after the emergence of the Treatment Action Campaign. Such a view is of paramount importance considering that HIV/AIDS has no cure to date. In this regards, I uphold the belief that the lack of cure is what produces disability and its socioeconomic burdens. This belief also compels me to engage with the question of how the social problem of HIV/AIDS is constructed in the particular cultural context of South Africa, and more importantly, if it is constructed in response to particular interests, whether political or economic. In this research I also wish to focus on the metaphors and imageries used to designate the stigmatized individual, and the strategies sufferers come up with in order to neutralize the pervasive effects of their stigmatisation. Taking in mind that stigma has strong racial and class roots in South Africa, one must ask the question if stigma, *per se*, is a salient feature of disability, a condition that foments new models of segregation in South Africa? In light of the conceptual direction this study shall take, this is a posture I shall defend. Departing from this premise, I also consider how the aforementioned life narratives sustain not only individuals but also the growing communities that emerge out of the life narratives, connecting disabled bodies to a wider society.

1.2 My Illness *Has a Meaning: Life-writing, Memoirs and Auto/biographies*

In *At Risk: Writing on and over the Edge of South Africa*, Sarah Nuttall pictures the starting point of South African life narratives in the post-apartheid age within the frame of a “new” age of South African writing (2007: 9). This specific point of departure, attending the cultural specificities and various concerns of this “new” age, especially in the social terrain, includes the different HIV/AIDS crises – the affective, the emotional and the political. The strong entry of HIV/AIDS, among other relevant issues, in scholarly debates (Barnett and Whiteside 2002; Kauffman and Lindauer 2004; Natrass 2007; Squire 2007; Feldman 2008; Thornton 2008; and Geffen 2010) is symptomatic of the new path taken in South African studies, where the social and the political take on a new dimension. This new dimension is concerned with understanding the preoccupations of invisible subjects, rendering them less vulnerable to the reminiscences of the past, the anxieties of a blurred present and the uncertainties of the future. In an attempt to tune into the winds of change within South African literature in general, and South African life-writing in particular, I have chosen to close ranks with the misrepresented so as to keep up efforts to maintain and strengthen social harmony and to resolve long-lasting conflicts of conviviality. The fact that intellectuals, writers and thinkers have put HIV/AIDS in the limelight alerts us against a possible deviation from the roadmap set out in the (in spirit, at least) forward-looking South African constitution. In this context of rapid and constant change, the fact that some vulnerable citizens run the risk of falling behind is a stark reality which is highlighted by the inefficient and slow of bureaucracies which fail to implement the basic rights expressed within the constitution. In this light, I believe that memoirists and auto/biographers perform a very important role in monitoring compliance with the constitution and the transition’s political accord. In this “new” age of renewed hope and optimism, one of the primary goals of these narratives is to assess the progress and pace of the

reconstruction of South Africa in the social terrain. Indeed, in their role as duty-bearers, memoirists and AIDS sufferers press ahead with and get involved in the completion of the process of transformation initiated by the country in the 1990s. HIV/AIDS life stories cannot turn their back on this pressing need, all the more so considering that, as the set texts in this dissertation attest, the lives of HIV/AIDS carriers are not grievable in the public eye.

This state of affairs evinces the imperative need on behalf of the writers to make room for the voice of the disenfranchised in their bid to reflect the transformation of South Africa through a transformation of literary forms that express fully the aforementioned. That life-writing allows the disenfranchised to engage in the production of cultural discourses of the “new” nation, going beyond the aftermaths of apartheid, is something I consider both evident and laudable. In life-writing, HIV/AIDS sufferers appear to be caught in the cracks of the reconstruction of the South African state after apartheid, as the epidemic was a foretold chronicle that, nonetheless, was left out of the negotiations for a transition to democracy. As a result of this, the new socio-political paradigm in South Africa has seen the flourishing of memoirs and auto/biographies as a means to openly deal with the unresolved issues inherited from apartheid, namely co-habitation and sympathy towards the multiplicity of realities embedded in the country’s cultural diversity. The testimony of HIV/AIDS sufferers is felt to be synonymous with the re-enactment of agency and empowerment, especially when these often dehumanized bodies inhabit the realm of the disenfranchised. The question, then, is whether or not South Africa can cope in the age of post-apartheid, an age strongly marked by the constructed idea of an idyllic transition (and the sometimes unrealistic erasure of past dynamics), with the different kinds of truth that have emerged with the proliferation of HIV/AIDS narratives. These truths seem to dismantle, point-by-

point, the successful account of a democratic South Africa, most significantly by pinpointing the failure of state services. In Gillian Whitlock's words, the truth of this "new" age, as reflected in life narratives, is based on "people's perceptions, stories, myths and memories" (2015: 76), thus revealing the true nature of life-writing and its key function in South African society today. This is, essentially, drawn together in a rather comprehensive and practical concept; that is to say, how to put a human face on the interplay between the "center" of society and its significant "others" or "margins." This implies the creation of links and interpretations of the issues surrounding both the spread and consequences of the epidemic that weaves a unique common narrative between those who suffer and those with the ethical obligation to assist and protect sufferers. Thus, life-writing is felt to be the literary genre that can give voice to traumatic suffering or stories that are still silenced but need to see light. As we will see in the coming chapters of this dissertation, the trauma of HIV/AIDS sufferers is accessible and retrievable, and the psychic trauma of sufferers stems precisely from outside actions they have no control over. The psychiatrist Lenore Terr defines psychic trauma as something that occurs "when a sudden, unexpected, overwhelming intense emotional blow or a series of blows assaults the person from outside. Traumatic events are external but they quickly become incorporated to the mind" (Terr, 1990: 8). In the process of reinterpretation of the intense emotional blows that AIDS sufferers experience, it is important to consider the strategies sufferers come up with in order to mediate on the effect of trauma upon their psyche. Very often, as their life narratives attest, the psychic wound does not rest solely with their HIV-positive status. On the contrary, the extent of the emotional blow depends on the response of the social group to the distressing event, and whether or not individuals take a supportive attitude towards the distressing event in question and thereby further encourage the process of

healing initiated by the sufferer once the latter. The very act of writing and telling others about how sufferers themselves compose illness and cope with the external threats of the disease emphasizes the necessity of sufferers to accelerate the process by which sufferers can regain normalcy. Such an act indicates AIDS sufferers are particularly sensitive to dangers that originate in the social sphere, as the participation of the latter is key to ensuring the construction of a protective environment that is conducive to healing. Paul Mitchell (2019: 182) highlights the value of the narrativization of the experience to promote the notions of agency and resilience on the sufferer as a trauma survivor. In this sense, AIDS testimonials, and in particular that of the survivors, constitute the legacy of the recent social history of South Africa in the post-apartheid period, thus reflecting a major shift in the concerns of South African scholarly debates in the democratic age.

South African scholars Nancy Jacobs and Andrew Bank build further on the importance of the accounts of this “new” age by reflecting the liveliness of this genre, “which hold[s] a high historical and sociological significance” (2019: 165). In their approach to why this genre attracts widespread public attention, the critics are quick to observe the function desire plays in individuals, for these seek “to read life stories that could not be told during the apartheid years” (2019: 166). Therefore, it is evident that after the prolonged state of tension, social breakdown, and the overall weakening of [of black masculinities] by crafting a\$apartheid years, South Africans are in dire need of connecting with others. In “Word Made Flesh”, Gillian Whitlock upholds the idea that life narratives operate as a kind of “soft weapon”. This “weapon” promotes cross-cultural encounters, claims for social justice and supports compliance of human rights, for these narratives “can personalize and humanize categories of people whose experiences are frequently unseen and unheard [and can also] trigger conversations and

interactions across cultures” (2007: 3). In the post-apartheid era, life narratives afford the average South African access to the emotional realm of deprived and marginalized individuals and thus building the foundations of sympathy towards others. Learning about the lives of individuals and sharing one’s own experiences is a form of connection, pulling disparate subjects into spaces conducive to social dialogue, ideological debate, and interaction to re-imagine South Africa and to awaken affect between opposing groups.

To this effect, it is important to flag up the work of Sara Ahmed (2004) who elaborates on the role of shared emotions to build individual and collective identities. In the context of South Africa, this latter aspect is crucial to the constitution of a new social fabric which is, in fact, the very first step towards the reshaping of national identity and commitments to others. In relation to the connections between identity and life-writing, Paul John Eakin states that life narratives “promise to enlarge our understanding of human identity formation” because these narratives “ground our human identities in our experience of our bodies” (1999: 1). Life narratives constitute the expression of our inner selves, and these are dominated by emotions that produce unique, plural and, more importantly, unified experiences of nationhood and selfhood. Sarah Ahmed focuses on the production of those emotions to align individuals and collectives with the nation, and in the case of South Africa the alignment with the nation largely depends on the ability to understand the suffering of neglected individuals, as is the case of HIV/AIDS sufferers amongst other social groups. In the words of Ahmed, emotions are about “attachments or about what connects us to this or that” and that “the circulation of objects of emotion involves the transformation of others into objects of feeling” (2004: 11). The question, then, is: what is it those connects individuals with a secured position in life to those who struggle to thrive in life or, simply put, survive?

What is the umbrella under which all members of the different communities might feel equally protected? What makes individuals in a disparate society equal? What comes into play here is the paternalistic role of the state and the perception of South Africans to determine whether or not its protective umbrella is effective or simply deceptive. The answer to these questions is what actually gives rise to an emotion of rage, grief, intense dislike or separation from others. In response to the latter, life-writing constitutes a solid group of responsive intellectual and writers with the potential to promote a seamless society if disparate individuals and communities connect with the emotion of belonging and sameness.

The nature of the emotion certainly counts when it comes to re-establishing and re-defining social bonds. The inability of South African authorities to meet social and political demands (the list, it would seem, is endless) in a country formerly devastated by flagrant social injustices operates as a driving force for progress. It is a way to claim for the transfer of powers to emerging communities which manifest a strong ethic of service in their responsibility towards sufferers. Emerging communities such as the Treatment Action Campaign are willing to serve the neglected, making clear they grasp the real meaning and importance of shared emotions in the new South Africa.

To take up on the initial argument held by Jacobs and Bank, and in conjunction with Ahmed's concept of "shared emotions," I want to highlight how Jacobs and Bank identify in their work a perceived sense of betrayal on behalf of the average South African. This emotion of betrayal appears to be responsible for the onset of multiple publications centered on the self and its problematic relationship with the more cavalier attitude of public institutions. In this light, certain narratives can be construed as signs of social unrest and disenchantment with the post-apartheid period. This social unrest helps to illustrate Ahmed's point that betrayal is the emotion that brings different people

together when reading the accounts of neglected HIV/AIDS sufferers. Finding out more about the extent of that betrayal can also justify an increased interest in this type of life narratives, for HIV/AIDS can also affect the lives of the fortunates or the affluent. Thus, readers can identify with sufferers' social reports on the state of health policies in South Africa, for all citizens are equal in the face of the functioning of public health services. This sense of betrayal, I believe, seems to bear an intimate relation with the only partial regeneration of South African politics, compelling readers to rely on the personal accounts of "dysfunctional," "otherized," citizens to truly measure the progress of democracy and civil rights in the country. Jacobs and Bank capture this sentiment as follows:

The interest of this recent reading public might be about groping towards re-imagining political possibilities in the light of a depressing spiral of revelations about corruption, failing social services and ultimately state capture. (2019:166)

In this context of seeming distrust and disenchantment with "what might have been", the testimony of HIV/AIDS sufferers is key to regulating their relationship with the South African state. The determination of sufferers to step across the boundaries of national traumas illuminates the continuation of the social, cultural and political turn initiated in 1994 but is incomplete to this date as it is perceived to be in an impasse and without a clear direction in its execution. As a result of this, sufferers are especially metaphorically incarcerated in mentally designed structures. These seldom trespass the scrutiny of the public eye which labels sufferers' claims as secondary or simply equates their problems with other so-called second-class citizens. Such a thing is fraught with danger for it clearly segregates individuals again at a time of union and fraternity.

The seductive power of life writing to set priorities, therefore, is to create change, and to continue with the daunting task of reforming the social tissue of the country. The strong focus on the connection between and within the social groups

formerly discriminated against in South Africa represents one of the points in the agenda that the local production of life narratives eagerly pursues. It contributes to resolving the pending challenges of non-western societies, like South Africa, as personal(ized) narratives are moving and informative of the flaws of the state; as is the case of HIV/AIDS life stories. In “The Ends of Testimony”, Whitlock states that the final goal of life narratives is deeply influenced by a humanitarian spirit and an observation of compliance with human rights where these are at risk. In his view, life-writing engenders compassion, mobilizes shame and inspires social justice (2015: 168). This is a key point in the analysis of life-writing as life narratives determine how people who are alien to the conflict presented in the life narratives come to be rendered human. We understand this within the context of conflicts being framed within a dialogical space that promotes the encounter of readers with the humane, and urging them to react in their respective scopes of action.

Because the lives of HIV positive people were not, until the turn of the 21st century, consistently documented in literature, the stories now narrated in this type of memoirs/(auto)biographies have been previously passed on to “selected” others orally, in the most absolute privacy, and when sufferers had the opportunity to speak in a very intimate and safe setting. This former trend in the sharing of life stories has certainly experienced a sudden turn in 21st century South Africa. The written testimonies of sufferers’ unrecorded events make unavailable stories available to an audience who strive for a sense of communion and hope. Shoshana Felman and Dori Laub (1992) have also discussed the goals of life-writing in their examination of the Holocaust, and both critics celebrate the entrance on the scene of the trope of the witness. In conjunction with this, Roger Kurtz (2018) argues that trauma is the leading concept of our contemporary age to understand the fitting of individuals, nations, and cultures into

global networks. South African AIDS life-writing can be framed within this perception, especially after the hearings of the cases brought by the Truth and Reconciliation Commission, as South Africa offers a national, non-western, focal point for the exploration of a global issue, as is AIDS, that shows the existing discrepancies in the actions taken on a global scale to fight off AIDS. This disparity between the Global North and the Global South in the ways of facing the pain and suffering associated with AIDS is reflected in South African AIDS life-writing, as it demands, as Cathy Caruth attests, “a new mode of reading and of listening” (1996: 9). The figure of the witness is thus extremely significant, as it anchors the expression of trauma to life-writing as a preliminary step to change. Michael Rothberg (2019) refers to the witness as the “implicated subject” or, as I put it, the “agent for change” within thriving communities. The use of both terms considers the benefits of the multiplier effect made by the call and echoes of these life narratives. Felman and Laub observe:

The specific task of the literary testimony is, in other words, to open up in that belated witness, which the reader now historically becomes, the imaginative capability of perceiving history –what is happening to others– *in one’s own body*, with the power of sight (of insight) usually afforded only by one’s own immediate physical involvement. (1992: 108 emphasis in the original)

I find Felman and Laub’s remarks insightful, yet disturbing, as the dark side of these words brings to the fore the need for the embracement of a pedagogical tone in contemporary South African life-writing. Average South Africans grapple with the real implications of the social history of the country. Thus, Felman and Laub’s call for “involvement” is a way to come to terms with the traumatic past of the country, for readers can experience the extreme deprivation and marginalization of some segment of the population in their own shoes. All this heralds the pedagogical power of life writing and, more importantly, the slipperiness of the limits of the country’s social history and its historiographic accounts as attested in the HIV/AIDS life narratives. As I understand

it, one of the purposes of life-writing is to educate readers on how HIV/AIDS sufferers illustrate the limits of the welfare state of South Africa. In this regards, I consider it to be of great importance to generate an appropriate response to the suffering narrated in the life stories, regardless of whether these stories are mediated or not. For the lives of HIV positive people to be grievable in literature their testimonies need to be moving, an observation I previously stated above in conjunction with the work of Sara Ahmed. In *Documentary Testimonies: Global Archives of Suffering*, Bhaskar Sarkar and Janet Walker also point out that moving the audience is one of the fundamental ends of testimony in what they call “the era of the witness” (2010: 1). In the life narratives that we shall be dealing with in this dissertation, I feel the capacity of tellers/writers to move readers to be one of the enticing aspects of these life narratives in order to mobilize those testimonies, and the implications these entail in the long run. In this way, circulating stories promote significant changes in the lives of the stigmatized, moving beyond a devastating experience, as is the contraction of a virus for which there is no apparent cure to date.

Mobilizing testimonies is desirable but mobilizing moving testimonies is essential to further civil rights in post-conflict societies like South Africa. Sarkar and Walker elaborate on the aspects of moving testimonies as follows:

[T]he faces and voices that emanate from closer or distant locations; the sounds and images that animate ubiquitous screens; the archives we establish and the histories we resuscitate. These are the new assemblages that compel us to bear witness, move us to anger or tears, and possibly mobilize us to action for social justice. (2010:5)

The critics highlight, in my view, one other central aspect of life-writing concerning the power of human relations and networks of solidarity when hidden histories become public, and that is the overflow of the collective connection of life experience. By sharing human experiences HIV/AIDS sufferers reaffirm their desire not only to

overcome a traumatic past but also to leave a recorded legacy of their struggle for life, which is everlasting and accessible to others. In life-writing, testimonies convey particular meanings serving the interests of social advocacy and activism, the clearest example in South Africa being the constitution of the Treatment Action Campaign, an accumulation of witnesses, which will be discussed in chapter two to illustrate the construction of the HIV nation within South African borders. The voice of HIV positive people confirms the shift from the (mis)representation of consumed individuals to one of self-awareness and empowerment. Life-writing is giving visibility to the multifaceted nature of HIV positive people, whose testimonies confirm their pedagogical value of this genre. The diversity of testimonies also evinces the manifestation of the many registers of the self. Such a quality confirms the optimum moment this literary genre goes through, and its service to the community by bringing to light the hitherto silenced social issues of national interest.

Memoirs, biographies and autobiographies are all forms of testimony and ramifications of the modes of empowerment. They all contribute to the construction of a collective and individual remembering, whose ultimate goal is to facilitate sufferers regain sovereignty over their lives and bodies. In this process, HIV/AIDS sufferers appear to be re-territorialized through their recognition from others, who act as witnesses of the effects of strong emotive testimonies and their transformative power. The act of witnessing reveals to what extent the different forms of life-writing, namely memoirs and auto/biographies, have permeated with force the contemporary age in South Africa. Here, I would like to comment upon the on-going discussion over the main differences between the various manifestations of life-writing, my interpretation of these, and what aspects of the on-going theoretical discussions can illuminate both my

analysis of South African contemporary culture in the face of the epidemic and the ethical issues raised by life-writing.

I have already hinted at some of the central concerns raised by testimony, which, as I understand it, serves to illustrate the interlocking relationship between memoirs and auto/biographies. I hope to provide now a reasonable context to enable readers to understand my approach to the existing genres in life-writing. I anticipate that my central premise, which is based on the study of the five life narratives comprised in this dissertation, is to embrace the concept of memoir as the most practical and convenient to categorize HIV/AIDS life narratives. I embrace this idea because all life narratives focus, in different degrees, on particular periods of the lives of the protagonists –often complicated and tough ones– and to the best of my knowledge, memoirs are wont to do so, very especially when considering that memoirs take on a more realistic approach to life. Memoirs represent real situations in the lives of people who are exposed to harm and in need of assistance at a particular time in their life paths when individuals are rendered vulnerable. In *Memoir: An Introduction*, Thomas Couser speaks of the “nobody” memoir (2012: 12) to tackle what it is like to be in the shoes of a diseased person or, as he puts it, “writing about *odd* bodies” (2012: 12, emphasis in the original). Biographies and autobiographies, as we know them today, also offer fragmented realities of the self; hence, the suitability of the term “nobody” memoir to refer to HIV/AIDS life narratives, where the freeing power of anonymity enables sufferers to articulate unfiltered discourses about their anger and disagreement with the position these neglected individuals held in the “new” South Africa.

In our contemporary age the concept of memoir operates as a hybrid, bridging element, a narrative that sits between biographies and autobiographies due to the fact that it combines elements of biographical and autobiographical nature. According to

Couser, memoir can refer to “any account of the author’s life, as if it is synonymous and interchangeable with autobiography” (2012: 17-8, emphasis in the original) or “refer to a narrative that is primarily about someone *other than* the author” (2012: 18, emphasis in the original) to refer to a subgenre of biography. In Couser’s view, memoirs have come to overshadow biographies and autobiographies, and I could not agree more with Couser’s insights, for it is a shortcut to unify the shaping principles of a literary genre that has been much debated without reaching a sufficiently solid consensus on its core characteristics. In my view, the genre needs to adapt and update the theoretical reasonings and interpretations that connect the various sub-genres of life-writing to make it more approachable and comprehensive. In *Memoir: An Introduction*, the scholar contends that “memoir is the literary face of a very common and fundamental human activity: the narration of our lives in our own terms. [Memoir] is rooted in deep human needs, desires, and habitual practices” (2012: 9). To this I would add that its essential value is that it ultimately depends on the degree of accuracy and insight with which the life events of a person are analyzed, if written by someone else, or the potential with which writing about one’s life brings a new notion of selfhood into being; that is to say, the potential of the experiencers to project themselves to a wider audience. In relation to this latter thing, Couser highlights that one of the primary objectives of memoir is “to make identity claims” (2012: 14), and each of the sub-genres seems to promote specific cultural models of identity, where culture specific elements determine the means of auto/biographies. Furthermore, it is also convenient to highlight that memoirs and auto/biographies also operate as sites for the exploration of trauma, as the latter is often brought to light, as will be seen in subsequent chapters. In this sense, the exploration of linguistic devices to narrativize the experience of the trauma survivor is of paramount importance. Ilja Srubar (2016) elaborates on the significance of language in order to

define meaning-formation and the revision of the highly sought after notion of normalcy. Thus, as Srubar notes, “the effect of the traumatizing experiences can be mitigated via their linguistic articulation” (2016: 27), but such a goal can only be achieved once the experience is retrievable, as noted earlier in this dissertation, especially if we take in mind, as Srubar indicates, that “the loss of language seems to have a protective function” (2016: 27). The temporary silence of sufferers is not tantamount to repressing the experience of sufferers. On the contrary, as Bloom (1997) suggests, silence is tantamount to creating a sanctuary that sustains the significance of the aforementioned concepts of meaning-formation and normalcy in the mind of the sufferer. Therefore, I argue that life-writing is linked to the articulation of sufferers’ experience in the sense that the range of experiences, as Srubar (2016: 27-28) suggests, could result in violence, conflict, and even persecution, but more importantly, in healing. Life-writing has the power to encroach on the privacy of sufferers, and on marginal and sensitive areas of their lifeworld, proving that speaking about the unsayable (Gilmore, 2001: 7-15; Roth, 2012: 77-86) is not only possible but necessary for sufferers to regain normalcy.

In the first place, I must admit that the difficulties that have arisen in scholarly debates around possible definitions of what memoirs and auto/biographies are or are not have certainly exasperated me. In his seminal publication, “The Autobiographical Pact”, the leading scholar in the field, Philippe Lejeune, considers the relations of biography and autobiography, and the relations of the novel with auto/biographies “irritating due to the endless repetition of arguments, the vagueness that surrounds the vocabulary that is used, and the confusion of problematics borrowed from unrelated fields” (1989: 3). My understanding of these forms of life-writing is no exception to what seemingly is a range of inconsistent, blurred, terms. The definitions and boundaries of the forms of

life-writing seem to have been a doomed attempt on the part of criticism to “tame” the literary sub-genres of life-writing, which the scholars Thomas Couser (2012, pp. 33-53) and Claire Lynch position somewhere “between or across genres” (2010: 209). James Olney shares a similar viewpoint, thus adding a frustrating undertone to the difficulty of critical thinking in establishing a more homogeneous approach to the forms of life-writing. This is so when Olney contends that “there is no way to bring autobiography to heel as a literary genre with its own proper form, terminology and observances” (1980: 4). I coincide with this observation as regards the issue of the influence of those culturally specific elements in defining the scope of application of the different forms of life-writing. The hybrid component and the blend of characteristics from other literary genres seem to take the helm of a “ship” lacking specific direction, especially when it comes to defining what features are embedded in autobiographies, biographies or memoirs. I have also come up against these three terms, each of which present a variation on the same basic situation: people’s lives can be narrated in order to support my central premise that memoir is the appropriate label for HIV/AIDS life narratives. It is important, furthermore, to emphasize this common feature within all the life narratives which I shall deal with in subsequent chapters of this dissertation. This can be summed up as the composition of illness and reconstruction of the self through the language of emotion and self-reflexivity.

The contextual reality of both South Africa and HIV/AIDS narratives requires a singular approach to the study of the ramifications of the self, as illness combined with the experience of apartheid serves to place characters in situations of extreme marginalization and stigmatization. Following this line of thing, Eakin contends “there is a legitimate sense in which autobiographies testify to the individual’s experience of selfhood, that testimony is necessarily mediated by available cultural models of identity

and the discourses in which they are expressed” (1999: 4). The experience of HIV/AIDS sufferers is characterized and mediated by a cultural model where the social and political environment makes it difficult to understand the underlying emotions and dynamics taking place within the ideological world of the sufferer. This is partly so due to the fact that HIV/AIDS carriers in South Africa are deemed unproductive, consumers of scarce public resources, and “deserving” of their inflictions for the sole reason of having unprotected intercourse and bringing shame to their families.

As a result of this sense of shame, HIV/AIDS sufferers are forced underground and into oblivion, as attested in most of the life narratives. Consequently, their life narratives constitute an act of rebellion. “Storying” HIV/AIDS brings a touch of the profound desire for transformation originating in the consciousness of disempowered and unheard individuals who suffer the unrelenting cruelty of their invisible condition. In this one sense, as Lejeune points out, “auto/biographical writing brings to light phenomena that fiction leaves in doubt” (1989: 6). This is the case in the life narratives concerning the lives of formerly invisible subjects during the age of apartheid in South Africa whose misfortunes have gone unnoticed until the possibility to air their grievances has become a tangible reality. Therefore, it is mandatory for me to explore the “margins” of life-writing within the parameters of the postcolonial and the transcultural. This is so in order to elaborate on the historical conditionings that have shaped the singularities of South African consciousness in the post-apartheid age.

My divergence from the European root of life-writing theory responds to the necessity of making South African microhistories known⁶. The term microhistory, coined by Carlo Ginzburg and Giovanni Levi in the 1980s, is of great value to unlock

⁶ In the course of my research I have come across a number of references to the Cartesian subject and the work of scholars such as, for example, Nietzsche, de Man, Freud or Barthes, to name a few. Although the work of these intellectuals can set sound methodological and theoretical preferences in the study of the self, their philosophical leanings toward the role of the author and the subject in life-writing cannot be applied to the cultural context of South Africa.

underlying realities, indeed, new cultures, shaped by the power of experience. The term is fitting for the new era in which South African scholarly debates try to usher in their attempt at discovering the hidden aspects of the country's convulse history. I shall refer to the application of this term further below in more specific detail in conjunction with the task of the biographer. For the moment, I shall highlight the variety of ethnic, racial, gender, sexual and socio-historical undertones in contemporary South African life-writing, including HIV/AIDS memoirs, embedded in those microhistories. This wide range of thematic elements offers a glimpse into the innovative spirit of life-writing, where hybrid cultures and the outcasts of society gain momentum.

The events of the epidemic in the southern tip of Africa have formed the perfect backdrop to the development of a new style of life narratives, stepping away from rigid categories of the self and embracing new forms of subjectivity and narrative sovereignty. Gestures of socio-political revolt abound in HIV/AIDS life narratives, and these accommodate a series of transcultural perspectives which are all related to the socio-political demands of sufferers. Many of these demands are common in other cultures where both the perception and representation of the neglected self-challenge dominant discourses about the construction of the normative self. In narratives of this type of illness, the performativity of the non-normative self and the meaning attached to the embodiment of such experience pose pressing questions about the process of how the self is (re)constructed within the life narrative, and how this self-projected to a wider audience. Thus, the reformulation of identity patterns and markers undergo a process of renewal in HIV/AIDS life narratives, and this stage is accomplished once the phases of grief and mourning give way to a phase of personal and collective empowerment.

South African life-writing charts the emotional, national and identitarian processes where HIV/AIDS sufferers build on the notion of power and agency. Jens

Brockmeier defines (auto)biographical writing as “such a powerful symbolic form and a genre of identity construction” (qtd in Baena, 2007: vii). Brockmeier’s approach to life-writing omits from the equation the issue of identity representation and thus highlights the spirit of constructedness of the auto/biographical narrative. In this regards, Janet Gunn discusses the nature of auto/biographies as a public attempt to make critical practice circulate widely, where a sharing of experiences becomes a critique. Marlene Kadar (1992: 3) also understands auto/biographical writing as a form of denunciation through critical writing in that resistance against dominant cultural practices generates opportunities for the merging of life-writing with postcolonial theory. In so doing, both fields of study validate the potential of life narratives to create a dialogical space in-between cultures where “the act of the self reading” (Gunn, 1982: 23) in one side enables the emergence of the self-conscious mind in the other, giving way to a feeling of “kin” and sameness.

Framed within the postcolonial and the transcultural, the process of (re)construction of the self in HIV/AIDS narratives is found, as Rosalía Baena points out, at the “intersection between cultural affiliations and processes of self-perception and self-representation” (2007: viii). In this context, difference stands out in positive terms. With that in mind, I shall illustrate that instantiations of illness in auto/biographical writing hold the testimonies of sufferers together as a way of contrasting not only experiences of pain and suffering but, more importantly, as a way of connecting forms of transcultural empowerment that are facing together the threat of a global disease. As I stated earlier in this section, mobilizing moving testimonies is essential to life-writing, and as a manifestation of empowerment, I contend that life-writing is an emotion in constant motion and circulation that occasions a variety of social, cultural and political movements. In *Rootprints, Memory and Life-writing*,

Hélène Cixous points to the expansion of the possibilities of emotions and how individuals dare to inscribe themselves in the writing/making of stories/histories. I find her understanding of life-writing particularly insightful when she compares the act of auto/biographical writing –a view that goes in line with Gunn’s notion of the act of reading one’s self– with “a drug that lights up instead of putting out” (Cixous, 1997: 41). That lysergic boost gives way to a series of confessions coming from the very inside of the sufferer “as if the page [was] really inside” (Cixous, 1997: 105). This taking outside-in, another central element of auto/biographical writing, reveals the noble quality of humans who, faced with debasement and lack of power and sovereignty, find in the pen and paper the almost narcotic opportunity to re-situate themselves in their social and cultural frameworks in accordance with their systems of beliefs. Cixous speaks of nobility as follows:

Our true nobility: there is a resource in us, even when we are reduced, when we are crushed, when we are despised, annihilated, treated as people are treated in the camps, a resource which makes the poetic genius that *is* in every human being still *resist*. Still be capable of resisting. *That depends on us*. (1997: 27 emphasis added)

Cixous’ words describe the inherent capacity in human beings to overcome adversity, to speak truth to power and to react in the face of any stifling situation. If in the eyes of Cixous reading the self is synonymous with drug consumption, understood as something addictive, then, we can establish analogy between writing about the self and how writing about the self is an addiction to the exploration of conscious self-care and the celebration of human awareness. These characteristics, in conjunction with Ahmed’s understanding of the politics of emotion in writing, make me locate autobiographies clearly within the realm of the emotional. Here, we find a distancing from the philosophical entanglements of notions on authorship and the subjective as formulated by other critics. I see autobiographies as acts of non-fictional resistance, rebellion, and

disclosure, where the expression of deep emotional thoughts, as a way of therapy, constitutes volumes of accessible self-representational writing advocating for the magnetism of confession and the benefits of self-knowledge. The seductive and persuasive appeal of stories rife with signs of vulnerability and actions for the empowerment of the disenfranchised render both writer and reader active agents for the transformation of the displaced, and by connecting a multiplicity of selves, writers and readers see themselves reflected in one another. Such an understanding thus facilitates the breaking up of artificial social walls erected in South African soil during apartheid, and whose foundations have resisted the fall of the apartheid regime. This interpretation of autobiography, attending the culture specific reality of South Africa, contains the core elements that are present in HIV/AIDS life narratives. Sufferers and readers alike thus find shelter in each other and build the foundations of true reconciliation as they open up their minds to an alternative cultural model of identity sustained by ethical principles. These elements, in turn, operate as a bridge between the genre of life-writing and the postcolonial sphere in its broadest spectrum inasmuch as HIV/AIDS sufferers champion the same social causes. The fact that South Africa has strong postcolonial roots also compels me to incorporate postcolonial discursive practices into my analysis of the construction and representation of the self in subsequent chapters.

Critics of the postcolonial trend in life-writing studies, namely David Huddart (2008) and Bart Moore-Gilbert (2009), clearly argue for life-writing's plurality. This latter aspect of their work is, in fact, an invitation to extend our notions of the self beyond the central concerns of Western practices. According to Linda Anderson in *Autobiography*, Western practices promote viewpoints of masculine, Western, and middle class subjectivities as the widely accepted and dominant form of life-writing (2001: 3). Contrary to this "hegemonic" view, the diversity of postcolonial writing,

especially in the areas of society, culture and politics, cannot but give rise to a critical study of the memoirs and auto/biographies produced in postcolonial areas that contest the so-called “center” proposed by Western discourses. Thus, Moore-Gilbert defines postcolonial life-writing as a discursive practice that is decentered (2009: 1-16), relational (2009: 17-33) and embodied (2009: 34-50), placing emphasis on the internal and external conditionings of each geographical area to reformulate past experiences. This is precisely one of the argumentative lines explored by Edward Said in *Culture and Imperialism*, where the critic advocates for the distinctiveness of these literatures based on the historically constructed experiences of their subjects over the time; and hence, the need to accommodate criticism accordingly.

Taking these analytical and critical features still further, critics of this trend largely benefit from the elusive status of the different forms of life-writing. Their insufficiently homogenized theoretical stances justify the entrance of the postcolonial in this on-going discussion with force. In his discussion on the intersections between postcolonial theory and autobiography, David Huddart has noted the inadequacy of the term autobiography on the grounds of the meaning attached to the term. Huddart contends theorists “cannot restrict [themselves] to a narrowly ethnocentric and paternalist model of life-writing, and if that is what autobiography tends to designate, then [postcolonialists] might do better using other terms to describe the most general tendencies” (2008: 2). In short, Huddart situates postcolonial life-writing within a narrative form of emancipation from the locus of knowledge. Indeed, and taking up on Gilbert-Moore’s understanding of postcolonial life narratives, the hybrid component allows “postcolonial life-writing [to draw] heavily on indigenous narrative resources and [to hybridize] to a significant degree the standard forms of metropolitan languages handed down by colonialism” (2009: 108). The exploration of alternative mechanisms

for interaction –linguistically, culturally and politically– among writers, sufferers and potential audiences, where different sets of values intersect, fully confirms Gilbert-Moore’s postulates. In this one sense, the construction and representation of decentered, relational and embodied subjects – and all these elements are present in the HIV/AIDS life narratives– show the centrality of these characteristics in the production of postcolonial life narratives, as they are integral elements of the narrative plot. This, I believe, proves right Gilbert-Moore’s idea that postcolonial life-writing evinces “relative autonomy from its western analogues” (2009: 129), for the exploration of the hybrid component in these narratives helps understand both the cultural forms and the resulting identities reflected in the HIV/AIDS life stories –produced in postcolonial South Africa– and the Western nuances in them.

This hybrid form can be seen as a major strength of postcolonial life-writing because it offers the perfect backdrop for the development of new audiences, more understanding of the complexities surrounding the postcolonial world in the cultural and political arenas. These two areas, the cultural and the political, have traditionally been the focus of postcolonial theory, and instantiations of both in the HIV/AIDS narratives can lead us to consider that the postcolonial condition is synonymous with the autobiographical. I uphold this belief, regardless of whether the memoir is written by the sufferer or someone else, because to have composed a narrative of illness means it is filled with autobiographical moments. These moments of revelation and communion originate in the writer’s and sufferer’s conscious experiences. Although four of the life narratives under study in this dissertation may well fall into the category of biographies, according to standard criticism, (due to the fact that they are written by someone other than the experiencer, and that they are authorized versions of past events) the term turns out to be, in my view, misleading. The so-called biographers have deliberately chosen

the topic of HIV/AIDS for personal reasons as well. This is evident when the narrative voice switches from the third person to the first one in their bid to achieve, through the lens of the sufferers, their own personal realization. This is evident in Jonny Steinberg's work and in Liz MacGregor's account of DJ Khabzela, where their own biographical sketches intertwine with the lives of the central characters in some passages. In these cases, both biographers (whom I consider to be memoirists) also undergo a healing process in the elaboration of the narrative. Indeed, a mourning relationship to the memoirists themselves runs parallel to the discovery of their subjects of study, as memoirists' open up wounds of the past which heal through their encounters with the ruins and the legacy of the apartheid state in the present.

The pulp-to-scholarly gamut of non-fictional narratives has vanquished the traditional configuration of biographies. HIV/AIDS life narratives confirm this trend in academic and intellectual circles. The use of the terms biographies and autobiographies are increasingly disused and in the process of becoming somehow archaic within the academic argot. Thus, these terms have been gradually replaced by life-writing, a more generic term that encapsulates former methodological procedures to elaborate on the stories of people. Despite the latest fashion in the use of term life-writing (something I personally feel more comfortable with in this dissertation) I shall, briefly, consider various aspects of biographical research so as to deal with the elaboration of the memoirs of HIV/AIDS sufferers. Those journalists and academics that have spent valuable time in creating moving narratives out of ordinary lives, and which mirror the fears and anxieties of a considerable handful of South Africans, merit praise and further attention. This is so due to the fact that their relentless work and loving attitude towards sufferers brings greater comfort and hope to those who walk alone through the uncertainties of illness. Life narratives, in general, and illness life narratives, in

particular, are a great ally to face the challenges of life at a time of acute personal emergencies.

To further my approach to biography I shall now focus on the theoretical aspects that memoirists resort to in order to make available unknown stories to people who find in them a good deal of thrust to keep believing in the small things of life or, in short, to keep flying in spite of sorrows. In the first place, I shall insist upon the manner in which existing cross-fertilizations among different disciplines such as literature, journalism, history, and historiography seem to pose a greater difficulty to provide biography with a clear-cut critical framework. In *Theoretical Discussions of Biography*, Hans Renders and Binne de Haan provide a comprehensive study of the term. Both scholars draw a distinction between the interlocking relationship between auto/biography and the disciplines of history and historiography separately. These critics develop their understanding of biography in close connection with the purposes of illustration and contextualization of historical events, which may be tantamount to saying that autobiography is, largely speaking, based on historiographical interpretative practice. Whereas these scholars acknowledge the strong presence of their ideological agenda in the writing of autobiographies, they present biographical studies with a lesser ideological burden. Renders and de Haan observe that biographers,

designate the study of the life of an individual, based on the methods of historical scholarship, with the goal of illuminating what is public, explained and interpreted in part from the perspective of the personal [...] to take greater interest in the importance that personal background can contribute to the study of history. (2014: 2)

The contribution of the personal to the public sets the scene for the role of microhistories in revising accepted precepts of the past, questioning the verifiability of the past by focusing on the representativeness of the “nobodies.” In the critics’ argumentation, I find particularly engaging their use of the term “camouflage” to refer

to the methodological procedures of the biographer, who, in their view, operates in the shadow of the novelist.

Therefore, as I will argue in greater detail in the upcoming section, biographers operate as mediators of the narrative. In this way, mediators externally redress past wrongs, probably coinciding with their own critique of the situation presented in the narrative, without the vivid emotional burden this process of remembering brings about. This is particularly the case of the sufferers, whose disordered and stored-up emotions prevent them from recapitulating their experiences by themselves in an orderly and meaningful way. Conveying their message effectively is crucial to generate a public response and to trigger change, and that is the fundamental goal of the narratives based on the testimonies of dismembered individuals. The relocation of sufferers in the society they inhabit, from which they feel alienated, gives added value to the experimental purpose of composing illness because, in the words of Giovanni Levi, “the unifying principle of all microhistorical research is the belief that microscopic observation will reveal factors previously unobserved” (2001: 101). From this point onwards, the memoirist enters the arena of microhistory to tackle not just the effects of the HIV/AIDS epidemic on the whole but moreover the position of the subject of study in relation to his/her incomplete account of epidemic, a subject which is under constant revision. So, technically speaking, the accounts of the epidemic under scrutiny in this dissertation, those written by someone else, fall into the category of microhistorical biography/memoir.

These accounts of HIV/AIDS focus on the failure of the transformation of the South African state along the revolutionary lines set by the anti-apartheid liberation movement during the last throes of apartheid and the early days of democracy. Giovanni Levi is one of the greatest exponents of microhistory, a branch of the so-called new

history, that promotes a historiographical practice which is experimental in its essence, and which advocates for the revision of the tools of research employed by the historian; in this case the memoirist who adheres to that methodology. In “On Microhistory” Levi outlines the main lines of action of this discipline, describing the behaviour of the implicated subjects as a way to explore their agency by deconstructing the notion of the normative. Levi describes microhistory as,

an inquiry into the extent and nature of free will within the general structure of human society. In this type of inquiry the historian is not simply concerned with the interpretation of meanings but rather with defining the ambiguities of the symbolic world, the plurality of possible interpretations of it and the struggle which takes place over symbolic as much as over material resources. (2001: 99)

Levi’s words are of paramount importance to understand the complexity of the cosmovision of HIV/AIDS sufferers. Memoirists strive consciously to shed light on the ambiguities of the symbolic world of sufferers who, more often than not, appear to be trapped in a state of disillusion with a manifested reality that is neither considered with them nor inclusive of their needs as vulnerable subjects. Bearing this in mind, I consider that writing a biography/memoir on illness demands a different way to interpret life, something that is more research-based as it implies awareness of how the subject of study copes with the passing of time. It also suggests a different approach to both the materiality of life and the materiality of writing about the self and about how to create a repository of knowledge on the pressing issues that shape or have shaped the existence of a given subject. This existence develops under specific circumstances that need to be further detailed in order to serve the purpose of healing and rehabilitation. Biographical writing is a purveyor of popular culture, values, and outlook. When the narrative seeds of hope, (self)-realization, and (self)-awareness bloom into human stories (or microhistories), then, we are faced with a piece of auto/biographical writing.

1.2.1 The Role of Narrative Mediation: The Task of the Biographer

The singularity and specific merit of Stephanie Nolen's *28: Stories of AIDS in Africa*, Jonny Steinberg's *Three Letter Plague*, Jim Wooten's *We Are All the Same*, and Liz McGregor's *Khabzela* is the act of union between writers, performing the role of mediators, and the sufferers. This union offers readers a unique chance to inhabit these voices of change, whether sanitary or social, from across the South African geography. In the act of public disclosure, both sufferers and afflicted members of society raise their voices to take center in the storytelling of their illness experience. One of the enticing aspects of these life narratives lies in the representativeness of South African civil society. Thus, readers come into the realization that HIV/AIDS affects people from all walks of life, and such a thing evinces that the disease has permeated South African society with force. In this regard, each of the narratives show to what extent the issue of class is of chief importance to combat the disease within the context of a welfare model to be developed. The cast of characters ranges from the son of Nelson Mandela to a disgruntled businesswoman, celebrities, rural entrepreneurs, average workers or fringe-dwellers. In doing so, the elaborated narratives provide an entry point for the world to catch up with the real meaning of living with HIV/AIDS and to accept their "Others." The scale of HIV/AIDS in Africa, in general, and in South Africa, in particular, deserves to put human faces on what we could, in conjunction with the current COVID-19 pandemic, be considered as one of the greatest health crisis of our contemporary age. The aforementioned biographers/ mediators (these terms are interchangeable and will be used indistinctively) avoid succumbing to the image of South Africa as a place of negatives in their approach to a very often misunderstood medical condition. Instead, they gear their efforts towards validating the function of established medical research and science, thus dismantling the belief that HIV stigma is associated with HIV testing.

The term “HIV sufferers” in South Africa often conjures up images of isolated, dying, men and women standing on streets, waiting for their final moment on earth. HIV/AIDS, as a disease, is expressed with coded words or euphemisms, at best, and more often than not is a neglected condition that weighs on emotions, and so too on the illusions and hopes of its carriers. This stereotyped image often comes to the minds of affluent South Africans who, despite being aware that South Africa is a country filled with huge contrasts and inequality, prefer to turn a blind eye to the suffering of these invisible subjects. The less wealthy are no exception to this rule; in short, almost nobody wants to identify with sufferers, acknowledge their presence or be part of their supporting network. Yet the truth is that a large number of South Africans are either affected by or infected with the virus. Stony silence reigns, and the breaking up of silence turns out to be their only possible way to regain dignity and lost honour. These invisible subjects, in turn, store up meaningful stories characterized by the need of seeing light for their counterparts to question their assumptions on HIV/AIDS. In post-Apartheid South Africa, the road to effective reconciliation goes through constructive dialogue among unequals, including the disenfranchised by HIV/AIDS, and biographers, in this respect, lead those HIV/AIDS sufferers from all walks of life through a narrative process that avoids the on-going objectification of their existences.

In this section I will tackle the major functions of the biographers within the frame of narrative mediation theory. This will help shed light on the building of empowerment and resilience in these life narratives. Primarily, the task of the mediator is to bring to life an array of unrecorded past experiences, capturing the silences and anxieties of a whole generation of people whose imperative need to make sense of their illness dictates their lives. In view of John Winslade and Gerald Monk (2008), the mediator operates not as second party in the co-authoring of the sufferer’s personal

account of HIV/AIDS but rather as a third party. This observation is relevant to the question that occupies us here because the sufferer is thus placed right against the problem that causes him/her disturbances. This latter element, the disease in itself, is the missing second party in the equation, and sufferers are faced with the task of interpreting anew the impact of living with the virus at a time of national “celebration” after the abolishing of apartheid. In this respect, Winslade and Monk (2008) and Monk (1997) point out that mediators facilitate the deconstruction of built-in ideas about how the world is or works, and more importantly, the way in which society responds to invisible traumas, as in the case of HIV/AIDS. The work of these two leading scholars in narrative mediation has, certainly, sharpened my understanding of the narrative mediation technique as reading this type of narratives requires a deep understanding of the contextual setting and the culture-specific elements out of which different plots develop.

Although HIV/AIDS narratives may all seem to follow, superficially, at least, the same pattern, the reality is that a wide variety of thematic driving forces exercise influence over the (re)telling of individuals’ HIV/AIDS experiences. For instance, power, temporal, spatial and class issues have a say in the reformulation of these experiences. The drafting of a new discourse aims to relocate the sufferer within the frame of a shift class forces, especially, on a national level. The discourse of sufferers ushers in a new balance of forces between those who inhabit the margins of South African society and those who hold positions of power, namely political leaders and business tycoons in the pharmaceutical industries. The work of David Epston and Michael White (1990) has also drawn my attention to the importance of the temporal condition in narrative mediation. The passing of time seems to be essential for the perception of difference in the interpretation of past events and also for change in the

narrative patterns to come into effect. In connection with narrative patterns, Epston and White contend that “a great deal of lived experience inevitably falls outside the dominant stories about the lives and relationships of persons” (1990:15). Therefore, the reshaping of the discourse of HIV/AIDS sufferers feeds essentially on the management of power relations through the exploration of the meaning of words (Michel Foucault, 1980; 2000). In this particular sense, sufferers appear to be in dire need of controlling the aspects that shape their understanding of the disease. For this to come about, the mediator, as Winslade and Monk (2008, 26-7) point out, must be capable of identifying with alternative conceptual avenues that lead to an alternative story. In so doing, narrative mediators operate as social change agents (Cobb, 1993), and their narrative approaches not only endorse the normalization of HIV/AIDS but also the adherence of sufferers to pro-treatment movements. The unique outcomes of sufferers’ stories are thus the product of the biographers.

This is precisely what the biographers in the literary corpus of this dissertation achieve, to a greater or lesser extent, through narrative mediation. They shed light on the unrecorded events that are left aside in their bid to propel a change of mindset (Folger and Bush, 2005) on the prevailing attitudes that prevent sufferers from questioning their roles in society. This is the case when sufferers’ sense of purpose entirely depends on outsiders who barely tolerate their presence in the public domain. This is especially the case once sufferers disclose their medical status. Thus, mediation plays a key role in bringing discourses of hope into people’s lives. The exploration of language and the reconceptualization of social relations not only help sufferers define their plight, but also helps them construct the world they live in anew by mapping out the disturbing elements of their former narratives. In his discussion of the renewal and reformulation of existing concepts and relations of power Foucault notes:

The problem is at once to distinguish among events, to differentiate the networks and levels to which they belong, and to reconstitute the lines along which they are connected and engender one another. From this follows a refusal of analyses couched in terms of the symbolic field or the domain of signifying structures, and a recourse to analyses in terms of the genealogy of relations of force, strategic developments, and tactics. (1980: 126)

In the process of encouraging strategic developments and tactics, mediators urge sufferers to inquiry into the reasons why negative responses to the representation of HIV/AIDS carriers affect negatively their sense of agency. The development of agency is, indeed, a very slippery terrain in the case of HIV-positive people, and certainly one of the areas of concern for mediators. The enforcement of human rights is at stake here, and learning to say “no” to the emotional inputs that cause damage to the psyche of HIV sufferers becomes a central aspect in the building of the narrative. It is actually necessary for sufferers to discern between the elements that constitute the foundations of a narrative conducive to healing, which is in the end one of the major goals of writing up these life stories. William Ury (2007) is quick to observe that in the role of mediation the protagonists are often faced with the need to set up their priorities so as to determine what experiences they embrace and/or reject, which contributes to drawing out possible differences between the resulting stories.

Another aspect that is essential to the reformulation of past experiences is empowerment. In the narratives under discussion empowerment appears to be an elusive concept. In theory, sufferers are empowered by the mediation process. In reality, as attested in the life narratives, the mediators feel also empowered by their own approach to conflict resolution. Such a thing clearly evinces the level of commitment of mediators to the strict enforcement of human rights, health democracy and participation of socially regarded disabled individuals via collaborative organizations. Their level of engagement with sufferers also responds to mediators’ innermost desire of leaving their mark on society by finding other expressions of ethical integrity that in some way

prolong the passion that sustains them, personally and professionally. In my view, this latter aspect provides sufferers with a medium through which their fears and overall feelings can be voiced. This augments a sufferer's sense of empowerment as these narratives unfold. Sara Cobb elaborates on empowerment as follows:

Empowerment has promised to enhance the involvement of the disenfranchised, facilitate sound policy planning, increase self-esteem, improve community relations, augment decentralization, and in general, return power to the hands of the people. (1993: 245)

In the selected passage, Cobb makes clear the role of the various nuances embedded in the term empowerment. More specifically, Cobb elaborates on the symbolic value of empowerment, as it is a process through which sufferers are faced with everyday challenges in their bid to promote the enactment of their personal agency. In this gradual process of empowerment and authority over the content, the mediator only manages the process. However, mediators do not seem to be responsible for the possible development of the internal disputes sufferers may have in the process of sorting out the so-called disturbing elements of their stories into a more coherent narrative of the HIV/AIDS experience. This view gives prominence to the idea that empowerment is a socially constructed characteristic inherent in all humans. Therefore, the successful manifestation of any form of empowerment is that which effectively neutralizes existing social and structural obstacles (Cobb, 1993, 2014; Winslade 2006; Winslade, Monk and Cotter, 1998). Furthermore, it is through the embodiment of empowerment that sufferers manage to re-interpret past wounds in ways conducive to a healing process. In this way, one can conclude that the expression of trauma is related to the manifestation of empowerment in individuals because, as Gilmore (2001: 7-15) and Roth (2012: 77-86) invite us to consider, speaking about the unspeakable connects sufferers to episodes of danger in their minds. Hence, the value of the adoption of a discourse that enables sufferers to confront their fears and longings as individuals that are part of an extended

web of sufferers is conducive to ameliorating the collective trauma of AIDS sufferers. In this process, it is important to consider Gabriele Rosenthal's examination of the existing interrelation between individual processes of remembering and collective memories. In line with the approach that I have taken in this dissertation, Rosenthal (2016) places emphasis on the geographical and socio-political contexts which nurture the testimonies of trauma sufferers and/or survivors. This is particularly the case when sufferers elaborate time and again on the re-construction of their past experiences in order to initiate the process of transformation whereby sufferers develop a new sense of belonging to the place in which the traumatic event, in this case the consequences of testing positive in a hostile environment, takes place. In the act of remembering sufferers strive to intertwine the relevant aspects of their testimonies with the real possibilities for advancement in their personal and collective struggles as marginalized voices. As Rosenthal observes:

A significant assumption [in relation to remembering] happens to be that the practice of remembering generates over and over again, and thus changes the collective memories of various societal groupings in diverse historical and institutional contexts. The process of remembering is determined by the now of the remembering and its influential discourses and collective memories, especially those belonging to the established grouping. (2016: 32)

As Rosenthal suggests, testimonies have the potential to re-write the history of individual and collective suffering, giving rise to a more complete and faithful version of the national collective memory which had not been previously documented and that, consequently, were erased from the national consciousness in an attempt to impose a particular view of the AIDS epidemic in South Africa. In this regard, mediation on trauma allows the re-negotiation of collective memory and opens up the possibility of bringing peace to the conflicts of social, historical and political nature that played out themselves within the frame of institutional power in South Africa.

On a more personal level, Marlow and Sauber (1990) build further on this idea by suggesting that among the benefits of mediation is the idea that it reinforces sufferers' self-esteem and their ability to make adequate choices in their lives. This is of paramount importance because decision making, as a manifestation of empowerment and owning one's voice, turns out to be reinforced by the gradual disappearing of painful emotions. This is conducive to the happiness and welfare of sufferers, who begin to feel integrated into the dynamics of public life in their bid to free themselves from the internally assumed stereotypes and prejudices that punish them indiscriminately.

The therapeutic benefits of mediation in storytelling elevates a sufferers' own perception of his/her identity and grants them the possibility to be an active part of national imaginary of a democratic South Africa, which in itself is an on-going process. That national imagery remains incomplete until South African society is ready to incorporate the wretched of the epidemic into community relations and on equal terms. James Pennebaker (1997: 95) contends that to elaborate on personal conflict leads to a sense of order and peace of mind, a process which is key to structuring sufferers' experience in their efforts to pursue the goal of recovery through psychological closure. In this process, sufferers are faced with a role that has a disquieting effect on them, and this is the main reason why having someone conduct the discussion on the impact of HIV/AIDS in their self-perception is resourceful and helpful. Ingemark (2013: 10) goes further by giving prominence to the idea that the problem or conflict must be envisioned as something temporary. Ingemark's observations are essential to understanding how sufferers identify barriers in the oppressive environment that seek to perpetuate their invisible role in society. Visibility matters because, in this way, as the epidemic will not vanish from popular consciousness, and thus it is important to remember the trauma of these sufferers so as to advance the implementation of a progressive social agenda.

Mediators, as stated earlier, act as actors of social change who push society in that direction so as to help in the arduous reconstruction of the social fabric in a post-conflict context.

1.2.2 The Memorialization of the HIV/AIDS epidemic in South Africa: Didier Fassin and *When Bodies Remember*

In this section I shall put forward the premise that Didier Fassin's *When Bodies Remember* (2007) offers valuable insights into the heated debate of the HIV/AIDS epidemic, not just because Fassin is deeply concerned with the most significant socio-historical event that defines the post-apartheid era, but also because the French scholar's exploration of the implications of the epidemic forecasts the concern on the need to memorialize this traumatic experience. It is through Fassin's approach to HIV/AIDS that the memorialization of the epidemic acquires a broader view, and this allows for a better understanding of the complex nature of the health crisis in South Africa. *When Bodies Remember* offers a contrapuntal⁷ reading of the epidemic, making room for Thabo Mbeki's postulates on which the latter's theory of conspiracy is based. In this light, Fassin's work has been instrumental in conceptualising the possibility of "new" narratives that the authors of the memoirs have, in different degrees, left unexplored. In particular, this work has made me understand the bias of the memoirists, especially when these have dealt with Mbeki's legacy.

In the first place, Fassin interrogates the HIV/AIDS crisis by providing a full sweep of the historical and political events that have shaped the complex conviviality of white and black population over the 20th century within South Africa. The colonial history of South Africa, further exacerbated by the long shadow of apartheid, implemented a model of society that has promoted persistent inequalities among the

⁷ Edward Said develops this term in *Culture and Imperialism* (1993) to interpret colonial texts, considering the perspectives of both the colonizer and colonized. In the context of Didier Fassin's work I find it useful to illustrate the differences expressed between denialists and non-denialists.

population on a large scale. Mbeki's AIDS denialism is precisely rooted in the idea that post-apartheid South Africa had to promote an African Renaissance, giving prominence to traditional elements and practices of ethnic groups, in order to heal the wounds of the past, thus breaking a culture of silence, violence and erasure. Secondly, the advent of democracy has placed South Africa into the ranks of globalization. This fact has given rise to the international public positioning of South Africa against the racialization of HIV/AIDS perpetrated by medical schools, at large. Fassin (2007:122) also refers to Mbeki's concerns with the perilous legacy of apartheid's educational system which is responsible for convincing blacks of their inferior status in social hierarchies as well as of their role as germ carriers. In this sense, the concept of racial inferiority and the notion that blackness is synonymous with disease have both made the idea of HIV/AIDS as a self-inflicted disease circulate widely among public opinion. Such an element could, possibly, be a residual attitude inherited from apartheid that black South Africans have internalized. Hence, It seems pertinent to turn to these issues in order to grasp the implications sustaining Mbeki's vision that the epidemic also stems from the consequences of historical events, taking the form of economic underdevelopment, chronic malnutrition or unsafe sexual behaviour in the present. Extreme deprivation, marginalization and inequality have created or exacerbated situational contexts conducive to the spread of the virus such as overcrowded homes in poverty-stricken homelands, venereal outbreaks or sexual abuses, to name but a few.

The aforementioned social and historical conditionings have seemingly pushed Mbeki away from western assumptions on the epidemic in South Africa. As a result of this, Mbeki started out with an attitude of distrust as regards western-aligned medical authorities. Mbeki's keen interest in the work of the leading HIV/AIDS dissident Peter Duisberg –whose influence is to be discussed in greater depth in chapter two–

constitutes a turning point in South Africa's AIDS policy. This turn justifies Mbeki's controversial position that antiretroviral therapies are poisonous and that HIV is not the cause of AIDS. It is very doubtful today whether HIV is not responsible for the development of AIDS, and as Fassin states "[t]he president's questioning of scientifically established facts, along with [Mbeki's] repeated refusal to make antiretroviral drugs available, has been rightly criticized" (2007: 16). However, it is important to reveal the shades of the epidemic, including the socioeconomic factors that have furthered into forms of human degradation and extreme poverty. These factors have affected the effective implementation of social and health protective schemes in South Africa, mostly due to the need to redress the gross socio-economic injustices and distortions of all sorts resulting from the legacy of nearly five decades of apartheid. Mbeki's discourse acknowledges the existence of HIV, and it is pertinent to highlight this view sets him apart from denialists, and as such he centres on the restoration of sense of dignity of South Africans. Mbeki's explorations on the mechanisms that can guarantee sovereignty, resource control and ownership in the long run appear to be the cornerstone of government's actions to moderate the impact of the epidemic on the population and to promote the modernization of the country's economic framework. In short, the improvement of living conditions in South Africa is, according to Mbeki, the key to curtail the dimension of the virus.

Paradoxically, as I will discuss in subsequent chapters where I critically engage with the set texts, HIV/AIDS sufferers complain in varying degrees about the burdens of the past, especially in cases where relations with the West and the heirs of the colonial period are concerned. By airing these grievances sufferers confirm that abject poverty has operated as a life threatening condition. Such a fact is not sufficiently taken into consideration by non-South African medical practitioners and analysts when they

speak at great length about the South African context, with most of their attention centring on what they considered to be the dominant sexual practices. Another aspect of this dissertation shall be to inquire into the scholarly work within the fields of medical humanities and the social sciences. The work of Didier Fassin provides a comprehensive analysis of the ideological stances that have shaped medical discourses and approaches to the singularities of the South African case. More specifically, the strong component of ideological-colonial precepts from the past has influenced the HIV/AIDS policy making processes in South Africa since the last throes of apartheid – this aspect will be furthered discuss in chapter two. HIV/AIDS is clearly a medical condition affecting the health of sufferers for the most part, and medical sciences are in charge of developing an adequate framework, including the design of mechanisms to scale up HIV prevention or control the epidemic, to improve the health of citizens. However, the examination of the role played by scholars in the field of cultural studies, namely humanities and social sciences, also merits further attention. HIV/AIDS is not exclusively a condition that causes harm to the human body. It also affects the social and cultural fabric of South African life, as the normalization of conviviality and social relations, a fundamental issue in the post-apartheid era to strengthen social cohesion, is relegated to a testimonial position. Only when South Africa was well into the first decade of the twenty-first century did the HIV/AIDS crisis gain momentum in literary and cultural discussions, coinciding with the publication of the first HIV/AIDS memoir written by the former constitutional court judge, Edwin Cameron. Until then, scholars working in the area of cultural studies have been lagging behind medical sciences in their interpretation of the epidemic. Therefore, HIV/AIDS narratives constitute a solid attempt to document the historical consequences of the epidemic from the standpoint of cultural studies. The narratives highlight the suitability of the analytical tools used in

cultural studies to interpret the other side of the HIV/AIDS crisis; that is to say, the social, historical and cultural.

All these points stated earlier in this section are fundamental at the time of establishing my position in relation to the HIV/AIDS life stories. Two models of post-apartheid society and of looking into the epidemic are clearly confronted and influenced by the ideology of proponents of different solutions. On the one hand, we have the “orthodox” (2007: 80), and on the other the “heretics” (2007:80) or the unorthodox, to quote Fassin. These two groups represent opposing beliefs in the reasons to why HIV/AIDS has spread out rampantly within South African borders. The orthodox group comprises established medical science, the Treatment Action Campaign members and characters and writers in the life narratives. These segments of the population find Mbeki guilty of committing genocide against HIV/AIDS sufferers through his purposeful neglect of the epidemic and failure to make anti-retroviral drugs available to afflicted individuals. The unorthodox, in turn, include members of the government and dissident scientists for the most part. Fassin does not take sides with any of the two groups; however, in his explanation of the situation the French scholar formulates a theory in which some of Mbeki’s postulates find shelter. Particularly, this is the case when Fassin points out those long-standing inequalities in South Africa along with subjugation to white interests have also a say in the rapid spread of the epidemic. The fact that established medical science has traditionally ignored Mbeki’s opinions on the complexities surrounding the colonial and racial history of the country, and health inequalities is something the epistemic community should reconsider in order to broaden their scope of analysis. Fassin provides a full sweep of the history of venereal outbreaks in South Africa and the response of authorities to them as follows:

The way people’s bodies were treated thus cannot be historically dissociated from the ideological and practical domination that culminated in apartheid. The

second one is embedded in the short term, the time of AIDS. But there is the time before 1994, before the epidemic. By not taking it into account, many features of today's situation, the codes of which have been previously designed, remain incomprehensible. The stigmatizing representations that the disease has given rise to are drawn from a stock of images accumulated over more than a century. Even more troubling, in the shadow of the regime that was about to be dislodged. Considering this past experience, which combines the ordinariness of colonial occupation with the exceptionality of the apartheid regime whose details are only now being revealed in the public space, enables us to account for the government's statements and policies much more effectively than does the vague notion of "denialism" commonly used to describe it. (2007: XIX)

In South Africa the present is haunted by the past. The latter still has a powerful presence in the configuration of social, political, economic and cultural structures. In this context of wanting yet not being able to look forward, the survivors of the epidemic have certainly taken a well-deserved step forward in the reformulation of their traumas associated with the disease. In this respect, the perceptions of sufferers and the nuances of their stories are all important in the sense that each of the accounts promotes a distinctive ethos. Life stories help deconstruct the idea that the metaphor of the rainbow nation was incomplete without the public restoration of past wrongs. This is essential to human progress, and in the case that engages us here progress is closely related to the development of assistance community to prevent and fight HIV/AIDS attending the culture-specific requirements of South Africa. Even though both sides, that is: the orthodox and the heretic positionings, agree that HIV/AIDS is a major problem and share the vision of a menaced future, they differ in their analysis of the situation and the triggering facts of an epidemic whose statistics, for example, went up from 0.7% of seroprevalence among pregnant women to 24.5% in the first decade of post-apartheid (Fassin 2007: 2).

In this shared vision of a complicated future, the notions of pain and suffering are deeply entrenched in the South African national imaginary. Due to the course of South African history, the vast majority of South Africans –mostly blacks– identify

with the causes of deprived groups and rally together against the once promised access to a decent life. For many HIV/AIDS sufferers, as the life narratives attest, the age of post-apartheid was their once in a lifetime opportunity to become legal subjects established upon the basis of law. The management of the health crisis has threatened to break their expectations, especially after Mbeki's reluctance to implement the public roll-out of antiretrovirals. In South Africa, HIV brings together the most disadvantaged layers of society, building momentum to generate a new wave of social protest to end up attaining pending rights and to embrace equal opportunity. The Treatment Action Campaign, known as TAC, champions that struggle in much the same way as before when the liberation movement took to the streets to demand justice. This organization and its function, which will be discussed later in chapter two, bring to light the shortcomings of South African democracy. The disappointment with the ANC, the ruling party of South Africa, which in the eyes of sufferers has bowed to the interests of the global capital they rightly criticized in the age of apartheid constitutes one of its primary guidelines of action.

When Bodies Remember illustrates the pressing issues of modern South Africa, where institutions have proven fragile in light of the evolution of the epidemic. As a result of this, political unrest and disagreement have emerged to contest the various entanglements affecting the immediate future of sufferers. Additionally, Didier Fassin's work revolves around a good handful of concepts that proponents of postcolonial theory uphold, giving voice to the anxieties of opportunity-starved people but giving, at the same time, some credibility to the ideologist –Thabo Mbeki– of this particular social-historical approach to HIV/AIDS. The very first of those tenets lies in the eradication of poverty, and to which is added the desire for a peaceful conviviality between the diverse peoples of South Africa. The current national structures of power and influence in South

Africa are modelled after those of apartheid, placing high in key strategic industries people whose ideas and political leanings are, in some cases, yet to be fully democratized. Therefore, the advent of democracy is not enough unless former oppressors catch up with the demands of democracy and citizens. Owing to these conditions, life-writing, as a literary genre, can advance the agenda of social agents. Fassin (2007: 123) contends that “memory feeds on history just as history is built up around memories”, and his remarks illustrates in a clear manner why the account of the epidemic needs to be articulated around the sum of the personal and public histories of ordinary lives. What is being remembered by sufferers actually happened and is reworded in a more positive way so as to contest, to use Fassin’s words, “the true sanitization of segregation” (2007: 134) and the reproduction of past stereotypes that have reinforced the image of black South Africans as a menace. The subjectification of black bodies by public health (Blauuw qtd in Fassin 2007: 145) provides an interesting arena for the analysis of trauma in HIV/AIDS narratives.

1.3 The Role of Trauma Studies in HIV/AIDS life narratives

In our contemporary age the concept of trauma is widely used to examine reactions to overwhelming physical and emotional events of distressful nature. The development of these events often reminds us of our condition of vulnerable subjects, whose bodies and minds reveal the existence of wounds and suffering that undermine human agency. Trauma has, indeed, different manifestations in the different regions of our world. However, when it comes to theorizing on the forms of trauma that are transforming human subjectivity’s very construct theorization is done through the powerful lens of western criticism. Sarkar and Walker discuss at great length the issues surrounding testimonies of traumatic events by “resist[ing] the universalizing gesture that establishes the West at the epicenter of a globalized world” (2010: 4). This hegemonic approach to trauma, Laura Brown maintains, is that experienced by dominant groups in the Western

hemisphere, comprising the white, educated, able-bodied and middle-class (1995: 101). In line with Brown's and Sarkar and Walker's critique of the adoption of a predominantly western approach to the study of trauma is the work of the leading scholar in the field Stef Craps, who calls into question the validity of a single and standardized way to describe the psychology of trauma. The value of Craps' contribution to trauma studies lies precisely in his ability to incorporate a postcolonial reading within the field of trauma theory; that is to say, the sight of the non-white, disabled and the actual recipient of different forms of violence, whether medical, economic or psychological. In "The Empire of Trauma" Craps observes that "breaking with Eurocentrism requires a commitment not only to broadening the usual focus of trauma theory but also acknowledging the traumas of non-Western or minority populations for their own sake" (2013: 19). The recording of dominant traumatic experiences results from key historical events deeply entrenched in the Euroamerican imaginary such as war-related violences, inflicted on disempowered social groups, and the Holocaust, for the most part.

Trauma is thus presented to us as a product of troubled histories, involving different collectivities, often with a clash of interests. The aftermaths of these episodes of trauma raise the question of whether or not human beings can consider the suffering of others, regardless of national, social and political affiliations, as their own. The fact that trauma is a product of history (Caruth 1995 and 1996; Craps 2013; Fassin and Rechtman 2009; LaCapra 2014; and Rothberg 2019) suggests the need to make a call for collective responsibility in our analysis of the intersections between history, past events, and historiography, the interpretation of those past events. Writing (about) trauma (LaCapra 2014) places literary and cultural studies at the center of the discussion, for it validates the cultural manifestations that have emerged in non-western

societies, as is the case of South Africa with HIV/AIDS life narratives, to move beyond the traditional focus of trauma theory. The HIV/AIDS trauma is basically located on African soil, thus escaping the centrality of the European and American gaze, especially after making treatments affordable to the average citizen. By taking up on the idea that trauma is a product of history I feel it pertinent to briefly consider the key issues that have provided the necessary the perfect breeding ground for HIV/AIDS to become a traumatic, disrupting, force. This force has altered human relations and societal structures in South African soil to the point of endangering the renewal of South African culture in times of post-apartheid.

In this light, I shall embrace the concept of cultural trauma to expand on the cultural manifestations of the trauma associated with the embodiment of HIV/AIDS as attested in the life narratives set in South Africa. I believe that the analyses of western representations of trauma cannot fully endow with significance South African manifestations of trauma. Local expressions of grief and suffering in South Africa respond to culture-specific elements that deserve special attention, especially in the process of elaborating on the micro-histories of exposure to death and ethical judgements, as is the case of HIV/AIDS sufferers in South Africa. These micro-histories are embedded in a larger framework, the macro-history of the nation, in which, to use Michael Rothberg's term, "the implicated subjects" (2019) are faced with the task of re-defining "solidary relationships in ways that, in principle, allow [the implicated subjects] to share the suffering of others" (Alexander 2012: 6). The identification of the so-called "implicated subjects," namely HIV/AIDS sufferers and their supporters, and national authorities and drug multinationals (each of which holding positions that remain irreconcilable) is of paramount importance in order to understand why HIV/AIDS sufferers are trapped in a power struggle marked by the geopolitical.

This power struggle between national authorities, embracing denialist-aligned positions, and drug multinationals, buying into the discourse of established medical science, further exacerbates the trauma of sufferers, for the latter become victims of cultural entanglements. For the redefinition of solidary relationships, it is necessary, then, to break the cultural constraints –mostly racist– that urge individuals, who are at the same time politically integrated into a new definition of collectivity, to detach themselves from the suffering inflicted on members of that new collectivity which, likewise, arise out of the ill healed wounds of a troubled history. This reconceptualization of collectivity, still fragile, is a key factor in the reformulation of the South African fabric, whose greatest example is recorded both in the South African Constitution and the Truth and Reconciliation Commission, advocates for a new notion of collective responsibility. This responsibility stems from the, sometimes, idealized spirit of peaceful conviviality in post-apartheid society. The embracement of responsibility implies the rejection of the social dynamics that, in the past, restricted solidarity to members of the same social class, racial or ethnic group; hence, the importance of approaching trauma from the perspective of culture.

In “Cultural Trauma: A Social Theory” Jeffrey C. Alexander contends that cultural trauma is a socially constructed artifact over the history of the nation. He comments:

Cultural trauma occurs when members of a collectivity feel they have been subjected to a horrendous event that leaves indelible marks upon their group consciousness, marking their memories forever and changing their future identity in fundamental and irrevocable ways. (2012: 6)

These words imply that efforts to understand traumatic events and to sympathize with its sufferers make room for the reconstruction of individual and collective environments in which cultural manifestations of trauma play out themselves. Although HIV/AIDS primarily affects infected individuals, I also contend that, in the end, its effects have

profound reverberations on a national scale as the HIV/AIDS crisis reads as a prolongation of the trauma and suffering experienced by South Africans through the age of apartheid in post-apartheid days. Thus, South Africans re-live the far reaching impact of social and cultural traumas. In *Everything in its Path: Destruction of Community in the Buffalo Creek Flood*, Kai Erikson elaborates on the notion of collective trauma. Erikson observes that collective trauma is “a blow to the basic tissues of social life that damages the bonds attaching people together and impairs the prevailing sense of communality” (1976: 153). His remarks shed light on the analysis of the social and cultural relations of post-conflict societies. If we extrapolate these words to the South African reality, Erikson’s observations loosely translate into the limitations of building a (new) cultural framework in the age of HIV/AIDS. The development of both new social bonds and the forging of a model of conviviality of inclusive nature are fundamentally at risk because of the epidemic. The transmissibility of the virus, through body fluids and intercourse, impedes the creation of spaces for social affect and intimacy in a society where racial prejudice already makes it difficult, all the more considering that carriers of the virus are not only undermined by displacement but also by social stigma. Hence, the renewal of the cultural ties necessarily relies on the construction of spaces for dialogue and understanding out of which sufferers feel emboldened to share the trauma of HIV/AIDS disability.

Those spaces for social affect and intimacy are, indeed, very much needed to overcome traumatic events. If human beings, as Jeffrey C. Alexander maintains, “need security, love, order and connection” (2012: 8) to recover their full capacities for social interaction after a traumatic event, and society stigmatizes them due to the virus, then the expression of their traumas finds the perfect niche in life-writing. This is so as it is a real possibility for HIV/AIDS sufferers to express their right to signify and to re-appear

in public life through the circulation of their life stories. Their micro-histories help to illustrate the importance of the permanent residues of the HIV/AIDS trauma in the contemporary age, as it is the byproducts of HIV/AIDS that impedes the transformation of sufferers into full-fledged citizens of South Africa. This is often a source of irritation and frustration for sufferers, as attested in the life narratives that are under analysis in subsequent chapters. By telling/writing their traumas sufferers give shape to their emotional formation through the language of reflexivity, which operates as a space highly informative of the creation of sufferers' distinctive ethos that would not be, otherwise, available to us. If the aim of airing traumas is mainly to bring back sufferers to the notion of collectivity by breaking them free from the repressive apparatus of the socially constructed artifices, then, it is important to generate a flow of communication that inspires survivors to sense their role in the spaces they inhabit in order to return to the theme of "normalcy."

The value of their life narratives transcends the act of telling/witnessing. It is, like the Truth and Reconciliation Commission itself, an opportunity to strengthen South African democracy by incorporating into the country's history, supported by partial and fragmentary, mutually excluding discourses that are in the process of unification, the absent micro-histories of HIV/AIDS sufferers. Anything less would be a national failure, a shot in the dark, giving rise, in the future, to a "new" national trauma propelled by the unfulfilled promise of change. Such a thing has the potential to reproduce the segregational structures of the past that were responsible for the multifaceted nature of the many traumas encapsulated in the country's complex history in terms of solidarity and conviviality. Therefore, the experience of the past must be at the service of the future nation-building policies to heal the nation. In communicating

the trauma of the diseased, South Africa lays the foundations of a culture of peace, caring and sympathetic to others and their plight.

In *Trauma, Explorations of Memory*, Cathy Caruth invites readers to reflect upon the ways trauma forces us to reconsider our notions of experience and communication (1995: 4). In doing so, Caruth describes at great length what she calls “traumatic symptoms” within the frame of objectivity. Although I find her invitation to explore forms of communicating trauma very useful, I must state that I disagree with the proposed “objective” view, for within the culture-specific context of South Africa the traumatic symptoms Caruth refers to clearly falls into the category of the subjective. I consider the “subjective” view more clarifying because the HIV/AIDS-related traumatic symptoms affect sufferers’ perception of identity and their capacity to resist the external and internal conditions of domination which previously prevented sufferers from re-imagining, understanding and re-presenting their innermost world. I understand that the expression of trauma is a sufferers’ bid to restore their dignity, an act of commemoration of the event and of a celebration of life in which characters become part of an extended web of community agents. In the act of re-presentation sufferers grasp the cultural meaning of the epidemic, and this is why, I believe, writing trauma allows what Caruth calls “the repeated possession” (1995: 4) of the wound in the mindset of the sufferer. In short, taming the ghosts of the past is the task of the sufferers which allows them to reconnect with human agency. As I stated earlier, trauma is the product of history; therefore, writing trauma is synonymous with the re-writing of history for “the traumatized (...) carry an impossible history within them, or they become themselves the symptom of a history that they cannot entirely possess” (Caruth 1995: 5). This is the reason why I think that by writing about their trauma sufferers become part of the aforementioned web of human relations in which the sum of

individual accounts of HIV/AIDS can draw up a history that is both consistent and representative of their anxieties, and, furthermore, entirely possessed by their protagonists.

The possession of the narrative is central to leave behind the feeling of repression that takes hold of the sufferers. The traumatic event, the contraction of the virus, remains unregistered, causing what critic Dori Laub calls the “collapse of witnessing” (qtd in Caruth 1995: 7) provoked by the keeping inside attitude of sufferers. In *Testimony: Crises of Witnessing in Literature, Psychoanalysis, and History* Dori Laub discusses the extermination of the Jewish at the hands of the Nazis during the holocaust. In so doing, he observes the possible dangers of an event that produces no witness of that violence, and the repercussions of an event that cannot be recorded in memory from within and by the survivors of the event. In short, he suggests that the true dimension and veracity of the genocide has remained unaffected due to the active participation of the survivors in the memorialization of the event. This assumption casts doubts on the involvement of other potential witnesses to reproduce that blemish chapter in the history of mankind. The possibility of the “collapse of witnessing” in South Africa is synonymous with witnessing the collapse of the nation had not HIV/AIDS sufferers taken a step forward to confirm the maturity of democracy in the country; that is to say, the possibility of rendering the unspeakable into a narrative of national interest, accounting for the underlying frustration of those who inhabit the margins of South African society. Particularly, this is the case taking into consideration that the Truth and Reconciliation Commission in South Africa had recently recaptured its past in the span of time between 1996 and 2003. Collapse as resistance could have rationalized the destructive, and silent, nature of the health crisis without a witness that accounts for the scope of that unprecedented pathology of infection. Laub contends:

It was not only the reality of the situation and the lack of responsiveness of bystanders or the world that accounts for the fact that history was taking place with no witness: it was also the very circumstance of *being inside the event* that made unthinkable the very notion that a witness could exist, that is someone who could step outside of the coercively totalitarian and dehumanizing frame of reference in which the event was taking place, and provide an independent frame of reference in which the event could be observed. (1992: 81 emphasis in the original)

The HIV/AIDS crisis has different witnesses of the event, most significantly mediators and experiencers but also those who refuse to be part of sufferers' return to "normalcy.". The advent of HIV/AIDS life narratives is a landmark achievement in South Africa, for the history of the epidemic was taking place, until Edwin Cameron's *Witness to AIDS* saw light, without the officially recorded testimonies of their central witnesses –and immediately after Cameron's other stories followed suit. Surviving trauma is, in the end, the encounter with the self, and the very first step towards the construction of a new normalcy that reflects why sensibility and society's obligations to others matter. History is to create more traumas, and our accessibility to stories that, in principle, are alien to us can determine our openness to experience trauma while in the shoes of sufferers. In this context, understanding HIV/AIDS disability promotes the enactment of a forward-looking agenda and legislation in the public field.

1.4 Understanding HIV/AIDS Disability

The HIV/AIDS epidemic in South Africa represents an on-going and lifelong challenge for sufferers. Antiretroviral therapy has certainly improved the living conditions of affected individuals with access to treatment, whose life expectancy was less than 18 months when the first cases of AIDS were reported in the 1980s⁸. However, despite the success of those treatments, the transformation of HIV/AIDS into a chronic and manageable disease is not synonymous with the end of suffering and discrimination.

⁸ Source: <https://www.npr.org/templates/story/story.php?storyId=120249388&t=1618587715256>
Accessed: April 15th 2021

HIV/AIDS disability in South Africa is felt to be a major public health problem that puts a damper on social and economic initiatives to secure the future of the country.

The socioeconomic context of South Africa, with persistent crises, stagnating social mobility, and deepening poverty, has led the South African Labour Court to define HIV as a disability⁹. This consideration recognizes the possible difficulties of HIV-positive South Africans in thriving in life. Sufferers are more often than not faced with discrimination because of the existing social prejudice and ignorance about the real implications that co-existing with the virus entails in the public domain. These two, prejudice and ignorance, represent a threat to the well-being of affected South Africans due to the fact that their physical and mental health deteriorates at a fast pace. Therefore, understanding HIV/AIDS disability through life-writing offers an opportunity to enter into a relationship of trust with sufferers.

The term disability is a generic term encompassing several restrictions on the active participation of individuals in public and private activities which, in the case of HIV/AIDS, is further aggravated by the risk of contagion. According to the World Health Organization, disability is an intrinsic aspect of the human existence¹⁰. Such an approach, however, has its shortcomings. Different societies throughout time have had to struggle with the ethical and political dimensions of disability in terms of policymaking so as to determine the degree of inclusiveness of disabled people. Historically, the meaning associated with disability has shifted from ancient Greece to indigenous cultures or (pre)industrial western cultures, and so, too, the involvement of disabled individuals in human activities.

Michael Oliver (1990) is quick to observe that in our contemporary age the issue of meaning has influenced the on-going discussion on the importance of definitions. In

⁹ Source: <https://www.justice.gov.za/policy/misc/aids.htm> Accessed: January 16th 2021

¹⁰ Source: https://www.who.int/disabilities/world_report/2011/chapter1.pdf Accessed: January 16th 2021

this sense, the scholar highlights that medical views and discourses have orientated the meaning of the term in the social sphere. In this field, certain medical discourses have been in cahoots with the mind-set and interests of capitalist, industrialized, societies, protecting only partially disabled citizens. More specifically, Oliver affirms that the mismanaging of disability can be understood as a form of social oppression. If this concern is extrapolated to South Africa, we may well conclude that HIV/AIDS disability, then, promotes new forms of segregation where segregation had already thrived in the past. In Oliver's view,

if [disability] is seen as a tragedy, then disabled people will be treated as if they are victims of tragic happening or circumstance (...) and be seen as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstance. (1990: 2)

Oliver's approach to disability is significant in the context of the HIV/AIDS epidemic in South Africa. The main reason for the embracement of this postulate is because it urges against the revising of the existing social contract. In this sense, the social and political normalization of the disease largely depends on the ability of AIDS activists, as a specific pressure group, to place people in institutions people that HIV-positive South Africans can entrust to accomplish the goal of normalization. Although the existence of HIV support groups in the life narratives provides shelter to infected people, these only alleviate high peaks of social oppression by promoting a sense of sameness among participants. However, support groups, often led by western NGOs without strong links to the territory, feel unable to provide lasting solutions to issues of inclusiveness, affection, and effective integration in workplaces and learning environments. Support groups can be part of the solution, but not *the* solution as these groups run the risk of creating a society that runs parallel to that of afflicted individuals. The possibility of a social model of disability opens up with the act of disclosure. However, understanding HIV/AIDS disability goes beyond the act of going public. HIV-positive characters

demand the strengthening of state structures, and such a thing implies the realization of the right of those tested positive to signify as disabled bodies in a changing South African society.

Following Lennard J. Davis (2006: 12), one of the aspects that draws his attention to the meaning of disability is the need to rank the capacities of individuals along some conceptual lines. These lines range from the categories of the abnormal/subnormal to above-average. The formulation of these categories is of help for my research as the HIV/AIDS epidemic in the southern tip of Africa revolves around the concept of the normal, a deceptive term that draws a distinction between the healthy and the unhealthy. Indeed, these categories can be examined in a manner that illustrates the ways which the normal, or the desire to be normalized, and the abnormal, give shape to the construction of different types of subjectivities that go in line with the singularities of South Africa. In light of the aforementioned, what is of special interest for my study is a means whereby one locates the culture-specific component that operates within this categorization. This information can be taken into account in the construction of a new approach to normalcy that promotes an ableist vision of HIV-positive people. In relation to this, I want to highlight how South African HIV/AIDS life-writing engages with the term disability by focusing not necessarily on the disabled body as the subject of study, as Lennard J. Davis (2006) notes, but rather as an interlocutor that traces down the socio-political barriers of disability.

In line with this shift in focus and meaning, responses to disability have likewise experienced a change in the perception of individuals and communities alike. This is symptomatic of the need to re-think HIV/AIDS disability in South Africa in more positive terms. Robert McRuer (2018: 1-54) is one of the precursors of this trend in disability studies. McRuer elaborates on the transformative way in which disability is

shaping and re-shaping the way we see the world through the lens of disabled individuals. McRuer's promotion of an ableist vision of disability has allowed me to establish connections with South African activism and affirmative actions in the field of HIV/AIDS. In fact, we can read the work of Zackie Achmat's Treatment Action Campaign, Nkosi and Gail's activism, and the relentless work of the former Constitutional Court judge Edwin Cameron in the South African legal system (chapters three, five and seven, respectively) through disability studies and as a form of protest against the South African government's reaction to the health crisis (chapter two). Writing about HIV/AIDS disability through an extrapolating of McRuer's proposal (2018: 12) is an attempt to theorize on the precarity and vulnerability affecting the lives of HIV/AIDS sufferers. In this sense, the Treatment Action Campaign, in particular, as the tangible expression of South African HIV positive people's discontent with Mbeki's administration, operates as a site for understanding and making visible AIDS sufferers' coping with an invisible disability.

Dan Goodley also contributes to this conceptual re-framing by embracing the development of a critical psychology of disability that "treat[s] the [HIV/AIDS] community in ways that challenge disabling conditions of everyday life" (2012: 310). Goodley's understanding of the psychology of disability sheds light on the idea that HIV sufferers are not objects of experimental study. I consider this particular approach relevant as, within this dissertation, I defend the argument that HIV disability is a temporary and context specific condition. The flowering of HIV/AIDS disability life narratives over the past decades provides a substantial cognitive repository for the analysis of those context specific conditions. In "Disability, Life Narrative, and Representation" G. Thomas Couser approaches this body of narratives as a cultural manifestation of the human rights movement. In Couser's view, "disability

[auto]biographies should be seen, then, not as spontaneous “self-expression” but as a response –indeed a retort– to the traditional misrepresentation of disability in Western culture generally” (2012: 400). Couser examines the effects of the social burdens of disability on subjects diagnosed with a disease, making room for the various interpretations of stigma as a perceived deviation from the normal body.

Chapter Two: A Brief Outlook of the Essential Historical and Political Aspects of the HIV/AIDS Epidemic in South Africa: Mapping the Discourses and Ideological Practices

2.1 Introduction

Having examined the key theoretical terms for my analysis of HIV/AIDS memoirs, I will now concentrate on the essential historical and political aspects surrounding the development of the epidemic in South Africa, as attested in the life narratives comprised in this doctoral dissertation. In addition to this, I shall engage with the different storylines about the spread of the virus in South Africa as a means to bring the reader to a closer understanding of the specific local realities in which competing discourses have ushered in the AIDS debate. Thus, in this section of the dissertation, I intend to highlight and assess the various responses of the South African state to the challenges posed by HIV/AIDS for the period ranging from 1984 to 2009. The life narratives discussed shall refer to and/or develop during this span of time. As HIV/AIDS is a non-visible disability, I contend that it is of paramount importance for my analysis of the political and sociological elements narrated in the life narratives to excavate further on the consequences of AIDS denial in South Africa. In this way, potential readers will be able to understand the nature of the backlash against the decisions made by the administration in the course of the epidemic.

In the history of the epidemic in South Africa, it is necessary to point out three landmarks prominent in its process of memorialization: namely the last years of apartheid rule, the decisions made regarding practical arrangements for the transitional period during Mandela's term in office, and finally, the post-apartheid years under Mbeki's mandate. Each of these periods is relevant to my research in order for me to develop textual analyses within the contours of the historical and political realities that have shaped the basis of both political activity, or lack of, and HIV/AIDS activism,

which takes a multifaceted approach to the disease in each of the life narratives. In this way, I point out the ties HIV/AIDS sufferers have endured over different periods of time to mobilize population, make visible their treatment needs, or overcome the long shadow of AIDS denialism.

This chapter opens with an analysis of the advancing epidemic when HIV/AIDS was, in apartheid days, a “small”, but constantly growing, issue for policy makers and public service providers. The 1980s in South Africa have clearly been marked by the challenging of apartheid and massively-attended streets demonstrations to ensure the success of the initiatives of the liberation struggle movement in the political terrain. The fact that almost all the efforts geared towards both the restoration of democratic rule, after decades of white minority rule, and the reintegration of South Africa into international organizations and treaties gives us an insight into why HIV/AIDS has caused such ravages in the coming years. In a country with a government that had pursued a policy of severe repression and segregation, the most compelling need for anti-apartheid activism could only be to regain sovereignty over the territory at any cost. Sovereignty came at a very high price, especially the moment it dawned on ANC-aligned sections of society that a new, and deadly, enemy, HIV/AIDS, was already out of control within South Africa. But how come that the outbreak of the HIV/AIDS epidemic was so disproportionately high in the southern tip of Africa? A handful of studies (Mbali, 2013: 149; Nattrass, 2012: 1-10; Jacobs and Johnson, 2007: 139) point towards the theory of a well-orchestrated conspiracy against the black population, seeking control over the country expressed in racial terms. Despite this suspicion, the early steps of re-building the nation largely ignored the theory of conspiracy to concentrate, instead, on setting the basis for democratic conviviality among disparate social and ethnic groups.

The second part of this chapter revolves around the process of the reconstruction of South Africa. The year 1994 was the culmination of decades of relentless work and activism to overthrow the policies of apartheid. The process of dismantling the system of apartheid in South Africa first played out itself by holding democratic elections, and secondly, by coming to terms with the traumatic past events through the constitution of the Truth and Reconciliation Commission (TRC) in 1996. These two episodes have laid the foundations of political normalization, bringing about the democracy and freedom that civil society and political exiles had long imagined. Within this context of euphoria produced by the advent of democracy, the elected president of the “Rainbow Nation,” Nelson Mandela, was faced with the colossal task of social and economic reform (Barbarin and Richter, 2001: 1-24). At that time, HIV/AIDS headlines ran in both local and international media; yet however much attention AIDS attracted during Mandela’s term in office, HIV/AIDS never occupied a priority position, neither in the policies nor on the development agenda of the president. Instead, Mandela’s efforts concentrated entirely on setting the conditions for a peaceful conviviality and economic progress. It is precisely at this critical moment in the history of South Africa that the epidemic raged out of control, giving rise to major social unrest, as reflected in the constitution of the largest post-apartheid social movement to this date: the Treatment Action Campaign, led by the now renowned HIV/AIDS and gay activist Zackie Achmat. TAC members, many of whom had endured violence for the ANC, would paradoxically become strong opponents of the ANC’s denialism in the Mbeki era.

The final section of this chapter focuses on the major events that have taken place in twenty-first century South Africa under the mandate of Thabo Mbeki, which was an age characterized by denialism and distrust of western approaches to the disease. In this historical period, South Africa stood at the threshold of exponential economic

growth, and the voice of the region was heard on the international scene –very especially when Thabo Mbeki was in office. South Africa capitalized on this new era of global relations by means of social and economic progress, although the greatest obstacle to full development continues to be the handling of the HIV/AIDS crisis. Mbeki's policies were increasingly contested, as the scope of action of his cabinet's policy were shrinking and adequate responses to the epidemic were never implemented on time. The dearth of initiatives in this field were mostly provoked by the subtle threat of interferences of ideological nature that produced, very especially in the area of human dignity and social development, effects that had been as destructive as any form of subjugation during apartheid. The latter clearly falls into the category of new forms of oppression and vulnerability that are likewise object of study in this dissertation.

With the rise to power of Jacob Zuma, the public roll-out of anti-retrovirals continued its expansion, slowly but surely, to comply with the Constitutional Court's sentence¹¹. However, the country entered into a severe economic recession, and South Africa had been since struggling in vain to recover from the economic downturn amid scandals of corruption cases and poor performance of the ANC. Despite the deterioration of the country in every single socio-economic indicator, the ANC had managed to resist the on-going attacks of the opposition parties. The ANC is still nowadays slightly above the critical 50 per cent threshold, although clearly showing signs of the political erosion of the ANC project and the uncertainty of its cadres. Jacob Zuma survived several attempts by parliament to unseat him in the National Assembly until the situation was unsustainable and the ANC was poised to replace Zuma, beset by corruption allegations. In the field of HIV/AIDS prevention, Zuma's statement that

¹¹ Source: <http://www.saflii.org/za/cases/ZACC/2002/15.html> Accessed: 17 August 2021

having a shower after having unprotected sex with an HIV-positive woman¹² stopped him from getting HIV did a disservice to this particular struggle. Despite the succession of Zuma in 2018, Cyril Ramaphosa is still trying to figure out how to revert this trend of weak economic growth, if any, and stagnant job creation. Additionally, the country's efforts to curb the HIV/AIDS epidemic have suffered enormously due to the COVID-19 pandemic, very especially after the country's lockdown and the ever growing pressure on public health facilities. The current COVID-19 pandemic has compromised the successful consolidation of South Africa's effective achievement of the UNAIDS 90-90-90 targets¹³ strategy under Ramaphosa's mandate, and the country needs to go back into compliance.

2.2 Early “Responses” to HIV/AIDS in the Age of Apartheid: Pieter Willem Botha and Frederik de Klerk

In *Plague, Pox, and Pandemics*, the historian Howard Phillips examines the history of epidemics in South Africa. To that end, the critic engages with the social history of HIV/AIDS, amongst other past epidemics, to reveal that the epidemic occurred at a very crucial moment in the recent history of the country, that is: the shift in power from white minority rule to democracy. In his bid to situate the HIV epidemic within the country's past, Phillips notes: “what epidemics often do is to accentuate many features and beliefs present in society, as well as to accelerate processes already under way therein” (2012: 10). Following up from this assumption, it is not preposterous to expect that, given the prevailing racist postulates of authorities, apartheid science tried its best so that apartheid government could benefit from the nascent virus. Thus, the unknown potential of the deadly HIV disease could even become the “unexpected” ally of

¹² Source: <https://www.news24.com/health24/medical/hiv-aids/different-political-stances/zumas-aids-shower-comment-comes-back-to-haunt-him-20160309> Accessed: 17 August 2021

¹³ Source: <https://www.msf.org/hiv-project-south-africa-reaches-90-90-90-target-ahead-deadline> Accessed: 17 August 2021

apartheid's ideology to naturally stamp out black South Africans in the age of democracy. Considering the epidemic began to take hold of South Africans in the context of a growing international economic boycott against South African rule, it is not surprising the apartheid government, recognizing its profound political weakness on an international scale, devoted itself to preparing the ground for its hypothetical return to office if the virus created a state of chaos.

In the year 2019, some compromising information¹⁴ about the involvement of South African institutions in human experimentation with HIV circulated widely, giving credence to the “ramblings” of black South Africans (see chapters four and six). According to this stunning information, the apartheid government plotted against black South Africans to eradicate them and to ensure that South Africa could become a white majority country in the long run. Although this information has never been confirmed by Ramaphosa's cabinet, such an assertion can easily fall into the realm of conspiracy theory, which Thabo Mbeki suggested very often in the past, pointing to the interests of the global capital in the region.¹⁵ Population control has been done with forethought in other parts of the world, and as alleged in the media coverage of the confession of the former member of the apartheid-era intelligence, Alexander Jones, “we were at war. Black people in South Africa were the enemy” (Ankomah). These words have certainly given sense to the ideological construction of health services in apartheid South Africa, consolidating structural disadvantages on the grounds of race and creating health structures subordinated to ideological concerns.

This policy of oppression and extermination must be taken to confirm that in the eyes of apartheid health officers, as Cedric de Beer notes, “people's health is directly

¹⁴Source: <https://newafricanmagazine.com/18285/> Accessed: 17 August 2021

¹⁵Source: <https://omalley.nelsonmandela.org/omalley/index.php/site/q/031v03445/041v04206/051v04302/061v04303/071v04308.htm> Accessed: 17 August 2021

related to the environment in which people live [...] and that health services should not be understood to be a rational response to ill health” (1986: 31). In other words, the state health policy was never aimed at developing health democracy, one of the TAC’s historical vindications, and only when the flow of Malawian migrants (Wiseman, 1998: 53-79) accelerated the spread of the virus within South African national borders did the apartheid authorities begin to test blacks. In doing so, the apartheid government assumed the epidemiological situation in the north of the country might be out of control. Wilkinson et al. provide an explanation of the reasons the virus spread fast in the context of labour migration:

The extreme isolation of workers coupled with prolonged periods of separation from their families, led a large number of migrants seeking multiple sexual partners. The close proximity of commercial sex-workers on the mines further put migrant miners at high risk for infection. (2015: 9)

Nonetheless, HIV/AIDS eventually spiralled into the biggest epidemic that hit the country in its history. Why the outbreak became an epidemic is a complex issue to address. The mobility of black labour has been an integral feature of the mining industries in the north of the country since its inception late in nineteenth century, contributing to the socio-economic woes faced by countless black South Africans and blacks from neighboring nations. It has been an important phenomenon with certain positive aspects in international eyes, but it has also brought substantial changes in family structures, associated with a climate of economic uncertainty in rural South Africa and neighboring countries, too. This, as Phillips (2012: 118) also highlights, was a vector of transmission in rural South Africa upon the workers’ return home. Phillips builds further on Wilkinson et al. and speaks at great length of how South Africa created perfect conditions for diseases, including HIV/AIDS and other venereal diseases, to spread. As Phillips notes,

Another longstanding category of men-on-the-move who expanded HIV's reach was long-distance truck drivers, who, already in the 1980s, as South Africa's road freight sector grew, were known to frequent sex-stopovers as they travelled along the country's roads and beyond its borders. Commercial sex of this sort offered many an opportunity for the HI virus to infect them and for them in turn to infect other sex workers, their wives or partners back home. (2012: 118)

Furthermore, it has to be taken into serious consideration the structural conditions of the health system in apartheid South Africa, where two different systems run parallel to one another. Thus, the majority of health facilities had a shortage of health workers and were largely unequipped for the real challenges posed by the virus at that stage. It is no surprise, therefore, that, as Leclerc-Madlala et al. write, “[a] desire to revive and to re-dignify African culture and traditional practices, long denigrated through colonial and apartheid processes, has characterised the African Renaissance project of the immediate post-1994 democratic period” (2009: 14). In the section to come I will engage with these challenges during the era of Mandela.

2.3 The Transition to Democracy and the Truth and Reconciliation Commission: The Foundations of the “new” South Africa in times of Nelson Mandela and HIV/AIDS

In “The Legacy of Anti-Apartheid”, Hakan Thorn begins a reflection on the achievements and remaining challenges of democratic South Africa during the tenth anniversary of the election when Mandela was elected in a landslide victory. Despite giving credit to Mandela's significant strides in developing both a global civil society and setting the basis of a welfare state, Thorn also echoes the voices of critical commentators who deem that the ANC government has been a failure. More specifically, the points of collision between advocates and opponents of Mandela's mandate lie in the government's response to HIV/AIDS and the influential role of supranational institutions and corporations in economic policy making (Thorn, 2006: 212).

By acknowledging this status quo, the critic elaborates on the inconveniences joining the ranks of global economic powers entail in view of the limited scope of action of the national government in certain areas, namely the provision of extended public health services and the development of a socialist-oriented market economy. In relation to Thorn's observations, Rohdeler et al. are quick to note that "to look at HIV/AIDS in South Africa is also to look at aspects of ways in which a globalized world operates" (2009: 4). The global lens provides an explanation of why the epidemic is also compounded by the dynamics of international politics, and how these are eventually reflected in the handling of the epidemic on a local level.

Following the analysis of the problem and the situation facing South Africa, Thorn also alerts us to the fact that the aforementioned issues cannot be put exclusively into a national framework that contributes to solving problems of socioeconomic nature. The "new" national reality demands a change in mindset, as it has to be seen in light of a fast-changing business and political environment. Thorn observes:

Poverty, increasing social cleavages and the AIDS disaster are presented as problems that have to be solved through national politics. South Africa's present problems are however related to global processes over which national politics has little control. Thus, just as apartheid was never just a national concern – in spite of the Apartheid's regime constant references to national sovereignty – South Africa's present situation demands political action stretching beyond its national borders. (2006: 212-213)

The role of the possible range of strategic alliances among different actors is clearly emphasized in Horn's words. The scholar envisions a future in which the eventual erasure of apartheid implies South Africa is to be increasingly depoliticized on a national level. Barnett and Whiteside (2002: 356) point in the same direction as Thorn and Rohdeler et al. when they note that the AIDS epidemic cannot be easily handled in accordance to the mechanisms of nation-states. This vision implies the consequences of the epidemic are visible on a global scale, urging societies to consider health issues

globally. Taking this premise in mind, in particular in the areas of economics and trade, building the foundations of economic recovery in South Africa has followed a pattern akin to Barnett and Whiteside's suggestion. In turn, the reconstruction of the social fabric in Mandela's South Africa has undeniably left out some pressing needs, HIV/AIDS being clearly a pending challenge.

This might be, in part, due to decreased surveillance of social and political agents who initially gave their leaders a vote of confidence with the advent of democracy. Thus, the transformation of the country entered into a phase of intensification led by economic powers after the election of Mandela, prioritizing poverty eradication strategies of liberal tendencies –under the watchful gaze of local and global business elites– over the accomplishment of the goals of the liberation struggle movement. As a result of this, the ANC-led future has developed within the frame of global capitalism, and this seems to have come into effect in exchange of a shrinking socialist agenda, neglecting the demands of HIV/AIDS sufferers for their inclusion in health schemes.

The existing stalemate on this relevant issue has developed within the frame of the “power-sharing” negotiations (Saul, 2014: 121) during the transition period. In his insightful analysis of the contributing elements to democratic South Africa, John S. Saul provides a comprehensive analysis of the issues arising from this period. Saul's views, in turn, help to justify Thorn's observation that, to some of the ANC-aligned segments, the action of government has been a failure in a number of areas. As John S. Saul wisely notes:

This is the kind of ‘fatalism’ offered up by many ANC apologists: mere resignation to ‘necessity’ as the rationale for the government's opting unapologetically for the capitalist road (however much such capitulation might be presented as being social-democratically-tinged). The essence of the position: Africa and Africans had no choice; whatever the outcome of taking the

rightward tack, 'there is no alternative' (as Margaret Thatcher so often reiterated). (2014: 123)

The ANC'S apparent shift to the right in areas as sensitive as the economy has also had a direct effect on the design and delivery of public services. Moreover, the spread of HIV during the last decade of the twentieth-century reached critical levels. And whilst the South African Truth and Reconciliation Commission was established in 1996 (Wilson, 2001: 1-32) to restore justice denied and dignity to the victims of apartheid, on one hand, and to punish perpetrators of violence, on the other, HIV/AIDS sufferers were suffering in silence, unattended to and rendered invisible. Such a policy proved dramatically erroneous and fruitless, giving rise to frustration and opposition because the post-apartheid principles of unity and integration were not fulfilled in the present case. HIV/AIDS sufferers would eventually experience firsthand the consequences of health apartheid, which is an anachronism in post-apartheid days.

With a liberal economic system left standing, the rank and file of the ANC demanded duty bearers solutions to curtail the alarming expansion of HIV/AIDS, especially after 1994. The desired equal status of all South Africans felt impossible and unattainable without the implementation of a national strategy to combat HIV/AIDS, and with that purpose in mind Zackie Achmat's Treatment Action Campaign (TAC) saw light in the year 1998. Initially, the TAC focused its efforts on demanding that the state developed a treatment plan for HIV/AIDS sufferers and pharmaceutical companies reduced the prices of life-saving drugs (Geffen, 2010: 49) so as to avoid, then as now, widening inequality in health democracy. In their study of HIV and the socioeconomic and demographic characteristics of South African society, Gilbert and Walker (2002: 652) share a similar view, as both argue that social inequity has influenced the spread of the virus and people's response to it. Furthermore, the critics point to health services in South Africa as the area that requires attention to promote equality among South

Africans, very especially taking into consideration the uneven pattern of expenditures.

As they note:

The inequalities identified in South African society are reflected in the health sector. Nearly three-fifths (58%) of the total health budget was spent on private health services which serve approximately 20% of the population, mostly White and those from higher income groups. The result is fewer health care resources for poorer people. (2002: 653)

This situation raised issues regarding the impediments for the consolidation of democracy in certain areas of South African public life. Moreover, the uncovering of the *Sarafina II*¹⁶ scandal was the last straw, and it further complicated the relationship between the government and AIDS activists. Such a thing infuriated the latter because their expectations of participation in AIDS policy in South Africa, as envisaged in the National AIDS Committee of South Africa (NACOSA) in 1992 (Schneider, 2002: 146), did not come true. Consequently, the exclusive adoption of the health department's approach to HIV/AIDS triggered much contestation, both on the streets and within the media. As Helen Schneider notes:

It is therefore not surprising that when knowledge of a ministerial decision to grant a contract of R14 million to create an AIDS musical (*Sarafina II*) became public in early 1996, there was an outcry from a range of non-governmental players. Reactions concerned the apparent secrecy of the process, the amounts of money involved and the problematic AIDS messages that the musical conveyed. *Sarafina II* rapidly took centre stage of politics, generating a huge amount of negative media attention for government and becoming the subject of the first investigation by the new office of the Public Protector. (2002: 147)

Yet, the uncovering of this corruption case directly linked to the struggle against the virus did not improve the future direction of AIDS policy in South Africa. On the contrary, it unleashed a period of growing confrontation between the state and civil organizations as to how to tackle the epidemic. As noted in Pieter Fourie's *The Political Management of HIV and AIDS in South Africa, One Burden Too Many?*, "particularly

¹⁶ The *Sarafina II* is the first corruption scandal that involved the Health Ministry of South Africa in the production of an HIV/AIDS musical. Problems in the tendering procedures were reported and the misuse of public fundings demonstrated. Source: <https://www.businesslive.co.za/rdm/politics/2016-04-08-nkosazana-dlamini-zuma-and-sarafina-ii--the-first-nkandla/> Accessed: 24 August 2021

in the aftermath of the Sarafina II debacle in 1996, the government started to close itself off from constructive criticism” (Marais qtd in Fourie, 2006: 4).

To further complicate things, when the dust of the *Sarafina II* scandal was in the process of settling a new AIDS scandal, the Virodene case (see next section), which directly involved Mandela’s successor, Thabo Mbeki, entered into the fray. The public outcry over the Virodene case confirmed the government’s estrangement from AIDS activists and other civil organizations working in the field of HIV/AIDS programmes on South African soil. Afterwards, in 1998, the controversy over the administration of AZT (see next section) broke out when Mandela prepared to hand over power to Thabo Mbeki. Thus, the Mandela era proved to be ineffective in the terrain of public health, and from that moment onwards, the consequences of catastrophic failure in AIDS policy rested on Mbeki’s cabinet.

2.4 The HIV/AIDS Debate in the Age of Thabo Mbeki

The AIDS debate in South Africa has gained momentum during Mbeki’s time in office. Mbeki’s presidency was marked by constant confrontation between the AIDS activists, the scientific community, and health professionals, who took sides with AIDS science, and deniers, among whom were several members of the government, including Mbeki. The support of the South African government to AIDS denialists, whose ideas achieved the category of official policy during Mbeki’s first term in office were fundamentally rooted in strong African nationalist tropes. The politicization of HIV/AIDS entered a phase of important public contestation, in which the country’s depoliticized mood gave way to an intense period of joint and concerted efforts between different civil organizations, as in the days of the last throes of apartheid, to defeat AIDS dissidents.

Notably, TAC’s leadership played a leading role in this ideological struggle with the government, displaying a wide range of actions related to AIDS awareness

programmes among grassroots and working-class urban sectors. They tackled dissidents and pharmaceutical companies in court, the media, and also took to the streets as a means to democratize established science in post-apartheid South Africa (Robins, 2004: 662). These actions gave AIDS activists weight and also put them in the public eye in their bid to find ethical solutions to the human tragedy of AIDS in South Africa which was compounded by the country's misguided policy that ended in people dying of AIDS prematurely.¹⁷

Steven Robins offers insightful views into the competing discourses of the Mbeki era, drawing a clear distinction between two neatly defined storylines: Mbeki's policy network built around dissidents and the story of the TAC and other civil groups that contested AIDS denialism. In tackling the complex cultural politics of HIV/AIDS in South Africa, Robins elaborates on the shaping of the ideological apparatus of dissidents who find in old racial stereotypes the root cause of the epidemic. Thabo Mbeki bought into that discourse, making clear that there was an attempt on western scientific and intellectual circles to pathologize the expressions of South African sexual behaviour to explain the high prevalence in South Africa.

Moreover, Robins documents the long-running dispute between the Medical Research Council (MRC) of South Africa and the government. The release of a report analyzing the outcomes of government inaction over past years added extra fuel to the problematic relationship between two ruling bodies. Tensions heightened further, and these placed the MRC, the health governance of South Africa, in a very difficult situation. As Robins observes:

Notwithstanding this challenge to AIDS stereotypes and prejudices, the 'cold facts' of AIDS statistics are likely to continue to produce competing interpretations, including those that construct AIDS as a 'black disease'. It is therefore quite conceivable that African nationalists such as President Mbeki

¹⁷ Source: <https://www.hsph.harvard.edu/news/magazine/spr09aids/> Accessed: August 20th 2021

interpreted these statistics as evidence of a long colonial and apartheid legacy of scientific racism. In other words, they were read through the color-coded lens of colonial histories of discrimination and dispossession. For Mbeki and his ‘dissident’ supporters, such findings were not the product of neutral, rational and universal scientific enquiry, but were understood as the products of historically constructed and politically driven processes embedded in specific histories of colonialism, apartheid and capitalism. (2004: 654)

In the life narratives, the full range of HIV/AIDS sufferers refer to Mbeki’s flirtation with AIDS dissidents and their contestation over AIDS science as the main obstacle to efforts to curb the epidemic. All this, together with Mbeki’s emphasis on the need for an African Renaissance (Gevisser, 2009: 12-18; Gumede, 2008: 187-216) to enhance African traditional scientific knowledge, as noted earlier in this chapter, delayed the elaboration of a coherent health reform agenda with health professionals and science establishment in due time and form.

Nonetheless, if we delve into the long-running history of this conflict, we can find the existence of an ANC-supported initiative to promote and develop a South African drug to cure AIDS – the Virodene scandal¹⁸. This case, however, reveals a great deal of inconsistencies with regard to Mbeki’s belief that anti-retrovirals were toxic, but it can provide certain clues about Mbeki’s sudden change of heart and his subsequent enforcement of the shaping principle of Mbeki’s African Renaissance which was centred around fomenting an Africa-based knowledge-sharing networks and institutions. Gumede (2008: 191-192) explains the first talks between a group of researchers from Pretoria University and scientists from Cryopreservation Technologies, a South Africa-based biotech company, whose researchers claimed they had found a cure for AIDS, and the South African government, as early as 1997.

Mbeki, then deputy president, was receptive to the researchers’ seemingly encouraging findings and was willing to support them in every single regard.

¹⁸ Source: <https://mg.co.za/article/1998-03-06-the-real-virodene-scandal/> Accessed: August 21st 2021

Unfortunately, the whole process turned out to be a disaster, especially considering the results of the research conducted by an external committee on the promising drug that had not been peer-reviewed by other specialists in the field until the MRC stepped in.

As Gumede notes:

Virodene was later shown by an independent panel, led by the South African Medical Research Council, to contain dimethylformamide, a toxic industrial solvent used in dry-cleaning. A month after the Virodene researchers so persuasively addressed cabinet, the MCC announced that Olga Visser and her associates were flouting accepted testing norms, and promptly banned them from testing their product on humans. Mbeki and Dlamini-Zuma were severely embarrassed. Opposition parties and the media hit out at the government. (2008: 193)

In addition to this, the later elected president of South Africa in 1999, Mbeki, and his health minister, Dlamini-Zuma, continued the daunting task initiated by Mandela in order to make foreign medicines available to ordinary people. They were determined to go ahead with the idea of breaking patents to produce cheaper generics on the grounds of the national emergency caused by the rapid spread of the virus. However, the confrontation between the government and the scientific governance of South Africa (Nattrass, 2008: 160-161), which turned down Virodene trials, truncated that possibility, and thus initiated a contentious relationship between both institutions that was marked by the constant interference of the executive branch.

The TAC, which was then on good terms with the government, had also organized protests across the country to pressurize pharmaceutical companies in their bid to, at least, compel them to make AZT available to HIV-positive mothers to stop the transmission of the virus to their babies. The ground was being laid so as to achieve such an important goal in the TAC's agenda, and the pharmaceutical companies, so as to avoid tarnishing their reputation, acceded to the request. To the astonishment of HIV/AIDS sufferers, the TAC and other civil and medical organizations, the recently elected government declined the offer, claiming it was toxic. Thereafter, the AIDS

debate became a racially charged issue and the government began to take sides with AIDS dissidents.

Amid mounting evidence of the effectiveness of anti-retrovirals to sustain the lives of HIV/AIDS sufferers, Mbeki joined forces with the proponents of a theory of conspiracy against African nations. AIDS deniers called into question the causation of AIDS, upholding the belief AIDS was the modern name for combined diseases closely related to malnutrition, poor hygiene, toxicity, and poverty, at large. The Virodene scandal, along with the *Sarafina II* scandal and the AZT issue, prompted the administration of Mbeki to explore alternatives for HIV treatment and care. Thus, Mbeki came into contact with Peter Duesberg and David Rasnick, the leading voices against the consensual view of the premise that AIDS stems from HIV (Gumede, 2008: 197).

In *Inventing the AIDS Virus*, the virologist Peter H. Duesberg theorizes on what the publisher of the book labels as “one of the great science scandals of the century” (Preface, vii). Moreover, Duesberg goes further by saying that AIDS “has remained absolutely fixed in its original risk groups” (1996: 217) in stark contrast with other venereal diseases. In his book, Duesberg provides Mbeki with the foundations of the latter’s reluctance to acknowledge that HIV causes AIDS. In broad terms, Duesberg argues for the construction of a political disease, which is, in turn, the argument Mbeki had clung to in order to justify the staggering number of cases in South Africa. In connection with the administration of AZT, one of the hotbeds of the rebellion against Mbeki’s denialism, Duesberg notes the following:

The development of an effective treatment for AIDS has been equally disappointing. The final report of the Concorde Study shattered the hope that “antiviral” DNA chain terminators such as AZT might at least prevent AIDS. The chilling news was that instead of preventing AIDS, the drugs helped to bring it on. (1996: 437)

This view was commonly shared by Mbeki and his controversial health minister, Manto Tshabalala-Msimang on AZT, which the government was being urged to administer to HIV-positive mothers and rape victims. Nonetheless, the insistence on the consumption of a diet rich in lemon, garlic, ginger and olive oil, and alleviation of poverty continued to shape the official discourse on the high prevalence of the virus in response to the demands of civil organizations, such as the TAC. Duesberg echoes the voice of Sonneband, who also cast doubts on the theory that AIDS was caused by HIV. Instead, both push in a different direction when explaining the spread of AIDS in Africa or Haiti as “their diseases might not be new at all and could reflect such factors as poverty and malnutrition” (Sonneband qtd in Duesberg, 1996: 222).

In Mbeki’s attempt to demonstrate, as Gumede puts it, that he was “a modern day Copernicus who would ultimately be vindicated” (2008: 198) he tried his best to persuade international leaders about the need to abandon AIDS science in light of the existence of avenues to voice dissent. As Gumede recalls, Mbeki sent a letter to Bill Clinton and Kofi Annan in 2000 where:

[He] passionately defended Duesberg and the other dissidents, and suggested that factors other than HIV could be the cause of AIDS in Africa. He called for a uniquely ‘African solution’ to the problem, as AIDS seemed to affect Africans differently to those who live in the developed world. He also defended his right to consult dissident scientists, and accused unnamed foreign critics of waging ‘a campaign of intellectual intimidation and terrorism’ akin to ‘the racist apartheid tyranny we opposed’ [...] it would constitute a criminal betrayal of our responsibility to our own people to mimic foreign approaches to treating HIV/AIDS. (2008: 198)

His candour triggered contestation from distinguished public figures in South Africa. This was the case after his incendiary statements in the opening of the international conference on AIDS held in Durban in 2000, when he reiterated that anti-retrovirals were not the solution. In response to Mbeki, Desmond Tutu sought to build bridges of understanding with the government. He commented:

In South Africa we have to introduce a vibrant and lively education for the people. Churches and religious communities are already playing a role but are hamstrung by the constant worry about what government will say, when they ought to be on the same side. (Tutu qtd in Gumede, 2008: 199)

Tutu's call for unity did not take immediate effect, but it certainly opened the way to further strengthening the cooperation between the different non-governmental AIDS associations working across the country. In this regards, as will be seen in this dissertation, the emergence of national and local initiatives combined with the solid implantation of more experienced NGOs and the legal expertise of leading national jurists were able to offer HIV/AIDS sufferers the necessary legal expertise advice. Together, they gave rise to new forms of political participation in democracy and, ultimately, defeated the government in the courts, forcing Mbeki's administration to abandon its denialist position and make drugs available through the implementation of the public roll-out in South African public hospitals and clinics all over the territory.

In addition to the aforementioned dominant storylines of the epidemic in the public domain, I shall like to add a third storyline in this dissertation through the analysis of the representation of the accounts of individuals from all walks of life living with the disease in South Africa. The perseverance and persistence of these individual struggles converted into a large community, the HIV nation within South Africa. In this age of modernity and global connectedness the discourses of community run strong, very specially in the social and political arenas. As attested in this dissertation, the late twentieth-century and the early years of the twenty-first century have been witness to what Tony Blackshaw calls a "conceptualist revolution" (2010: 6) in the theoretical discussions held about the aspects that give shape to communities.

Other internationally recognized scholars (Bauman, 2001; Turner, 2006) have pointed out the benefits associated with modern communities, as is the case of HIV/AIDS sufferers in South Africa, and their ability to create spaces that host the

illusion of security for disenfranchised subjects in the age of globalization. The set of life narratives in this doctoral dissertation reveals the HIV nation as a projection of sufferers' desired world, who have thrived in life despite the state and not because of the state. More importantly, these projections fundamentally rest on solid ethical and social foundations, and that is most laudable. In the case of South Africa, where the decreasing participation of the state institutions in AIDS welfare policies, as a whole, compromised very seriously the living conditions of vulnerable citizens. Thus, the making of the HIV/AIDS nation suggests new ways of thinking between and within existing communities. Considering the historical and political aspects of the epidemic in South Africa, each of the life narratives invites individuals and sufferers alike to use criticism in a myriad of ways and as a way of emphasizing community agency.

In short, after reviewing the historical and political events of the HIV/AIDS epidemic in South Africa I can conclude that, as in the words of Nicoli Nattrass, "AIDS policy is too important to be left in the hands of technocrats" (2012: 189). One more time, in the course of its history, South Africa has proved to the world how increased political mobilization and cooperation have been fruitful, as in the past. The realization of a community of equals in a sensitive area as is health democracy has turned out to be a defining aspect of their existences. HIV/AIDS sufferers, in many ways, have demonstrated their understanding of post-apartheid South Africa truly conjures up images of sameness, solidarity, and dignity.

Chapter Three: Mediating HIV/AIDS in Stephanie Nolen's *28: Stories of AIDS in Africa* (2007).

3.1 Stephanie Nolen: An Outsider's View of HIV/AIDS in South Africa

*28: Stories of AIDS in Africa*¹⁹ (2007) is the debut collection of AIDS life narratives of Canadian journalist and writer Stephanie Nolen, who is currently the global health reporter²⁰ of the *The New York Times*. The collection documents the lives of *28: Stories of AIDS in Africa* people infected with HIV in Africa. The South African characters in this collection, namely the child Mpho Segomela, recalled through her grandmother Magdeline Segomela, the artist Thokozani Mthiyane, the LGBTI and HIV/AIDS activist Zackie Achmat, and Nelson Mandela, whose son died of AIDS, struggle to come to terms with the traumatic memories of living with HIV in the midst of the confusion produced by denialism as a policy in Thabo Mbeki's South Africa. In her extensive professional career, Nolen has shown a great deal of sensitivity in covering numerous social and political problems ranging from international wars and conflicts to issues of gender and malnutrition in South-East Asia or the HIV/AIDS epidemic in Africa.

The latter is the issue that occupies us here, and in the words of reviewer Preeti Malani *28: Stories of AIDS in Africa* “[shares] tales of courage, despair, and hope illustrating the utter devastation brought about by AIDS” (2008: 591). As the South Africa-based stories attest, the cast of characters experience multiple forms of trauma. In particular, the trauma of government inaction, unwanted isolation, barriers to treatment for HIV-positives, individual and collective helplessness, and violence permeate this stunning collection of life narratives. This makes it clear that the effects of AIDS denialism are visible and have also given rise to a politics of social exclusion.

¹⁹ Hereon I will refer to the collection of stories as *28: Stories of AIDS in Africa*.

²⁰ Source: <https://www.nytc.com/press/stephanie-nolen-named-global-health-reporter/> Accessed: 28 August 2021.

Nolen's mediation, in addition to disseminating the author's consistent view that anti-retrovirals are the only reliable option to contain the course of HIV in infected bodies, documents the problematic relationship between sufferers, and those affected by the diseases, and the South African state.

The collection of stories is the fruit of her intense fieldwork reporting on the ravages of the disease across sub-Saharan Africa, whilst witnessing the magnitude of the AIDS catastrophe in her bid to produce a work of transformative nature. In so doing, Nolen engages readers, in general, and western readers, in particular, with both early action and constructive dialogue about the need to address both the consequences and challenges of the epidemic on different levels, namely gender equality and justice, social and health policies, and a range of possible humanitarian responses to the different crises posed by the virus. The book opens with an account of Nolen, in which the author shares with readers the motivations that prompted her to explore this important and timely topic. Among these reasons is, apart from the already mentioned view of the author, her growing concern about the shrinking attention of western societies to HIV/AIDS in non-western countries. The epidemic continues to take its toll on African communities across the continent, and *28: Stories of AIDS in Africa* is a reminder of how disparate health democracy is on a global scale. This concern of Nolen has grown bigger after working closely together with countless communities on the verge of disappearing in the face of the epidemic (Nolen, 2007: 3).

Nolen discusses at great length the impact of the disease on a community level, revealing how HIV/AIDS dictates the fate of sufferers and their families in hostile environments. The stories set in South Africa evince how the disease is not only tied to sex but also to safety concerns, conflict, poverty or ethnic beliefs. A closer analysis of the profile of the characters reveals the unfolding storylines of trauma, attending the

singularities of characters from disparate social backgrounds. These stories set in contemporary South Africa conjure up a myriad of emotions, namely regret, disappointment and hope, as well as considerations about the functioning of the state, death and social justice. By putting different human faces to HIV/AIDS in South Africa, Nolen illustrates the multifaceted nature of the trauma associated with the disease in post-apartheid South Africa. These local expressions of grief and suffering stem from the colonial and apartheid periods, and these combine with the reasons HIV/AIDS spiralled into the biggest threat that hit South Africa after apartheid hitherto. As mentioned earlier in this dissertation, the many facets of trauma include the moral degradation sufferers go through, sexual abuse, spiritual abuse, abandonment, displacement, “otherization,” forms of violence, emotional abuse, and, in short, all the unnecessary deaths over the past decades, to name but a few examples. In her insightful analysis of the trauma of AIDS, Sarah Schulman notes:

What have we internalized as a consequence of the AIDS crisis? As with most historical traumas of abuse, the perpetrators –the state, our families, the media, private industry– have generally pretended that the murder and cultural destruction of AIDS, created by neglect, never actually took place. They pretend that there was nothing they could have done, and that no survivors or witnesses are walking around today with anything to resolve. They probably believe, as they are pretending, that the loss of those individuals has had no impact on our society, and that the abandonment and subsequent alienation of a people and culture does not matter. (2012: 155)

Thus, the testimonies comprised in *28: Stories of AIDS in Africa* pay tribute to Schulman’s observations, taking the reader through the capacities and longings of disabled individuals in their bid to overcome trauma so as to reimagine the contours of the “new” South Africa. In this new landscape of hope, survivors and witnesses inscribe themselves in the realization of new structures of meaning associated with all the pain and suffering that AIDS victims have undergone in the history of the epidemic to

perpetuate themselves in the minds and imagination of the yet to come consolidated South African democracy.

3.1.1 Aspects of South Africa-based HIV/AIDS Stories

Post-apartheid South Africa is witness to the HIV/AIDS catastrophe with nearly 7.7 million people affected by the disease, although this is not widely acknowledged. This pandemic of staggering scope and scale has rendered individuals and families, at large, more vulnerable than they were before, often consigning people with HIV/AIDS to social censure. Breaking the silence around HIV/AIDS in South Africa is necessary to bring to heel the strongest outpost of denialism. Within the larger framework of Africa, as de Waal notes, “the continent, it seems, is in a state of collective denial” (2006: 10). South Africa has long ignored the AIDS epidemic, denying since the advent of democracy that the spread of the disease occurred within their national borders at a fast pace. As a result of this denial, inappropriate public messaging on HIV/AIDS awareness has proliferated, and the need to redress that imbalance has also led Nolen to document the effects of misinformation and inaction upon population.

Nolen delves into the trauma of four South African individuals living with AIDS in order to grasp with greater clarity the deeper meanings associated with being HIV-positive in this country. Taking in mind the legacy and aftermaths of colonialism and apartheid in contemporary South Africa, we might well consider trauma as “a product of history and politics, subject to reinterpretation, contestation and intervention” (Wertheimer and Casper, 2016: 3). South Africa falls within this definition, as it has an eventful history that illustrates the burnout of long struggles and the desire of the (descendants of) colonisers to subdue indigenous South Africans to their interests. As I will discuss in this chapter through each of the storylines, trauma in South Africa is inherent to its society, and as such, it is reflected in their testimonies to a greater or

lesser extent. The culture of violence has a long history in South Africa, and the response of the South African state to the epidemic might well be the confirmation of the continuation of this culture of violence in the post-apartheid era. This has given rise to new accounts of psychological trauma, and life-writing is one of the fields that is creating synergy for positive change (Wyatt et al., 2017: 249). Such an element evinces that forms of violence have not only evolved in South Africa but also that these are deeply entrenched in its national imaginary. This makes the implications of HIV/AIDS a compelling topic for healing the wounds of this diseased nation.

Historically, South Africa has been a place of contested boundaries (Ross et al., 2011; Hickel, 2012), witnessing numerous interracial conflicts both over the land and the control of natural resources. Black South Africans have also striven as far as is humanly possible to mitigate white minority rule, providing evidence of their combative spirit to contest the imposition of white rule upon them. As a result of endless long-running disputes, most significantly during apartheid, trauma has scattered over the land. Moreover, one could also argue that the aftermaths of trauma might as well be a contemporary identity marker of South Africans, as scars are still visible –as seen on page 88. Therefore, the need to (dis)close the pervasive effects of trauma in the contemporary age cannot but be regarded as an act of moral and social justice. In line with this, the South Africa-based testimonies seek to provide HIV/AIDS sufferers with redress and an opportunity to raise their voices against the well-founded fear of social censure and exclusion in a land that has long imagined freedom and mutual understanding. These stories of AIDS, in addition to airing grievances, are an opportunity for reconciliation and the re-enactment of both individual and collective agency.

Although the turn of the century has come to signify a watershed in South Africa, the country is yet to consolidate a framework of peaceful coexistence and progress. The advent of democracy constituted a major turning point, all the more so considering South Africa's past outbreaks of violence and racial conflict. These historical facts have contributed to the creation of a distinctive national ethos that is deeply influenced by the strong presence of collective trauma which manifests itself in the stories under examination in the coming sections. Thus, the entry of South Africa into the ranks of globalization has run parallel to some significant national landmarks, namely the Truth and Reconciliation Commission (1996) or the writing of a forward looking Constitution (1996). The latter, despite its ambitious tone, has not yet fully given rise to the consolidation of a society based on the respect for human rights, as attested in *28: Stories of AIDS in Africa*. All these major changes in public life happened at the same time that the AIDS epidemic developed in stony silence, encroaching upon the lives of South Africans after decades of segregating policies, racial inequality and prolonged suffering.

South Africa contributes with four narratives to Nolen's collection of twenty-eight stories set on African soil. Each of the stories focuses on the sufferers' testimonies as a way of raising awareness and building the necessary commitment within society to forge a national response to displacement and ostracism. This high proportion of South Africa-based HIV stories gives an idea of the magnitude of HIV/AIDS within the national borders of the current African powerhouse. As will be seen in the sections to come, South African life narratives offer insightful views into the pending challenges of the country, most of which deal with the democratization of medical treatment and the inclusion of disabled individuals. More importantly, the absence of these two core elements have either triggered or aggravated a traumatic reaction due to the creation of a

medical apartheid, whereby the privileged can afford life-saving drugs. Furthermore, the narratives also shed light on the need to open up a profound national reflection on the place that AIDS occupies in the national imaginary, most patently when taking into account the transformation of South African demographics because of the ravages of HIV/AIDS in this country. Political impediments of all sorts have tried to disguise the impact of such transformation, plus the active role played by the denialists, many of whom are highly placed in institutions and have systematically cast doubts on both scientific knowledge and medical findings. In this regard, AIDS has been most blatantly instrumentalized and deployed for ethnic and racial stereotyping, operating as a double-edged sword in the political terrain –as was seen in chapter two.

In her capacity as mediator, Nolen places a particular emphasis on the political turmoil within South Africa, as the political reaction to the health crisis has given rise not only to social unrest but also to a period fraught with demands of health democracy, especially in “Zackie Achmat.” The South African testimonies in *28: Stories of AIDS in Africa* make reference to the words of the former president, Thabo Mbeki, who has consistently denied the links between HIV and AIDS, to oppose this controversial view that clashes with the findings of established medical science. Meanwhile, criticism (Nattrass, 2007; Nattrass and Kalichmann, 2009) upholds the idea that Mbeki’s views were grounded on dubious scientific assumptions and the fear of renewed racial discrimination on the part of the international community. Against this backdrop, the enforcement of denialism as the authority’s official discourse has added difficulties in dealing with the virus. As a result, the pain and suffering of South Africans have fallen into oblivion, giving way to metaphors and euphemisms to refer to the devastating effects of AIDS without acknowledging its brutality. Moreover, the social fabric of South Africa has seriously deteriorated, which is aggravated by the shrinking of its

labour force. The immediate consequence of this deterioration translates into the jeopardizing of the socio-economic future of South Africa in the long term, as seen in “Mpho Segomela” and “Tokozani Mthiyane.” The South African testimonies gathered in *28: Stories of AIDS in Africa* overwhelmingly point to the failure to react in time to this threat as the main consequence of the shattering effect of HIV/AIDS in the country.

The delay in the implementation of AIDS policies in South Africa has seriously compromised the generational renewal (Poku, 2005; van der Vliet, 2004). Thousands of untimely deaths have left countless AIDS orphans and have further weakened the capacity of the country to provide an adequate response to this humanitarian crisis. The immediate consequences of the lack of government action and the growing stigma associated with HIV/AIDS are reflected in the expressions of fear and unwanted isolation that are comprised in the life narratives. The multifaceted nature of the virus manifests itself as a condition of human vulnerability, in some cases, and of precarious existences, in some others. As a mediator, Nolen gives prominence to the strategies sufferers come up with in order to resist adversity. In relation to this, Judith Butler (2016) elaborates on the significance of the forms of vulnerability and resistance, pointing out that mobilization and gatherings in public spaces, both of which have a strong presence in *28: Stories of AIDS in Africa*, open the platform for synergies and the political expression of discontent. This, in turn, is symptomatic of sufferers’ desire to face vulnerability and their oppressor(s). As Butler notes:

First you resist, and then you are confronted with your vulnerability either in relation to police power or to those who show up to oppose your political stance. Yet vulnerability emerges earlier, prior to any gathering, and this becomes especially true when people demonstrate to oppose the precarious conditions in which they live. That condition of precarity indexes a vulnerability that precedes the one that people encounter quite graphically on the street. (2016:12)

As stated earlier, breaking the silence is the starting point of any reflection process, and protest is the public expression of resistance and disagreement with forms of

oppression. In the case that occupies us here, the vulnerability of the characters, especially Zackie Achmat and Thokozani Mthiyane, develop within the contours described by Judith Butler as they strive hard to regain normalcy and to improve the quality of their lives in the “new” South Africa. In going public, characters not only share their concerns with a wider audience and those in the same situation but also initiate a process by which they establish as the point of departure for the desired normalcy.

More specifically, as the stories attest, dealing with HIV/AIDS involves uncovering the intimate secrets of sufferers concerning their sexual practices, sexual partners and addictions, amongst other things. However, by revealing the core components on which these lives are constructed, vulnerable and disempowered subjects, or the ones closest to them, participate in the reconstruction of their past experiences. These life stories articulate a solid network of experiences, a repository of knowledge, whose ripple effects go beyond the individuals concerned, as these perform a public function to educate readers –as seen in chapter one. These life narratives provide counselling and assistance to the disadvantaged. As White and Epston point out in relation to life narratives, by entering “a world of interpretative acts, a world in which every retelling of a story is a new telling, a world in which persons participate with other in the “re-authoring,” and thus in the shaping, of their lives and relationships” (1990: 82) a healing process takes place. The mediated narration of the sum of individual traumas represent stand-ins of collective trauma, thus depicting a nation gripped by fear and in dire need of rehabilitation.

Nolen’s desire to explore the situation of neglected individuals, who face a terrible emptiness, is further exacerbated by the condition of a non-visible disability. As Couser points out in *Recovering Bodies: Illness, Disability and Life Writing*, the study

of marginalization in literary studies still needs to bring to centre stage stories of disability and illness (1997: 13). Although the situation has slightly changed for better since the publication of Couser's work, Nolen also builds on Couser's theoretical paradigms in order to locate their lives in a normalizing context. The stories raise awareness about the benefits of a joint collaboration on the struggle for visibility and public recognition despite the issues of authority that may emerge in the case of memoirs of illness (Couser, 1997: 6). Each of the narratives endows sufferers with the necessary support and legitimacy to stake a claim on their rights to exercise their citizenship actively. 28: *Stories of AIDS in Africa* is the final outcome and Nolen's contribution to the field of AIDS literature in South Africa, proving the assumption that literature mirrors society and that it is an effective tool to catch up with the recent social history of South Africa (Jacobs and Banks, 2019: 166).

South Africa is no exception to this cross-border issue. Despite recent improvements in healthcare policies, AIDS continues to be a major problem, whether or not people feel prepared to meet the challenges of living in an ailing society. More often than not, these stories are broadcast today but forgotten tomorrow. This fuels Nolen's motivations to trigger discussion on this timely topic. The publication of these testimonies constitutes a rich and varied archive, documenting a kind of resilience specific to the singularities of post-apartheid's disrupted society. And in order not to forget these testimonies Nolen seeks to raise awareness about the impact of HIV/AIDS on this invisible but large community. The HIV/AIDS crisis in (South) Africa, as the author acknowledges, has changed her perception of the disease, especially considering that "AIDS was a fully preventable illness at home" (2007: 3).

Her westernized views on HIV/AIDS have undergone a process of change in every aspect, especially in the areas concerned with medical care after seeing few

people benefit from the progress of scientific knowledge. As a consequence of this, Nolen explores the kaleidoscope of attitudes towards the virus. In this process, Nolen embraces, in much the same way as the sufferer, the reinterpretation of the socially constructed meanings attached to the virus. This mental shift allows Nolen to approach the epidemic within a South African perspective and through the eyes of sufferers which contributes to curbing western conceptions of the virus. More importantly, Nolen's tracking of events promotes an unwritten ethical code of conduct towards the disabled in (South) African soil. The latter is of utmost importance given the fact that the perception of HIV/AIDS in Europe or North America differs quite significantly from that of their, still today, "otherized" African counterpart.

The claims of the South African characters are symptomatic of a wider unease that affects people from all walks of life. HIV/AIDS permeates all layers of society, from leading statesmen to ordinary citizens to infants, showing its lack of mercy and the real face of horror; that is to say, the death agony of sufferers. More specifically, in the stories set in South Africa, Nelson Mandela and Graça Machel give voice to the untimely death of Makgatho Mandela, the last surviving son of the charismatic leader. Zackie Achmat, founder of the Treatment Action Campaign (TAC), shares his commendable efforts with Nolen and discusses at great length the yet to come political transformation of South Africa in the social terrain. Children with AIDS invite readers to consider if something else could not be made to grant them an opportunity in life, as the story of Mpho Segomela reveals. And finally, the story of Thokozani reminds the readers that HIV can get us in the most unexpected ways in the course of our daily interactions. For six years, Nolen has been involved in HIV/AIDS arena, chronicling the progress of the disease and death, on one hand, and the political strength and

determination of a community of sufferers to challenge stigma and discrimination, on the other.

3.2 Children Are Not the Missing Face of AIDS: The story of Mpho Segomela

When Nolen began her work on HIV/AIDS the plague was well under way in South Africa, and medical personnel such as Rosina Letwaba, “the indefatigable nurse” (Nolen, 2007: 239), were part of the very much-needed web of people fighting the disease in unattended urban areas. By 2001, already 5 million South Africans were infected with HIV, and the bulk of them found it difficult to access adequate treatment, especially the poorest segments of the population. Mpho and Magdalene, her grandmother, are the true reflection of HIV/AIDS in South African shantytowns, where the taunting of neighbors make coping with AIDS even harder. Conversely, this harsh reality reveals Nolen’s astuteness to commodify their image as Mpho’s story “might get newspapers readers interested in AIDS” (Nolen, 2007: 241).

Lack of access to and/or difficulties in accessing health care has acted as an important barrier to gaining equality. Equality is one of the foundational myths of democratic South Africa, as enshrined in its constitution²¹. Furthermore, this aspect not only prevented sufferers from enjoying the joys of a newly turned democratic state, but also dragged their caretakers (Breckenridge et al., 2019: 504) along with them, as is the case of Magdeline. The story of Mpho is a good example of the vital role played by the quite extended “gogo support groups²²” in South Africa, which effectively reached to areas where the health and social services of the country did not.

²¹ See Bill of Rights in Chapter 2 of the South African Constitution.

Source: <https://justice.gov.za/legislation/constitution/SACConstitution-web-eng.pdf> Accessed: 9 September 2021

²² These are groups formed by grandmothers who support their orphan grandchildren and other vulnerable children who are alone and at risk.

Source: <https://www.gogotrust.org/gogos/> Accessed: 9 September 2021

One of Nolen's major concerns when writing about AIDS in South Africa lies in the fact that the spread of HIV/AIDS has seriously undermined family structures and, consequently, their purchasing and money-saving capacity. This is an essential question central to survival, and it has affected the protagonist of the story, whose basic needs were barely covered as a result of the family's severe financial strains (Freeman and Nkomo, 2006: 303). Such an element, as the story attests, has had a terrible impact on the social fabric of diverse communities –especially on children as Mpho– in their attempt to moderate the impact of the epidemic on families living below the poverty line. This has caused disruption in families and their social development, cutting off the transmission of knowledge from generation to generation in the case of orphans. Nolen thus recalls it:

They were sheltering their sisters' orphans, their dead brother's young wife and baby. One way or another, everyone had the disease. And it meant they earned less, that they grew less food, that fewer children went to school, that no one had any savings. Lillian talked of all the people who had "passed," and I had a sense of a community quietly evaporating around me. (2007: 2)

Nolen takes as her premise the assumption of collective responsibility for the safeguarding of communities, where surviving people assume the paternalistic behaviour of the state and the caring of sufferers in extremely difficult circumstances. This situation adds value to Couser's insights when the scholar argues convincingly that memoirs of illness can promote patronizing attitudes on the part of the biographer (1997: 6-7). The story of Mpho, a child who died an early death, might well illustrate Couser's thoughts as well as the idea that collective responsibility slows down the deterioration of the fabric of communities, the central theme in *28: Stories of AIDS in Africa*. Mpho's story is the shortest of all but surely the life narrative that best reflects the dynamics of HIV in a poverty-stricken community, as is the case of Alexandra township in Johannesburg.

The opening of the story provides readers with a glimpse of the burden of the disease when Nolen says that “[Mpho’s] mother had died of AIDS when Mpho was a baby, and her granny, Magdeline Segomela, was raising her” (2007: 239). Magdeline, also infected with the virus, lives on a modest state pension and is thus dependent on the generous help provided by the NGO run by Rosina Letwaba. The family struggles to stay together despite the fact that death is in the offing and an ever-present feature of their existences. This threat represents the major source of stress and trauma for the Segomelas, as unity is precisely the engine that keeps them going. For this reason, breaking the bond that unites them furthers the fear of isolation that arises within Magdeline. This feeling of fear is furthered once it dawns on Magdeline that Mpho is put into treatment too late, when the child has already developed full-blown AIDS, and consequently, anti-retrovirals barely work on her. Mpho’s death was preventable, and only exceptional circumstances surrounding her case, namely structural disadvantages and difficulty in accessing medicines, have led to such an outcome.

The expression of trauma is further exacerbated in the story when the grandmother, who had already buried her daughter, has to bury the twelve-year-old Mpho. When Magdeline tells Nolen “I’m lost. I’m lost” (2007: 241) it brings home the level of trauma that AIDS-related narratives brings upon the underclass in South Africa. The case of Mpho Segomela and her relatives in South Africa, besides providing a representative stance of the havocs caused by the epidemic in South Africa among the poor in urban settings and developments, puts one in mind of Sarah Schulman’s examination of the politics of AIDS and death associated with the replacement of individuals. Martin J. Murray (2011: 20-22) provides means of understanding the variety of tactics and procedures used to plan the spatial politics of post-apartheid Johannesburg, namely the construction of fortified spaces, as is the case of the new

CBD²³ located in the north of Johannesburg in the both affluent and artificially created area of Sandton to provide the city with the desired safety level that, at the same time, required the cleansing of fringe dwellers like the Segomelas, who lived on the other side of the highway that separates Sandton and the township of Alexandra. The fact that the city of Johannesburg needed to replace low-income citizens with affluent citizens for tax collection purposes seems to be incidental rather than accidental. More specifically, I want to establish an analogy between Schulman's analysis of the coincidence of AIDS in the 1980's in New York and the impulse given to the process of gentrification that ran parallel to that period of tremendous upheaval. Given the similarities in urban planning between South African and US large cities, I argue that AIDS also fulfilled a function of social transformation in Johannesburg, making room for the privileged at the expense of the disenfranchised. As Schulman notes:

That [AIDS sufferers] lost their homes and died is pretended away, and reality is replaced with a false story in which the gentrifiers have no structure to impose their privilege. They just naturally and neutrally earned and deserved it. And in fact the privilege does not even exist. And, in fact, if you attempt to identify the privilege you are "politically correct" or oppressing them with "reverse racism" or other non-existent excuses that the powerful invoke to feel weak in order to avoid accountability. (2012: 27)

In the case of the Segomelas, we can see how the process of gentrification in Johannesburg adds a new layer of trauma to their HIV-positive status and the stigma associated with it: the removal of their memories attached to what once was their home. The dearth of the allocation of resources to fight off the disease in poor areas responds to a well-orchestrated urban planning to transform the city into a global metropolis (Nuttall and Mbembe, 2008). Although Mpho was on antiretrovirals, her untimely death reveals the bitterest side of the disease; that is to say, the failure of public health services in the Mbeki era. Death shows the shortcomings of South African health

²³ CBD stands for Central Business District

democracy, as three generations within the same family are unable to break the cycle of poverty, with their ultimate fate was scrawled on their foreheads the very moment HIV got them.

Another noteworthy aspect of the story comes about in the closing paragraph when the dimension of the epidemic reveals its savagery as “there was no space left for new graves” (2007: 242) and the gravediggers had to “[reopen] the grave of Mpho’s mother, dug down, and buried her daughter on top” (2007: 242). This depressing end confirms victims’ deprivation of dignity, and leaves the reader dumbfounded.

3.3 Thokozani Mthiyane

In her approach to HIV/AIDS, Nolen tries her best to present characters both in positive terms and in a respectful way. Thus, the protagonists are often portrayed and introduced to the readers in flattering terms. Most of the life narratives focus on the abilities of characters to transform the social spaces they inhabit. Such is the case in “Thokozani Mthiyane”, where the Canadian professes a deep fascination and admiration for the “soft-spoken poet and artist with leonine features and heavy dreadlocks studded with cowrie shells” (2007: 331) whom she overtly considers a friend. In Nolen’s words, “Thokozani is so much of [her] world, when [they] argue about books and eat pizza and gossip about friends, that it is hard for [her] to believe that just a few years ago, he felt his life so circumscribed” (2007: 341). The description of the relationship between Nolen and Thokozani gives clear glimpses of the strong bonds that can hold together the biographer and the subject. This fact demonstrates the enormous potential of life-writing to act as a bridge between disparate social realities. Putting to one side issues of class and race to concentrate on the aspects that develop the subject’s identity within the discursive frame of memory affords a new affective dimension to this life-writing (Smith, 2016 (1999): 629-656).

Thokozani's identity and memorialization of his experience with the disease is marked by the dynamics of HIV/AIDS in the area of Durban, the former cradle of anti-apartheid solidarity struggles in the 1980's, and the area where in times of freedom young people "had 70 percent lifetime chance [to] contract HIV" (2007: 334). This staggering number gives Thokozani an outstanding sensibility that helps him sweep aside the negatives around the disease. In this sense, the story of Thokozani allows Nolen to elaborate a discourse on the importance of mobilization in the prevention of HIV/AIDS. Co-existing with the heart-wrenching news of HIV/AIDS over and over again also drives Thokozani to have safe sex and to promote the use of condoms among his friends, acquaintances and the youth in his bid to promote an AIDS-free society.

Much to his chagrin, those around him preferred to ignore the dismal reality, adopting the most incredulous position while they stuck to the romantic idea that, once they rid themselves from apartheid rule, they could live their lives to their fullest, unmolested. As Thokozani puts it, many of his friends consider that AIDS "won't happen to [them]" (2007: 335). Thokozani walks Nolen through the mysteries of HIV and teaches her all the euphemisms so that Nolen can fully understand, as a complete outsider, the secrecy that underlies the disease in South Africa –as will be seen in chapter four. Consequently, Nolen takes advantage of the cultural entanglement triggered by AIDS to navigate through the different euphemisms because, as she notes, "[she] need[ed] the vocabulary of AIDS to do [her] job" (2007: 331). Nolen's mediated discourse shows how Thokozani is an open-minded person who does not fear talking about the culture of sex, in contrast to Mandela's view –as I will discuss further below–, or about why, to the best of Thokozani's knowledge, infection rates are disproportionately high in South Africa. Thokozani embodies a different prototype of African masculinity, one that needs not be "tamed", dismantling the Western one-

dimensional image of the South African black men as a “sexually predatory men” (2007: 334). One must view this in light the biographer’s words, when she states that “a pile of research shows [Africans] have no more sexual partners than people in any other part of the world” (2007:334). Nolen is touched by the bad news when she learns about Thokozani’s infection, and she de-robes herself from the skin of the journalist in order to adopt a supportive attitude towards Thokozani. She notes:

I’ve talked a hundred times with people who have recently learned they are HIV-positive, *but this was something different*. Just like always, we made tea and we chatted about the latest political scandal –but everything was utterly changed. I understood with a new and visceral clarity how bizarre HIV is, how people look the same and know they’re dying, how the presence of minute strands of RNA in tiny cells can become the biggest in a room. Suddenly I was revisiting, in an urgent and intimate way, all the things I believe about AIDS –that it can be a chronic disease, that it doesn’t have to change everything, most of all that a cure will be found. “There will be a cure,” I said to him. (emphasis added, 2007: 336)

This introspective reflection of the memoirist places emphasis on an ableist²⁴ vision of HIV/AIDS, and on the impact that finding out about the medical status of a friend has on her, as the receiver of bad news. The fact that the non-visible disability becomes visible urges Nolen to reconsider her views of Thokozani, all the more considering Thokozani spread a message of safe sex.

Thokozani’s efforts to make his discourse of safe sex practices circulate widely among his acquaintances finds no reward. By contracting HIV, Thokozani slid into a period of narrow introspection, and within the narrative, Nolen presents Thokozani as an individual who suffers in silence because he is “still coming to grips with the idea of this germ festering inside him, killing him slowly; with the fear and distaste he sensed from his friends, many of whom had stopped calling; with how to break the news to his frail mother” (2007: 336). Within this grieving process, Thokozani finds shelter in creative writing in order to find the right words to express both his distorted emotions

²⁴ Typically the term ableism refers to the discrimination of people with disabilities. However, Nolen does the opposite in *28: Stories of AIDS in Africa*. Source: <https://www.nccj.org/ableism>. Accessed: 29 September 2021

and troubled subjectivity, creating opportunities for the expression of healthy grieving (Wiechelt and Gryczynski, 2011: 209). In this way, he can put his troubling thoughts in order, many of which stem from his resistance to admit that despite using condoms the virus had entered his body.

In particular, this HIV/AIDS life narrative deviates from the standards in that Thokozani's account of trauma does not stem from the lack of inclusiveness, the need for political accountability, the importance of bearing witness or the need for health democracy. Rather, trauma takes the form of social disintegration and the unspeakable, and in this latter sense readers witness the process by which Thokozani struggles with the sensory aspects of trauma in his attempt to translate these into a thoughtful and meaningful expression of his AIDS experience. Although in the story Thokozani navigates through the ins and outs of the culture of sex in South Africa, rendering the narrative more engaging, his experience is a reminder of the sufferers' critique of the "new" South Africa's forms of conviviality in large cities such as Johannesburg. This aspect evinces the existence of some socio-economic and cultural factors, often put aside, that accelerate the risk of HIV transmission. Rampant crime and insecurity in urban settings also exacerbate the already traumatic question of contracting the disease. The protagonist of the story epitomizes this rarely explored mode of transmission through the narrative of Thokozani contracting the virus in an attempted robbery at gunpoint at his neighbor's residency while the old lady was being robbed. This episode offers an account of HIV infection caused by violence, something that is seldom mentioned as the widespread belief is that it is a sexually transmitted disease. In this regards, Nolen is quick to note it:

Stories like TK's are a phenomenon almost unknown in the West. In countries where the HIV infection rate is below one percent, there is only the most infinitesimal risk of ever encountering the virus this way (...) HIV in Africa is almost always discussed, and researched, in terms of sexual transmission of the

disease, and it is true that these cases make up the vast majority of infections but it is also true that unsafe blood supplies, reuse of unsterilized medical equipment, sharing of razors for traditional scarring or circumcision or prison tattoos, car accidents and violent crime all spread the disease, and there is little solid data on how much these kinds of transmission are accelerating the epidemic. (340-341)

Despite this tragic event, much of the narrative centres around the ability of Thokozani to hold his head high and to remain confident about the future, thus promoting the aforementioned ableist vision of HIV/AIDS. Amid this challenging picture of personal faith and determination, Nolen recreates an atmosphere of intimacy conducive to personal history disclosure whereby Thokozani articulates a discourse of resistance and embraces resilience.

The use of language in the story seeks to encourage lives that make sense as well as the reinforcement of the notion that sufferers are productive members of society, and whose longings render them human in every which way possible. In regard to this remarkable aspect of the narration, Drewery and Winslade note that individuals “have learned to focus on personal deficits in ways that speak of failure rather than accomplishment, that produce social hierarchies [...] and that erode our sense of communal interdependence and common purpose” (1997: 32). In this light, life-writing once again proves to be an essential tool for effectively addressing the complexities generated by the virus on a social scale, repairing the torn fabric of the microcosms they inhabit. This fact makes individuals reconnect with one another and such a thing can have a ripple effect on the construction of a community of equals. Something shifts when individuals are no longer isolated, and confronting trauma leads sufferers to come to terms with one of the basic conditions of our human nature; that is to say, vulnerability.

3.4 Zackie Achmat and Nelson Mandela: Hopping the Fence Around AIDS

The increasing sense of politicization of AIDS in Zackie Achmat's narrative and Nelson Mandela's second-hand knowledge of AIDS reveal another remarkable core component of Nolen's collection of stories: the role of mediation in breaking the silence and the fences around AIDS. Very often, personal accounts of HIV/AIDS are far from the media spotlight, and, moreover, are regarded as expressions of personal failure and thus are not commodified. However, these two cases have made national headlines within South Africa, and have become clear examples of the idea that a closed view of trauma is open to new interpretations, especially in terms of disparate power relations (Zackie Achmat) and the enactment of personal agency (Nelson Mandela). The emergence of new epistemologies is very present in these two life narratives because their accounts develop corporeal experiences of illness that explore the social construction of health, on one hand, and the deconstruction of the artificial barriers imposed by disability in the private sphere, on the other.

These new epistemologies fundamentally rest on the power of mediation, which compel the sufferer to step across the symbolic boundaries of past traumatic wounds. These boundaries take the form of social exclusion and confronting them, besides reasserting the idea that sufferers continue to be subjects, is tantamount to progressing towards the desired future. In this regards, the incorporation of literary devices into the fabric of these life narratives enables characters to become part of a larger web of human relations. This web aims to encourage a shift in national attitudes towards HIV/AIDS disability for the consideration of nation-building policies of inclusive nature. As a biographer/memoirist, Nolen epitomizes how this shift is possible only if it is based on cooperative partnerships. In doing so, sufferers feel not only empowered, but also in command of how the narrative is constructed as they decide what memories they embrace and/or reject. The socio-political transformation of sufferers is, indeed, an

essential feature of the stories by which characters withstand public scrutiny and the constraints imposed upon their ability to act freely. The experiences of sufferers are thus reframed in such a way as to reflect how disenfranchised individuals manage to produce new identities, abandoning the status of object (Zackie Achmat), and to call into question the ethical nature of party discipline (Nelson Mandela).

For example, the narrative in “Zackie Achmat” and, to a lesser extent, “Nelson Mandela”, is sparked by the desire of both persons to act as agents of social and political change. In so doing, they contravene, in different degrees, the social and political mores in post-apartheid South Africa because they oppose the “redemptive discourse of nation-building, forgiveness and reconciliation which was established by the workings of the TRC” (Grzeda, 2015: 67). Following this line of thinking, Zackie Achmat and Nelson Mandela are successful in their bid to oppose the optimistic discourse of post-apartheid South Africa, as they face the most pressing challenge of the first decade of twenty-first century South Africa: HIV/AIDS. They manage to do so through their active participation in the deconstruction of the dystopic elements that push HIV/AIDS sufferers to the margins of society. More specifically, their accounts subvert the sense of the powerlessness, the loss of human emotions and affiliation, and the oppressive and monolithic nature of political discourses on HIV/AIDS. As the narratives evince, huge transformations are needed to move forward in spite of the inefficiency of the South African government to gauge the extent of the epidemics. Zackie Achmat, for example, recalled that chapter in modern South African history when the activist-led Treatment Action Campaign fought government’s denialist position and fought also against the political party, the ANC, which Achmat supported during apartheid:

TAC put that love aside, and stepped up its campaign. In late 2000, Zackie and a friend flew to Thailand, bought five thousand generic fluconazole pills for 28

cents each and publicly carried them into South Africa. The government detained them on smuggling charges. (Nolen, 2007: 176)

Although Achmat's attempt to distribute the anti-retrovirals among HIV/AIDS sufferers was most likely doomed to failure, this heroic action made it difficult for Mbeki to draw attention away from his controversial statements on AIDS. As Nattrass is quick to point out, "Mbeki questioned HIV science and claimed that the pharmaceutical industry was conspiring with the US government to inflict toxic drugs on Africans" (2012: 2). Nolen's narrative approach to HIV/AIDS is biased towards validating the consumption of medical drugs to inhibit the onset and the development of the disease. This is so in contrast to the view held by Mbeki, and Nolen gives priority to this medical solution over the analysis of possible conspiracies that originate from pharmaceutical lobbies. Within this narrative, Achmat not only assumes the already mentioned claim by Nattrass, but he also goes further when he speculates that Mbeki's position stems from the president's personal experience in the struggles against apartheid rule when a white minority government was involved in white elephant projects to target black South Africans (Nolen, 2007: 175-176). The textualization of memory makes clear that mediation offers Achmat the chance to reconnect with his subjecthood in imaginative ways to ensure sufferers a meaningful and dignified life.

Nolen's appropriation of discourse also calls into question the objectivity of the story by offering "the opportunity for reformulations of the workings of power in social relations" (Winslade, 2006: 504). Reformulations take the shape of dissenting from the ANC as an expression of new pluralism in the political realms of the "new" South Africa. For instance, the story of Zackie Achmat reads as "one of the first expressions of open, organised dissents against the government's AIDS policies" (Nattrass, 2007: 47). This narrative approach locates sufferers within a normalizing context, promoting a sense of liberation and equality. In this way, a healing process begins to take place,

similar to that intended in the Truth and Reconciliation Commission of 1996. This act of social and moral justice undermines the destabilizing factors that have led characters to a troubled subjectivity. In making their claims through an organized political body, as is the case of the TAC, the subjectivity of their participants is now imbued with a sense of well-being and social rehabilitation (White and Epston, 1990). Due to the mediation process, Achmat and Mandela manage to make their motivations clear as regards conflict resolution. According to Sara Cobb, this type of mediation offers possibilities for empowerment and, thus, “disenfranchised segments of the population are legitimized through their own efforts to gain control over their lives” (1993: 246). Although Cobb’s remarks are more representative of Achmat’s situation than they are of Mandela’s, it is important to highlight the degree of political autonomy regained by Mandela in showing disagreement with the ANC publicly. Indeed, it is an act of rebellion and a form of empowerment which is most laudable given his former role as president of South Africa.

Empowerment comes about when Nolen creates the conditions for normalizing HIV/AIDS, and here she amalgamates the political and the personal within the narrative. Nolen also enters the political at the very outset of Nelson Mandela’s son’s story when the former leader summons the Johannesburg media to account for the death of his son. In this instance, Nolen places emphasis on Mandela’s suffering when he is introduced as someone who “had never looked more old, more pained [and] more worn by all that life had asked of him” (2007: 313). The narrative thus downplays the atrocities experienced by Mandela during apartheid. Nolen, in turn, gears towards the stored-up emotions of the Mandelas when the charismatic leader decides to break the silence and go public about the cause of Makgatho’s death:

Let us give publicity to HIV/AIDS and not hide it, because the only way to make it appear like a normal illness, like TB, like cancer, is always to come out and to

say somebody has died of HIV. And people will stop regarding it as something extraordinary. (Mandela qtd in Nolen, 2007: 313)

Mandela's public announcement is of paramount importance. In the first place, his words represent a turning point in his way of addressing private issues, especially those that stem from sexual encounters. Secondly, Mandela changes his mind, steps forward and expresses his willingness to tackle this problem. The situation awakens in him the need to offer redress to past victims, thus assuming to some extent his share of responsibility in the mismanagement of the AIDS crisis. Here, Nolen's mediates a narrative that reflects Mandela's own trauma, as he was hostage of much insecurity concerning his role in the AIDS crisis, and this particular incident reveals the nature of his vulnerability. There is pain but there is also a combination of frustration and regret in Mandela's briefing that opens up the discussion on the role of politics in the spread of the virus in South Africa. In the past, Mandela would often refuse to talk about HIV/AIDS publicly on the grounds of ethnicity –he is an elder Xhosa and as such social etiquette in his ethnic group sees this is inappropriate. As a result of Mandela's reluctance to discuss sex issues in the past, the virus rapidly gained ground mostly because it was not part of the political agenda. Other priorities in the social, economic and political terrain dwarfed AIDS. The immediate consequences are well-known, as South Africa became the most infected nation in the world during his term in office (Nattrass, 2007). Indeed, this is one of the few criticisms made of Mandela's service to South Africa. In this regards, Nolen's narrative voice sanitises Mandela's tarnished image, and the story of his son's death soon fades into the background. Instead, much of Nolen's narrative centres on Mandela's commitment to rid South Africa of the scourge of AIDS in the company of his wife, Graça Machel. One of Mandela's first steps in amending past wrongs was the use of his revered image to campaign against official

denialism. In doing so, he proves that disclosing the AIDS national trauma is also the duty of a respectable statesman:

Even in 2005, when eight hundred people a day died of AIDS in South Africa, no one liked to say the word. And that, Mandela said, was why he and the family had decided to go public: to bring dignity to the dying. “Doctors, the nurses and other medical staff in hospital are going to talk about it: ‘Did you know that Mandela’s son or grandson has died of AIDS?’” he said, mimicking the gossip. “And it gives a very bad reflection indeed to the members of the family that they themselves could not come out and say bravely that a member of the family has died of AIDS. (Mandela qtd in Nolen, 2007: 315)

Mandela’s plan of action revolves around two fundamental issues, awareness and action. In this particular life story, the practice of discourse mediation evinces the heated debate within the family to determine what steps to take on this issue. It was thanks to Graça Machel’s first-hand knowledge on AIDS deaths that the family eventually disclosed it, despite the initial reluctance of a few members of the clan (Nolen, 2007: 319).

From that time on, Mandela became very critical of the role of the South African government in the HIV/AIDS crisis. In his political forays, Mandela adopted a relatively hard-line stance on government action and took sides with the strongest social group that emerged in post-apartheid South Africa: Zackie Achmat’s Treatment Action Campaign. This ideological shift gained ground when Nolen gave the floor to Graça Machel, who reminded the readers of the tremendous work carried out by Mandela after the presidential election in 1994. Machel discusses at great length the priorities of Mandela to ensure democracy and conviviality among diverse races and ethnic groups, who despite living in the same country knew very little or even nothing about other social groups. Needless to say that the transitional period was marked by great divides within the population; something that encapsulated the potential for community tensions. This concern overshadowed his lack of response to the emerging health crisis

in South Africa as the country risked being on the verge of a civil war. As Machel notes:

In the first years of freedom in this country, the leadership concentrated on building the relationships to make sure the transition would work –and not to allow anything to jeopardize what was being built so carefully, to make sure above all that we prevent bloodshed in this country. (Machel qtd in Nolen, 2007: 321)

However, Nolen's mediated discourse is also ambiguous. This ambiguity is fraught with the potential to create confusion about the role of Mandela in the HIV crisis. Mandela's achievements in the construction of an egalitarian society became blurred, and Nolen's previous default position towards giving prominence to the role played by Mandela give way to a sense of laziness and aloofness, very possibly to enhance the Achmat's activism. This is the case when Nolen brings to the fore the moment when Achmat tests HIV-positive. At that moment, the third person narration brings greater focus on the fact that in the times of late apartheid HIV was not yet a major threat to South Africans:

The virus was still largely unknown in South Africa: the apartheid state had made a concerted effort to cordon the country off as AIDS spread in other African nations and less than one percent of the South African population was infected. But Zackie's community of gay men, many of whom travelled frequently to Europe or North America, was beginning to get seriously affected. Several of his friends had died. His test came back positive. (2007: 169)

Nolen's words contradict the somewhat popular belief in the West that HIV is predominantly a racialized virus and an African phenomenon. The image of Europe and North America, which in those days were strong cultural signifiers of South Africans' much longed-for ideals of freedom, appeared to be entry points for HIV. Whereas the assumption that HIV mostly affected sub-Saharan Africans is true, this is also a misleading and an incomplete view of the epidemic, as well as a dangerous reductionism of its dynamics. This belief is deeply ingrained within a western mind-set and, most likely, responsible for inadequate response of the rich nations to fund the

fight against the virus. In the first place, as the stories in *28: Stories of AIDS in Africa* attest, western views tend to disregard the root cause of the epidemics in the southern tip of Africa: the taboos associated with the culture of sex. Once again, Graça Machel takes the floor and makes it clear that “in [their] part of the world everything related to sex is so private” (Nolen, 2007: 320) in her bid to locate the rapid spread of the disease within the frame of a cross-border issue that originates from a cultural practice that deviates from that of the West. Additionally, and for reasons unknown, Zackie Achmat’s testimony does not shed light on the question whether he contracted the disease after selling sex to older white men. In apartheid South Africa that possibility was high, but the narrative does not offer any further detail on this relevant issue and this constitutes an important gap in the story of a central character.

After four decades of global AIDS research, the virus continues to be a public issue in South Africa. Yet sufferers do not fully enjoy the benefits of medical research due to the stigma associated with it. The context of mediation neutralizes the effects of stigma and in turn reinforces opportunities for resilience. In the process of reconstructing both narratives Nolen grants the Mandelas and Achmat authority over the content. Thus, Nolen not only redeems them from pain and suffering but also facilitates their right to signify within the domain of the therapeutic benefits of narration because “inhibiting memories and thoughts of the trauma requires a mental effort that affects the body as well, and disclosing them releases this tension” (Camila Asplund Ingemark, 2013: 8). These types of life narratives open a window into the complex realities of HIV disability, teaching civil society how to approach, and understand, issues of health and vulnerability in their bid to re-assess the shortcomings of South African democracy. In *28: Stories of AIDS in Africa*, the context of mediation and, by extension, life-writing, illustrates the influence of this literary genre to turn the sum of individual traumas into a

national therapy. Consequently, the multifaceted nature of HIV/AIDS takes centre stage, becoming a matter of national interest in its attempt to face with heads held high post-apartheid's national trauma and normalize the social position of HIV sufferers and their relatives.

Such is the case in Zackie Achmat's narrative, very especially when his bold political activism is in the headlines to challenge Thabo Mbeki's political stagnation. Thus, Achmat's individual trauma achieves the category of national when his story is in the public domain. Nolen's mediation in Achmat's experience takes up on Didier Fassin's idea of AIDS biopolitics (2007: 290), as seen in chapter one. The narrative centers on Achmat's relentless efforts to make antiretrovirals affordable to everyone in South Africa. Despite Mandela's initial support in this campaign to rewrite the Medicines Act and, as a result, permit the production of cheaper drugs, the heroic response found strong opposition from the U.S. pharmaceutical lobby. Needless to say, it could have saved thousands of lives in the face of the urgency of the epidemics:

GlaxoSmithKline, Bristol Myers Squibb and thirty-eight other big drug companies sued the government, and in the U.S. the industry aggressively lobbied the Clinton administration, which obligingly threatened trade sanctions if South Africa went ahead with changing the law. South Africa's government, desperate to generate economic growth in its efforts to rebuild the country, in turn bowed to U.S. pressure and dropped the new legislation. (2007: 172)

The immediate consequence of U.S. pressure resulted in the backtracking of South African authorities on their commitment to provide the drugs to the most vulnerable. This setback further exacerbated inequalities in South Africa, where survival was in the hands of the very few who could afford this very expensive treatment, yet this injustice only served to fuel the combative spirit of Zackie Achmat. From that moment onwards, Nolen's narrative focus gives a considerable boost to Achmat's activist profile in his bid to transform the social fabric of democratic South Africa. This is another example of the resilient nature of the South African activist to get rid of the pervasive effects of stigma

on HIV sufferers. Those early days of democracy came to represent a major threat to those most vulnerable subjects, many of whom feared the return of exclusionary policies. Nolen's narrative thus portrays Achmat as an empowered subject with the capacity to lead crowds on marches so as to protest against the lack of health democracy.

Nolen depicts Achmat as a national hero, a god-like figure, who caught the imagination of poor South Africans and their growing discontent with a flawed democracy. This narrative strategy, besides reading it in terms of solidarity, also aims at articulating a discourse of human reassertion. The latter is essential to life-writing, and within the socioeconomic and socio-political context of South Africa it reads as a clear step forward to come to terms with the yet insufficiently disclosed traumas of the nation. The narrative gives prominence to the contentious relationship between Achmat and Mbeki, whose ill-timed remarks considering AIDS and his denialist position sparked further conflict. Nolen's engagement with the necropolitics (Mbembe, 2003) of South Africa foregrounds issues of health democracy, especially when Achmat defeats the government in the national courts. In his reflection on the singularities of the South African case Didier Fassin observes:

While modern forms of "governmentality" consider life the main target for government action, while the "technologies" of living organisms are the primary characteristic of normalization systems, while the disciplines of the body and the regulation of populations, following Foucault (1976), sum up the state's mode of intervention par excellence, South Africa [...] has been portrayed as an exception in the supposedly universal process of civilization. (2007: 265)

Fassin strikes at the weaknesses of South Africa by pointing out in a rather mild way the areas that require urgent action. In line with this, Nolen's voice puts institutions in the spotlight, proving correct Turner's idea that "institutional patterns are always imperfect, inadequate, and precarious." (2006: 28). This illustrates how public institutions lagged behind civil movements, as is attested in the stories examined in this chapter. By

inscribing the multiple manifestations of human vulnerability in *28: Stories of AIDS in Africa*, subjects articulate discourses of ideological and political contestation that emerge powerfully from the margins in pursuit of the rights of HIV sufferers to signify after traumatic experiences of deprivation and loss of agency. Following this, Couser elaborates on the function of life-writing on illness and disability stating that “disability memoir should be seen [...] not as spontaneous self-expression but as a response to the traditional misrepresentation of disability in Western culture generally” (1997: 7).

3.5 Conclusion

The multiple barriers constructed around AIDS have not only hampered progress in democratic South Africa but have also consolidated a kind of “medical apartheid”. *28: Stories of AIDS in Africa* reflects on the need to compel authorities to react and act against the serious threat that HIV poses to the future of South Africa. Besides contesting AIDS biopolitics, these life narratives provide an arena for the development of spaces of personal and national disclosure in which Nolen initiates a dialogue between the HIV community and society. The written account of these testimonies unfolds the uncanny aspects of an epidemic that has killed more people than any war or natural disaster on the African continent. Life-writing, in this respect, besides voicing the unspeakable also provides a foil to criticize the social discrimination and state violence with which characters co-exist and grapple, as was discussed in chapter one, when I stated that the holocaust linked trauma studies and life-writing. In *28: Stories of AIDS in Africa*, Nolen articulates a discourse of empowerment that gives visibility to a dispersed community, often living disconnected lives in absolute isolation. Indeed, the memorialization and textualization of HIV/AIDS in the post-apartheid era prove to be correct Jacobs and Bank’s remark that in South African life-writing “the political

overshadows the rest” (2019: 165). When apartheid rule came to an end, Mandela urged black South Africa to forge a model of forgiveness for the world. In the post-apartheid era, HIV/AIDS gives South Africa an opportunity to forge, this time, a model of inclusiveness for the world, and Nolen’s collection of stories contributes its bit to it.

Chapter Four: Small Town, Big Hell: Living with HIV/AIDS in Rural South Africa in Jonny Steinberg's *Three Letter Plague* (2008)

4.1 Introduction

After the restoration of democracy in South Africa, one of the most significant events, if not the most, has been the HIV epidemic and the scope of the response to this. The epidemic represents a serious threat to the vision of South Africa's future as one of mutual care and respect. After a century of democratic absence, the drafting of the constitution has granted the less privileged sections of South African society, mostly based in rural areas with difficult access, an opportunity to thrive. Despite this, as Steinberg's work attests, a large number of rural South Africans remain excluded from the trends of prosperity and the opportunities afforded by the new socioeconomic order of globalization. This view has been further reinforced by the politics of social exclusion and social distancing resulting from fear and stigma. Thus, Steinberg's narrative puts the spotlight on the influential role that established medical science could play in improving the living conditions of rural South Africans, many of whom are either affected by or infected with the virus.

To begin with, I am interested in the way Steinberg's mediated narrative creates a space of intimacy and reflection whereby the memories of the main character, Sizwe, find a place between the public and private domain. Furthermore, the narrative also sheds light on the internal social dynamics of these, at least in appearance, simple communities. Nothing could be further from the truth, and Steinberg carries out a research which evinces the strong social condemnation of HIV sufferers. The latter feel the stigmatization that comes with the disease and this alerts potential sufferers of the necessity to remain silent on this issue. The often disguised conflicts in rural communities play themselves out within a set of complex human relationships that are largely influenced by deeply ingrained local beliefs, where cosmetic appearance is of

paramount importance. This renders the building of bridges between different social groups difficult, a situation that is outside Steinberg's understanding due to his position of privilege, as a white person with a consolidated professional career. As Gabay notes, Steinberg embodies both the white civilized ideal subject and a system of privilege that rests on universal and ahistorical codes that represent such status within the social landscape of South Africa (2018: 236-8).

Jonny Steinberg's *Three Letter Plague* (2008), in this light, is an investigative biography that looks at how personal memory is used to counter the country's official memory's attempt to obliterate the wounds of AIDS. Steinberg explores the intrinsic aspects of the HIV/AIDS epidemic in rural South Africa. In so doing, the biographer, in Steve Weinberg's words, goes beyond "any articulated theoretical foundation" (qtd in Lidström Brock, 2017: 32). The narrative thus focuses on the representation of the complex mental landscape involved in the governing nature of the relationships between different social groups in the village of Ithanga, one of the areas severely hit by the epidemic. It is precisely through the lens of a privileged white person who appears to be dismayed by the on-going out-of-hand prejudices of villagers against HIV sufferers that the readership enters into the slippery ground of HIV/AIDS dynamics. *Three Letter Plague* unfolds the reasons why rural South Africans find it hard to express their concerns regarding the epidemic. This, more often than not, is a personalized account of living around the epidemic which also makes room for a concern that the poorest will remain vulnerable as their coping strategies, fundamentally based on compliance with tradition and reliance on alternative and affordable therapies, continue to crumble.

The use of language in Steinberg's *Three Letter Plague* also merits analysis. *Amagama mathathu*, meaning three letters in IsiZulu²⁵, is the term used by villagers to

²⁵ IsiZulu is the language spoken by Zulu people.

refer to the unspeakable, and the use of euphemisms abounds in the narrative. In general, this is symptomatic of the health crisis facing one of the remotest and smallest communities in South Africa's Eastern Cape. Such an attitude reveals the strong connections between the prevailing culture of silence regarding the high prevalence of the virus in the region and the suppression of emotions, and the long-lasting effect of trauma in HIV-positive people, who fear any attack against them. As stated earlier in chapter one, the loss of language performs a protective role (Srubar, 2016: 27). However, silence prevents Sizwe from narrativizing his own trauma with the fear of AIDS that possesses his body. In this sense, Steinberg explores the boundaries of Sizwe's silence in order to identify what Pujolràs-Noguer and Hand define as "the crying wound that irrationally and recurrently assaults [Sizwe's mind-set]" (2019: 8). It is to this community where Steinberg travels to gain first-hand knowledge of the battle to survive AIDS and to thrive in life. Steinberg plunges into the complex intricacies of AIDS in rural South Africa with the support of Sizwe. The latter is significant as it is an area difficult to explore as an outsider. The fantasy world of villagers relies much on their ability to exclude the far-reaching impact of the disease on them from their minds.

Some of the continuing –and unresolved– traumas that affect a large amount of South Africans go beyond the retrieval of democratic rights. For this reason, and in search of solutions to silence the still growing contemporary traumas associated with the epidemic, the circulation of AIDS narratives in South Africa are necessary to give visibility to the process and experiences accumulated in the struggle for social justice in the democratic era. Giving voice to ostracized and marginalized sections of society is part of Steinberg's agenda in his attempt to dignify the living conditions of HIV sufferers in rural South Africa.

The story is set in a poverty-stricken and predominantly black rural district of the Eastern Cape, where Steinberg befriends a man whose nickname is Sizwe Magadla, a rural entrepreneur. Sizwe runs his own spaza shop²⁶, with good prospects for the future and has also managed to escape from poverty amid seeming socioeconomic chaos. His humble origins leave no room for doubt. Steinberg presents Sizwe's mother as a woman who "fetches water from the river and firewood from the forest, or has never seen a working television or attended a day of school, or traveled any farther than the one-horse town of Kokstad." (2008: 230). This information allows the readership to consider to what extent Sizwe's level of socioeconomic protection increased as well as the lack of access to commodities during his upbringing, and this contrasts with Steinberg's level of individual welfare. Despite the clash of worldviews, the interaction between Sizwe and Steinberg illustrates the possibility of the reshaping of public memory in South Africa. Sizwe is in love and about to marry Nwabisa, yet his fear to get tested best grasps the true dimensions of what living with HIV/AIDS entails in Ithanga. People are faced with the dilemma of either being tested for HIV, and have a chance to be placed on treatment, or coming to terms with the fatal consequence of ignoring the epidemic, if deemed HIV-positive, and die a silent and terrible death. The latter has allowed the outbreak to intensify and spread with almost no control. In this biography Steinberg seeks for responses to the epidemic from KwaZulu-Natal: the most affected area by the AIDS epidemic in South Africa.

This chapter examines the ravages of the AIDS epidemic in a rural context which is, in many cases, dominated by superstitious beliefs. In Steinberg's investigative biography²⁷ the study of the role played by traditional South African healers – *sangomas*– takes center stage. The enormous appeal of *sangomas* among rural South

²⁶ South African slang for the typical corner or small shop.

²⁷ I explain my understanding of this term in the chapter 3.

Africa gains considerable ground from conventional medicine, and *Three Letter Plague* illustrates the confusions raised by alternative therapies. In this regards, it is of paramount importance to consider the extent to which the trauma colonial and apartheid regimes created a traumatic reaction and rejection to anything that was considered “Western”. Therefore, as a reaction to this trauma that has been passed down through the generations there is a gravitation towards indigenous forms of belief as a refuge from that traumatic past. Herein lies a great paradox: that same trauma that propels a seeking a seeking of refuge into an African past is creating new traumas through HIV/AIDS. This criticism of *sangomas* is a clear commitment of Steinberg with established medical science. The existence of two competing discourses on how to tackle HIV/AIDS, western and indigenous, adds extra fuel to the existing unease and restlessness caused by shame and fear against which silence seems to be the preferred option.

The narrative engages with the meaning of silence within a community that is, in reality, raging within. Rural South Africa, in particular, is terrified about the impact the disease has on the social fabric because their HIV prevalence dwarfs that of urban South Africa. Such a situation presents a dismal panorama, which, I suggest, threatens the very future of an entire nation. Steinberg, in this sense, captures the essence of trauma with a blend of socio-political and socioeconomic reports. The realistic element of the life narratives of Sizwe and other villagers epitomizes the tensions of the pending challenges of South Africa in the area of social cohesion so as to boost equality. The pervasive effects of the HIV crisis also make room for the analysis of the traumatic wounds in Sizwe’s psyche, and his psychological deterioration is a noteworthy aspect of Steinberg’s approach to HIV/AIDS. Apparently, as Steinberg recalls, the consolidation

of Sizwe's upward mobility and the foundations upon which his economic progress is built largely depend on his ability to remain healthy and safe:

[W]ere [Sizwe] to test positive he would have to call off his marriage, send Nwabisa and the child in her womb back to her home, and live his remaining days like an ox. But I did already know him well enough to see that he had made his impending marriage the very kernel of his identity, and that it was not the sort of identity, nor the sort of marriage, that could withstand the presence of the virus in its midst. (2008: 273)

In other words, for Sizwe's individual self-realization to come true he ought to be able to keep his family safe and aware of the risks outside of the household. Sizwe is witness to the progress of the disease in the bodies of some of his relatives. This fact highlights the destructive nature of the disease. Besides having the potential to change everybody's situation for the worse in the blink of an eye, it also seems to prevent, to some extent (and in the eyes of indigenous South Africans) Sizwe from exercising his relatively new citizenship in a young democracy. The virus has the power to erode Sizwe's social capital by not only isolating him from the flow of cash within a social context where money is always scarce, but also by pushing him away from the contours of safety, respectability and from being a quality role model for the youth in Ithanga.

Three Letter Plague offers an insightful view into "a rural, peasant version of Mbeki's politics" (2008: 86) which illustrates that "[m]any were convinced that AIDS was really an unannounced campaign of racial genocide" (ibid.). This widespread ideological positioning has given rise to a defensive nationalism promoted by Mbeki's belief that drug multinationals sensed an opportunity for huge profit in the African market. And such a thing is further reinforced, as we have mentioned before, by the idea that the sexual excesses of (South) Africans have brought them the nightmare of AIDS, a position Mbeki was opposed to on the basis that covert racism and latent hostility towards Africans were behind those accusations. Nonetheless, these beliefs constitute the perfect breeding ground for shame and stigma amongst an indigenous population.

The complex picture and harsh reality of the village of Lusikisiki compels Steinberg to feature how stigma, and not just HIV itself, is behind the premature death of thousands of South Africans, many of whom choose to die a horrible death in order not to fall prey to violence and disgrace. Steinberg's work, as Astrid Erll has argued, is mediated not solely through Sizwe's mind, but moreover by Sizwe's culture at large (2009: 2). Bearing this in mind, Steinberg takes the readers through the major challenges of health providers in the remote geographical area of Lusikisiki, where there is a 70 percent lifetime chance of contracting the disease (UNAIDS 2018). This fact alone creates a stifling atmosphere where AIDS has come to dwell within the social structures of the families in Lusikisiki. In Sizwe's home village, endless HIV/AIDS backchat further stigmatizes sufferers, making it difficult for them to assert their human condition whilst their neighbours' point the finger of blame at them. The latter brings to the fore the threats of social sanction to sufferers. This biography unravels the effects of bodily disintegration in rural communities as a way to mirror society itself, paying special attention to the particular stages of human grief and suffering that colonize both the disabled body and mind of sufferers.

4.2 Understanding the Complexities of Rural Livelihoods

According to Patricia C. Henderson, "few academic studies have closely examined the excruciating suffering that individuals undergo through the illness, and in terms that they would recognize" (2011: 22). *Three Letter Plague* makes room for the exploration of these nuances within a complex social milieu that manifests its diversity not only in cultural terms but also ideologically. Sizwe himself, who hosts uncertainties and embodies the fear of the disease, and this cast of different characters contribute to feeding the discussion from different angles. This is significant in determining whether HIV is a creation of western science deeply rooted in racial hatred, or something that can be fought with western drugs, diminishing prejudice against western science.

Although it might be convenient to state that both options are improbable. First and foremost, in his work Steinberg wants to insist on Sizwe's need to get tested. Apparently, this is Sizwe's single option to overcome the feelings of fear and distress that arise within him as regards his troubled subjectivity. The story of Sizwe is at once the story of his whole community and therefore it provides a representative stance of the collective rural anxieties.

This degree of representativeness can be easily extrapolated to other sections of South African society. And to this particular end the narrative engages with the relentless work of Dr Hermann Reuter in the microcosm of Lusikisiki, on the one hand, and with the structural forms of community violence that grow out of the public recognition of disabilities in the rural world, on the other. The Medecins Sans Frontieres (MSF) doctor arrived to Lusikisiki at the time when the Mbeki's administration was camped on denialism (Nattrass, 2012; de Waal, 2006) with the idea of leading the implementation of an antiretroviral therapy program in the area to support sufferers and to prevent new cases. In his bid to create the right conditions for HIV testing, counseling and prevention, Dr Hermann struggled with the various ethnic beliefs and biases against the disease. Steinberg and Dr Hermann were faced, too, with the difficult task of dismantling the ambiguous beliefs promoted by the Mbeki administration in a predominantly ANC-aligned territory. Steinberg seems especially concerned with a view to identifying the weaknesses of South Africa in the political arena, namely the allocation of public resources to curb the epidemic. The strong presence of Dr Hermann's voice throughout the biography makes it conspicuous. Steinberg also expresses concern at Mbeki's beliefs:

Mbeki's ideas on AIDS were always complicated and never clearly articulated. By the time they filtered down to provincial ANC strongholds such as the Eastern Cape, they had become a cocktail of nativism, ersatz epidemiology, and anti-imperialism: the drugs are toxic; the West is dumping poisons on Africa; the

problem is poverty and ARVs cannot help someone with an empty stomach. (2008: 102)

Poverty, as Mbeki points out, is certainly a socioeconomic factor to be taken into consideration. It is true that access to resources enables sufferers to enjoy better material conditions of existence, including advanced medical care. At the same time, it is also misleading as poverty itself does not justify the increasing number of cases that South Africa has experienced at the turn of the century and during the first decade of the new millennium. Ruth Hall, for instance, is quick to observe that mobility and labour migration are vectors of HIV transmission, along with poverty, very especially within the former Homelands or *Bantustans* (2008: 131). Former labor migration to the gold mines located in the area of Johannesburg was a considerable source of income in Lusikisiki district, “a former reservoir of cheap labor for Johannesburg’s gold mines” (2008: 6). Steinberg also makes explicit references to the close interdependence between former Transkei districts and the economic elites of South Africa (2008: 26). The migrations related to this long-standing economic relationship have sustained rural households but have also brought workers and their families countless diseases. AIDS is amongst them. When asked about the first cases of HIV in the area, Kate Marrandi, a local trained health carer for HIV who was affected by the disease verifies the aforementioned:

Yes, I remember well. The first cases were in 1996. People working in the mines came back seriously ill. We took them to the doctors in the main street and at the hospital. The doctors would say: “These people are HIV-positive. We cannot help them. You must take them home and treat them with herbs. (2008: 159)

As a result of the exponential growth of HIV cases in Lusikisiki, poverty gained substantial ground in the area. The gradual loss of this source of income –the mines– due to the migratory flow in the span of time between the 1980’s and the early 1990’s affected rural households beyond the loss of employment. According to Janet Frohlich,

these migrations are regarded as one of the entry points for HIV in rural communities, as fathers have traditionally worked away from home (2005: 351). Many contracted the virus in the course of unprotected sexual encounters out of wedlock and returned later on to rural areas where the virus found their wives after intercourse. The breakdown of family structures is one of the consequences and this gives rise to “skipped generation” households that are for the most part dependent on the elderly. *Three Letter Plague* visualizes this silenced trauma which can be considered as forms of structural violence.

More interestingly the narrative furthers the participation of the community in the unveiling of secret passions, constructing narratives of liberty and licentiousness. These popular narratives are out in the open but discussed in privacy and out of earshot of other people. The male pensioners, especially, play two roles within this issue in that they act as providers of food and security yet are also the key drivers of the epidemic. The topic comes out in discussion when Kate MaMarrandi is conducting a workshop on the HIV transmission in one of the communities. In the course of the workshop, one of the attendees casts doubts on witchcraft as a way of transmission, and feels rather stunned at seeing that, in the eyes of elderly women, the disease comes as such a surprise:

‘I do not agree with the way of Wizards. It is from sex.’ She paused and when she began speaking again it was MaMarrandi she addressed. ‘What’s difficult for me is that even old ladies are HIV-positive. I don’t know why.’ MaMarrandi took off her reading glasses, folded them carefully, and put them in her breast pocket. ‘Maybe I should explain’, she said. ‘The pensioners, the men, after pension day, when they have money in their pockets, they sleep with young girls. They give them money and then they sleep with them. They come back to their wives with the disease. Also, there is a way the old women get the virus themselves. You have, just for example, an old lady with a shebeen [unlicensed tavern]. When the young boys come and drink, she watches for the one with a lot of money. He calls her *magriza*. She doesn’t like that. She doesn’t like being seen as a granny. She will propose love to him to show she is not a *magriza* and she will get the disease from him.’ (2008: 225)

The governing principles of gender relations in this particular case offer insights into the materialistic mindset of rural South Africa. Mostly men, but also women, make use of either their economic strength or their capacity to boost it, and whatever the case, AIDS, power and seduction mingle together, causing the spread of the disease. Men pensioners hold power and brag about it by imposing their sexual fetishes on young girls. The future in the village is anything but promising and young girls are willing to have sex, taking the risks related to prostitution in a sporadic fashion in order to sustain their lives in an stifling atmosphere. Another example of this within the narrative can be found within a prevailing patriarchy present in Zulu culture when Sizwe's future wife, Nwabisa, quits her job the moment they start living together.

HIV is shown as the cause and consequence of the deterioration of the social fabric and traditional structures. MaMarrandi describes the functioning of different age groups in the old days and the key role these had traditionally played until the advent of democracy when the tight indigenous practices loosened their grip on the strict enforcement of tradition:

‘When you were growing up,’ I asked her, ‘was there much less sex than now?’ Her face remained impassive and her gait steady, but she began to speak and did not stop for a long time.

‘You can’t compare that time with this time,’ she began.’ They do not listen today. When we were growing, we grew up in groups –young adult girls, middle girls and young girls. The oldest group had their boyfriends who were to ask them to get married. They looked out for each other, and they cared for the middle group: they made sure that the middle group does not do wrong things. The young adult girls would watch the girls in the middle group closely and when they noticed that one of them is maturing to a certain stage they would approach her and tell her it is time for her to have a boyfriend. They would sit her down and tell her what to do. They explain that you must not have sexual intercourse. The boys as well, they had adult boys teaching them how to behave. When they reached the point they got married, they knew it is time now to have intercourse in order to give birth.

‘Today, they are not listening. There is something called freedom that is confusing them. If you tell them it should not be like this, it should be like that, they tell you that you are abusing them. And so we have a generation of AIDS.’ (2008: 226-7)

The erosion of the centuries-long Zulu tradition of respect for the elderly is due to the absence of traditional role models in every age group. The loss of an intergeneration web of relationships further complicates efforts to build an environment conducive to mutual respect and care, including those related to health issues. The youth consider the “days of ignorance” are gone now and that the constitution is an open invitation to assert their rights as citizens. Furthermore, the advent of democracy and the drafting of the Constitution, namely section 27 in the South African constitution, grants them access to adequate health care services if the youth fall ill, turning the social shield into a disgrace in disguise. The tendency within youth sex education has gravitated towards giving much less attention to the psychological development of young girls and boys. As a result, this generation of AIDS sufferers has to reconnect with their cultural roots and redefine the way they want to project themselves to a wider society. In *Three Letter Plague*, the integration of the AIDS generation into society takes the form of social responsibility. Kate MaMarrandi is the character that best epitomizes this idea, and her work with the afflicted people of Lusikisiki gives reason to be optimistic. MaMarrandi draws on society’s assets and pools all its resources together for the sake of the common cause. This is the case of extended families in the villages, which appear to be torn apart by the rapid growth of the disease in the area. In this regard, MaMarrandi’s relentless work at the community level evinces the importance of both repairing and strengthening the damaged social fabric.

The biography illustrates to what extent a significant number of villagers can no longer enjoy the benefits of the support of extended families. Traditionally, these were units of economic and emotional support that have also dwindled as a result of the epidemic. In this context, the creation of an extended web of human contacts in the form of support groups in clinics or the permanent presence of members of the Treatment

Action Campaign, hereafter on TAC, in the area take on the responsibility of strengthening the social fabric of rural communities and educating people on what HIV/AIDS represents in their communities. This is so in order to develop the critical skills of villagers so that they do not discriminate AIDS sufferers or undermine the agency of sufferers. In the eyes of villagers, being marked with illness equals social apartheid and close surveillance. Steinberg recalls this experience:

Such information is not easily absorbed. In the weeks and months that followed, those who had tested positive were silently separated from the rest of the village. They were watched. Nobody told them that they were being watched. Nobody said to their faces that their status was common knowledge. But everything about them was observed in meticulous detail: whether they coughed or lost weight, or stayed at home ill; whether they boarded a taxi, and if so, whether the taxi was going to the clinic; above all, with whom they slept. These observations were not generous; they issued from a gallery of silent jeerers. (2008: 34)

Lack of proper infrastructure and adequate medical knowledge to reduce the impact of the epidemic on villagers seem to require programs such as that of Dr Hermann's sponsored by *Médecins Sans Frontières*. Those beliefs about the effectiveness of treatment are, in turn, embodied by the reluctant and simultaneously ambiguous position of Sizwe. Sizwe expresses his concerns as to the practicality of Dr Hermann's approach despite this being the only option available for survival. In the mindset of Sizwe, villagers will sooner or later discover who is positive in all the villages within the area, and such an element foregrounds the fragmentary nature of the virus, as it divides people into productive and non-productive members. Indeed, the biography examines social fragmentation in detail so as to elaborate on Sizwe's fears. In the course of the workshops conducted by MaMarrandi on HIV several participants air their fears and social grievances that may erupt into social instability. Everybody is on the lookout and on testing day villagers assemble together to keep track of the event and to find out who is positive and who is negative to put social distancing measures into practice:

Nomvalo is small enough for everyone to know everyone else. And, whether as participants or observers, everyone is interested in testing day. Things probably unfolded just as they had the previous year in Ithanga, where the nurses came to test and the counselors to counsel, and Sizwe had noted who went in, and how long it took them to come out. By the end of the day, about a dozen Nomvalo women had tested positive for HIV. I cannot say for certain, but given that they were counseled by fellow villagers, and that a great many pairs of eyes must have watched them on their way to and from the testing unit, it would be surprising if their status was still confidential by the following morning. (2008: 213)

Such a mentality, also shown on display as regards Sizwe's gossiping spirit, compels Sizwe himself to find shelter under the protective umbrella that only solitude and cautious silence may grant him. But solitude and silence are interrupted by Steinberg's desire to make Sizwe's story visible as well as his journey through the devastating effects of the epidemic. Sizwe's memories voice the collective experience of trauma in the face of the most challenging health issue in post-apartheid South Africa. As an invisible disability, HIV/AIDS becomes visible in the eyes of villagers on testing day due to the protocol procedures of medical personnel and counselors when tests come back positive. At this point, it becomes clearer how Sizwe's fears operate as stand-ins for collective trauma in the rural community. Villagers who resist being tested are faced with the forms of oppression that emerge in rural setting, which take the form of the brunt of the gossip, in the first place, and the lack of support of the official public discourses that failed to consider AIDS as a key component of prevailing discrimination in the stifling atmosphere described in the life narrative. The loss of livelihoods and normalcy are also part of the equation considering that AIDS prevention does not include a developmental agenda where employment and social support are the cornerstones of sufferers' dignity and integrity.

The ideological legacy of Mbeki is also notorious when Sizwe is somehow distrustful of the good intentions that have motivated the arrival of Dr Hermann. Sizwe is biased towards supporting, whether intentionally or not, the official discourse that

South African authorities had circulated widely among the population. More specifically, the idea that established medical science had been blinded by the racism of its practitioners becomes an obstacle. As a consequence of this, Sizwe casts doubts on the effectiveness of antiretrovirals:

‘I have three problems with antiretrovirals,’ he said crisply. ‘First, people do not know about them. We don’t know them here. Second, it seems you must get sick before they give you the antiretrovirals. You must wait until you are sick. I do not like that. Why must you get sick first?’ He has been staring at his hands as he speaks. Now he lifts his head and looks me in the face. ‘The third reason is the biggest reason. I feel terrible for the people living with this disease inside of them. It is there for their whole lives. I think of Thandeka living with the disease her for the rest of her life, and I feel so sorry for her, I wonder whether she can cope with that, whether anyone can cope with that. A cure is much better.’ (2008: 82)

Sizwe echoes incessant rumors about a possible cure when he entrusts Steinberg and tells him that “[s]ome people believe that the whites have developed a cure for AIDS, but that they are holding it back. They are waiting for enough black people to die so that when we all vote in an election the whites will win and F. W. de Klerk will be the president again” (2008: 157). These thoughts are revealing for they provide evidence of the imperative need to consolidate protective devices that can ensure rights to the lower social groups of South Africa in the face of the epidemic. People grieve according to their past experiences and keep their memories alive in order not to forget that the tragedies that had once confined black citizens to the margins of society, and which are still present in the collective imaginary. In the narrative, Steinberg illustrates how Sizwe’s fears operate as stand-ins for the trauma of the rural community in which he tries to thrive in life.

4.3 Narrative Mediation, Grief, and Trauma

Nigel Hamilton describes biographies as useful tools to navigate through the multifaceted challenges of the various humans concerns that endow with meaning the existential doubts of humans and their roles and interactions with other individuals in

the democratic world (2008: 1). In this regards, *Three Letter Plague* is no exception, as it explores the anxieties of rural South Africans through the representation of Sizwe's moral dilemma with AIDS. However, it is exceptional in that its narrative goal seeks the swing of public opinion towards the use of antiretrovirals and the endorsement of established medical science. This is especially the case when Dr Hermann becomes involved in the issue but also mistrusted by those highly placed in institutions. Both Dr Hermann and Steinberg appear to be in varying degrees angry about the blundering decisions of medical personnel and the administration as to how to tackle the issue of AIDS training and treatment. Why someone like Jonny Steinberg is willing to write about AIDS inevitably raises the question of what intrigues him about this topic. Steinberg himself is a white academic who enjoyed and benefitted from the privilege of whiteness but is nonetheless touched by the overwhelmingly challenges posed by the epidemic in a land with relatively scarce resources –see also chapters 3, 5 and 7.

One must therefore ask the question: for whom is Steinberg producing this work? The writing of biography is a form of historical analysis and a repository of knowledge, and an interpretation of the HIV/AIDS crisis becomes as a means of both recovering and (dis)closing the national trauma of South Africa within a rural context. The fact that Jonny Steinberg also breaks his silence about his own experience with his fear of the virus is significant. Steinberg's writing is also testimonial, especially when he recalls he tested negative after several episodes of unprotected intercourse, thus validating the idea that the racialization of HIV/AIDS was a racist construct also in South Africa. Additionally, it is also a revealing testimony in that it proves whites were as promiscuous as blacks, at best. In the actual context of South Africa, *Three Letter Plague* gains great importance in its educating of the population and to curtail the spread of false beliefs around the transmission of the virus that bear an intimate relation

with the ancestral traditions of Zulu people. His work is a biographical study that largely sheds new light on politics in the face of a promising era that has now crumbled to pieces as the avalanche of HIV cases threatens South Africa's generative capacities. Objectivity and the ability to see the world through Sizwe's eyes push him to embrace as much objectivity as possible (Ambrosius, 2004: ix). Western individualism is the key for the success of biographies, as people need to identify with their social milieu. *Three Letter Plague* is a key contribution in this regard as it triggers a social debate about a very important issue that clearly transcends democratic values. The choice of this particular literary genre responds to the inclusive spirit of the architecture of the "new" South Africa, specific to the apartheid post-conflict, to find forms of collective expression, and David Huddart notes how "different cultures require different forms of thick description in order to capture their different ethical orientations." (2008: 2). Traditionally, as Anita Rupprecht notes, the genre auto/biographies has "denote[d] the narrative inscription of an abstract and unique individual agent moving through time and space" (2002: 35), thus excluding any other way of imagining the individual within the larger framework of both a social and political process aimed at the construction of interethnic and intercultural dialogue. These dialogues are crucial to bolstering notions of sameness and equality among South Africans regardless of class, gender or ethnicity. *Three Letter Plague* enables people who live on the margins of society to take centre stage, thus claiming for the visibility of the diseased subject, whose language of fear and suffering, but also of hope, takes shape in relation to those aspects around their lives that are defined as relevant. This is the case of Sizwe, whose inability to fully express his concerns require of Steinberg's presence to make sense of the outer world, reflecting the singularities of rural South Africa. At the same time, such collaboration illustrates the collaborative process of a language of interpretation that can voice the

uncertainties of a whole nation. Those aspects that I mentioned as important provide an arena for the development of a national identity that is worked out through a discourse of collective selves. This latter consideration is revealing in the sense that it subverts the ideological and theoretical foundations of auto/biographies. According to Moore-Gilbert, the origins of auto/biographies have clearly displaced the non-white subject on the grounds of the lack of a sophisticated consciousness (2009: xii). Bearing in mind the segregationist past of South Africa, South African life narratives challenge the idea that the lives of non-white individuals are devoid of complexity and depth. Moore-Gilbert's statement foregrounds the racist ideological background of the genre, but more importantly, it provides an entry point to postcolonial studies to engage in a productive and dialogical process between fields of study.

It is in this process that auto/biographies generate a new epistemology of knowledge where the postcolonial subject is no longer excluded, in the first place, of the national imaginary landscape, and secondly, it counters the ethnocentric components that govern the conventions of auto/biographies by promoting a heteroglossic narrative, thus granting the visibility of non-white realities in an ideological text world mainly dominated by white ideology. In fact, *Three Letter Plague* undermines this view. It evokes the desire to share the often denied recognition to the marginalized subject that their conscience is also a sophisticated one. The problem lies in whether the West has consistently seen the importance of inclusiveness or, on the contrary, has not needed to see it because the acknowledgement of such a postulate presupposes a source of ideological destabilization to the interests of the canon, also in the sphere of auto/biographies. Western tradition has thoroughly chosen the terms in which certain geographical locations are entitled to adhere to it, mostly through race and class, and

also what identities, leaving aside potential alterities, are part of the construction and representation of a western tradition in terms of identity.

In this sense, *Three Letter Plague* reads as a postcolonial biography, altering radically the affective ties to land attachment, on one hand, and the established networks in it. The absence of a well-established cultural criticism that is capable of making the particularities of the South African rural world accessible to readers is central. Readers in the west have consistently misinterpreted and misunderstood the foundations of hybridity, and that is a blindspot that Steinberg's narrative benefits from in its attempt to fill the huge vacuum left by the lack of representation. *Three Letter Plague* elaborates on the ethnic and identity conundrums of KwaZulu-Natal's rural people to illustrate the complex ideological word that Zulu people feed on to translate their cosmovision into an understandable language for non-whites. Specific social groups and pressure in rural South Africa give prominence to the concept of collective identity.

Does South African identity derive from the group? If so, do the role models such as that of MaMarrandi in the text promote a new attitude towards sick people? Can they belong? William S. McFeely says that we all "share a basic human curiosity about our fellows" (1996: xiii), and illness memoirs, in particular, is a sub-genre where sufferers act as sites of exploration for human pathos. Learning about Sizwe's life also raises the question of what type of existential issues face Steinberg. He once claimed to be "exploring the health-seeking behavior of ordinary people" (2008: 305), but this concern in Steinberg arises out of a past personal experience which he recalls in his attempt to compel Sizwe "to take [him] to a place inside [Sizwe] he had not shown [Steinberg] before" (2008: 338). As Steinberg offers the readers this autobiographical stimulus to pursue the topic further, he realizes that those feelings of vulnerability and unprotectedness he has dealt with during his university days at Wits in the late 1980s

have not changed a great deal in early twenty-first century South Africa. The essential aspect to draw a distinction between Steinberg and Sizwe is basically that Steinberg has survived the fear of being tested whereas Sizwe cannot face testing, as testing represents the possibility that his life might be turned upside down if the test comes back positive. Steinberg recalls his first HIV test as something “short of catastrophic” (2008: 334). His test came back negative. Sharing his experience with Sizwe empowers him to be more inquisitive and, as a result, Sizwe opens himself up to dialogue at the same time that he sticks to his incomprehensible fears in the eyes of Steinberg:

‘If I know I am HIV positive,’ he said, ‘I will no longer be motivated to do the thing I am doing now, I mean the thing I am doing right now, what I have spent the morning doing here with you – putting all my energy, every moment I am awake, into my shop. It will all be meaningless for me. I will stay in bed in the mornings [...] I am doing all this for my children,’ he finally said. ‘If I have AIDS, then all this work is no longer for my children.’

‘Because you will die before you have accumulated enough wealth for them?’

‘Because if I die while my children are too little to take what’s theirs, my money will end up going to people like my father and my brother. These are people who do not help me to earn my money now. They are not interested in helping me with my business. My dad did not educate me. That’s fine. I do not blame him for that. Now, I support him, and when my brother needs money for the doctor it is to me that he comes. But they do not help me with the business.

‘*So that is my first reason.* If I die of AIDS, Mfanawetu will not get my money. Some others will get it. That is why I will not test. If I test positive, I will no longer get up in the morning to work.’ (2008: 342-3 emphasis added)

At this point in the narrative, when this is close to its end, Sizwe opens himself up when he confides in Steinberg that all he wants is to secure the well-being of his family. His deepest desire is to leave a legacy for his newborn, who also embodies Sizwe’s chance to live beyond the grave, as a tribute to himself, and in the memories of his child. This desire appears to be deeply ingrained in Sizwe’s yearning desire for stability, peace of mind and well-being. Sizwe aims to provide Mfanawetu with a more privileged upbringing, with material stability, and away from any sort of deprivation. Sizwe is depicted as ambitious, and in his mindset commodities are synonymous with a higher social status in their communities. Thus, Sizwe pursues his personal agenda eagerly in

order to consolidate a reputation among his neighbors, especially taking in mind he runs a local business that, simultaneously, acts as a meeting place for villagers. His ambition and thirst for wealth accumulation is irresponsible, at best, as it also casts doubts on his understanding of well-being, which is far from the principles of mindfulness. This is so when, despite not wishing to know about his medical condition, he nonetheless expresses his desire to procreate regardless of the implications that AIDS entails in the long run –a similar pattern is also observed in Khabzela’s life narrative in chapter 6.

The second reason for Sizwe’s resistance to get tested lies in the issue of respectability and appearances. When asked about whether he wants to disclose his real identity or not he refuses on the grounds that everybody would know about him, assuming that the book would reach the hands of all his neighbours and customers. Additionally he also rejects Steinberg’s proposal on the basis that he might be betraying his people, which, again, removes old prejudices that are rooted in the colonial and apartheid periods. This reads as a kind of covenant among blacks not to share information with white people, which makes room to question whether Mandela’s plea for reconciliation was effective in the heart of South African culture:

He thought about it for a moment or two. He had nothing to hide, he said. There is nothing in his views about AIDS of which he is ashamed; they are reflective of the views of many black people. Even in the things he has revealed of himself, there is not much that would surprise those who knew him. Despite all that, he said, he wanted to keep his pseudonym.

Why? He gave me a hundred reasons during my two-week stay in Lusikisiki that February, but none rang true. He trusted blacks to understand the things he expressed in the book, he said, but not whites; they would make trouble. Or he trusted whites, but not Indians. He was babbling, filling up space: he did not want to say.

The closest he came to expressing his real fears was on the last afternoon of my trip.

‘I would be accused of giving away black people’s secrets,’ he said. ‘It is like what you are accused of when you act as a guide. (2008: 351)

Sizwe is a contradictory character himself, and whose fears often disorient Steinberg.

He shows a tendency to contradict himself and the truthfulness of his testimonies is put

in questioned. This is due to the fact that Sizwe is suspicious of Steinberg's real intention, and it is as if he is to check Steinberg's reliability on a daily basis, as the above quote illustrates. He also seems to forget Steinberg's whiteness when he makes a sweeping statement and acknowledges, in the first place, that white people are usually suspicious of treachery. Then, he goes back on his word and blames the Indians on his own personal entanglements, evincing that conviviality between different social groups in post-apartheid South Africa requires greater efforts in order to promote an space for dialogue and mutual understanding. Sizwe's distrust of whites and Indians is the confirmation that in post-apartheid South Africa the cracks of inter-racial relations are identified, and more importantly, of how these relations are somehow maintained despite the ubiquitous and ethnic leveling nature of the virus.

In this space of personal confusion, the multifaceted expressions of grief that are associated with HIV render visible a longing for emotional interdependence. This feeling is further exacerbated by a prevailing climate of mistrust and envy. Sizwe elaborates a discourse on the impossibility of developing strong social bonds in a place in which "the path from poverty to success is watched and noted, and not always with generous eyes" (2008: 20). Furthermore, the expressions of grief also refers to the loss of health and the potential lack of income that go in tandem with the disease. This space provides an entry point for the discussion of the implications that being HIV positive entails in rural South Africa. It is, in fact, a place that in the narrative appears to be doubly marginalized and that is often excluded from the construction of the post-1994 national imaginary, which is mostly informed by the unstoppable winds of change promoted by globalization. Lusikisiki is presented, on the contrary, as one of the strongholds of ethnic culture in contemporary South Africa. This same space is also

underestimated by the discourses of urban modernity and aesthetics that have arisen in the “new” South Africa, especially considering that globalization has passed it by.

In the narrative, this space of reinterpretation and contestation acts as a buffer zone between Sizwe’s inner and outer self, showing to what extent he is willing to entrust his secrets to Steinberg, and conversely, as Steinberg seldom shares his personal views with Sizwe because, as Steinberg states in the quote below, he is in Lusikisiki to write and learn about HIV/AIDS in rural South Africa. If so, he does so in exchange for some information for his own research. This buffer zone, likewise, portrays the tensions that have caught Sizwe’s imagination, and it is the space from whence Sizwe’s silence begins to elaborate –internally– on the yet to emerge narrative of fear and emotional distress. Steinberg captures one of those moments as in the example that follows:

Sometimes, when we go walking together, all I need do is point at something, anything – a circle carved into the hillside by a bolt of lightning, an unusual tree, a hilltop – and a story will flow from him. About illness he is not comfortable sharing his thoughts. The tension pulls his head into his shoulders and he observes me warily. I am knocking on the door to a universe in which I do not belong – because I am not family, because I am white, because I am a writer, because there are matters about which one does not speak lightly, and others about which one does not speak at all. But I am here, after all, to write about illness. (2008: 136)

The selected passage clearly and unequivocally develops some of the concerns of Steinberg; most significantly his determination to create a story about the emotional world that surrounds the epidemic. More importantly, it evinces Steinberg’s awareness of Sizwe’s resistance to talk overtly about the place that HIV occupies, both in his life and the microcosm he inhabits, and which happens to be the locus of inhuman and degrading treatment to sufferers.

The question of reliability is still unresolved at this point in the story. And the way in which Steinberg is finally going to deal with the matter of reliability for Sizwe to put aside mistrust and to open up about his memories will require a great deal of effort

and commitment. The on-going conversations between Steinberg and Dr. Hermann prove how Steinberg tries his best to gain Sizwe's confidence in the midst of an atmosphere that is rife with tensions. Many of the discussions between Dr. Hermann and Steinberg revolve around possible strategies to break down communication barriers with Sizwe. Steinberg is aware of the restrictive social structures in which Sizwe is trapped, but of which he is also the victim of. Therefore, the idea of persuading him to develop meaningful friendships out of the possibility of going public and talking about HIV take center stage:

Your friend Sizwe, if he goes to test and he tests positive, then yes, the people in his community will know, and he will make some enemies. But the friends he makes will be more important than the enemies. The people testing positive develop meaningful relationships, the sort of relationships they have never had. (2008: 98)

This quote anticipates the possible consequence of Sizwe's greatest fear that his neighbors can find out his state of health if the test comes back positive. But Dr. Hermann is quick to point that only if Sizwe dispels the doubt will he be able to become part of a trusted network of solidarity, enjoying the blessings of true friendship as a path to internal peace. Sizwe's "keeping inside" attitude is deeply rooted in his sense of the cultural divide within an extremely frightened community. Lusikisiki is apparently a pleasant place close to the sea that can give visitors refuge from urban stress. It is surrounded by nature and described as ideal for bird watchers, but the tensions underneath remain latent because people "find no work at all" (2008: 26) and because each single step out of line can be punished. This aspect becomes of paramount importance in order to understand why Steinberg struggles to get hold of Sizwe's testimony in one of the remotest areas of the Eastern Cape. In this particular location time seems to go slower and progress seems not to take place as expected. This is one of the most, if not the most, victimized community as regards HIV statistics within South

Africa (UNAIDS 2018). Since economic progress and prosperity are not in the offing, the prevailing ideology encourages villagers to isolate sufferers both socially and economically, thereby perpetuating the structures of abject poverty. This aspect strictly enforces a thoughtful and introspective profile on Sizwe. Sizwe's refusal to test and his silence, however, offer possibilities of interpreting these two core aspects of the story through the subjective lens of Steinberg, for whom the theory of conspiracy (see Natrass 2012) finds support in some sections of Lusikisiki society. Key members of the population uphold the belief that the "doctor's needle" is "an instrument of genocide" (Steinberg, 2008: 189-90) to restore the old apartheid regime. With HIV/AIDS, the fears of the past come to life again, and Lusikisiki, a place with monolithic beliefs, and where progress has fallen short of what modern South Africa hoped to achieve in rural areas, becomes the perfect setting for the emergence of old prejudices.

4. 4 Silence, Stigma, and *Sangomas*

This suspicion, in turn, sustains somehow the belief that issues of AIDS mourning are built on the aftermaths of apartheid (Thomas, 2013), and more importantly, the popular misconception endorsed by *sangomas* since, according to their beliefs, "there are two ways to get AIDS. One is through sex. The other is through people, people who hate you" (2008: 218). The spread and general acceptance of the second way among locals is particularly risky, particularly because it makes room for indigenous superstitions. *Three Letter Plague* combines indigenous notions of health with those that belong to Western countries, thus showing the twofold strategy for fighting the epidemic, and, consequently, the cultural divides that result from them as well.

Although the existence of a well-run testing programme in the story is not likely to be ousted from the village, Steinberg documents the challenge that *sangomas* represent to the consolidation of HIV treatment. In connection with this, traditional healers claim they can cure AIDS with "herbs [they] have been told to fetch in [their]

dreams” (2008: 253). This one instance positions Steinberg’s narrative focus at the critical intersection between science and alternative science, especially when the traditional healer provides an account of the lack of effectiveness of Western drugs. In her analysis of the conduits of knowledge between the living and the dead, Patricia C. Henderson observes that ancestral shades “[have] chosen to bestow upon [the healer] the gift of divination and/or healing” (2011: 116). Divination infuriates Dr. Hermann due to the lack of empirical evidence it provides. Steinberg checks indigenous beliefs against Hermann and the latter opts-out of the discussion as a sign of contempt for the lack of proper medical knowledge of healers in, at least, the areas concerning infectious diseases.

However, in the text, supporters of *sangomas* provide an account of what in their eyes has an undermining effect on HIV sufferers’ human dignity. These testimonies relate to drug distribution:

It is humiliating. Before the gaze of their community they are outed as the bearers of a disgraceful disease; they must sit in support groups run by fiery young women and for the rest of their lives they must swallow ghastly pills that serve only to remind them that they are sick and that each cough or bout of diarrhea could lead to death. (2008: 258-9)

The selected passage underlines some pressing issues of the human condition, namely the unnecessary lengthening of human suffering and the debasing treatment of HIV sufferers in the public eye. The scene explores the nature of the representation of both individual and collective trauma exacerbated by the looming possibility of death. The employment of historical present in Steinberg’s *Three Letter Plague* delves into the aspects of human misery. Likewise, there is also criticism of the inappropriateness of social and human accompaniment in the last part of HIV sufferers’ lives, highlighting, once again, the social divides between the healthy and the sick. For this reason, HIV communities should strive to foment the inclusion of those who tested negative in their

day-to-day activities to normalize what being HIV positive entails. One enticing aspect of the support group talks is precisely the possibility of airing their problems as the outcasts of rural society.

The breaking of silence and cultural divides are essential for the construction of the HIV community in *Three Letter Plague*. In this regard, the narrative takes a sudden turn when Kate MaMarrandi and Nombuelo, two community workers, appear on the scene. MaMarrandi serves as a role model for Sizwe. It is due to her presence that Sizwe begins to look within himself to unlock his own traumas and “to make sense of the past in order to live with it in a less painful way” (Roth, 2012: 77). Sizwe best embodies the idea that trauma creates an almost ever-lasting silence, as he feels trapped in those episodes of danger, real and imagined, in his mind, and feels incapable of encountering a manner to articulate the various conflicts that torment his mind on the meaning of living a life lived with AIDS. In this sense, I argue that Sizwe goes through different states and processes as the story unfolds and as he becomes intimate with Steinberg and the community workers based in Lusikisiki. More specifically, Sizwe moves from a process that illustrates Cathy Caruth’s concept of the struggle to represent the traumatizing event (1996: 6) to a process in which he gradually elaborates on the meaning formation of his experience with AIDS (Srubar, 2016) until his trauma is retrievable. This shift in Sizwe’s attitude towards HIV/AIDS proves the healing power associated with the narrativization of the traumatizing event as well as the therapeutic benefits of such an instantiation of empowerment in life-writing. In so doing, the character of Nombuelo plays a significant role in the personal development of Sizwe as an individual who engages with the community. Nombuelo develops a strategy that rests on the healing power of verbalizing internalized traumas and fears. This responds to the need for breaking the divide between the HIV positive and the HIV

negative, thus promoting the principle of inequality. Against this, Sizwe remains ambiguous and “doesn’t want to know for sure on which side of the line he stood” (2008: 300). This exercise compels him to confront the nature of his fears, very especially when he confesses he fears losing his hard-earned reputation within the village.

From that moment onwards, Steinberg’s efforts are to unravel true ethnic motivations for there is no possibility for Steinberg to illustrate the working dynamics of HIV and ethnicity without Sizwe revealing more private aspects of his subjectivity in greater depth. For this reason, Steinberg himself shares his own past traumatic wounds with Sizwe and recalls his testing experience. This is of utmost importance taking into account that Steinberg is willing to understand why Sizwe refuses to test, providing an space for the articulation of Sizwe’s fears and anxieties. Eventually, this narrative of illness plays itself out in Sizwe’s mindset and “the trauma [he is] imagining, it is something [he has] already experienced; [he has] already survived it” (2008: 346). This aspect of Sizwe combines the power of trauma with the power of the mind, as Sizwe truly experiences the meaning of being HIV-positive when he actually refuses to be tested on the grounds of his own fear. In his mind, Sizwe connects with the shock of testing positive. The sociologist Kai Erikson describes this type of traumatic experience as if “something alien breaks in on you, smashing through whatever barriers your mind has set up as a line of defence. It invades you, possesses you, takes you over, becomes a dominant feature of your interior landscape, and in the process threatens to drain you and leave you empty” (Erikson qtd in Leydesdorff et. al, 1999: 2). In *Three Letter Plague*, Steinberg makes the interior landscape of Sizwe readable, translating the body language of Sizwe into a discourse that builds on the normalization of the fear of AIDS

as a human experience that reminds us of our inherent vulnerability to external threats, as is the case of HIV/AIDS.

4.5 Conclusion

In conclusion, *Three Letter Plague* provides a full sweep of the AIDS epidemic on the levels of health, culture, ethnicity, politics, trauma and community studies. The publication of Steinberg's biography of both Sizwe and his community covers a wide range of topics insightfully. Despite covering all these topics the narrative does not offer a resolution to Sizwe's conflict, which remains a mystery. *Three Letter Plague* constitutes the bedrock of powerful human values and experiences out of which South Africans and rest of the world's citizens are able to confront or even question their own fears in relation to this deadliest infectious disease. Such a thing requires not only the personal disclosure of individuals' in terms of sexual appetites, which very often includes admitting individuals behave in ways that allow HIV to spread, but also strength to accept that unsafe sex can change the fate of individuals and their relatives, as caretakers. The perception of black men in the white imaginary, as a clear social construct that seeks to undermine black agency, often leads to consider black men as hyper-sexualized subjects whose sexuality must be tamed in order to preserve purity. This will be discussed in in greater depth in chapter 6. In regard to this, AIDS life-writing is an open window into complex social realities of our contemporary age, and this is most laudable.

Chapter Five: Nkosi's Haven: A History of Resilience and Efforts in Support of Children with HIV/AIDS in Jim Wooten's *We Are All the Same* (2005)

5.1 Introduction

Post-apartheid South Africa continues to face a period fraught with demands of social justice and the need to cooperate to address the challenges brought about by the HIV/AIDS epidemic. Both the opportunities and the challenges associated with the spread of the epidemic in South Africa have underpinned the redefinition of the country's social protection and healthcare systems. AIDS has become one of the biggest killers of South Africa²⁸, and the sheer number of victims is still disquieting today. Against this background, South African children have turned out to be the innocent, invisible victims of the disease. The lack of access to measures that could prevent mother-to-child transmission of HIV when these were available has left a deep imprint on today's South Africa. The growing number of AIDS orphans evinces that institutional action has to be taken immediately to halt this additional side effect of the virus, with permission of the current COVID-19 pandemic.

In this regards, the senior correspondent with ABC news, Jim Wooten, creates a story whereby he engages with the evolving socio-political landscape of South Africa after over 40 years of apartheid. *We Are All the Same* (2005) enters into the life of Nkosi Johnson, a Zulu child infected with HIV, who has developed full-blown AIDS. Despite trying his best to beat the odds, Nkosi dies at age 12 after a long battle with AIDS and its opportunistic infections. However, his death was anything but in vain. Nkosi's legacy lasts till today as one of the most representative persons of an era in which HIV/AIDS care had to be built almost from scratch in South Africa. His host mother, Gail Johnson, a white South African of Jewish origin, who was also adopted by

²⁸ Source: <https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/south-africa> Accessed: 21 September 2021

a middle class white family when she was a child, provides for him. Gail is in the midst of a personal crisis, fighting to keep afloat a business that is never going to bring her satisfaction until she puts an end to that senseless situation in her bid to do something more social and meaningful with her life. Together they manage to break down the barriers of fear, intolerance and social exclusion. Their boundary-breaking contribution to the fulfilment of human rights in South Africa implies high standards of active citizenship, which is most laudable.

Nkosi's story touches the heart of the American journalist, Jim Wooten, whose work on the life of Nkosi responds to the fact that he was "powerfully drawn to this child and this woman, as much as [he has] been drawn to Africa [himself]" (2005: ix). The personal experiences of Nkosi and Gail put a human face on pressing human rights and the daunting statistics of South Africa's HIV high prevalence among children. Still today, these statistics shock the nation and the entire world despite recent efforts to curb the epidemic. Wooten's mediated narrative places great emphasis on the historical, political and emotional realm of Nkosi's life narrative, although in times of coronavirus the actual COVID-19 pandemic has very possibly dwarfed the HIV/AIDS epidemic. In so doing, the ethics and dignity of both this child and his host mother astonished the country, paving the way for others to stake a claim on their rights to survive their acute illness and benefit from the available antiretrovirals on the market. Such a thing requires breaking the silence and abandoning anonymity.

Likewise, the author takes on an active role in the narrative, making himself part of the story to fully understand the emotional terrain on which it occurs. Thus, Wooten also pays attention to the social milieu in which the story is set for the most part. The transformation of the city of Johannesburg is a symbolism that reveals the steady

deterioration of human relations and the continuing decline of the economic fabric, which is directly linked with the HIV/AIDS epidemic as one of its triggering facts:

Johannesburg, the country's largest city –the financial, cultural, and commercial powerhouse of South Africa– had deteriorated into one of the most dangerous places in the world, its central business district a cardboard city, with hawkers, the homeless, thugs, muggers, pickpockets, and gangsters cramming the streets and jamming the sidewalks (...) Nationally, an average of one rape occurred every minute of every hour of every day, the highest rate in the world. This statistic included a horrifying number of sexual assaults on children, even infants –the grim product of a widespread belief that having sex with a virgin would somehow either protect a man from the HIV virus or remove it from his body. (2005: 180)

Almost two decades after the publication of *We Are All the Same*, and despite some notorious improvements, such as the adoption of the policy of universal treatment, South Africa remains the epicenter of the AIDS epidemic²⁹. Bearing in mind that Johannesburg remains a fledgling economy, the regeneration of the social fabric is a must. Both the city and the country appear to be in dire need of a breath of fresh air and thinking to face the threats posed by HIV to South Africans and to recover from a culture of violence deeply ingrained in the local and national culture. Wooten, Gail and Nkosi walk the reader through the psychoemotional world of a community that is falling apart in the face of HIV/AIDS, which justifies the idea that the construction of an all-inclusive community is anything but a minor goal.

5.2 Geographies and Cultures of the Dispossessed: Scraps of Memory

This section examines the social and ethnic background of Nkosi Johnson, whose family suffers the poverty inherited from decades of exclusionary socio-economic policies. Jim Wooten begins *We Are All the Same* by locating the reader within the complex history of Zulu people, building further on the consequences deriving from the colonial encounter with both the British and the descendants of the Dutch, the Afrikaners. The resulting unequal balance of power has not been deterred by the arrival

²⁹ Source: <https://www.csis.org/analysis/worlds-largest-hiv-epidemic-crisis-hiv-south-africa> Accessed: 24 September 2021

of democracy, and prevailing violence in post-apartheid South Africa, as noted earlier, has also contributed to the spread of the disease. One of the examples of South Africa's culture of violence has been discussed in chapter three (see section on Thokozani Mthiyane), and in *We Are All the Same* Jim Wooten deals with another representation of the historical roots of the country's structural disadvantages in urban settings. For instance, Loren Kruger (2018: 30-31) highlights how the post-apartheid violence has its roots in poor urban planning and inadequate land use in the apartheid era, giving rise to episodes of violence and the consequent deterioration of the social fabric. This is the case presented in Nkosi's life narrative when Wooten explores the family background of the child, and the difficulties they go through in order to scrape a meagre existence in one of Johannesburg's shanty towns. Zen Marie (2018: 106) builds further on Kruger's insights and places emphasis on the invisibility of systemic violence, often enmeshed in administrative layers, to justify the failure of urban governance to prioritise services in socially and economically depressed areas. Nkosi's family is accurately represented by the observations of Kruger and Marie as suffering from the lack of proper infrastructure and poor sanitation, amongst other pressing issues, compelled Daphne to give Nkosi up for adoption. Such an event has furthered into Nkosi's biological family's trauma, as they belong to a generation of Zulu people that had been previously uprooted from their ancestral land and forced into labour migration to survive. The immediate consequence of the disconnection of support from their ancestral community results in the further exacerbation of their social and economic outlook, rendering them still more vulnerable in the face of HIV/AIDS. Additionally, another traumatic consequence of the falling apart of their ancestral culture translates into the fact that their sense of attachment to place is vanished, forcing them to inhabit the no-space, where they belong neither to the global South Africa promoted by the workings of capitalism nor to the mixture of black

ethnic cultures that cohabit in shanty towns, where they barely tolerate themselves on the grounds of old ethnic quarrels.

Wooten's historical approach to the falling apart of Zulu people, especially after the period of forced migrations which dislocated family and clan structures, is key to tackling the root of the problem in light of the contemporary and grasping the context in which Nkosi was born, surrounded by women. The latter is significant because it illustrates one of the cracks conducive to the breaking up of Zulu families. This stems from those early days when the booming of the mining industries in South Africa forced Zulu men to take up employments away from home to pay imposed taxes in the midst of escalating violence in late nineteenth and early twentieth centuries, respectively. This fact highlights the erosion of traditional Zulu communities, and the beginning of a big ordeal through which Zulu culture was to pass. Such an element places emphasis on the gradual loss of ceremonies and rituals that used to bring together the members of the community in the past. The fact that the members of the community can no longer rely on the system of traditional networks of solidarity represents an impediment for the further development of Zulu communities.

The history of Daphne, Nkosi's biological mother, attests to the fact that the disintegration of the Zulu social fabric is partially responsible for her abject poverty. Daphne has to leave the village to earn a livelihood in her bid to provide an adequate life for herself and for her daughter, Mbali, and her mother, Ruth, in Johannesburg. The family works in harsh conditions to scrape a living, and it is in Johannesburg where Daphne contracts the disease after having sex with a stranger. Abject poverty makes it impossible for them to thrive in life, all the more so considering the further implications that the disease entails, namely ostracism, marginalisation and stigma. Extreme poverty is not new to any of them. Ruth, the grandmother and matriach of the family, recalls

that, when she was a child, poverty was already deeply-rooted in Zulu settlements in Johannesburg and that “among the first phrases she learned to say was *kodwa silambile*” (2005: 12) which is the Zulu phrase to express “we are hungry” in English. Nkosi’s mother, Daphne, “would only know deprivation” (2005: 18). The psychological effects of chronic poverty make room for themselves as the narrative unfolds, providing serious insights into the implications of economic violence in South Africa. Before she passed the HIV condition to Nkosi she gave birth to a healthy baby girl she named Mbali, but they were all destined to a sad fate due to structural factors such as systemic racism and the unequal distribution of wealth. It is in this aspect where Jim Wooten focuses on his account of the life of Nkosi without giving up on his efforts to underline that, whatever the difficulties involved, the child never surrendered. Nkosi fights for his right in the company of Gail at a time when the country was mute to the subject of HIV/AIDS at the very turn of the twenty-first century, and in the midst of a national celebration.

We Are All the Same discusses at great length the social and structural determinants of HIV risk and vulnerability in informal settlements, such as social marginalization, stigma and discrimination. In this sense, one of the central themes in the narrative is the lack of discussion on HIV/AIDS in South Africa, and this draws Wooten’s attention to investigate it further. The narrative portrays people’s unwillingness to come to terms with the epidemic. Instead, their choice is to speak of HIV/AIDS only in abstract terms, as has also been discussed in chapters three and four, where the issue of social stigma and silence around the expression of grief and mourning have been dealt with in order to illustrate the impossibility of some of the characters to face the implications that HIV/AIDS entails in the long run. It is not until page forty-six that Wooten refers to HIV/AIDS by its name. Until then, a wide range of euphemisms such as “the thin disease” or “the radio disease” (2005: 46) are often used

among black South Africans, Zulus amongst them. In the midst of all this, children like Nkosi grow unprotected. Wooten's narrative mediation gives prominence to children's and women's rights in its emphasis on developing HIV/AIDS-friendly policies in such areas as childcare, access to adequate medical treatment and the right to have an opportunity to thrive in life. The first part of Nkosi's life narrative draws attention to the fact that Nkosi was born into a very poor family, struggling to survive in a social context in which the rule of crime and the brunt of indiscriminate violence rather than the rule of law dominates. Thus, the narrative delves into the ordeal suffered by Nkosi's family when their neighbors in the shacks find out about both Nkosi's and Daphne's medical condition. As a result of social pressure and close surveillance, the family is, again, uprooted from their community, and forced to leave their place as the outcasts of what was once their home. In the course of their involuntary exile, Daphne comes into contact with Gail Johnson after learning that Gail is running a home for terminally ill AIDS patients, mostly gay men, in Johannesburg. This event changed the course of their lives, as they started together the great mission of giving HIV/AIDS visibility in the public sphere.

One of the central aspects of Nkosi's life narrative lies in Wooten's ability to gather together the scattered roots of modern Zulu culture. In this way, Wooten, in a pedagogical note for readers who are not familiar with Zulu culture, raises awareness on the process of deterioration that has sped up considerably since 1948, dismantling the distinctive ethos of South Africa's largest ethnic group. Rosenblatt and Nkosi draw attention to this fact when they claim that former independent Zulu agriculturists "were forced to work for next to nothing in the mines, fields and factories and other locations where their Euro-African oppressors needed laborers" (2007: 68). This process of forced labour and deterioration of Zulu culture, which, as noted earlier, also takes the

form of forced exile, is largely presented as the core element of the deterioration of the social fabric in *We Are All the Same*. Thus, the reader witnesses the effects of the mechanisms of social and economic impoverishment on the psyche of the matriarch, Ruth, and how she is unable to find a way out of the impasse in which they are trapped. The early stages of the story, namely chapters one and two, center around the reasons why Zulu people, including Nkosi's family members, scattered to remote areas where they could, at least, subsist on very low incomes. Wooten elaborates further on the origins of the trauma that strikes the whole family in his attempt to understand the psychology of conflict. In this way, Wooten provides reasonable context for the understanding of Daphne's complex situation. In this context, the relational structures of the changing and transformational social relations in South Africa take centre stage. This drawback gives rise to structural impediments in the pursuit and achievement of life goals and against the harmonization of social bonds in what was once Zululand, especially after the banishment and death of the last Zulu king Cetshwayo in 1884 and the *Mfecane*³⁰ (Cope, 1995). Within the limited ideological world of apartheid, to use Wooten's words, "young Zulu girls focused more on boys and babies than on dreams of a different life" (2005: 41). Such an attitude towards life on the part of individuals like Daphne might as well respond to the lack of a realistic promise of relief or good prospects for upward mobility. In place of a dreamy life, flirting and sexual encounters fill the vacuum left by apartheid's deprivation. The continuing marginality strictly enforced by mobility restrictions also foregrounds Daphne's inability to transcend the imaginative constraints of apartheid's rigid class and race systems. In that context, Daphne finds pleasure in unprotected sexual encounters and the disease is, perhaps, the inevitable outcome of the sum of atrocities perpetrated over the last decades.

³⁰ Source: <https://www.britannica.com/event/Mfecane> Accessed: 21 September 2021

A handful of studies (Henderson, 2011; Ross et al., 2011; Saul and Bond, 2014; Garb and Mokoena, 2019; Hlongwane and Ndlovu, 2019) document the gradual disempowerment of Zulu people over the last two centuries. Material impoverishment, cultural loss, forcible removals, labour exploitation, and forced labour migration, amongst other issues, have undeniably affected the future of Zulu people. All these have also influenced the course of Nkosi's family's lifetime, including his own, as his poverty is the result of a process constructed over the years by white oppressors since colonial times. Nalkur (2005: 461) points out the way Wooten unites "South Africa's political history with the epidemiological development of HIV/AIDS" to bind together the importance of public policies, future endeavors and the construction and representation of post-apartheid's national memory. Indeed, this connection turns out to be of paramount relevance, as described both in the text and the Constitution, to the modern construction of South Africa. Section 27 of the constitution of South Africa indicates that everyone has the right to have access to health care services³¹. The whole family, in turn, appears to be trapped in a pattern of acts contrary to the purposes of development and emancipation, which proves that the lack of social justice has its roots in the postcolonial impasse after the abolition of apartheid, when the maintenance of white privilege was tantamount to implementing a democratic system. Profound and sustained socio-economic inequality paint a disturbing picture of the conflicts that are causing upheavals in this land devoid of opportunity or hope for them. Additionally, lack of access to adequate treatment and Zulu beliefs in relation to AIDS, namely the attribution of illness or misfortune to spirits, undermine their chances to survive (Clapson, 2010: 18). Wooten's knowledge of and abiding interest in South Africa stems significantly from his readings of Alan Paton's *Cry, the Beloved Country* (1948) and

³¹ Source: <https://www.gov.za/documents/constitution/chapter-2-bill-rights> Accessed: 28 September 2021

Nadine Gordimer's work. The Nobel Prize winning author has largely influenced Wooten's perception of South Africa, a place that Wooten had long imagined. Healy-Clancy's critique of Gordimer's literary work in times of apartheid highlights the political commitment of Gordimer's writing, and how it "led her to appeal to liberal values of individual creativity in interest of radical political transformation" (2019: 250). Wooten draws from the same spirit that ushered in the theoretical foundations of democracy, seeking to air the inconsistencies of democratic South Africa and/or highlight the areas that require urgent action, as is the case of children born with HIV. This condition is further exacerbated by the widening gap between white and black South Africa.³²

In line with this, Wooten evinces that the greatest nemesis Nkosi faces is not exclusively the physical disease. Abject poverty, in combination with the shattering of a common ethnic legacy that accompanied the reconfiguration of black South Africa, gains ground substantially in order to determine the fate of the child at a very early stage in his life. At the very outset of the narrative Wooten states that Nkosi "was born in a place that did not exist" (2005: 8), "in a village with no name" (2005: 15) or a place where "no one given a choice would choose to be born" (2005: 16). These are the words chosen by the author to make it clear that poverty, pain and suffering are an essential part of the equation in Nkosi's brief but intense life. Wooten's words also reveal the panorama of thousands of black South Africans all over the country suffering from a variety of physical and emotional harm. Furthermore, poverty, pain and suffering also come to be the result of the forcible removal of Zulus from their pastoral lands, often romanticized by those living in Zulu strongholds, to the Bantustans and/or the townships, which the narrative only partially reproduces.

³² Source: <https://edition.cnn.com/2019/05/07/africa/south-africa-elections-inequality-intl/index.html> Accessed: 24 September 2021

Uprooted and stripped of their identity and culture Ruth Kumalo, Nkosi's grandmother, struggles to raise her children and her grandchildren in squatter camps in the slums of Johannesburg, living under conditions of poor hygiene and settling for the way things are. And along with this has also come the loss of an entire livelihood, the erosion of traditional values, knowledge, land tenure and, to some extent, even forms of care. Thus, Zulus were no longer farmers or herders; they lost control over their self-sufficiency; and their economy began to crumble to the extent that Zulus could not but migrate to urban settings in search of a livelihood. This is precisely the case of Daphne, whose situation in the words of Wooten best epitomizes the continuing failure of a culture forced into drift:

The old Zulu traditions of strong marriages and healthy families had faded into obsolescence. Like the colorful costumes and crafts of the past, they had become quaint if charming relics, not concepts with which Daphne was at all familiar. And who could blame her for concluding, having had no contact at all with her own father or her grandfathers and having already lost track of Mbali's father, that the father of the child growing inside her was similarly irrelevant to her life? He simply did not matter, and if he did not matter, why bother with his name? Like millions of other black South Africans, Daphne had learned not to dream, had learned, as her mother had learned, to be realistic. (2005: 26)

The selected passage evinces how for Daphne there is not much to expect from her life except a broken existence and a dysfunctional family. Yet, in her innermost self, Daphne disagrees with that view and gives Johannesburg a second try in her bid to ameliorate the loss of her children's developmental potential. Particularly, that is the case of Nkosi, whose health state becomes a source of concern and preoccupation for Daphne. Despite the promising news about the end of apartheid, the political arena is of no interest for she "[realizes] with a deadening sadness that the boy [is] ill –very ill– and not getting better" (2005: 43). The looming end of white minority rule in South Africa was not tantamount to considering that the country was going to be a better place overnight right after the abolition of apartheid in 1994. Nonetheless, Daphne is

determined to do whatever she deems necessary to help her son at a time when her health is also constantly deteriorating, and that leads her to suspect the possibility of HIV. Eventually, she manages to make an appointment with a doctor, telling her she had developed AIDS and that she had very possibly given the sickness to Nkosi. It is then when Daphne gets all the pieces right. At the community level, Daphne begins to suffer the disease in silence, fearing the reaction of their neighbors in the shacks. Much to her surprise, her secret is one that does not remain for long and her ordeal is made public, meaning that ostracism and rejection gain momentum in the most unexpected way:

[T]he doctor who had told her of her condition called the beauty salon where she worked and informed Daphne's employer of her condition. Almost immediately she was dismissed from her job. In another week or so, as word spread through the neighborhood where she and her children and Ruth and Cynthia were living, the five of them were summarily evicted from the two miserable rooms Daphne had rented.

"We begged the lady," Cynthia said, "but she wouldn't change her mind. She said Daphne was too sick to live there, and she thought probably the boy was, too, so we had to leave. My mother was angry at the woman and spoke hard words to her and called her many names, but Daphne just pleaded with her and offered to clean her house for free if she would let us stay. She still said no. I think she was afraid she would catch the disease from Daphne or something. I think that's what everybody was afraid of. They didn't want to be anywhere near us. (2005: 59-60)

Paradoxically, a similar situation is observed regarding the COVID-19 pandemic and some people's reactions when they found out nurses and doctors were living next to them. It remains a mystery, though, why the doctor betrays the confidence of Daphne. Clearly, the doctor's health assessment does not comply with the standards of medical confidentiality, jeopardising her future. As a result of the doctor's malpractices, which clearly shows the ignorance, even among the medical profession, of how HIV could be spread, Daphne not only loses her job to someone else but also the possibility to provide for Nkosi. At that point in the narrative, the child stands at a critical juncture and at a very decisive point, all the more so considering that without treatment Nkosi is to be

found, sooner or later, at a serious risk of harming himself. Apparently, Daphne does not hold a grudge but must battle on, both jobless and homeless. In the end, the shacks are not a safe place to live in anymore. Daphne's and Nkosi's HIV condition, besides uprooting them from a wider society, fractures the family, dissolving any community bond by turning them into outcasts. As Wooten observes:

Daphne had become anxious about the increasing level of hostility toward her and the boy from some of their new neighbors in the little squatters' camp, many of whom seemed to subscribe to the same notions about AIDS as had her former employer and her former landlady. Even Ruth, her own mother, seemed less and less interested in keeping the family together. She and the neighbors were frightened of the mysterious disease and those who were infected with it. Some of the neighbors had made veiled threats. Others were not so subtle. One day Daphne found a menacing note left under a stone in the dirt in front of their shanty. It said simply *Leave!*

When she read it, she made a radical decision. (2005: 98)

It is against this background that Daphne faces a choice: either place Nkosi for temporary adoption or condemn him to a slow and painful death. The same doctor seems to push in that direction when he lets Daphne know about the existence of the Guest House for terminally ill AIDS gay men in a middle-class suburb in Johannesburg. Without hesitation adoption becomes the only possibility to give Nkosi a chance in life despite the serious implications such a decision may entail for the whole family. This was possibly a source of relief for Daphne, anticipating the fact that she could no longer take care of the child. It is the right thing considering the hostile environment that surrounds the family in the shacks. Bearing in mind the situation, this creates an impasse in that Nkosi's very last possibility to grow in a community of equals where all are treated with the same respect and everyone can contribute to a greater or lesser extent.

5.3 A Ray of Hope in the Struggle: Steps to Owning a Voice

The second part of this chapter focuses on the role played by Gail Johnson in providing a safe and healthy environment for Nkosi. The unstoppable progress of the disease is

well underway in Nkosi's case. His state of health is alarming by the time he joins the group of gay men living in the Guest House run by Gail, and whose presence fills the house with joy and merriment. It is at this stage in the narrative that Wooten ties the future of Nkosi to that of Mandela and the evolving future of South Africa. This analogy conveys the political tensions of those days and the fragility of life, which in the case of Nkosi is assumed through the image of itinerancy that marks it:

It's fair to say that during this time both boy and country were struggling to make the best of an uncertain future in the face of a grim inheritance from the past. Whenever the marathon negotiations between the old regime and Mandela's African National Congress appeared to stall, a chorus of black voices was raised, impatiently demanding a solution, threatening an escalation of armed insurrection if none was forthcoming. (2005: 107)

Much work still remained to be done, but the magic of Gail's relentless work in those days of uncertainty is equal to the task. As Rob Nixon puts it in his analysis of the transition period in South Africa, citizens "needed not only to overturn racism, but to reshape the society's cultural values and institutions in anticipation of its democratic metamorphosis" (1994: 157). This is certainly the spirit that drives her work as a creator of well-being to the service of the vulnerable and the dispossessed by apartheid. Wooten recalls her words in which "[she] thought [she] believed [she] could somehow do what no one else had ever done, which was to change the outcome of this infection" (2005: 108). Gail's attitude enables her to be an agent of social change and not merely a passive spectator, fighting "the prevailing cultural antipathy toward homosexuality" (2005: 101) in today's only African country where same-sex marriage is allowed, despite the fact that homophobia still abounds and crimes against LGBT people continue to be perpetrated in large numbers (Brodie, 2020; Gevisser, 2020). Wooten highlights the human and social qualities of Gail, and to some extent she is often presented as a pioneer in the field of social reform within the framework of post-1994 South Africa.

Parallel to her endeavors, Gail Johnson goes through a tough time in her life. She was by then experiencing one of the most complex and dangerous crises ever in her life. Gail's marriage is in the slow process of breaking up, and she struggles to find the necessary strength to put an end to it. Her efforts concentrate on the dreary routines of working politics as a public relations consultant in an increasingly internationally isolated South Africa in apartheid times. Indeed, she spends most of her time trying to save her business while the last throes of apartheid fill her life, paradoxically, of both uncertainty and relief. She needs to give a boost to her life and find something that keeps her going. At the same time, however odd it might sound, a gleam of hope spurs Gail's efforts in the fight for democracy and against an AIDS crisis already in the making, which later on would hit the country the hardest. Her profound desire to build a multiracial South Africa almost from scratch is best epitomized by her fostering of Nkosi. Gail thus validates the principles of unity and integration that the "new" South Africa purports to put forward. At the same time, the narrative reflects internal national tensions among different social groups, especially when Wooten comments on how "Daphne's family were subject to a system and practice of twentieth-century bondage no less cruel, no less repressive with no realistic promise of relief and no prospect of emancipation" (2005: 40). In this sense, Gail represents progress as she wants to put unity and integration into practical use regardless of race.

Gail gets to grips with AIDS for the first time in late 1988, when her best friend's brother dies a lonely death. Gail herself describes her first experience at witnessing AIDS as shocking and as something unspeakable to her husband, Alan, because "[she] had no words to describe it, not to Alan, not to anybody else. [She] was traumatized by it" (2005: 93). Nonetheless, it is precisely that trauma that energizes Gail in her bid to build a community, especially in those early days of the transition to

democracy in which everything was still to be done. Her actions fill modestly but effectively the vacuum left by the apparent breakdown in the government's renewed commitment to provide shelter for the vulnerable in the yet to come "new" South Africa.

One central question raised in the text is Gail's motivation to regenerate the social fabric, including appeals to build interracial partnerships. This is a remarkable fact as Gail contributes to laying the foundations of a "new" society that will have to rely on mutual cooperation in order to overcome the old regime and to debunk apartheid's stereotypes and ideological twistings of how far human development and social relations should work. Although Gail never assimilated into white society, which treated blacks with contempt, "she was not unaware of the history of the place" (2005: 86). Her upbringing in Pietermaritzburg, "the altar at which Afrikaners worship their history" (85), in today's province of KwaZulu-Natal, was marked by the strict sense of order enforced by apartheid authorities. In this regard, Gail acknowledges that the oppressive atmosphere in one of the strongholds of apartheid made her reconsider her role in the country. Gail's consciousness is at odds with the prevailing atmosphere, and that fact places her somehow in the position of a social misfit, as she appears to be alienated from the outreach of apartheid structures.

While her parents do not seem to endorse apartheid as a political system the narrative invites us to consider Gail's disappointment with their lack of a clear commitment against it. This can be read in terms of social imprisonment as the apartheid shackles imposed on Gail are never removed from within the private sphere due to her parents' lack of criticism of this. More specifically, she seems to criticize their acceptance of the whole system under the guise of social conformism and the inviolability of their status-quo as part of the white privileged minority:

“It wasn’t the racism –the apartheid– that was so built into the place,” Gail later said. “That wasn’t what appealed to them. It was just the order of it, all the neatly organized predictability. That’s why they liked it, *I think*. Everybody had a place. Everybody had a status.” (2005: 86, emphasis added)

Gail’s memories of her upbringing reveal her eagerness to enjoy life, and casting about for new challenges she ends up working for a while in Victoria Falls. It is in Zambia where she feels empowered and freed from all guilt, and renewed in her spirit. The psychological distress associated with the senselessness of racism gives way to a period in her life that transcends apartheid and the imaginative constraints of it. That period of much needed reflection endows her with new strength, which is tested when Gail is faced with pregnancy without the support of her father, who is uninterested in a future together. As in Daphne’s case, the man is also irrelevant to Gail’s life; hence the sympathies of the latter towards the former much later on. Pregnancy is a turning point in Gail’s life for she once and for all takes control of her life. Her parents reject the baby, suggesting she is a wayward woman and urging her not to keep the baby she carries. The ideological clash between Gail and her parents pushes Gail to stray from the path of her parents. A new approach to life thus takes shape, and such a thing reads as a symbol of reassertion and authority over her decisions, freeing herself from her parents’ ideological burden as to whether becoming a single mother is appropriate or not – although she married later on with Alan and had another child.

From that moment onwards, both Gail’s agency and commitment to social improvement continue to expand. This is further reinforced by the haunting image of her best friend’s dying brother on whose face and body could be seen the relentless advance of AIDS. Wooten is quick to note that “AIDS was not restricted by apartheid in its array of victims” (2005: 93). This is an interesting observation on his part because it proves right the idea that the all-encompassing monitoring system of apartheid was faulty and that all citizens were equal in the face of AIDS despite apartheid’s efforts to

label the disease as one of gay men. This latter idea is precisely what fuels Gail's response against the silent spread of AIDS in the country. As a result of her engagement with the AIDS cause her life becomes meaningful:

Her marriage was not improving, it's true, but otherwise her sense of detachment from her own life was beginning to fade. At the old mansion in Houghton, among the dying men, in the company of others who cared as much about them as she did, *she found a place where she thought, just maybe, she might belong*. It was called the Guest House. (2005: 95)

Caring for the outcasts and those living on the margins of society nurtures and shapes her perception of community, with a particular emphasis on the notion of restoring dignity and humanity to all residents. And the fact that the caring house is a *guest* house gives prominence to the idea that all residents are temporary and/or about to die within the comfort of a secure environment. Her community work combines successes with failures, such as the closing of the Guest House due to financial constraints. From this position of privilege and marginality, Gail cannot avoid becoming embroiled in a lingering series of complexities. Many of these stem from a history of unequal access to representation and the subsequent absence of the various forms of narratives to voice them. *We Are All the Same* is a reminder of the calamities particular to the postcolonial reality of South Africa, which Loren Kruger (1995) locates in the post-1994 era as the liminal postcolonial moment of the country. As such, Nkosi's life narrative voices disguised stories for the sake of progress and social advancement. In her bid to dignify Nkosi's existence Gail's unconditional love goes a step further when she, still haunted by the recent failure of the Guest House, envisions a place where women and children with HIV/AIDS do not have to lose sight of human development.

The construction of the shelter home for HIV positive women and their children is an idea inspired by Daphne, and a tribute to the thousands of black South African young women in the same situation, without the support of the state, repudiated by their

neighbors, and forcibly displaced. In relation to this, Nina Veenstra (2006) is quick to observe the gaps in the social security package and the need to review welfare approaches in the context of HIV/AIDS in South Africa. In her study, she urges South African authorities to reformulate the welfare state, very especially at the household level. Most of the gaps in the social protection system are found, as the narrative attests, in this field. For example, the fact that Daphne is part of South Africa's relatively robust informal economy prevents her from accessing means tested grants. In this scenario, HIV exacerbates chronic poverty and limits, therefore, social protection to specific sections of the population. The project of the shelter is somehow modelled after this deficiency and begins to take shape in Gail's mind when Daphne's health deteriorates alarmingly. In Gail's view, "each visit could very well be the last one" (2005: 123). Soon after the last visit Cynthia, Nkosi's aunt, calls Gail to inform her about the death of Daphne. As a consequence of this, Nkosi is heartbroken:

I already knew my mummy was very sick, and I already knew that my mummy and I both had the same sickness, and I knew we both would die with the same sickness, but I didn't know she would die so soon, and it made me very sad, and I cried a lot when my auntie told me she had gone to heaven and that I would not see my mummy anymore. (2005: 124)

Thus, the child involuntarily joins the fast growing community of children orphaned by AIDS on the continent. Wooten elaborates further on this social tragedy on South African soil, highlighting the key role played by those who strongly advocate for the community-care approach. The escalating numbers of orphaned children due to AIDS-related illnesses (Breckenbridge et al., 2019; Lombe et al., 2019) put forth a large number of issues that orphaned children like Nkosi might face. The most obvious one in Nkosi's case is the inability of his extended family to cope with financial distress and the routine demand of daily life associated with the disease. As Wooten puts it:

In most of the countries, very little attention is paid to these children, either by the government or by the churches or charities. In a very few places, there are

informal arrangements for community care. The AIDS orphans are unofficially adopted by the villages where their parents had lived, by their uncles and aunts and grandparents, or perhaps by close friends or anyone else willing to lend a hand in their care. (2005: 126)

Although Nkosi is well aware of his good fortune in having found a place where the kindness of Gail makes a difference, the child must deal with the enormous psychological distress inherent in the loss of his mother. Nkosi sinks into a moderate depression, which operates as a reminder of his terminal condition, too. Gail is skilful and diligent in her duty as a mother and wisely confronts the somehow dreaded discussion of untimely death with Nkosi:

“He said he did not want to die,” Gail recalled. “I said, ‘Nobody does, sweetie, but we all do.’”

It was then that his tears began to flow.

“He said, ‘I know that, Mummy Gail. I know that—but I still don’t want to die. I want to live to be old, like you.’”

Gail stifled a giggle at his last remark; she was, after all, only forty-eight. She told the boy in the most serious of tones that she and everyone else who loved him would do everything possible to give him a long and happy life. “That seemed to satisfy him,” Gail later said, “and before long he was back to being his old self.” (2005: 129)

Within this context, the feeling of sameness arises as to how Nkosi can be part of an extended web of human relations. The child can no longer deal with the notion of constructed difference about his own consciousness, limiting his profound desire to share and to express his inner world and creativity with a wider audience. Daphne’s death makes Nkosi reconsider his position in the world he inhabits but that he seldom enjoys to its fullest due to unwanted isolation and loneliness. In democratic South Africa Nkosi remains captive of public ignorance of his condition, suffering in silence well into his childhood social injustice and being held hostage by the strong constraints from within post-apartheid South Africa. To some extent apartheid’s restricted mobility continues to hamper Nkosi’s agency. In one of his encounters with Wooten, the child openly discusses his perceptions on race with the journalist. More specifically, Nkosi

elaborates on the construction of whiteness as privilege when he tells Wooten “[he] wish[es] that God had made [him] white [...] because [he] believe[s] that white children don’t get HIV and [he] think[s] black children do get HIV” (2005: 162). Largely speaking, these words hold great truth, especially taking into account that the virus has rarely infected white babies in Western countries or South Africa. As its core is a discussion of the ways white supremacy tends to perpetuate itself in every single domain of life, it also implicates him in his life with Gail:

“I think I would rather be living with a white family,” he once told me, “because I can eat good food. Every meal I can eat a balanced diet. I don’t think I would still be alive if I was all the time eating black-culture food, which I don’t mind eating but I believe it is not very good for me.”

“I can remember that my real mummy was actually living in an old shack in the township that had dirty toilets, and I know that with my funny blood I must be living in a clean house with clean toilets.” (2005: 162-63)

This is an awkward position, as Nkosi profits from his privilege, proving right Richard Dyer’s remarks on whiteness when the critic points out that the social and political effectiveness of whiteness is a shifting border in which the category of whiteness remains both unclear and unstable (1997: 19-20). Dyer offers several keys to understanding the postcolonial legacy of South Africa, where the permanent presence of white people makes of South Africa a very singular and unique case on African soil. More specifically, Dyer (1997: 18) argues how the incursion of Europeans into non-white territories –and the subsequent assimilation of non-whites into the culture of the colonizer or the rejection of it– favoured the development of a full concept of race, with whiteness on the cusp of races. The establishment of this artificial and socially constructed category reveals that the real link between disparate races relies not on sameness in terms of physical features or skin colour but rather on the set of spiritual beliefs, as Dyer suggests. That seems to be the real boundary around the notion of whiteness. Nkosi trespasses that imaginary border, and both his border-crossing and

Gail's welcoming of Nkosi constitute an act of rebellion by which the child is able to embrace an enthusiastic approach to life and the shifting reality of a multiracial society already in the making. Both represent the future of conviviality in South Africa, and the eradication of racial prejudice.

5.4 Nkosi and Gail: United We Stand! The Modernization of South African Public Institutions

Another relevant strand on this debate concerns the very substance of Gail and Nkosi's actions to put the government in the world spotlight. Part of the narrative reflects the showdown between politics and science and activism. Wooten intertwines the story of Nkosi with that of other Africans in neighboring countries, showing that the HIV/AIDS crisis is a problem in all sub-Saharan Africa that requires strong political leadership. Different responses and solutions to the epidemic elsewhere in Africa that evince the slackness and lack of motivation of South African authorities. Particularly, this is the case of former President of the Republic of South Africa, Mr. Thabo Mbeki, whose position on the AIDS debate has been discussed in previous chapters. Both Gail and Nkosi emerge unscathed from the various difficulties they find on the road to becoming fully fledged subjects of law. This is the case on two occasions. The very first one takes place when the narrative recalls Gail's first attempt to enroll Nkosi in a nursery school:

Gail understood that the fear of AIDS victims was a fear based on widespread ignorance of the disease, the same fear that resulted in the daily punishment and social rejection of its victims in South Africa, in all its many ethnic communities. Because she thought Nkosi needed some regular contact with other children, and given the fact almost no other mothers would bring their children to play with him or welcome him into their homes, she decided to enroll him in a neighborhood nursery school and kindergarten. Because she did not try to hide his condition from those who ran the little school, she was told in no uncertain terms that Nkosi was not welcome. Gail was repulsed by their attitude. (2005: 119)

The selected passage reflects the shared assumptions of the different sections of South African society, ignoring the longings of a child who lives a life in isolation, away from

typical children's activities. Nkosi's medical condition predominates over his welfare in the public sphere, calling into question South Africa's compliance with its renewed commitment to social justice. This is a matter of concern with respect to the democratic accountability of the country. In this part of the narrative Wooten's attention turns to the inner emotional world of Nkosi, all the more so considering the recent death of Daphne. The narrative recalls how Gail's constant attention to Nkosi becomes draining for her until the moment Nkosi is determined to stake a claim on his rights as a child:

[t]he undersize boy who could be so endearing and exasperating, like all boys, suddenly announced to her that he was tired of spending his days alone with the maid while Gail was out running her business.

"I want to go to school," he told her, "just like everybody else."

Gail was surprised. "Actually, I was stunned. It was the last thing I expected from him—and that's because I stupidly believed we were providing everything any child could want. In fact, what he really wanted, we were not giving him, which was the opportunity to be a child among children."

Her first thought when she heard his request was of his blunt rejection by the nursery school when she tried to enroll him as a much younger child. Her second thought, in her own words, was, "By God, if that's what he wants, then that's what he gets—even if it kills me." (2005: 130-31)

Neither Nkosi nor Gail have the slightest idea about the fact that both of them are about to embark on a crucial fight that would change the course of things and of South Africa's immediate future as well. As Wooten points out, both "were about make a bit of South African history" (2005: 131). Nkosi expresses his desire to move forward towards normalizing relations with other children, within a normalizing context that promotes his autonomy and preserves his uniqueness as a positive trait. This is symptomatic of the child's resilient capacity, placing great emphasis on the need to acknowledge that he is like other children.

Both the child and Gail are open about Nkosi's infection at a time when in 2000 South Africa "most of its 43 million citizens were still unaware or in denial of the most significant details of the virus" (2005: 135). The pedagogical undertones of *We Are All the Same* are a question of democratic health in the yet to come reconstructed

coexistence among different sensibilities. The whole adventure is, indeed, a good chance for citizens to actively engage in a potentially successful participatory process. Nkosi's case is also an opportunity for a locally conducted exercise of interaction between civil society and the, then, untested administrative capacities of democratically elected institutions to build consensus around new policies, thus anticipating solutions to the demanding challenges posed by AIDS. It is at this point when the narrative takes a different turn, standing at the crossroads between ethics and politics.

The school casts doubts on the schooling of Nkosi on the grounds of, in their view, the potential risks involved. Parents energetically refuse such a possibility, infuriating Gail, who holds no grudges but insists on Nkosi's right to attend school like the rest of children. As Wooten notes:

The news of Nkosi's application quickly found its way into the local media, both broadcast and print –Gail swore she had nothing to do with it– which soon prompted dozens of parents, black and white, to gather outside the school to protest his enrollment. One woman carried a hand-printed sign that read, WE DON'T WANT YOU, NKOSI! To allow him into the classroom would be dangerous for their children, they argued, perhaps even fatal. It was unfair, they insisted, to expose their children to a boy who was HIV positive. (2005: 136-37)

As understandable as parents' concerns might be, it is not healthy either. The whole issue raises the question as to determine of what importance is a welfare state if the latter is unable to protect and ensure the rights of the most vulnerable citizens. In terms of institutional capacity, it is the most compelling opportunity for institutions to evince the transformation of the public commitment enshrined in the constitution into specific policies. As Wooten states, "there was neither a law nor a regulation that prohibited HIV-positive children from entering South Africa's public schools" (2005: 136). To fill in this loophole, Wooten, a journalist himself, drops a broad hint at the role of media in enhancing dialogue to ease tensions between two opposed visions of the subject matter to be considered. The power of the media instrument to influence people's opinion on

this newly converted national issue is essential to create an atmosphere conducive to mutual understanding and to pursue new steps towards the inclusion of marginalized members of society:

New editorials appeared in the local papers almost daily, most of them favoring Nkosi's admission, asking the city government to step in or, in lieu of that, urging the national government to act [...] Gail was on television regularly, defending Nkosi's admission –and he was on television, too. “All I want is to go to school,” he said again and again in his soft soprano. “All the other children go to school, and I want to be just like all the other children. I don't want to be alone.” (2005: 139)

At that moment, Nkosi's admission and Gail's defense of it would gain momentum, thus becoming not only a benchmark for children's rights but also a national matter which would often be on the front page of national newspapers and magazines. This fact, besides raising public awareness on the issue of HIV/AIDS, provides clear evidence of the powerful nature of both Nkosi and Gail, who stand united for the consolidation of social progress in the late 1990s in South Africa. The story of Nkosi also puts a strain on the social solidarity networks of South Africa as it serves to validate whether or not the foundational policy of all-inclusiveness is put in practical use. Given its impact on the future success of civic coexistence, issues related with HIV children in conflict with legal vacuums achieved the category of “major concern”. The response of the national government pushed in the direction of safeguarding social rights:

Finally, acknowledging the enormous pressure for someone in authority to deal with the situation, the national government stepped in. In late February, just in time for the new semester, the South African Parliament, in session in Cape Town, enacted an antibias statute that made it illegal to keep HIV-positive children like Nkosi out of public schools. (2005: 140)

The outcome of these discussions made Mandela's words good when he committed himself to building equality and said that “never and never again shall it be that this beautiful land will experience the oppression of one by the other” (qtd in Etuk 2008:

154). This landmark achievement has helped redefine the boundaries of an existing community, allowing Nkosi to believe he belongs there and to develop friendship with other children. After their public crusade, Nkosi's reward was opportunity and equity.

International media would pick this story up, such as, for example, *The Guardian* or the BBC, amongst others³³. As a result of this, Gail and Nkosi embark on fundraising events in the United States. Several trips to the U.S. reinforce the sense of Gail's relentless work in ensuring that HIV/AIDS children and their mothers are part of the political agenda without further delay. In the United States Nkosi takes on very seriously the role of HIV ambassador, ensuring Americans have a clear understanding of HIV/AIDS and its meaning in the lives of both blacks and whites:

He was onstage almost all the time, meeting people, answering questions from callers on the radio, making little talks at women's clubs and AIDS organizations, at two or three schools. I didn't anticipate before we left that he had already become such a little star in New York— but that's what he was. Of course, that was right down his alley. I think that's actually what kept him going when the going got tough. (2005: 154)

Visibility in the United States also constitutes a good chance for Gail to give a boost to her cherished project, the shelter for HIV-positive women and their children. The shelter would eventually open its doors under the name of Nkosi's Haven, after capitalizing on all the attention their story had attracted³⁴. Again, the notion of sameness becomes of paramount importance because Nkosi "felt a great kinship with them, if not because of race then certainly because of the commonality of their disease" (2005: 150). Sharing the HIV condition with formerly invisible subjects helps Nkosi cope with the disruptive and often distressful elements of his sometimes troubled existence, especially with his

³³ Source: <https://www.theguardian.com/news/2001/jun/02/guardianobituarie.s.aids>
Accessed: 24 September 2021

³⁴ Source: <https://www.seattletimes.com/seattle-news/in-south-africa-a-welcoming-home-for-hiv-positive-mothers-and-their-kids/> &
<https://www.britishmuseum.org/collection/term/AUTH233307> Accessed: 24 September 2021

diarrhea and chronic fatigue, which are common symptoms of the disease (Spirig et al., 2005; Nicholas et al., 2010).

The construction of the shelter gives Nkosi an identity, and shapes his perception as an individual who can be of use to society. The child senses he can make something meaningful with his life, despite the obvious limitations of his illness. Empowerment, an essential feature of life-writing (Bateson, 1989; Olney, 1998 & 2017; Couser, 2009; Moore-Gilbert, 2009), takes the shape, in Gail and Nkosi's case, of service to the outcasts, the dispossessed. The construction of said shelter best illustrates how important is to put in practical use the ethics of community care that Nkosi and Gail promote through their discourse of sameness and equality. In this way, the story of Nkosi goes beyond the pages of *We Are All the Same*, giving rise to the emergence of affective bonds through the powerful articulation of life-writing which, in turn, helps to neutralize the impact of the silences of trauma on affected individuals. In particular, Nkosi disconnects with his own grief the moment he breaks his silence to regain authority over his daily routines, expressing his desire to attend school and make friends. Nkosi deploys human rights discourse and instigates affective responses with certain moral undertones and evaluations regarding the implementation of a more socially oriented agenda in the "new" South Africa. The child's experience with AIDS is used as his vehicle of self-expression and self-construction, thus promoting both mechanisms of affect and change in transformative action. Nkosi and Gail's activism further develops resources for human rights, complementing the relentless work of Zackie Achmat's Treatment Action Campaign in the area of childhood through the creation of solid affective bonds. Love for the suffering person and for the HIV/AIDS community demands a high degree of self-sacrifice, as attested, especially, in Nkosi's, Achmat's, and Cameron's life stories. Such an active approach to AIDS activism

confirms Sarah Ahmed's idea that the so-called "love groups" act as driving forces for change, and HIV/AIDS life-writing is imbued with a deep love for recovery and human dignity. As Ahmed points out, "[l]ove is narrated as the emotion that energises the work of [love groups]; it is out of love that the group seeks to defend the nation against others, whose presence then becomes defined as the origin of hate" (2014: 123). The recognition and implementation of the rights of AIDS and HIV-positive people to live a healthy and meaningful life is certainly a means of redressing past and current injustices in South Africa, and of enabling the disadvantaged to live with greater dignity. However, there still exist some outstanding issues on which authorities need to step in so as to join forces with HIV/AIDS activism, especially considering that no significant improvement is evident in other areas of public life in the context presented in the life narrative.

Most transgressively, and central to Nkosi's biography, is the second chance Gail and Nkosi have to engage, if unintended though, in public debate with authorities. This second episode takes place when Nkosi is invited to participate as a keynote speaker in the international conference on AIDS held in the city of Durban. Shortly after their successful introduction in the United States, the national government is at last willing to express its views on AIDS. However, Mbeki and Gail and other AIDS activists do not speak the same language. Mbeki believes in the idea of an omnipotent apparatus which operates in the shade in its attempt to commit genocide against blacks. Here, Mbeki acknowledges the many dangers looming on the horizon in the mid term due to the spread of the virus:

"For too long we have closed our eyes as a nation, hoping the truth was not so real.

For many years we have allowed the HIV virus to spread...and now we face the danger that half of our youth will not reach adulthood. Their education will be wasted. The economy will shrink. There will be a large number of sick people whom the healthy will not be able to maintain. Our dreams as people will be

shattered.” No one in the government had nailed it any better than that. (Mbeki qtd in Wooten, 2005: 188-89)

From Mbeki’s perspective, any strategy for combating AIDS is to attack abject poverty and hunger, questioning the cause of AIDS –as seen in previous chapters– in the terms established by western science. This latter thing is precisely an obstacle which hinders the government’s relationship with the scientific community. Against this backdrop, Gail and other activists consider that perhaps the discourse of an HIV-positive child at the conference might make Mbeki change his mind. But the truth is that his own personal belief, as with Mandela but for different motivations, was creating a stifling atmosphere in the country, especially when two drugs –AZT and nevirapine– were offered in large quantities to South Africa at no cost to reduce the odds of mother-to-child transmission of HIV. Still, he would question the existence of the virus and what is worse, he angered average South Africans when he declined the offer:

Archbishop Desmond Tutu, the Nobel Laureate, was shocked. “The government’s stand on nevirapine,” he thundered, “has made South Africa the laughing stock of the world.” Mandela, the former president, said nothing. Nothing in public, at least. His friends said he was in an awfully tricky and difficult position. He did not disagree with Tutu regarding the government’s policies on AIDS and AIDS medications, but at the same time he did not wish to be seen as interfering with Mbeki’s stewardship of the country. AZT was already available at several private clinics and hospitals in the country, but the government issued a national ban on its use by prohibiting them from prescribing it for HIV-positive patients, including pregnant women, in public medical facilities. The reason given? AZT was untested and dangerous. (2005:190-91)

Later on Nkosi would take up on the issue of AZT. Wooten, in his former role as a war reporter, insists throughout the narrative on the actual fact that HIV/AIDS has killed more Africans than armed conflicts (Elbe, 2002). In his argumentation Wooten praises the attitude of the former Ugandan president, Mr. Museveni, whose government policies and programmes had been geared towards strengthening the various components of his strategy to curb the epidemic:

“In other words,” Museveni concluded, “AIDS is not only on our national agenda, it is in our minds all the time. In my meetings, when we discuss the economy, imports and exports, anything at all, whatever it is, we do so within the context of AIDS and HIV. When we discuss budgets and taxes, we do so with the understanding that the presence of the virus among us and its threat must be part of our planning. When the subject is the military, we acknowledge that it is a threat to our national security [...] The number of Ugandans being infected was steadily declining because something had been done. An effort had been made. (2005: 173-74)

Within the South African context, Wooten draws a clear distinction between Mbeki and the former Ugandan president, Museveni, suggesting the latter is a referent in the struggle against AIDS on African soil. Museveni’s actions are in stark contrast with Mbeki’s, who seem to champion the idea of an African renaissance as the best possible solution to tackle (South) African misfortunes. However, Museveni may not be such a positive referent as regards the legislation his cabinet passed in parliament, criminalizing the transmission of HIV and granting doctors the possibility to violate confidentiality and disclose sufferers’ status without consent.³⁵

At the conference both Mbeki’s and Nkosi’s stances stand for the opposite of one another. Nkosi delivers a political speech claiming for equality, overshadowing Mbeki’s controversial speech in which the former president calls on the scientific community to develop enough tolerance to respect his theory of conspiracy and genocidal misconduct (2005: 203). On the contrary, the child comes up with a clear and simple discourse that goes straight to the heart of the audience, reflecting Nkosi’s meaning-making process of the disease. His words are the product of his familiar environment, one which combines the power of love with self-confidence and autonomy. Nkosi’s account of the disease far indicates that the child is not insensitive to the context of the disease both in the inner and outer spheres of his household. His words show a high degree of resistance to isolation and ostracism, as he continually

³⁵ Source: <https://reproductiverights.org/press-room/uganda-president-signs-callous-law-criminalizing-hiv-aids-transmission> Accessed: 25 September 2021

negotiates and internalizes the society's values and systems of beliefs in relation to HIV/AIDS that attempt to exclude HIV sufferers. If beliefs shape our perception of reality, then, a new system of beliefs will have to circulate so as to neutralize prejudices and discrimination against the victims of HIV. Nkosi advocates for the continuing renewal of the social covenant resulting from post-1994 South Africa. The speech also suggests that Nkosi is aware of the dangers in his everyday contexts, where ordinary interactions with other human beings are not constructed as risks or embodiments of danger, but rather, linked to caring and affection. The speech reflects the social deconstruction of the disease within the context of the child, who finds the perfect balance between generosity and a forward-looking attitude to compel parties to abandon clumsy policies in the field of AIDS. The whole discourse revolves around two major axis, compassion and love for infected people:

“We are all the same.”

Smile.

“We are not different from one another.”

Smile.

“We all belong to one family.”

Smile.

“We love and we laugh, we hurt and we cry, we live and we die.”

“Care for us and accept us. We are all human beings. We are normal. We have hands. We have feet. We can walk, we can talk—and we have needs just like everyone else. Don't be afraid of us.”

“We are all the same.” (2005: 205-06)

A plea for both reconstruction and reconciliation is the hallmark feature of a child's discourse, for whom the loss of his mother and his own innocence have influence over his political agenda. His testimony brings any supporter of denialism into ridicule or contempt, suggesting that the questioning of the very virus that is gradually eating him away is perhaps shying away not only from reality but, more important, from politics. The conference was one of Nkosi's last public appearances before his passing away. However, the echo of his words are a glimpse of Gail's vision for the future, a strong

driving force to achieve her goals and to dignify the existence of the innocent victims of the HIV scourge in South Africa.

5.5 Conclusion

We Are All the Same is a deeply human narrative that reminds the readers of the need to create bonds of shared values and actions. These validate –and grasp the essence of– a range of viewpoints from within the voices and experiences of the marginal and the disavowed. These bonds of shared values take the form of solidarity between and within the different social movements and various organizations involved in the struggle for sufferers’ dignity. The building of human webs foregrounds the cooperation that is necessary in order to celebrate the success of a community of sufferers, largely ignored by mainstream public opinion and ostracized by those highly placed in the ranks of globalization, for whom HIV sufferers are a curb on the economy. The articulation of an alternative to protect human assets at risk, as is the case of HIV-positive children, can only address socio-economic change in mobilizing effective community responses to the multifaceted challenges posed by HIV/AIDS. The accounts of suffering also make room for hope and illusion to prove right the assumption that, in the end, we are all the same.

Chapter Six: The Rise and Fall of a Celebrity in Liz McGregor's *Khabzela: The Life and Times of a South African* (2005)

6.1 Introduction

*Khabzela: The Life and Times of a South African*³⁶ (2005), the biography of Fana Khaba by the journalist Liz McGregor, documents the circumstances surrounding the untimely death of the celebrity caused by AIDS. Although “there were few others in the country in as good a position from which to fight the virus” (McGregor 2005: 149), Khabzela’s choice not to be put on antiretroviral therapy reveals how the existence of an ambivalent constellation of beliefs, namely the clash between African and western beliefs, is at the very heart of his decision. As seen in chapter four of this dissertation, the same ambiguous attitude emerges in *Khabzela*. Despite his position of privilege, Khabzela refused to take the path that would have best preserved his health, dying demented, crippled and covered in bedsores at the age of 35. This terrible outcome is, nonetheless, a reminder of the profound mistrust of anything labelled as “western” that, at the same time, is a response to South Africa’s past colonization as well as Khabzela’s commitment to the so-called Afro-centric medical tradition that Mbeki purported to put forward –as seen in chapters one and two of this dissertation.

In this investigative biography³⁷, posthumously published, McGregor casts light on the central question of the biography, namely why Khabzela did not save his own life. As seen in previous chapters, the HIV/AIDS epidemic was crouched within silence at a time of national celebration. As it turns out, different forms of trauma have extended throughout the country, and by documenting the life of a celebrity, McGregor not only breaks the silence around AIDS but also uses trauma as a crucial model for exercising pressure on institutions, all the more so considering that in Khabzela’s case

³⁶ Hereafter on *Khabzela*

³⁷ I understand the term ‘investigative biography’ as one that involves specific knowledge and research skills in the field of journalism, as is the case of Liz McGregor.

the traumatic experience is both retrievable and unrepressed because, however odd it might sound, his experience is not connected to grief. This shift in pathological discourse demonstrates that a lot of stories of grief and suffering still needed to see light, and, more importantly, remembered to teach society the incalculable value of their protagonists' silence. The emergence of that trauma – namely the erosion of sufferers' personal identity, lack of purpose, deterioration of relationships, unsafe emotions, treatment failure or, simply put, fear of death– has led to episodes of empowerment in order to regain normalcy. The trauma scholar Anne Whitehead argues that “[t]rauma arises when a stimulus is so powerful that it breaks through the protective shield and floods the underlying mental apparatus” (2009: 95). In South African AIDS life-writing, I consider that the power of the stimulus and the potential of the mental apparatus lie in the possibility for AIDS sufferers to become witnesses of their own fears and personal failures, a cathartic moment, and to engage intensively in the production of psychotherapeutic narratives that facilitate the re-shaping of the identity of disenfranchised individuals and collectives in their bid to embrace normalcy. South African AIDS life-writing gives a sense of continuity to the original purpose of the Truth and Reconciliation Commission in the sense that these narratives cover a broader range of subjects and reach a wide conceptual diversity. This conceptual diversity includes a closer understanding of the human condition within the specific social, historical and cultural context that enable the writing and disclosure of personal experiences whilst keeping intact the uniqueness of each of the individuals that form part of an extended web of AIDS experiences, thus giving this cathartic moment a distinctive edge.

In the case that occupies us here, regaining normalcy is synonymous with the stimulus that keeps AIDS sufferers doing battle so as to be fully included and recognized in the protective scheme –the constitution– that South Africans established

in 1996 to leave behind the old dichotomy “oppressor and oppressed” and to look to the future with more optimism and confidence. Hence, the normalization of AIDS in South Africa is, in this sense, a key benchmark for the full restoration of the spirit of the constitution, granting dignity and protection to AIDS sufferers. *Khabzela* contributes to the creation of a historiographic archive of the epidemic in South Africa.

The latter constitutes an integral part of illness memoirs because, as trauma scholar Roger Luckhurst argues, “to historicize is to ‘normalize’ events” (2008: 65). The Truth and Reconciliation Commission of 1996 opened up a period of public commitment with national and collective memory as well as one of public concern with how the traumatic events of the apartheid era could be inscribed in all spheres that constitute South African society. The construction of this national narrative represented a breakthrough in terms of collective efforts after decades of segregation, despite being incomplete or having failed to address the injustices of the past (Stanley, 2001; Mamdani, 2002). HIV/AIDS life narratives are imbued with a sensitivity reminiscent of that historical landmark in the contemporary age, and trauma and discrimination are again the instruments to mobilize post-apartheid society. In this case, HIV/AIDS sufferers claim their right not to be forgotten –as enshrined in the constitution– through individual accounts of their experiences with HIV/AIDS that bring together not only a valuable body of knowledge, but also the healing power of words that explain the many nuances of the recent history of trauma in the post-apartheid period, which takes the shape of AIDS orphans or premature deaths, amongst other pressing issues. Christopher J. Colvin (2019), places emphasis on the importance of AIDS traumatic-memory-making in the post-apartheid era as an essential component of socio-political reparation in order to appeal marginalized individuals and social groups to promote a more inclusive approach to reconciliation and peaceful conviviality.

In this chapter, I shall examine Liz McGregor's *Khabzela* within the conceptual framework of metanarratives. In his seminal work, *The Postmodern Condition: A Report on Knowledge*, the philosopher Jean-François Lyotard, who pioneered the term, describes it as a comprehensive account of historical events and experiences (the AIDS epidemic fits this category well) that give and legitimize meaning to specific events in accordance with universal values (1984: 34-35). If we approach Lyotard's concept of metanarrative as narratives about narratives of historical significance, then, we can assume the assumption that AIDS testimonies are unified by a consistent belief that their personal experiences with the virus have been neglected throughout the history of HIV/AIDS. As stated in previous chapters, I uphold the idea that South African writing, in general, and South African AIDS writing, in particular, revolve around a strong educational component that makes South African culture accessible to uneducated readers in a meaningful way. In this sense, South African AIDS writing is imbued with this Lyotard's understanding of metanarratives. As seen in previous chapters, the testimonies of AIDS sufferers constitute a well-founded critique of their extended perception of the widespread misconception of progress by the scientific and political elites of South Africa, which consistently failed to include AIDS sufferers within the protective umbrella of progress by denying them the possibility to survive AIDS when scientific progress could have contained the ravages of the virus on their bodies. Lyotard (1984: 3-4) sustains that the status of knowledge, and science falls into this category, has altered the course of what we call post-industrial societies after the 1950s. In so doing, the critic equates knowledge with power, and if we extrapolate this relationship to the context of the epidemic in South Africa, we could argue that science, as a form of knowledge, and politics, as a ramification of power, have failed to legitimize the meaning generated through the articulation of the various discourses of

AIDS sufferers. In this regard, the story of Khabzela builds on the historical significance of the traumatic events associated with both the epidemic and the culture specific context of South Africa in which the individual experience of Khabzela delineates stand-ins for experiences of national trauma. Neither finding a treatment –or even a cure– nor the implementation of a prevention system can erase the aftermaths of HIV and AIDS from the national imaginary (Tyrrell, 2021: 188); hence the value of legitimizing the experience of illness as a metanarrative told through the lens of micro history, as seen in chapter one.

In order to deal with the psychic scars and mental wounds of trauma in *Khabzela*, I will engage with the celebrity’s childhood background and his subsequent transformation into one of the greatest exponents of kwaito culture in contemporary South Africa. These two central aspects of the story, besides evincing that an integral part of South African life-writing lies in its pedagogical component, especially in terms of nation-building, will help us understand the conditions for the arousal of Khabzela’s sexual identity which I consider fundamental to shed light upon Khabzela’s distorted notion of masculinity and risk-taking sexual practices. In this life narrative, the representation of the politics of sex, and its consequences, is also essential to understanding the impact of the sexual revolution, in the late 1990s and at the very turn of the new century, and the enjoyment of civil liberties for individuals and families in post-apartheid South Africa. Furthermore, the ethics of community care also gains momentum in the story when the narrative focus moves to Khabzela’s shifting emotions as he puts himself in the hands of *sangomas*, whose role in the HIV/AIDS crisis is seriously called into question considering that these are perceived to feed off sufferers’ desperation, as previously discussed in chapters three and four of this dissertation. In this regard, Khabzela, as a public figure, is the generator of a cultural discourse through

which McGregor presents the dominant perspective of the memoir: the benefits of taking antiretrovirals. The fact that *Khabzela* coincides with the rise of the illness memoir, and with the worst years of the epidemic in South Africa, turns Khabzela's story into a "misery memoir" (Luckhurst, 2008: 119) that sells well. This aspect is relevant, as McGregor, in the same way as *sangomas*, capitalizes upon HIV/AIDS. Thus, the commodification of Khabzela's image through the practice of narrative mediation is of paramount importance. Such a strategy seeks to promote an attitudinal change towards the existing misconceptions of the virus among South Africans. This is the case considering the prevailing rhetoric of AIDS denialism in the Mbeki era and the flourishing of *sangomas*, who often claim they can cure the disease.

The social and political storylines in *Khabzela* illustrate that Mbeki's ambivalent position on AIDS is instrumental –as seen in chapter two–, as it serves the purpose of giving prominence to African nationalist tropes. In *Khabzela*, McGregor gathers testimonies of people whose views on HIV/AIDS, in many cases, follow the postulates of Mbeki, and also challenge the author's perspective. McGregor, in turn, rejects those views when they emerged; however, the mere presence of those testimonies alerts us to the fact that Mbeki's controversial views were replicated in certain segments of South African society, thus placing additional value on the legitimization of knowledge promoted by HIV/AIDS life narratives at a time of acute national emergency. It is through the presence of the rhetoric of AIDS denialism that McGregor explores into the reasons why black South Africans express a profound distrust of western medicine. Such an element allows the emergence of another aspect of trauma that is deeply entrenched in the racist and racialist past of South Africa, especially taking in consideration two opposing forms of knowledge that grapple with each other. *Khabzela* best epitomizes this conflict, and by drawing on the recollections of Khabzela's

encounters with *sangomas*, McGregor finds out that “ambivalence about HIV/AIDS was not confined to the president and his health minister” (2005: 28). Thus, the textualization and memorialization of Khabzela’s experience with AIDS opens up a huge window into the complex ideology that sustains the existing HIV/AIDS culture³⁸ in South Africa. The childhood and youth of Khabzela, as will be dealt with in the coming section, provides valuable insights into the different layers of trauma, and this merits further attention in order to understand the aspects of the celebrity’s rise and fall.

6.2 Khabzela: The Transition From Soweto to Kwaito Star

In this section, my analysis of *Khabzela* will revolve around the significance of the key distressing events that marked his vital path. In *Khabzela*, the readers cannot experience the traumatic instances as there is no such thing as the reworking of the traumatic event on the part of the sufferer but, rather, the reconstruction of a whole series of distressing events that come together to create conditions conducive to spreading the main message of the life narrative. In this sense, McGregor provides an incomplete and fragmentary slice of Khabzela’s life that moves between a combination of the history and historiography of the epidemic, on the one hand, and the personal story of the celebrity told through the lens of Khabzela’s innermost circle.

The social portrait of Khabzela reveals extremely intimate moments, including the internal conflicts of the celebrity as to whether taking anti-retrovirals was the solution, or his upbringing in a fatherless household being raised under the strict doctrine of Jehovah’s Witnesses under the close surveillance of his mother, Lydia Khaba. All these largely influenced his exposition to a wider audience. For that purpose, McGregor engages with Kenny, one of Khabzela’s closest friends during childhood and

³⁸ My understanding of this term includes sexual norms, male-macho attitudes that encourage multiple sexual partners, and risk-taking practices that involve body fluids and blood.

adolescence, to shed further light upon the nature of those distressing events in Khabzela's life. As Kenny's testimony confirms, most of Khabzela's childhood traumas stem from the stigma associated with his membership of Jehovah's Witnesses. The fact that breaking the silence offers some catharsis to Kenny does not escape McGregor's keen eye. Given the fact that McGregor barely met Khabzela, she makes the most of her meetings with Kenny to trace down the early steps of Khabzela and to get an overall picture of what his childhood in Soweto was like. The role of Kenny is significant as he elaborates on the hardships of growing up in Soweto, especially in connection with the social sphere of the Khabas where religion is an important driving force of their conviviality which functions as a form of escapism from apartheid's iron fist. Cross-references to the apartheid are also provided, but more importantly, Kenny also provides a key foundation to stop the progress of HIV/AIDS. As Kenny points out,

In the eighties, we had violence, apartheid and all that. And when we started to relax after apartheid we had Aids [sic]. You survived the violence and the apartheid and now you have to fight to survive Aids [sic]. But Aids [sic] is easier to deal with – just stick to one partner. (2005: 42)

In relation to Kenny's words, McGregor is quick to observe how Kenny is in dire need to create a narrative, a comforting one, to make sense of the untimely death of his beloved friend (2005: 41-42). By participating in McGregor's reconstruction of Khabzela's experience with the disease, Kenny also initiates the healing process of the witness, for he also endured similar suffering in the past. Indeed, Kenny's contribution to the biography deserves special attention. Kenny's testimony provides a picture of Khabzela that shows the celebrity's vulnerability and helplessness from a perspective that incorporates sensory aspects of trauma into the life narrative. The emotional realm of Khabzela sees light when both, biographer and witness, recall the indignities and humiliations Khabzela underwent as a child. Kenny and Khabzela belonged to the same Jehovah's Witness church and, therefore, both were also the targets of the same

offensive and abusive comments, which clearly found their way to the heart of both of them. McGregor thus summarizes the experience:

Kenny said he initially made friends with the young Fana because he felt sorry for him. Fana was bullied – partly because he, like Kenny, was a Jehovah's Witness, and partly because of his unprepossessing appearance. "He was ugly," said Kenny bluntly. "He had blemishes; a very bad skin. Even at church, the guys would make nasty comments about him. I saw these guys teasing him and thought I must protect him." And even though their lives were to take off in totally different directions once they reached adulthood, it was a friendship which endured until Fana died. The two families were and still are intimately entwined. (2005: 42)

Such experiences help the reader understand Khabzela's modest social background and what had possibly sparked his desire to become a womanizer the moment he enjoyed enormous popularity on the dance floors of South Africa. In this regard, it is important to bear in mind the centrality of material comfort, and how the materialization of comfort has had a profound impact on the course of the HIV/AIDS epidemic in South Africa –as was illustrated in previous chapters. The dearth of robust social bonds with other boys is also manifested by Khabzela's disengagement with anti-apartheid activities. Away from the political activities of the liberation struggle, Khabzela, as Kenny recalls, "retained his own moral centre" (2005: 53) and, uninterested in ANC-aligned activities, left school without matriculation³⁹ to pursue his dream of becoming a DJ, and used his sense of humour and apolitical nature to disarm potential enemies within the township. Khabzela's personal evolution had a before and after with the advent of democracy, which undoubtedly gave way to an era of celebration, rewards, excesses, and, ultimately, AIDS.

This shift in politics gave way to a reformulation of national culture, and this new mood translates into Khabzela's initiation into a macho culture, first as a taxi driver, and later as a prominent DJ, that is also characterized by the advent of Kwaito

³⁹ Matriculation is the South African term for graduation in secondary school.

culture. In this process of personal transformation, which runs parallel to the transformation of the South African social landscape, kwaito plays a significant role in Khabzela's life. Bhekizizwe Peterson argues that "kwaito is an eloquent testimony of the agency of young blacks, especially their desires to create their own narratives and meanings in response to the harsh and hostile urban landscapes in which they find themselves" (2003: 197). This cultural current, with its engulfing narratives and meanings, has penetrated with force into the world of the youth, shaping their perception of reality in terms that, in the eyes of conservative South Africans, include conduct constituting a violation of the principle of Ubuntu⁴⁰. In the story, this "new" post-apartheid reality that conjures up emotions of economic empowerment and explosive sexual desire accentuated Khabzela's yearn for hedonism and social ascent. It is this change in his understanding of life priorities propelled by Kwaito culture where we find Khabzela imbued with a rebellious and hopeful attitude of renewal towards himself, which goes in line with Gavin Steingo's idea that, in post-1994 South Africa, the emerging black middle-classes and elites had created a politics of aspiration (2005: 334). This perception of aspiration among black South Africans, as is the case of Khabzela, gives an impulse to such efforts promoted by the so-called black economic empowerment and thereby contributes to rebuilding confidence in black people's skills now that South Africa has entered with force in the trends of the global economy. The possibility of aiming high in life endows Khabzela with a sense of power that was barely experienced by him hitherto. This key moment of enhanced self-awareness boosts Khabzela's self-esteem as well as his sense of empowerment to levels that also contaminate human relations due to the influence of capitalist tropes and sexual lust in his utterly renewed cosmivision.

⁴⁰ Ubuntu is a philosophical and ethical rule about togetherness and caring for the members of the community.

In this new culture of promiscuity and endless pursuit of pleasure, HIV/AIDS thrives to the point of becoming a central identity marker for an entire generation, the so-called “Y generation.” In the course of Liz McGregor’s interviews with different characters’ alternative approaches to the disease and safe sex are both explored and buoyed by McGregor. The perspective of Liz McGregor on key themes influencing Khabzela’s choice to refuse anti-retrovirals, showing how Khabzela agonizes over whether he should accede to the life-prolonging drugs or die a terrible death, goes much deeper than the controversial views of prominent South African politicians on AIDS or the demands of pro-treatment movements. The life narrative of Khabzela is an accurate reflection of the social makeup of post-apartheid South Africa, where dying of AIDS is definitely not the end of suffering but rather the prolongation of the national trauma, and this memoir provides an entry point for a critical examination of the redemptive discourse of national celebration promoted by the drafting of the country’s forward-looking constitution and the hearings of the Truth and Reconciliation Commission in 1996.

McGregor’s perspective places emphasis on culture-specific and interpersonal relations, and often analyzes the flimsy frame of the rules pervading the modern, and predominantly macho-centred, social context of post-apartheid South Africa. This is especially the case of townships such as Soweto – Khabzela’s birthplace – where the prevailing post-apartheid booming culture in former ghettos asserts a much greater difference between developing urban areas and developed urban areas. As stated earlier, McGregor’s narration of Khabzela’s life places great emphasis on the emerging power of kwaito culture, with which McGregor was not initially very proficient, so as to engage with the new cultural wave of the country and the ideas that circulated widely among young South Africans, especially in terms of sex and gender roles. This new

large cultural wave, known as Kwaito, has entered social life with force, eroding the principle of Ubuntu and giving rise to a “materialistic lifestyle”⁴¹ (2005: 148). Impey (2001: 45) argues for Kwaito’s appropriation of the term “defiance” as a fashion statement that unleashes amongst young black consumers a desire to express a new set of dreams, confirming the new generations’ detachment from the racial injustice, political protest and strong sense of community of apartheid years. Insisting that we practice a more caring culture, the biography also reveals how deep inequality lies right inside the inner ruptures of the country in the face of the epidemic.

From the onset of the narrative, McGregor states her position on HIV/AIDS, taking sides with the convenience of anti-retrovirals to curb the epidemic in South Africa. As she puts it, anti-retrovirals “greatly improve the quality of your life but cannot rid your body of the virus altogether” (2005: 5). In short, she openly advocates the supply of drugs to keep those infected with the virus alive, assuming her perception of the disease is a universal one; that is to say, the virus can only be contained with western medicines. As a white woman writing about the life of a black celebrity, she also acknowledges “[she] came upon Fana Khaba by accident” (2005: ix), suggesting that conviviality between blacks and whites is yet to be articulated. Meeting with Rimmon-Kenan (2002: 73), McGregor’s “focalization is not free of optical-photographic connotations” and includes “cognitive, emotional and ideological orientation” to shape readers’ opinion. In short, the containment of the virus is presented as the safest bet. In order to develop the backbone of her discourse, McGregor constructs the narrative through the lens of different focalizers, including the three encounters with the celebrity before his death. As McGregor notes,

⁴¹ It is a lifestyle that reflects life in post-apartheid’s black urban areas and townships. The term loosely translates into English as ‘vicious’, showing the materialistic approach of its followers to culture. Kwaito lyrics can be misogynistic.

I had three long encounters with Fana Khaba before his death but the virus was already eating away at his brain and not much of what he told me made much sense. I have put together my picture of his life mostly from interviews with his family, his friends, his colleagues and the many members of the medical and alternative healing community whom he consulted during his last frantic attempts to defeat the virus. So, this is a life told in retrospect; through the eyes of other people, with all the gaps and shadings that that inevitably involves. (2005: xi)

The incorporation of the testimonies of Khabzela's innermost circle into the narrative allows McGregor to interpret the key events in the life of Khabzela from different angles and with differing assumptions and expectations. These testimonies, which cover the span of time from Khabzela's childhood to adulthood, are of paramount relevance because they also mirror the life of the first generation of South Africans to reach adulthood after the abolition of apartheid, illustrating the key idea that the celebrity's life provides stand-ins for national concerns. In this sense, *Khabzela* provides a faithful account of a generation's downfall, documenting the ravages of post-apartheid culture and its impact on South African youth. The reviewer N.S. Zulu argues that the celebratory mood of democracy also gave rise to confusion and how "the consequence of relaxing morals and values might have encouraged a culture of promiscuity and hedonism" (2009: 56), which facilitated the spread of AIDS. Khabzela flags up this new culture, becoming a role model of entrepreneurship for the youth of South Africa and, at the same time, a victim of unprotected intercourse for sheer pleasure. In this latter case, McGregor states clearly that among the purposes of the book is "help to open up debate" and "show the many thousands of people who loved and admired [Khabzela] the consequences of his choices and help them to make better ones" (2005: 236). The biography reads as a symbol of this enterprise of social break-up.

The exploration of the existing social barriers in post-apartheid South Africa is one of McGregor's area of concern, and whose interpretation of social and sexual relations calls into question the centrality of desirability and seduction in the mind-sets

of young people. These two have great persuasive capacity among the youth, who understand desirability and seduction as the gateway for liberation, giving rise to a misunderstanding of the notion of freedom. This idea is further exacerbated by systemic gender inequality, cultural practices, and limited social mobilization around the prevention of HIV. Maud Blose (2012: 50-52) upholds the idea that kwaito music and culture play a significant role in perpetuating the objectification of women –which Khabzela follows to the letter–, mostly because kwaito reduces women to objects of pleasure, and because women themselves also play a role in their own exploitation to gain visibility in the music industry and society. This view has been partially contested by critic Angela Impey, who upholds the belief that “by acting out the very symbols of their sexual objectification, [kwaito] has provided a medium through which women have been able to construct a commanding presence in the music industry” (2001: 44). In this way, McGregor’s feminist concerns are emphasized, especially when she makes room for Khabzela’s accounts of his countless sexual encounters with women, before or after musical gigs, who very likely got AIDS, and even pregnant, by him. When Khabzela tells McGregor “I drive around Soweto and I look at all these women with their HIV-positive children and I think: they’re all mine, mine and God’s” (2005: 1) the core message underneath these words shows Khabzela’s remorse for the transmission of the virus to his sexual partners, which he never expresses explicitly, as he is imbued with the trends of power, desire and seduction. Bearing in mind that kwaito culture promotes specific gender roles, giving men authority over women, unprotected sexual relations are likely to create the conditions for the spread of the virus. In this sense, as stated earlier, having multiple partners is regarded as a sign of prestige in the ideological world of kwaito. Desirability and seduction play themselves out in a variety

of ways that reward promiscuous attitudes, and these have become a trendy way to signify success in the social terrain.

By dismantling the deceptive intricacies of desirability and seduction in the new cultural wave, McGregor's discourse helps forge the consciousness of the new generations in critical terms so as to alert them to the potential negative impacts of unprotected intercourse on their communities. This idea is also pinpointed by N.S. Zulu in his review of *Khabzela*, as, in his view, "the new forces of democracy have eroded the traditional cultures that once upheld the virtues of safe sex" (2009: 56). It is precisely these new forces of democracy that lie at the heart of the renewed forms of trauma in South Africa. The wiping out of the former virtues of safe sex has had a devastating impact on all the layers of society, mortgaging the future of South Africa, where younger generations are portrayed as reckless and increasingly diseased.

Therefore, the need to educate the youth on the idea that erotic appeal and materiality entail serious risks in the long run appears to be a central concern in McGregor's approach to Khabzela's life, confirming the value of this text as a metanarrative that seeks to promote a less narcissistic/materialistic approach to life. Thus, new alternatives to cultures based on endless pursuit of pleasure and unhealthy promiscuity, as is the case in *Khabzela*, are put in value "in order to avoid national suicide" (N.S. Zulu, 2009: 57). McGregor initiates a journey into the underbelly of the life of a national icon in her bid to illustrate how becoming a celebrity also overlaps with forms of vulnerability, namely emotional. The story of Khabzela invites potential readers to consider the reformulation of a new set of values in accordance with the progress made in the political and economic terrains. Hence, the importance of the promotion of values that preserve human dignity, the culture of care, and perseverance to achieve the very sought success and visibility of people who, as Khabzela himself,

came out of the darkness into a global and consumerist society without ever considering the risks associated with the sexual excesses in kwaito culture.

6.2.1 “Y Culture” or the Merge between Kwaito Codes and AIDS

In *Entanglement: Literary and Cultural Reflections on Post-Apartheid*, Sarah Nuttall fleshes out the details of the emerging post-1994 youth cultural form known as “Y culture.” The critic outlines the conditions for the booming of the first genuinely urban cultural form in post-apartheid South Africa that emerges from townships, which developed in conjunction with the styling and visual culture of post-apartheid South Africa. In this “new” era, township life occupies centre stage as the stronghold of anti-apartheid resistance that in the democratic age is in dire need of re-modelling. In Nuttall’s words, “[t]ownship culture is translated from a socio-economically stagnant into a high-urban experience” (2009: 118). Bhekizizwe Peterson, in turn, locates “Y culture” within the contours of a “lost generation” that is deeply influenced by the “ethos of consumption that engulfs its practices and visions as downright bootstrip capitalism as you are likely to encounter within the citadels of whiteness” (2003: 120). McGregor draws on Nuttall’s and Peterson’s analysis of this cultural manifestation to explore the transformation of Khabzela into a leading voice of the so-called “Y Culture.”

Sarah Nuttall (2004: 435) describes this generation as a form of hybrid culture constituted through a remixing of the township and the city, of the township in the city. In her analysis on the stylization of the self in post-apartheid South Africa, Nuttall reformulates intergenerational connections within the frame of the transformative realm of post-apartheid urban cultures. Patrick Bond (2000: 39) defines the setting that fosters this new environment for opportunities as the place for “the *nouveau-riche* character of Black Economic Empowerment (BEE)”, and Khabzela is in tune with the aspirational

mood of the “new” South Africa, assuming somehow the responsibility to pave the way for the empowerment of young blacks. In this capacity, Khabzela takes on the role of the paternal referent he lacked as a youngster to ensure the youth feel both valued and confident in their skills. Nonetheless, Nuttall is quick to highlight the underbelly of the social and cultural makeup of the “Y generation.” The critic observes:

These visual cultures are the loci of a language of aspiration, a language that, as we will see, both speaks to and silences psychic and material “reminders” beyond the text: crime, economic hardship, and bodily frailties, even death itself, in the wake of the HIV/AIDS pandemic. (2004: 432)

Nuttall’s analysis of “Y culture”, which lays the ground for the possible effects of the AIDS crisis and its traumatic undertones, is shared by Dirk Hartford, Khabzela’s employer at Yfm radio station, when the latter feels the fence around AIDS hampers public debate on the social breakdown caused by the disease. Such an observation also illustrates the socio-cultural transition in South Africa from the collective to an individualistic ethos, where the fulfilment of individual aspirations is at odds with the prevailing discourse of nation-building. In his former role as a member of the SABC⁴² strategic planning unit, the then intact mouthpiece of the apartheid state, Dirk observed nobody was targeting emerging black audiences and sensitivities – and the HIV/AIDS crisis was gaining ground. As he puts it in *Khabzela*, “the gap was wide open” (2005: 93), and it was necessary to direct special attention to HIV/AIDS and youth concerns. Sensing an opportunity to take action, Dirk unsuccessfully tried to launch a youth-oriented radio station driven by the fundamental principle of demographics, as the vast majority of citizens in the “new” South Africa were young people⁴³ who, as he recalls, “were written off by both the old and new establishment as a “lost generation” who had sought liberation before education and were therefore uneducated and ungovernable”

⁴² The South African Broadcasting Corporation is the public broadcaster in South Africa

⁴³ Source: <https://www.populationpyramid.net/south-africa/2020/> Accessed: August 10th 2021

(2005: 93). Therefore, in practical terms, resistance to change was also deeply ingrained in the already in the making “new” system, which banned kwaito music, Dirk’s personal bet to appeal to new young audiences, as “obscene” and “shit music” (2005: 94). Kwaito’s bad reputation in certain circles confirms Pietila’s analysis (2013: 143) of the critical voices raised against kwaito in that this music genre is, to some, characterized by its “aversion to political preaching”, “purported lack of understanding of political history,” and “as regrettable developments after the politicized era of the struggle.” Frustrated by the lack of effective change in the SABC, Dirk embarked upon the founding of Yfm on his own.

Steeped in black culture, Dirk was aware of the fact that Yfm could make a difference by opening up sex education and youth programmes to the young people of South Africa. The very first pamphlet of Yfm, “sex, drugs and kwaito” (2005: 100), proved to be in sync with the concerns of average young South Africans aged between 16 and 34, who did not miss out on the message. Discussing sexual issues, whether it was safe sex or unsafe sex, became a top priority, and more importantly, Yfm provided an important space for knowledge-sharing among the youth. As Dirk recalls,

What made Yfm unique was that there was real dialogue about real issues. Because the kids who were phoning in were not isolated cases. If they haven’t been raped, they are having sex in all sorts of hectic ways. There’s a lot of research to prove it. The majority of young girls’ first experience of sex in South Africa isn’t consensual. Most are forced into it. The whole youth culture is like that. If I tell you I like you, basically, it means I want to fuck you [...] Insofar as we had an agenda, it was to raise consciousness around the issues of sex and encourage safe sex. Our view was that kids weren’t talking to their parents about sex and vice versa. It’s a taboo area [...] we were right in the middle of the AIDS pandemic and we felt we had to do something about it. (2005: 100)

When Khabzela entered into an alliance with Yfm, he soon identified with both the social mission of the radio station and the need to change the mind-set of a generation to whom apartheid had damaged beyond imagination. His Sunday radio show, Positive Youth of Gauteng, was tremendously successful, as “he had the intoxicating power of

agency” (2005: 109). As a cultural emblem of the disenfranchised, whose strong rejection of global cultural imperialism came to be a strong identity marker, Khabzela “took the community with him” (2005: 111) as he rose. This was especially the case considering that the youth of South Africa were unprepared to take the big leap in the terms set forth by globalization:

After 1994, black youth were catapulted into the wider world with few of the life skills needed to deal with it. Pressures on them were even more intense than on white youth because each black person employed to push up black numbers in lily-white companies had the weight of the entire community on his or her shoulders. (2005: 112)

Khabzela’s support to the reformulation of township life was fundamental to convey the idea that Sowetan youth need not to equate their lives with that of white South Africans or import African-American lifestyles. On the contrary, he retained the essence of township culture even if he made the trek from Soweto to the affluent area of Rosebank in the north of Johannesburg. Greg Maloka, a former employer of Khabzela, thus describes this move:

But it is really only a partial move. Most retain the family house in Soweto, where grandparents and other members of the extended family still live. They come back almost every weekend for weddings, funerals, birthdays, or for a night’s *jol* at a shebeen or club. The township is where their circle of friends originate and where they feel most at home. (2005: 115)

Although retreating to the north of the city, Khabzela’s life is an exercise of self-revelation and a model for Sowetan youth because of his ability to climb the social ladder. Additionally, he also remained true to his roots, which granted him the love and loyalty of his people. This was one of Khabzela’s anxieties, revealing, too, his awareness that his exceptional situation is very possibly the feature that renders his life engaging and worthy of analysis.

Khabzela’s story evinces all sorts of excesses, especially when McGregor focuses on Khabzela’s outward expression of masculinity and waste of money. His

acting out plays itself out under the guise of the standards of South African normative masculinity, and surrounds the celebrity with a means of power and authority over women. Khabzela's troubled self appears to be in dire need of excitement, finding in sex the best way to release internal tensions and to boost his self-esteem, even if it was at the cost of contracting HIV/AIDS. McGregor evinces how Khabzela's troubled sexual encounters with steady lovers and random women hampered his accomplishments, proving right the assumption that embracing hegemonic notions of South African masculinity and fame come with a price.

6.2.2 The Representation of Khabzela's Assimilation into Mainstream South African Masculinity

This section examines the connection between mainstream South African masculinity and HIV/AIDS. The performativity of hegemonic notions of masculinity in *Khabzela* brings to the fore one of the major security issues South African women have to face in the field of public health, namely their limited scope of negotiation in sexual relations, men's preference not to use condoms, and the subsequent risk of contracting the virus. Susanne M. Klausen (2015: 214) points out that HIV/AIDS is a way of killing women, and that the on-going oppression of women under ANC rule suggests the benefits of the liberation struggle never reached women. This view is also sustained by Nechama Brodie in *Femicide in South Africa*, who interrogates the history of violence against women in South Africa, showing that state and civil responses to what it seems to have been an endemic crisis for decades is far from satisfactory. As Brodie claims,

[South Africa has] a specific problem of violence against women, particularly sexual violence and fatal violence against women. Yes, these acts take place within a broader culture of brutality which becomes only sharper, harder, more vicious the closer you look at it – but these acts are also distinct within the hostels of interpersonal violence that effectively define our country's history over the past four centuries. (2020: 1)

Brodie offers insights into the ramifications of the country's culture of violence whose reverberations affect the female body and her reproductive rights, compromising the future health of South Africa. In this sense, *Khabzela* delves into South Africa's culture of gender and sexual brutality, not necessarily physical, through the representation of masculinity in kwaito and township culture, both of which embodied by Khabzela. Fame provided him with the opportunity to make up for lost time, recover from childhood trauma artificially, and have the experiences he had always longed for as a young adult to redeem himself. In the context of this life narrative, the burden of Khabzela's past has had an impact on Khabzela's relationship with Sibongile, who contracted the virus due to Khabzela's relations with other women out of wedlock. In Kenny's eyes, the love story between Khabzela and Sibongile "was always doomed because he was not ready to settle down" (2005: 141), and such an attitude infuriates Lydia Khaba, who has first-hand knowledge of her son's flirtings with other women, and whose desire is Khabzela "to have a stable relationship" (2005: 141). Such a postulate confirms the outdated view of Khabzela's mother on masculinity, as the culture specific context of post-apartheid South Africa –which is far from endorsing a romantic notion of masculinity and is shaped by stereotypes promoted by media and advertisement– places emphasis on promiscuity as the hallmark of the expression of masculinity. Patricia Hill Collins (2004: 281), in this light, argues that powerful mass media controls stigmatize and pathologize black sexual practices, and this promotes a gender ideology that blames black people –particularly straight men– for the spread of sexually transmitted diseases.

The examination of Khabzela's expression of masculinity reveals a great deal about the pervasiveness of patriarchal assumptions about the role of women and the prevailing sexist ideology in contemporary South Africa. In this regard, Khabzela's

particular disposition, and his “mastery” of women, subverts the traditional belief that black women are held in higher regards than black men, mostly because of their role as breeders, as this fact helps to perpetuate the structures that sustain white supremacist ideology (Greene, 2008: 2). By infecting women with HIV, Khabzela neutralizes Greene’s view, and such a circumstance renders women useless for reproductive purposes. The effects of patriarchy and sexism, as seen earlier, result in the intensity of women’s oppression in the microcosm of *Khabzela*. Nonetheless, it is pertinent to highlight that one of the aspects of *Khabzela* in terms of its value as a metanarrative lies precisely in the contrapuntal reading that McGregor offers on the realness of the widely acknowledged belief of male authority over women. McGregor also calls into question the realness of Khabzela’s picture as a bona fide womanizer when she claims that, in reality, Khabzela is more dependent on women than he actually believes. The journalist observes:

He seemed to me essentially a fragile creature, deeply dependent on women and their approval. The picture that emerges of Fana’s world does not reflect the traditional South African stereotype of women as victims, men as brutes. The women seem to have had a strong sense of themselves and their needs while men danced around them, trying desperately to meet these needs, fearful all the while of their own pointlessness if they failed to do so. (2005: 142)

The foregoing discussion places emphasis on Khabzela’s frailty, as he may not fully conform to the traditional stereotype of South African men. It is necessary to highlight that the post-apartheid context has also given rise to more diverse nuances of masculinity. Such expressions celebrate the distinctive features of township life and black economic empowerment, as an expression of the decolonization of black male identity. This latter element coincides with Khabzela’s anti-imperialistic ideology, as stated earlier. In his analysis of hip-hop and masculinity, which can be extrapolated to kwaito as the sister genus of hip-hop, Timothy J. Brown argues that this type of identities “resist white appropriation and definition [of black masculinities] by crafting a

new identity” (2006: 191). This view, however, also foregrounds Khabzela’s dependency on women, as he needs women to craft a new identity and to brag about publicly about his conquests. The fact that McGregor identifies Khabzela as being desperate to meet women’s needs is a confirmation of his dependency on women. Yet, it is convenient to highlight how the core elements of South African masculinity remain in place because, as Robert Wyrod reminds us, “having multiple partners remain[s] a privilege that accord[s] pleasure, social status, and escapism” (2016: 179). Moreover, such a shift is not in contrast with the actual fact that, regardless of clichés, the celebrity holds a position of power, as he provides for the material well-being of those around him. In this sense, a number of considerations have to be made in relation to Khabzela’s understanding of privilege both within the contours of black culture and within the context of post-apartheid South Africa’s attempt to empower the black population in economic terms.

For instance, Lewis-McCoy tackles both the shifting reality and the challenges of black masculinities in light of the contemporary. In his analysis of the current situation, the black scholar elaborates on the notion of black male privilege, which he locates at the intersections of race, class and gender oppression (2014: 75). The term “black male privilege” is a key concept in shedding light on Khabzela’s problematic relationship with women, particularly with Sibongile. Khabzela embodies the spirit of black economic empowerment, which places men at the forefront. As such, the manifestation of this new ethos establishes its identity in opposition to the racist and racialist ideological components that prevailed in the past but also in terms that promote the widening gap between men and women in South Africa, as the concept of hegemonic masculinity in South Africa determines new forms of gender oppression. As Lewis-McCoy notes, “men are coerced to pursue notions of hegemonic masculinity

which represent the often unattainable marker of ‘true manhood’” (2014: 77-8). In *Khabzela*, these notions of hegemonic masculinity take the shape of materiality, namely flashy cars, tailor-made clothing, and the ownership of women at the purest playboy style. In this way, Khabzela conforms to the standards of masculinity. As McGregor puts it,

In Fana’s company the sinners probably felt even more at ease, given that he did a fair amount of sinning himself. Not heavy-duty gangster sinning like burglary, hijacking or murder. But when it came to a materialistic lifestyle and predatory sexuality, Fana was up there with the best of them. On air, Fana regularly boasted of his conquests. He referred to his penis as his ‘anaconda’ and made regular reference to its activities. As in “my anaconda ate last night” or “my anaconda is hungry.” (2005: 138)

The instrumentalization of the role of women, acting as pleasure providers, consolidates Khabzela’s perception of black male privilege. He can fulfil women’s desire to “brag to other girls” (2005: 139) in a highly competitive social context, in which pretending and false appearances dictate how women’s status depends on men’s position on the social scale. Additionally, women’s active role in performing gender stereotypes, where, as Blose notes, “women are often seen to have become willing participants in their own exploitation” (2012: 51) shows that persisting disparities between men and women in post-apartheid South Africa take their toll on the female body. Very often women find themselves trapped in situations resulting in unwanted pregnancy and/or the contraction of the virus, and representations of both are reflected in Khabzela’s life narrative when the consequences of lust and pleasure gain momentum.

In “The Politics of Sex,” Robert Grant (2000) offers insights into the mind-sets of consumers of sex, as is the case of the celebrity, in order to address the role played by promiscuity in the so-called politics of “erotic love,” where sexual fantasy pushes lovers to overplay in the sake of sexual domination and complacency. The critic’s view on this issue helps to build further on the notion of black male privilege, as lust and

promiscuity go hand-in-hand. In this regard, Grant elaborates on the objectification of individuals in sex and the psychology that drives that type of sexual narratives. As Grant notes,

Lust leaves the subject in a solipsistic void: the same, perhaps, in which he began. There are some who seem content with this. But for the others there is the solace only of promiscuity (an incessant, futile renewal of the personal object) or the lewd solidarity of their own unhappy kind. Lust is far from irredeemable: one can be educated, or educate oneself, or simply grow, out of it. (2000: 89-90)

In the light of these observations, Khabzela's sexual practices are meaningless, but the sexual act in itself, and more specifically the possession of the female body, defines the public scene which bounds Khabzela to hegemonic practices of masculinity, including unprotected intercourse as an ephemeral form of stable bond between lovers. The question that arises from this situation is whether Khabzela finds real satisfaction in that moment of intimate union with the other or whether the other is just part of Khabzela's relentless quest for pleasure and self-affirmation of his carefully crafted identity over the years. However, from the moment Khabzela tested positive his perception of reality experienced a sudden turn, as he loses control over his actions as he gradually lost his mind as a result of his newly-acquired medical status. Such a perception of regression in Khabzela intensifies his sense of fragility and vulnerability, which definitely cements his Zuluness. It is at this point when Khabzela finds relief in spirituality and traditional Zulu beliefs.

The fact that Fana relies on traditional beliefs and customs to justify his unusual behaviour is nothing new, as he is well aware of the fact that *sangomas* act as a link between the afterworld and the world he barely inhabits. Margaret Clapson (2010: 18) observes that it is something customary in Zulu culture to explain attitudes as that of Khabzela through the presence of mystic forces and restless ancestors who often possess the body and spirit of their potential victims. As stated earlier, in these fraught

times of the HIV epidemic in South Africa, a considerable number of HIV-positive black South Africans, for the most part, have turned to ancestral beliefs and the esoteric as a way to find a cure in place of the widely acknowledged medical treatment. The scant acceptance in black communities of western knowledge is deeply entrenched in the mind-sets of black South Africans. Such a feeling of distrust, which remains latent, locates us in colonial South Africa, when boundaries were contested and warriors relied on ethnic rituals and performances to combat foreign intruders (Crais, 2002: 42). Nancy Jacobs' review of Crais' work builds on the exacerbating dissimilarities between two antagonist worldviews promoted by historical and cultural differences that explain why "many black South Africans translated their experience of the modern state into African understandings of occult power" (Jacobs, 2004: 176). South Africa, as a former colony, has been modelled after the influential experiences of Great Britain in different fields that affect the course of public affairs at present. This concern we have already see in chapter five in connection with Nkosi's biological family and the hardships they endured as a result of the gradual disintegration of Zulu culture and families, which forced them into labour migration and condemning them to ostracism and alienation to scrape out a miserable existence. This legacy has met with the broad opposition of different ethnic groups in South Africa, compelling many of the latter to cling to their traditions not only as a for of resistance but also as a form of contestation over the dominance that is, to a lesser or greater extent, exercised over the socio-cultural sphere of the country. Nicky Falkof (2015: 61-62) also traces the historical roots of Anglophobia in the mind-sets and imaginaries of the various South African ethnic groups, reinforcing the old negative belief pattern that equates western symbols of power and knowledge, and science is embedded in this latter group, with evil. Crais' and Falkof's observations help us understand how the impulse of ethnic beliefs has also

entered the terrain of social health, and Khabzela's story account for the breadth of appeal of ancestral beliefs among black South Africans even if these cultural practices had a real effect on the gradual deterioration of his health. Indeed, from the moment he tests positive for HIV/AIDS, Khabzela focused his attention on successful collaboration with traditional healers in his attempt to find a cure for the disease, as will be discussed in greater detail in the section to come. The emergence of this clash of beliefs and tensions between established medical science and witchcraft also evinces, as Falkof (2015: 72) is quick to observe, that the west continues to be haunted with and appalled by a form of knowledge expunged from western imaginaries. The persuasive language of *sangomas* offer sufferers an alternative affective discourse linked with older African belief systems and this provides them with tranquillity and, in the case of Khabzela's damaged psyche, this has a soothing effect on him.

6.2.3 Conflicting Values: Traditional African Medicine, Western Medicine and the Instrumentalization of AIDS in the Social and Political Arena

In this last section, I will examine Khabzela's relationship with *sangomas*, the final stage of his experience with the disease, and the instrumentalization of AIDS as a political weapon, as attested in the life narrative. At this point, Khabzela, having contracted full-blown AIDS, was bed-ridden and was agonizing in the very last days and weeks of his life. The circumstances surrounding his death have drawn attention to questions relevant to the country's HIV/AIDS policy making, and this has opened up debates about the role of *sangomas* in the epidemic. In this sense, the publication of *Khabzela* has invited readers to reflect on the need for the South African public discourse about the deadly virus to go beyond the provision or not of pharmaceutical drugs in public hospitals and clinics across the country.

Some voices (Weintraub et al., 2018: 116) argue that the situation of the epidemic in South Africa demands a multifaceted approach to the disease, suggesting

the incorporation of *sangomas* into the National Health Service. Despite the country's slow public roll-out of anti-retrovirals, the situation remains far from satisfactory as regards the statistics where the HIV prevalence of adults aged between 15 and 49 borders on 20%⁴⁴ in 2021. Whereas it is true that *sangomas* enjoy a considerable breadth of appeal among black South Africans, it is also true this is mostly due to the structural disjunctures created by the apartheid system in terms of biomedical services (Decoteau, 2013: 405). What is evident is that there is definitely something singular and distinct in the mind-sets of South Africans, especially those who develop closer ties to traditional healing practices, in order for us to understand the problematic co-existence between the two forms of understanding scientific knowledge and illness, which appears to be a cultural rather than a biomedical battle.

In their study of the role of traditional healers in the treatment of HIV/AIDS, Walwyn and Maitshotlo (2010) cast a light on some of the aforementioned concerns. More specifically, both researchers point out that in the context of the HIV epidemic in South Africa “a large proportion of HIV-positive South Africans regularly consult traditional health practitioners (THPs) for their health care needs, despite evidence of negative interactions with antiretrovirals” (2010: 11). Most alarmingly of all is some of interviewed *sangomas*' ignorance of the use of condoms as a means of prevention. One of the opinions expressed by a *sangoma* in the aforementioned research was as follows:

In the past there were no such things as condoms or HIV in our society; ever since condoms were brought to us there is a high rate of HIV/AIDS because they are infested with diseases. Proof is in that oil lubricant. (2010: 13)

This type of territorial beliefs, however much a minority, have gained substantial ground among South Africans, patients and *sangomas* alike, who often do not take into account that receiving the life-saving antiretroviral therapy is still nowadays the only

⁴⁴ Source: <http://www.statssa.gov.za/publications/P0302/P03022021.pdf> Accessed: August 14th 2021

effective way to prolong their lives. As noted earlier in this chapter, Khabzela is no exception to this rule despite the fact that he was well-informed about the risks of unprotected intercourse and the importance of sticking to the adequate treatment he once initiated after getting the financial support of Yfm to cover his medical expenses. Nonetheless, critical voices that claim the opposite have been equally vocal and influential in the on-going discussion on how to best tackle the HIV epidemic in South Africa.

A handful of studies (Barney and Buckingham 2012; Grimsley 2006; and Seigal and Schrimshaw, 2006) highlight the benefits of spirituality and ancestral beliefs in South Africa despite their controversial views on how to deal with HIV/AIDS. More specifically, Barney and Buckingham (2012: 52) note that the way spirituality has been de-emphasized, in a rather imperialistic form, along with the general view that sufferers are social outcasts, have both contributed to the rise of spirituality among HIV sufferers in South Africa. This can be perceived as a coping strategy to escape newer forms of oppression. In this way, as the Barney and Buckingham (2012: 52) point out, spirituality and reliance on *sangomas* are closely associated with the newer forms of vulnerability that have emerged in post-apartheid South Africa in the wake of the epidemic. In line with Barney and Buckingham's remarks, as noted in this chapter, Khabzela had developed a very strong rejection of what he considered to be imperialistic modes (western medicine), even if he initially took the anti-retrovirals in his keeping of his promise to Yfm.

Furthermore, his Jehovah's Witness-dominated upbringing has also made room for the increasing presence of spiritual beliefs once his physical condition began to decay. A vivid example of such beliefs in Fana's mindset was his fervent admiration for Irene, the first *sangoma* he came into contact with, and with whom Fana established a

good friendship. Indeed, at that point in the biography, McGregor expressed her surprise because of Sibongile's approval of Irene, and the fact that Sibongile overlooked that Fana's temporary recovery was not because of Irene's herbs but because of anti-retrovirals:

But it also struck me that Irene was equated in their minds with 'medicine'; white western medicine. She was not jealous and territorial; she allowed ARVs as well. But she also brought in divine agency and emotion, which western medical practitioners failed to do – probably quite short-sightedly, if you look at where most of their Aids (sic) patients were coming from. And she was, as Masi pointed out, white. Possibly, Irene presented the point of reconciliation Fana so desperately needed between his warring Christian and traditional African beliefs. (2005: 179)

The biggest problem facing Khabzela was the dearth of confidence in western medicine, being convinced that antiretrovirals may have caused side effects on his body. In the course of an interview with McGregor, Irene explains how Fana was then paralysed and bed-ridden and how shortly after drinking her herbs he was on his feet again, almost miraculously. From that moment onwards, Fana gave up on western drugs:

He took [the antiretrovirals] for a week. He said he was getting worse. It was in his mind that they are going to kill him. So they couldn't do much in his body because he didn't believe in them. After a week, he said: 'No more anti-retrovirals. Say anti-retrovirals and I'm going to scream.' (2005: 181)

Adam Ashforth (2005: 220) discusses the vital role played by *sangomas* in South African culture, as these are perceived as essential for dealing with diseases from the perspective of the body, mind and soul. These three are precisely the major concerns of Khabzela when he tries to fight off the virus, as he truly believes in the divine intervention of ancestral spirits while his body is ebbing away rapidly. Irene, who claims to have seen the dying coming from death unto life, caters for Khabzela's desire. Her views are as follows:

I do believe the Holy Spirit dawned on me. A force greater than myself led me to believe this was a divine intervention and the only cure as the Holy Spirit is like a consuming fire. Despite the negativity, mocking and criticism, I had not been disappointed. My highest expectations were met and my first patient with full-

blown Aids (sic) recovered and tested negative after using the medicine for only four months. Realising that this is a God-given miracle, I decided to call it Amazing Grace. My mission is to reach out to the oppressed and dying. (2005: 183)

In summarizing her meeting with Irene, McGregor leaves no doubt of her dominant perspective on the issue of HIV/AIDS and on her objections to people such as Irene who enters the business of “saving lives” without any remorse or moral discernment. McGregor believes Irene “was one of many people giving false hope to desperate people – and making money out of it” (2005: 187).

Cynthia Cook (2009: 161) shares a similar story with readers when she recalls the experience of a young woman who was simultaneously treated by both a medical doctor and a *sangoma*, the latter upon her family’s request. As the condition of the young woman improved, due to anti-retrovirals, the *sangoma* wanted to take credit for the young woman’s recovery. Such a thing would have clearly sent out a wrong and potentially deadly message to HIV/AIDS sufferers. In the year 2004, as Cook (2009: 261) also notes, the South African government gave priority to the following up of this kind of reports, passing the Traditional Health Practitioners Act and making provisions for the establishment of a *Sangomas* Council to allow them practice medicine – although it prohibited *sangomas* from diagnosing or treating patients with HIV/AIDS and other terminal illnesses. Such a law triggered a lot of discussions, and Doctors for Life International “challenged the law on the grounds that Parliament had failed to facilitate public involvement before passing the bill” (Cook, 2009: 263). Eventually, it was reinstated in 2007.⁴⁵

Understanding the interplay of western medicine and traditional health practices is a Herculean task, as they stand for the opposite of one another. I consider Weintraub

⁴⁵ Source: https://www.gov.za/sites/default/files/gcis_document/201409/a22-07.pdf
Accessed: August 13th 2021

claim that “traditional and biomedical treatments around the world have long co-existed as concurrent or parallel explanatory models and methods to manage sickness and misfortune” to be a correct observation (2018: 116). Therefore, the need to regulate these practices, especially in the aftermath of mediatic cases such as that of Khabzela, plus thousands of other individuals who suffered and trusted traditional practices to find a cure, was also a pressing need in order to create a climate of trust and to define the scope of application of each discipline. Ashforth also comments on the interest of the South African government “to reveal the scientific foundations of traditional medicine” (2005: 220) on the grounds that, in the eyes of large segments of South African population, *sangomas* are trustworthy and consulted for primary care needs. These scientific foundations for the regulation of traditional health practices have found shelter under the umbrella of the so-called “African Renaissance,” which Thabo Mbeki advocated as early as 1999. As a proponent of this trend, Mbeki expressed his disagreement with the prevailing economic models that were far from providing solutions to countries such as South Africa.

The heated discussions within South African on how to moderate the impact of HIV/AIDS on its population also make their way into *Khabzela*. Particularly, the use of two herbal preparations called “Amazing Grace” and “Africa’s Solution” give shape to Mbeki’s repeatedly expressed wish for giving prominence to African medical knowledge. With the blessings of the then Minister of Health, Dr. Manto Tshabalala-Msimang, who sent Tine van de Maas, another *sangoma*, to help Khabzela give a boost to his immune system with a lemon and garlic based preparation, the narrative enters into a nebulous terrain. The entry of the former Minister of Health in the biography is synonymous with the entry of the mouthpiece of full HIV/AIDS dissidents, supporting the treatment of Tine and her assistant, Nellie, as the correct approach to defeat

HIV/AIDS on South Africa soil. The former Minister of Health makes a strategic move in her bid to take advantage of Khabzela's media pull, and as McGregor puts it,

Their dream [the South African government] was to have [Tine's] programme offered in all clinics and all hospitals. "If our programme is implemented in all the clinics, then the clinics will be empty. The hospitals will be empty because if you fix the malnourishment, you will fix all the problems. (2005: 210)

These views confirm that Khabzela was a victim of the AIDS of the first stages of the epidemic in South Africa, and his story keeps the wounds of AIDS denialism open. The approaches of *sangomas* to treatment have also elicited a vigorous response to such a postulate. McGregor equates modern *sangomas* with former colonizers, thus pinpointing traditional healers as one of the vultures around the AIDS epidemic in South Africa. Ironically, this highlights how both representatives of the west and local ethnic groups equate the implementation of anti-retrovirals with new forms of colonization. Modern *sangomas*, as former colonizers, have also colonized the minds of AIDS sufferers by selling the idea they could cure AIDS. *Sangomas* have thus sensed an opportunity for profit in the midst of chaos, forgetting about the fundamental goal of their activities: prevention and counselling. This is by all means a distortion of traditional knowledge for their own benefit. In so doing, McGregor notes the absence of provisions with regard to developing a protection scheme for HIV/AIDS sufferers, putting increasing pressure on the ANC government to centralize sanitary over ideological concerns. As McGregor notes:

But I thought [*sangomas*] had no place in a modern, democratic South Africa. I thought it a source of shame for us that they were given such ready access to desperately ill people to practice their potions on. Like many white people before them, they were using Africa's poverty to create a playground for themselves where they could play out their self-aggrandising fantasies. (2005: 212).

The lack of a clear HIV/AIDS policy in South Africa, or at least one adopted in consensus with non-denialists, has been a defining aspect of the HIV/AIDS crisis in

South Africa. The fact that the former Minister of Health, Manta Thsabalala-Msimang, undermined and casted aspersions on anti-retroviral treatment while simultaneously promoting the “benefits” of traditional healing (Nattrass, 2008: 159). Such an element evinces the views of denialists were rooted in the response of the South African government to the health crisis.

This public positioning has made extremely difficult the work of renowned experts in the field of HIV/AIDS medicine in South Africa. Khabzela would certainly stick to the idea that anti-retrovirals were poisonous, which was further reinforced by the then official public discourse. McGregor recounts the experience of Dr. Spencer when the journalist finds out Khabzela had a brief consultation with this specialist while going through Khabzela’s file at Yfm. This encounter is labelled as “totally unsatisfactory” (2005: 222) by the doctor, who afterwards comes to realize, as was the case according to the letter of referral (2005: 228-231) McGregor has access to before Khabzela is admitted to Johannesburg hospital, that the celebrity was suffering from advanced HIV infection with widespread disease of the brain. As Dr. Spencer notes,

I remember that particular incident because it was so bizarre, he said. He was difficult. He came in with an attitude. He said: ‘I’m HIV positive and I want treatment but you can’t use anti-retrovirals on me!’ I replied that I didn’t treat HIV with diet or herbs. He stalked out. It was a totally unsatisfactory encounter. He was in my office for less than a minute [...] He was hostile, an angry young man. I thought he must be demented. Aids (sic) encephalitis, for example, is a condition that often causes people to behave in aggressive or unpredictable ways. (2005: 222)

The consultation with Dr. Spencer allowed scarcely a glimpse of a more rational approach to the disease, but this did not last long. Khabzela was faithful to the end in relying on food supplements to overcome an infectious disease when his story might well have been the chronicle of a survivor.

6.3 Conclusion

Khabzela explores the HIV/AIDS epidemic as a vast, yet intertwined, experience with the self and other in the face of a human tragedy. The biography draws on the significance of the celebrity's sex experiences, delving into the ways in which sexual intimacies feature in our lives. McGregor's attempt to shed light on why Khabzela eventually died leaves no room for reinterpretation. His unshakeable faith in traditional South African knowledge is motivated by his experience with institutionalized forms of racism and racial oppression, on the one hand, and with the reverberations of his problematic upbringing as a Jehovah's Witness, on the other. His desire to redeem himself from the wounds of the past compelled him to comply with the requirements of a macho culture in order to assimilate into the expression of mainstream South African masculinity in the terms established by a shifting cultural reality. This fact has given rise to a series of events and misfortunes that catapulted him to fame. The pursuit of endless pleasure in sex, even at the cost of contracting the virus, helped Khabzela to be absorbed into the practices of hegemonic South African masculinity becoming an object of desire and, at the same time, a diseased subject, whose thirst for authenticity and sameness led him to death. In *Khabzela*, the shattered "self" is felt to be incapable of finding his way out in life after the contraction of the disease in terms of meaningful resistance against his newly acquired health condition, showing his inability to rise from the ashes as he did in the past when he was a township boy filled with dreams and legitimate aspirations of social and upward mobility. Death offers no possibility for redemption, and his story foregrounds one sequence after another of a catastrophe that, in his case, was avoidable.

My analysis of this biography also evinces that building solid communities and networks of trust is a pending challenge of democratic South Africa. In this sense,

inappropriate public messaging and a poor outreach campaign on HIV/AIDS awareness have both facilitated repeated incursions of traditional healers into the implementation of adequate health policies, whose offer of a non-existent cure was way more powerful and seductive than the possibility of keeping HIV at a bay with pharmaceutical drugs. Furthermore, the contradictions in Khabzela's public discourse at Yfm, where he often advocated for the use of condoms and the promotion of healthy sex practices, clash with his sexual acts. This shows that the celebrity's internal state of chaos mirrors the national mood dominated by confusion and the desire to thrive in life at any cost. Khabzela, and subsequently, a good handful of South Africans played the role of god in the sense that, as participants of this new cultural wave, they knowingly ignored many of them would likely go through HIV/AIDS in the future as regards their continuing risk-taking practices. This biography is thus a reminder that despite the abolition of apartheid, trauma continues to haunt the imagination of South Africans, as I will add on this in this section.

Chapter Seven: HIV/AIDS and Treatment: An Appeal for Social Justice in Edwin Cameron's *Witness to AIDS* (2005)

7.1 Introduction

In *Witness to AIDS* (2005), the former Constitutional Court judge Edwin Cameron – now retired– addresses the uneven impact of HIV/AIDS on the different social groups in South Africa⁴⁶. This is the story of a resourceful white man with a low profile, based in Johannesburg, and whose experience of AIDS illustrates the continuing debate about how South Africans can build a fairer society in the face of the far-reaching impact of the epidemic. Edwin Cameron is a well-known public figure in the country for his commitment to human rights both in the old apartheid days and the democratic era. Cameron's desire for a health democracy and diligence have inspired hope and change for thousands of South Africans who otherwise would have faced an untimely death⁴⁷. Edwin Cameron contracted the disease when people hardly knew anything about the virus in the 1980s. The attempt to describe his experience with AIDS clashes with the conventional representations of AIDS memoirs previously discussed in past chapters. The fact that his own death was not imminent is of paramount relevance as this causes him to not articulate a discourse where pathos is central to the narrative mode. Indeed, one of the most, if not the most, salient features of Cameron's memoir resides in the fact that his account of AIDS does not seek to be a fully comprehensive explanation of his dealing with AIDS from an emotional perspective. On the contrary, Cameron silences the process of personal mourning to concentrate entirely on the prevailing differences

⁴⁶ Source: <https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/south-africa#Groups%20most%20affected%20by%20HIV%20in%20South%20Africa> Accessed: August 19th 2020

⁴⁷ Source: https://data.unaids.org/pub/externaldocument/2008/20081031_edward_cameron_bio_en.pdf Accessed: September 19th 2020

between affluent and non-affluent South Africans. This feature is relevant for the analysis of the memoir, as it evinces the social transformation of the country is incomplete. Additionally, issues of class are also noted, and these further accentuate disparities in access to therapy. By drawing a clear distinction between the existing hierarchies in South Africa, Cameron expresses his disappointment with the premise that HIV-positive South Africans are able to buy their lives in a pharmaceutical market directed by, and marketed for, westerners. Cameron considers such a situation as both a violation of human rights and a death-delivering obstacle as it highlights that scientific knowledge is only affordable for the country's moneyed elite whilst excluding a large segment of the population. This dichotomy can thus be read in terms of whiteness and class, and these are still recurrent themes in a contemporary South African context, given the complexities of its varied social spectrum, as was noted earlier in chapters three, four, five and six, where we saw how Zackie Achmat, Sizwe, Nkosi, and Khabzela were faced with class issues, racial impediments or spiritual constraints to be allowed to have a future despite HIV/AIDS. The contrasts and disparities within society are further exacerbated by different responses to HIV-related complications, cultural norms and practices –especially on an ethnic level– and the, still, limited social mobilization around HIV prevention and coverage of the, then, existing social assistance programs.

Considering Cameron's financially secure position, the author expresses, paradoxically, his deepest regret over this position of privilege. In fact, the way privilege is constructed in his memoir represents a source of inner conflict that simultaneously grants him the opportunity to recall his engagement with AIDS from the standpoint of the survivor, especially considering he does not want to cope with the survivor's guilt when others around him die of AIDS. In *Witness to AIDS*, this position

of privilege is complicated by those racialized power structures of the old regime which are still prevalent and which, on the one hand, he himself finds deplorable yet, at the same time, is personally implicated with in that they have enabled him to enjoy those opportunities that most of his fellow citizens were denied of on the simple grounds of skin colour. The exploration of guilt is an ever-present, and distinctive, feature of Cameron's memoir. By engaging with the implications that guilt entail, Cameron avoids becoming embroiled in the dynamics of dependence and sorrow, which is a common characteristic to be found in this type of life narratives (Couser 2004; Moore-Gilbert 2009). He celebrates, in turn, a journey into life marked by his overcoming of AIDS because, in his words, "[t]o accept sympathy and support means acknowledging weakness and dependency. I wasn't ready for this. AIDS had to wait" (2005: 21). In this respect, Ashlee Polatinsky is quick to note that Cameron "writes his story after he has recovered, in a time when he is able to live with, rather than die from, AIDS" (2009: 62). This is a significant aspect of Cameron's understanding of AIDS as he feels emboldened to take risks in his approach to the material instantiation of the disease. In so doing, Cameron makes ethical claims upon the readership but, more specifically, upon institutions and corporations inasmuch as his ideological standpoint is not just seeking an empathic reaction but, moreover is soliciting a call to action where the production of drugs is concerned. As Cameron notes:

Drug treatment can now stop viral replication. AIDS is therefore a manageable condition. The drugs that disable viral replication exist, in ample number and manifold combinations. They are capable of being produced cheaply. What prevents their inexpensive production and ready distribution is in the first instance laws, national and international, that protect the exclusive rights of the corporations that have intellectual property title (patent rights) to them. Where the drugs are available and accessible, and are administered under proper medical management, AIDS illnesses and deaths have been reduced by as much as 90 per cent. (2005:44)

Witness to AIDS enters the on-going discussion of AIDS biopolitics within the particular context of post-apartheid South Africa (Nattrass 2012; Cameron and Richter 2008; Potts 2009; Colvin 2005), calling into question the functioning of the welfare state in the democratic age after decades of segregational policies. More specifically, Cameron's discourse centres around the political will of the government to tackle the problematic relationship between AIDS activists and the pairing formed by AIDS dissidents and Mbeki's cabinet. Cameron takes advantage of both his popularity and social position to build further on the questionable ethics of scientific knowledge, intellectual property and the arbitrary nature of the government, which takes sides with AIDS dissidents in its bid to conduct a broader debate on the causes of the epidemic. Cameron's personal disclosure operates within the frame of a systematic and public denunciation of the obfuscation with which national bodies and elected representatives handle the health crisis in the context of an acute national emergency (Gumede 2008). As a result of this entanglement, Cameron often falls prey to internal doubts, and his expression of despair suggests Cameron slides into a mild depression. This state of mind, which is part of grieving, is felt to be tinged with individual helplessness because despite his efforts to build bridges between AIDS sufferers and elected bodies the situation of HIV/AIDS sufferers does not improve significantly in any of the areas of major concern. In the case of South Africa, this barrier is tantamount to determining not just who deserves to be saved but rather who can afford –materially speaking– to keep burning the flame of hope, and increase one's chances to survive in the midst of the epidemic. Cameron's account of AIDS, however, offers significant insights into the various manifestations of a non-visible disability, turning readers into witnesses of the suffering caused by the erasure of sufferers in public policies.

The memoir reflects the success of its participatory process by involving authoritative voices on HIV/AIDS studies such as Nathan Geffen⁴⁸ with whom Cameron co-authors two chapters. Similarly, Zackie Achmat, another remarkable influence on Cameron's memoir and with whom Cameron develops a close friendship, is often referenced in the book as an example of perseverance and the embodiment of a social compromise that mirrors the spirit of the "new" South Africa. The foreword is by Nelson Mandela whose son died of AIDS earlier in the year of publication of the memoir, and this fact alone gave a considerable boost to the AIDS debate within the country. *Witness to AIDS* falls into the category of what Robert F. Sayre labels as a "cultural document", in that the text moves beyond the boundaries of the personal. In the case of Cameron's memoir, AIDS, as a limited form of articulation that is outside the reach of ordinary human experiences, entails the creation of both a personal and public story that invokes the understanding of South African macropolitics through Cameron's intellectual formulation of the country's recent history.

7.2 Edwin Cameron: A Personal Journey into Life

As noted earlier in the introduction, Cameron's memoir is not a chronicle of the dying. It was written in a period of survival, of relative hope in which the disease was, at least, manageable for him. Consequently, *Witness to AIDS* is also written in a period of empowerment when HIV/AIDS was no longer a symptom of the disordered and perverse pathology of homosexuals (Hildebrand, 1992) or the final outcome of the psychic trauma highlighting a set of complexities around sexuality and self-esteem (Rohleder, 2016). This shift in perspective implies that both his choices as an individual and his sense of agency remain intact. This is tantamount to saying that Cameron enters

⁴⁸ Nathan Geffen is an HIV/AIDS researcher whose work is a response to HIV/AIDS denialist claims. Geffen is also a close associate of the Treatment Action Campaign (TAC) and drafts many of the statements by the TAC.

such a fascinating struggle as a subject rather than as an object, as is usually more the case with marginalized communities. Furthermore, the suppression of affects related to the author's personal and frightening experience displays a mental control over the disease *per se*. This attitudinal perspective is in stark contrast to those narratives we have discussed in previous chapters of this dissertation, inasmuch as these mostly focus on how HIV/AIDS presents a serious threat to one's human health and sense of personal realization. The emotional realm is thus set to one side in Cameron's account of AIDS, focusing instead on practical issues in his bid to dignify the existence of sufferers. Underlying this narrative trait is the sense of mission that Cameron aims to accomplish as he aims to pursue an agenda of social and political reform. Cameron takes practical steps to implement mechanisms for the protection of AIDS sufferers through his support of the reform of legislation in South Africa. This is a priority target to stop the dismal social prospects of AIDS sufferers, who see themselves increasingly marginalized in the "new" South Africa. The HIV/AIDS epidemic is a socially produced trauma whereby sufferers, most often-vulnerable subjects, find the building of social bonds problematic as well as projecting themselves as productive members of society to a wider audience. Cameron, in this sense, is startled by the effect of human ignorance on the perception of the disease in the social realm; hence the importance of a legislative shield. The transformation of ignorance into a focus of discrimination compels him to reconsider areas in which law can reduce or prevent the damaging effects of this behavioural response to the disease. It is in this regard that Cameron has a vital role to play in promoting institutional cooperation for the advancement of the underprivileged.

There are several factors behind this situation, and in particular certain mechanisms of structural discrimination that constitute the occasional traumatic undertones of the memoir. For instance, the opening chapters of *Witness to AIDS*

address these factors when Cameron describes, at great length, his fight against AIDS from a position of privilege. The latter bears an intimate relation with the construction of whiteness as a social artifice that places in most cases affluent whites on the top of social and economic hierarchies. For instance, Peggy McIntosh (1989: 29) considers privilege a predominantly racially determined condition of “unearned assets” which provide white people with either material comfort or the possibility of making comfort tangible through the realization of invisible provisions. In line with this perspective, critic Robert P. Amico discusses white privilege within the frame of structural inequalities (2017: 4), highlighting the fact that those who are in a place of structural advantage are, in fact, unable to see their own advantage. Khiara M. Bridges builds further on Amico’s insights on privilege by detaching privilege from an exclusively racial environment (2019: 459) in her attempt to place the issue of class at the centre of the discussion. In *Witness to AIDS*, Cameron experiences relief through privilege and the comforts attached to it. However, it is due to the fact that Cameron sees his own advantage, in contrast to the view held by Amico, that he is able to open up a process of enquiry and interpretation about the existing structural inequalities in South Africa. Cameron’s understanding of privilege is not blind to the reality of those around him in South Africa and other African countries where the HIV/AIDS epidemic has reduced the life expectancy of the underprivileged⁴⁹. Even if only temporarily, Cameron finds himself plunged in the underworld of the underprivileged when he observes that:

For the first time I knew what it meant to experience a loss of expectation of living. I knew with certainty that I would fall ill soon. And then I would die. Death would assuredly overtake me within a year or two. Even discounting these dramatic presentiments. AIDS put a short, sudden and shocking limit of my life. In December 1986 it was for me what for tens of millions of Africans it still is today – and imminent term of death. (2005: 48)

⁴⁹ Source: <http://www.statssa.gov.za/publications/P0302/P03022018.pdf> Accessed: August 20th 2020

Clearly, he was wrong to anticipate an imminent death. AIDS equated him with the less fortunate, who would surely undergo a different fate: death. One, then, must pose the following question: What saved Cameron's life? Certainly, his social position and the privileges associated with whiteness have played a key role in safeguarding his status-quo. Given his position of privilege, Cameron is involved in the movement to end government inaction on HIV/AIDS, and the writing of his memoir constitutes a challenge to the structural mechanisms of privilege. In relation to these mechanisms, Cameron points out that the source of different manifestations of inequality is entrenched in the reproduction of certain relational divisions that seem to be typical of modern capitalist societies. This is exactly the context of the "new" South Africa when the country enters the ranks of globalization in the post-apartheid era. In his analysis of structural inequalities, critic Bob Pease locates relational divisions "within the context of institutional and structural arrangements" (2010: 3). The same critic elaborates on the concept of oppositional consciousness for "subordinate groups to identify dominant groups as oppressors" (2010: 5) as a means to address the perpetuation of persisting inequalities in South Africa.

Additionally, Cameron's memoir is designed to raise public awareness on the need for human dignity for HIV/AIDS sufferers, who are often both the target of discrimination and victims of unfair treatment if their status as HIV/AIDS sufferers is disclosed. Thus, *Witness to AIDS* plays an essential role in the building of an audience, mostly because the specificity of Cameron's testimony constitutes an address to trigger a response and to identify possible contexts in which the privilege associated with whiteness comes into effect. In the context of both late apartheid and post-apartheid South Africa (the setting of his memoir) Cameron pinpoints the construction and

maintenance of the structures of privilege as a constant motivation for him to tackle the existing inequalities in South Africa and, as Pease suggests, “to explore the potential of subordinated groups to mobilise collective actions against inequality” (2010: 7). In connection with this, it is also important to consider Steve Garner’s idea that the meanings attached to the construction of whiteness have not acquired a consensual meaning, and that the expression of whiteness is both time and place-specific so as to conceptualize this social construct that could give rise to diverse forms of exclusion (2007: 1). Garner’s understanding of whiteness allows us to approach the flexibility and fluidity of whiteness as a discursive deconstruction of non-whites that creates some sort of cultural, ideological and dialogical framework through which the production of a social critique of race is enacted. Following this reasoning, apartheid South Africa has made use of racist ideas within the whiteness paradigm (Howard, 2004) in its bid to make evident the effects of both class and division of labour on social groups under apartheid and to consolidate white supremacy.

Cameron elaborates further on the concept of white supremacy, bearing in mind that it is a multifaceted concept and, in this respect, he highlights the linkage between the political and socio-economic systems whereby white South Africans enjoy structural advantage and rights that are not within the reach of other racial groups. He notes that in South Africa “the epidemic is enmeshed with the politics of race and sex and death” (2005: 75), demonstrating that white supremacy is ever present in South African institutional and cultural assumptions. As a white person, Cameron’s upward occupational mobility is never undermined, confirming that both whiteness and privilege operate as functions of power regardless of their degree of visibility. In regards to this, Crankshaw (1997) suggests that persisting inequalities in South Africa have come into effect not exclusively as a result of racial divisions but as a direct consequence of class differences in the form of

disparate wages. The shortage of skilled white labour (Mariotti, 2011) further consolidated this tendency so as to envision and induce the feeling that South Africa was a first-world country in times of apartheid. Although the origins of these socioeconomic differences were predominantly based on apartheid's racial taxonomies, the issue of class, and the construction of the so-called *déclassée* that runs parallel to it, together with the lack of specific governmental policies to bring the epidemic to a halt in its early stages,⁵⁰ contributed to the rapid spread of HIV/AIDS among the less privileged members of society – blacks for the most part. Crankshaw elaborates on the processes by which South Africa's ruling white minority created the middle and upper classes and the dangers this would entail in the long run. He observes that:

If occupational differences are being reinforced by differential access to services such as housing and education, then class inequality is likely to worsen in the future. The new South Africa will therefore have its new 'winners' and 'losers' and, although the history of racial oppression will leave its own legacy of racial inequality, future inequality will be driven increasingly by class divisions. (1997: 121)

Building on Crankshaw's arguments, differential access to treatment has also given rise to health inequalities, and therefore, to the well-founded idea that also in the case of HIV/AIDS there are "winners" and "losers". In *Witness to AIDS*, Cameron discusses the ethical implications of the development of a strict system of classes in South Africa and its far-reaching impact on the health of HIV sufferers, mostly poor blacks, due to the impossibility to pay for treatment in the private sector. Although this latter concern is an issue that has come up repeatedly through this dissertation, it is important to highlight in this final chapter the strong commitment of all the protagonists and biographers to closing the gap between the affluent and the poor in democratic South Africa. This has certainly been a strong link between all the stories and discourses promoted by the cast

⁵⁰ The current president, Cyril Ramaphosa, has implemented a national plan to stop COVID-19
Source: <https://sacoronavirus.co.za/> Accessed: August 17th 2020

of different characters. The then astronomical prices acted as an impending barrier, making the benefits of treatment useless for the bulk of the people living with the disease on African soil⁵¹, and this is something he opposes from the outset of the narrative:

In this setting my own position was one of exceptional privilege. My job as a High Court judge paid well. At the end of 1997 my High Court job was paying me pre-tax less than R30,000 per month [the equivalent of roughly US\$4,000]. This was much less than leading lawyers earned in private practice. But it was about eight times the average salary of employees in the business sector – and almost thirty times the average monthly income of all South Africans taken together. This put me in an income bracket beyond the dreams of most Africa’s 700 million people – and also of most of the continent’s thirty million people living with AIDS and HIV. So I had choices – the choices that relative affluence conferred. The question was how to exercise them. (2005: 15)

His affluent position and “exceptional privilege”, as he puts it, prevent Cameron from experiencing the disease the way ordinary South Africans do. As noted in earlier chapters, AIDS manifests itself as a condition of deprivation and social degradation that certain individuals experience whereas society, at large, does not appear to be affected by the epidemic. This, in turn, is problematic because the impact of the HIV/AIDS epidemic forces both individuals and communities to rethink the limits of our capability to respond to the threats and challenges posed by the silent spread of the virus. However, Cameron veers off into a different direction propelled by the favourable winds of socioeconomic factors. Thus, the way he makes sense out of his AIDS experience differs significantly from that of other individuals discussed in previous chapters. Cameron comes up with a particular understanding of the illness where the notorious absence of loss and social stigma allow him to embrace a future-oriented approach to life. Money and access to adequate healthcare moderate the impact of the

⁵¹ Source: <https://www.kff.org/global-health-policy/fact-sheet/the-global-hiv-aids-epidemic/>
Accessed: August 17th 2020.

disease on him, and this allows him to both aim high in life and develop his interests and professional career to their fullest.

The relationship between class and vulnerability becomes conspicuous, giving rise to a different epistemology of illness as narrative, which in Cameron's case is predominantly one of mastery over pessimistic thoughts and contestation of neoliberal globalization, an issue we will discuss later on in this chapter (see 7.4). Despite acknowledging moments of uncertainty and vulnerability, these do not constitute the core elements of the narrative. However, these moments of uncertainty and vulnerability allow the reader to shift into the position of Cameron, the person, in the few instances in which he manages to de-robe himself from Cameron, the High Court judge (Polatinsky, 2009). An example of his exploration of the boundaries of the experiences that make people human, namely vulnerable, comes to the fore when he shares his first impressions on what it means to be HIV positive:

People sometimes say that they couldn't go on living if they knew that they had HIV. Or that they'd 'just' kill themselves if they ever got AIDS. It's a stupid and unreflective thought. I know, because I used to think it myself (...) [I]ike them, I now experienced no existential hesitation. I just wanted to keep on living. I wanted my health back. Urgently. I wanted to breathe easily, freely again. I could not let diagnoses of PCP [pneumocystis carinii pneumonia] and all that they seemed to imply get in the way. And I had plenty to distract me. Perhaps my inner commotion was more palpable to those closest to me than I had thought. To them I spoke about HIV. (2005: 20)

These types of testimonies abound in chapters one and two of his memoir; what Cameron titles "Second choices" and "Just a virus, just a disease", suggesting that, in his case, the contraction of the deadly virus in the context of South Africa might not necessarily lead to a drastic outcome. It is in these chapters that Cameron addresses the effects of the virus on the human body in the broader context of a normalizing and supportive atmosphere. However, it is when Cameron provides his description of AIDS that he lays the ground for the discussion of those aspects he deems problematic:

AIDS is a disease. It is an infection, a syndrome, an illness, a disorder, a condition threatening to human life (...) a political challenge, a human disaster. AIDS is known. It has been analysed assessed assayed tested measured surveyed considered reflected documented depicted exhaustively described (...) [o]ur knowledge of it is clear and precise. But the disease is also unknown. It is guessed estimated projected approximated sketched debated disputed controverted hidden obscured. Still, it is mere fact: an event, a circumstance, a happening, a reality as present as the ocean or the moon. AIDS is mouth and tongue and scar and nerve and eye and brain and skin and tum and gut. AIDS is smell and feel (...) [h]uman waste (...) AIDS is fear (...) AIDS is stigma disgrace discrimination hatred hardship abandonment isolation exclusion prohibition persecution poverty privation. AIDS is metaphor. It is a threat a tragedy a blight a blot a scar a stain a plague a scourge a pestilence a demon killer rampant rampaging murderer. It is made moral. It is condemnation deterrence retribution punishment, a sin lesson a curse rebuke judgement. It is a disease. (2005: 42)

The manner in which these terms flow, without commas in the original, evinces how Cameron performs a well-rehearsed reflection on the multifaceted nature of the virus. Eventually, this metaphoric language attempts to convey a physical manifestation of that invisible virus that Cameron hosts in his body, and of which he is held hostage. The virus targets him but, simultaneously, he fights it off and tries to understand the dynamics of the virus in his attempt to cope. He is, in fact, witness to all those processes that have also destroyed his body's defence mechanisms, causing the actual breakdown of his immune system. As Rohdeler observes, the most obvious definition of AIDS, the fact that it is a disease, comes last (2015: 65), and this is precisely the idea Cameron purports to put forward by highlighting in the first place the various manifestations of the virus Polatinsky, on the contrary, gives prominence to the idea that Cameron struggles to signify AIDS as regards the omission of punctuation marks (2009: 64). However, something that is made evident in this passage is that the cathartic effect of his wording of AIDS has a soothing effect on him. He is then able to identify the all-encompassing nature of the virus, accepting it is present all over his body but, more importantly, that human knowledge can ward it off. From that moment onwards Cameron's articulation of AIDS clearly falls into the domain of established medical

knowledge which advocates for the idea that one need not die of AIDS as a result of infection, regardless of the manner in which one has contracted the virus.

Although it seems quite obvious that HIV is, in most cases, contracted through unprotected penetrative intercourse, the connections between sex and HIV/AIDS and stigma continue to be a source of embarrassment that needs to be addressed. With that objective in mind, Cameron engages with this stigma in close interdependence with the binary shame-sexuality and white stereotyping of black sexuality and sexual conduct. *Witness to AIDS* is, in fact, the first narrative in South Africa that conveys the difficulties of living with HIV/AIDS for homosexuals (Demmer, 2007), and therefore the first one in dealing with the stigma associated with this chronic disease, thus playing a pedagogical role. The latter is something that Cameron highlights in order to validate a discourse that encourages sufferers to get rid of stigma and to break the prevailing silence around it. In approaching the question of stigma, Cameron notes:

Certainly for me some of the internal shame seemed to come from the fact that my HIV came from a sexual act (...) Though always, in my practice and social and political life, I expressed myself as resolutely open and proudly gay, perhaps my sense of shame derived from the fact that my virus was homosexually transmitted. Or so I thought (...) Perhaps therefore the internal stigma is connected with merely sexual –not homo– or heterosexual. Perhaps in our deepest selves we feel that a sexually transmitted infection shows others that we have been ‘caught out’ (...) Perhaps we still regard ourselves as guilty of some sort of sin of sexual contamination, as marked by moral inferiority, by an uncleanness or exposure of body, and hence a sense of moral inferiority. (2005: 71)

From Cameron’s words, it is evident that he feels doubly “otherized.” In the first place, the crossing of heterosexual boundaries, at least in appearance, has punished him for he inhabits the land of homosexual pleasure and desire. This idea seems to come to his mind when he states that he considers that HIV is a homosexual disease, and such a thing is, according to Siya Khumalo (2018), based on a wrong assumption that religious moralists circulated widely in those early days of HIV/AIDS. The understanding of

same-sex sexual relations in the South African public sphere is regarded as a grave sin, a major transgression, and the contraction of the virus, in view of moralists, serves sinners right. Zackie Achmat opposes this view in his pre-AIDS memoir, stating that HIV-positive people are simply “[g]uilty of enjoying sex” (1995: 326), and Cameron is no exception to this rule. In Cameron’s narrative, guilt is likened to shame but the former is the result of trying to find a way out from the constraints placed on individual and collective agency. It is, perhaps, the inevitable consequence of all the stored-up emotions resulting from oppression and disapproval when oppressed individuals are in search of recognition and reparation. Here, again, it is necessary to link reparation with the recognition of the fact that the exercise of privilege largely depends on whether or not privileged groups make use of their position, under the guise of knowledge and skills, to justify power. Moralists, in the end, forget that HIV is a manageable disease like any other disease that is chronic. Pieter Fourie, in this light, tackles the issue of HIV/AIDS and homophobia in South Africa, commenting on the aspects that compel black Africans, in general, and South Africans, in particular, to stigmatize sufferers. A cursory glance at homosexuality in Africa reveals that,

Homosexual behaviour is considered ‘un-African’, and homosexuals are stigmatised and socially isolated. HIV and AIDS are also considered a ‘white-man’s disease’, and homosexuality is scapegoated as the decadent force that had brought the disease to the African continent in the first place. (2006: 43)

Fourie, furthermore, builds further on the foundations of the black-and-white construction of the stigma associated with HIV and AIDS on African soil when “othering” in reverse pops up in the discussion (*ibid.*, 59). In this context, the relationship between AIDS and homosexuality achieves the category of “un-African.” This view reinforces the assumption that homosexuality is something “white,” and consequently black heterosexuals blame on white homosexuals for the spread of the disease. The reaction to the disease thus promotes “stigmatising societal responses [that]

are the product of complex beliefs, many of which are rooted in views around sexuality and sexually shared infections” (Carlisle 2001: 119). Interestingly, in *Witness to AIDS*, Cameron elaborates on the perception of white-on-black sexuality –the opposite direction–, evincing the clash of the stereotypes arising from sex imaginaries and cultures. He observes:

Despite huge strides in sexual openness and public discussion, sexual behaviour and cultural differences remain a fraught topic. This is rightly so. Sex is the most intimate physical act two people can perform together. Rightly, it generally takes place in private, between consenting adults. Seclusion may be necessary to give us a haven for expression and release of inmost feelings that do not easily countenance daylight (...) This in turn stems from the vestigial sense of shame we seem to feel when our moments of sexual connection and sexual release are marked by or evidenced in a sexually acquired infection or illness (...) Nor is it wholly surprising that at least some in Africa allege that the conventional approach to HIV entails a damning judgement on Africans’ sexual behaviour. (2005: 96-97)

The taming of black sexualities, as we have seen in chapters three and four of this dissertation, is rather a simplistic approach towards the nature of the HIV epidemic in South Africa. Perceived differences between white and black sexual conducts evoke shaming and blaming, reinforce social stigma, and eventually, widen the gap between white and black South Africa.

The examination of shame also takes centre stage in Cameron’s memoir, all the more so considering that, in the public eye, as he recalls back in the mid-80’s when he contracted the disease and back in the late 90’s when he finds out he has full-blown AIDS, blacks and homosexuals were directly involved and both were singled out for shame and blame. In fact, the received knowledge when the earliest cases of HIV/AIDS made the headlines, and when HIV/AIDS was an unknown syndrome killing certain segments of the population, was that the four H’s⁵² were responsible for the spread of the disease: Haitians, heroin addicts, homosexuals and haemophiliacs. Since the first

⁵² Source: <https://timeline.avert.org/?43/content/stigmatising-4-h%E2%80%99s>
Accessed: June 28th 2021

cases of HIV/AIDS were reported, the progression of the virus has developed in close interdependence with homosexual social and cultural practices. Cameron, in turn, tries to break the links that equate homosexuality with AIDS. The very act of Cameron's disclosure in the commission of judges constitutes a step forward towards transparency and the integration of sufferers in the public imaginary. Here, Cameron emphasises that he:

[H]ad chosen to speak out even though legally and ethically I was entitled to remain silent. This choice was available to me 'for very particular reasons – because I have a job position that is secure, because I am surrounded by loved ones, friends and colleagues who support me, and because I have access to medical care and treatment that ensures that I remain strong, healthy and productive.' (...) 'For millions of South Africans living with HIV or AIDS,' I went on 'these conditions do not exist. They have no jobs, or their jobs would be at risk if they spoke about their HIV. They not only lack community support, but face grave personal danger if they do so. And, most importantly, they do not have access to proper medical care and treatment (...) I concluded by stressing 'my hope that my decision to speak today may contribute to a greater climate of openness and caring, and to the prospect of proper medical treatment, for all South Africans living with HIV or AIDS.' (2005: 62-63)

Given his popularity among South African elites and intellectuals, Cameron's decision to go public has the potential to make the struggle for the rights of HIV sufferers significantly visible at the height of the epidemic. Additionally, he clearly states how his position of privilege grants him the opportunity to place the medical and affective needs of sufferers on the agenda and, more importantly, bring it to the fore, as he is also able to sense in the act of disclosure that his words move the audience to embrace his account of HIV. This is remarkably important as the act of disclosure is a testimony that also creates HIV/AIDS witnesses from outside, and this opens up the condition of the possibility of experience. Furthermore, the opportunity to experience the geographies of trauma out of the traditional Euro-American view, as Stef Craps (2013: 21) reminds us, becomes conspicuous in the case of South Africa as an example of trauma that, as Craps notes, "is rooted in a particular historical and geographical context that [has] long been

ignored by academic researchers, including activist scholars fighting for public recognition of the psychic suffering inflicted on the socially disadvantaged” (2013: 21). In the case that occupies us in this dissertation, the HIV/AIDS experience in South Africa is rooted in culture specific contexts, as discussed in previous chapters to a lesser or greater extent, that differ significantly from traditional accounts of HIV/AIDS that stem from the western hemisphere. In this sense, the successful account of the survivors has made HIV/AIDS-related discussions a less urgent topic due to both the effectiveness of drug therapies and its institutionalization. One way or another, in *Witness to AIDS*, Cameron feels that either more people are infected with or affected by the virus:

For a few palpable moments the commission’s judges, lawyers and politicians sat in stunned silence. I sensed that some of them had family – or feared they had family – who were closely affected. Perhaps their fears were closer still. Then the silence was broken by one, more, many questions. They seemed to embrace me, respectfully, supportively, even ardently (...) There is nothing shameful about HIV or AIDS. If we can talk about it, we normalise it. And the sooner AIDS becomes a normal disease, the sooner we will be able to deal with it unemotionally and effectively. (2005: 63)

Cameron is not the only witness of the HIV/AIDS social tragedy. This fact turns out to be of paramount importance, mainly because it is by sharing all the stored-up emotions that Cameron triggered of a reaction that fomented the necessary help and support of those around him to advance a progressive agenda in South Africa.

7.3 Why Witness to AIDS? At The Interface of Human Rights and Democracy

The title of Cameron’s memoir is the premonitory dream interpretation, as was the case after the mass implementation of the national strategic plan (NSP) for HIV and other sexually transmitted infections (STIs)⁵³, that the widespread use of antiretrovirals in

⁵³ Source: <https://sanac.org.za/wp-content/uploads/2019/02/NSP-2007-2011.pdf> Accessed: 10th of September 2020

Source: <https://www.sahistory.org.za/article/history-official-government-hivaids-policy-south-africa> Accessed: 10th of September 2020

South Africa could put the brakes on untimely deaths. The eventual acceptance by the entire political leadership of South Africa that HIV causes AIDS has culminated in a national plan to stop the spread of AIDS. However, until this significant change in mindset came into effect, it is very remarkable the strong presence of political institutions in all the memoirs. The title of Cameron's memoir accounts for it, as *Witness to AID*, is open and gives rise to different interpretations in that it offers a glimpse into the future direction of the epidemic in South Africa. One of the possibilities presupposes that ghosts from the past do not turn up in the present in the form of a life threatening disease. This is partly because of medical breakthroughs in past decades that have given HIV/AIDS the category of a manageable disease, and also, in part, because of the transformation of the cultural meanings of the epidemic within the social terrain. The impact of the latter is significant for it suggests, in the first place, that the homophobic image⁵⁴ of HIV/AIDS embedded in our collective memory and imaginary, and which stems from the social misconceptions about the virus that proliferated in a rather unchallenged manner in the media of the 1980s and 1990s, has been successfully contested.

As a result of this perceptual shift, strategies for self-representation –life-writing among them– have gained momentum. These serve to address those silenced discursive blank spaces with testimonies which serve to restore human dignity. The sociologist James Gillett (2003) contends that self-representation is a form of activism that has the potential to render private issues of HIV/AIDS sufferers into public issues through the

The NSP for HIV and other STIs has always been renewed since its early inception in 2007. The very first attempt to make drugs available to population dates us back to 2003, though. However, the provision of ARVs was low, triggering new protests against it. It was in 2007 when the government came up with to date's current plan.

⁵⁴ Source: <https://theconversation.com/aids-homophobic-and-moralistic-images-of-1980s-still-haunt-our-view-of-hiv-that-must-change-106580> Accessed: 14th of October 2020

regeneration of the social fabric in depressed, post-industrial societies. In his view, self-representation and the spread of alternative mass media have brought about a significant shift in the representation of HIV/AIDS sufferers, as “mass media were misrepresenting those directly affected by the epidemic and hence fuelling a growing moral panic regarding HIV/AIDS” (2003: 609). Likewise, the former president of the AIDS society of Asia and the Pacific⁵⁵, Dennis Altman, is quick to note that the epidemic developed within the frame of the economic rationalizations of Reagan and Thatcher (1994: 14). Such combination of liberal and conservative political ideas and the rising epidemic of HIV led to the criminalization of the LGBTQ community members, whose lifestyles were openly criticized and came to embody the fears of a society in a state of anger.

This view connects with the idea that the productive capacity of post-industrial societies –including South Africa– was seriously threatened due to the allocation of public resources to combat the risks of the epidemic. Thus, community responses to the virus until the turn of the twenty-first century increasingly concentrated on the stigmatization of sufferers. This fact has pushed carriers of the virus to the margins of society, a process of “otherization”, and with no possibility for the narration of their experiences, neither through the practice of mediation nor through the lens of a first-person narration. Cameron experienced, at first hand, the circulation of those ideas, which makes his testimony essential to develop sympathy towards the experiences of homosexual communities with HIV/AIDS. In this regards, it important to highlight social exclusion has played a vital role in the sexual behaviour of HIV sufferers who, in many cases, were desperate to develop intimate relations to combat ostracism. Animosity against and ignorance of the anxieties of this community required the articulation of a community-based response to “alter structures of inequality and

⁵⁵ Source: <https://www.latrobe.edu.au/about/management/organisation/senior/vc-fellow-altman> Accessed: 17th of October 2020

subordination which are often seen as inherent and unchangeable” (Altman, 1994: 10). Cameron’s testimony envisions the role of life-writing for the contestation of the dominance of the South African state’s vision in the tale of HIV/AIDS. The galvanization of public opinion against the single view of the state evinces that there is a certain degree of subversive potential in re-writing the stories of those who were, very possibly and with the benefit of hindsight, the victims of one of the more unfortunate chapters in the history of the twentieth century.

In this manner, readers have been able to engage with sufferers in the movement for the democratization of HIV/AIDS through the educational power of life narratives that serve to re-connect civil society with civil rights movements. The fact that the virus is no longer regarded as deadly, and that sufferers can and, more importantly, want to, account for it, evince the key role that the transfer of life knowledge plays in the transformation of social spaces into arenas for political discussions. The collection of testimonies on both the different interpretations and commonalities of the aspects concerned with the personal experiences of sufferers is indicative of the social disruption caused by conservative ideology. The account of the survivors enables readers to sympathize with sufferers and to create very much needed networks of solidarity aimed at solving structural inequalities in the field of social care. Central to this process of collaboration is the creation of the figure of the witness, who is not necessarily and/or exclusively the experiencer, but the receiver too.

The figure of the witness is of utmost importance in the context of the epidemic in South Africa because, as Craig Demmer observes, “[South Africans] need to recognize that these memoirs represent an important attempt to crack the institutionalized silence that surrounds the HIV/AIDS epidemic in South Africa” (2007: 297). And lest South Africans forget, accountability plays a major role in Cameron’s

experience with HIV and AIDS for he not only witnesses the whole process but, also, escapes from the clutches of death. As Cameron observes, “[t]o survive AIDS is to feel the joy of escape, and the elation of continued life. It is also to bear the duty to speak, and the responsibility to bear witness” (2005: 122). In doing so, he also creates a bond with readers, who operating under the category of audience, of witness, advocate for the continuation of the HIV/AIDS discussion in the public and private domains, intensifying actions on the strengthening of human rights. In this regard, the choice of Cameron to start the narrative in the epigraph is meaningful and effective. It helps elucidate upon the importance of remembering the victims of the HIV/AIDS national tragedy in close collaboration with the role attributed to the audience previously introduced and for not to hide the persisting challenges posed by the HIV/AIDS crisis from the public eye⁵⁶.

For that purpose, Cameron relies on the authoritative voice of the Jewish-Italian intellectual, Primo Levi, to set the predominant tone in the narrative; that is to say, the moderation of the account of the survival to constructively build on the reinterpretation of past wounds in as meaningful a way as possible. This assumption justifies, perhaps, Cameron’s choice of the most appropriate time for intervention; that is to say, once he has recovered from AIDS, once society has crushed resistance to the emotional stress associated with discussing it openly and once South Africans acknowledged the obvious: HIV/AIDS is not a homosexual disease. Moderation and self-control are the predominant features in Levi’s reformulation of his experience with nazism, and the same approach lays the ground for Cameron’s restrained articulation of his HIV/AIDS

⁵⁶ Source: <https://www.newscientist.com/article/mg19526123-800-the-hidden-tragedy-of-africas-hiv-crisis/> Accessed: 10th of September 2020

experience, which requires the participation of communities to keep the symbolic value of remembering alive:

For these survivors, remembering is a duty. They do not want to forget, and above all they do not want the world to forget, because they understand that their experience were not meaningless. (qtd in Cameron 2005, epigraph)

The emphasis on remembrance, memory and commemoration in Levi's words suggests the forging of a self through affiliation with others and through advertising such affiliation in sharing the final product of a reflective step. The process of witnessing constitutes in itself the very act of remembering, which in the case of *Witness to AIDS* reflects Cameron's imperative need to reframe his story from a perspective that is of service to the oppressed and neglected. Additionally, Cameron's testimony holds significance beyond the wording of his experience because it empowers other sufferers who can now count on the support and expertise of a leading figure in the field of law to air their grievances. In fact, this has been the case, as other representations of AIDS followed suit in this respect.

As a witness to AIDS himself, Cameron gives prominence to the notions of surveillance and observation. By showing how these two operate in different social and labour environments readers can realize about the importance of emboldening protest movements. The resulting alliances and community affiliations are proven to be critical in establishing stronger mechanisms for the protection of vulnerable subjects that are, at the same time, part of an extended web of human relations driven by shared values and ideals. These community affiliations are borne of the dissatisfaction with the functioning of the state and the systematic and institutionalized ill-treatment of sufferers who are faced with the commercial interests of private corporations. The actions of these community affiliations revolve around the far-reaching consequences of their criminalization in the eyes of society. This comes to illustrate the concept that non-

fiction generates a perception of reality, whether social, cultural or political, that enables individuals to act as citizens and to move away from the role of mere spectators to one that fights against the dehumanizing approach to the disease.

In chapter four of the memoir, “The tragedy of AIDS denialism in South Africa”, Cameron tries to narrow differences with denialists when he supports the idea that science and medication are not enough and that a broader response to the causes of AIDS is mandatory. Cameron’s desire to build bridges with denialists reveals a great deal of knowledge of practical needs in the field of HIV studies, as he seems to be open to explore new ideas and initiatives in order to improve the living conditions of positive people. The same openness in establishing practical arrangements in other areas relevant to AIDS sufferers, where progress has been minimal, is expected from South African institutions. His desire to reach to a negotiated solution includes the opportunity to hear Thabo Mbeki, with whom Cameron seems to be in tune to a certain point when it comes to identifying some of the roots of present day’s health crisis. As Cameron notes,

[p]overty manifestly exacerbates all African pathologies, and excessive reliance on medical interventions can be a dangerous distraction from broader, more long-lasting social solutions. And President Mbeki’s emphasis on the broader context of Africa’s ailments is part of a heroic campaign against a grossly unjust economic world order, which holds Africa captive to its history of colonialist exploitation. [Mbeki’s] historic legacy might yet lie in his leadership of this broader campaign, with its insistence that the world should acknowledge the burdens of racism and colonialism that African economies and African people are still forced unjustly to bear. (2005: 119)

While there are significant differences between institutional responses to HIV/AIDS across the world, these are clearly the outcome of the dominant political ideology and political economy of the country in question. Possible responses to the health crisis appear to be nuanced and the product of historical and culturally-specific conditions. Altman puts forward, as an example of this, the concerted efforts made by countries

with access to fewer resources such as Uganda or Zambia in contrast to the reluctant attitude of affluent Japan to face the epidemic (1994: 14). The case of Japan, as a rich country, is particularly striking, but it is also a good example to illustrate the idea that AIDS denialism has nothing to do with the amount of available resources to combat the epidemic. On the contrary, it proves denialism is something deeply ingrained in the culture of the country. Nepal (2007: 137) provides a key to identify why AIDS denialism is also rooted in Asian countries, including Japan, and it has to do with forging an Eastern response to the epidemic. This reminds us of Mbeki's African renaissance. In short, the construction of independent opinions is at stake in both cases. Largely speaking, Japan is considered a conservative society where prestige is mostly acquired through seniority and age. In this sense, the social conservatism of Japan and South Africa – in times of Mandela – prevented these countries from fighting off the virus. As was noted in earlier chapters, Mandela, as an elder Xhosa, felt HIV/AIDS fell outside his field of competence. The fact that Japan did the same clearly deconstructs the idea of South Africa as a backward nation but it gives prominence to the idea that cultural restraints take centre stage when it comes to dealing with the impact of HIV/AIDS on population. Furthermore, in William Gumede's *Thabo Mbeki and the Battle for the Soul of the ANC* (2008), Mbeki vacillates over his views on the HIV/AIDS crisis in South Africa. The biographer puts in the spotlight what he calls "South Africa's combustible social mix" (2008: 190) as part of the legacy inherited by Mbeki because "apartheid regime had been deaf to calls for action, seeing AIDS largely as a disease that affected gays and blacks" (ibid., 190) and Nelson Mandela "effectively ignored AIDS, avoiding the subject on the grounds that, in his culture, an elder did not publicly discuss sexual issues" (ibid., 190). This cultural norm is an allusion to the fractured social fabric resulting from the aftermaths of apartheid, in which ethnic beliefs prove to be

monolithic in the face of the epidemic. Furthermore, the complex dynamics of the South African labour system, which significantly relies on migrant's and South African men's mobility to fill temporary positions, and the dysfunctional nature of families as a consequence of the combination of the former two further complicates the possibility to discuss in detail the issues raised by AIDS on a family level. Due to labour migration, extramarital relationships have become both the norm and the source of many untold HIV stories from within the lives of ordinary citizens. These circumstances were the perfect breeding ground for the current overwhelming dimension of the HIV and AIDS epidemic in the southern tip of Africa.

All these silent witnesses on the epidemic make for continuing tension when it comes to the demand for openness on the part of community-based organizations such as the Treatment Action Campaign. As Gumede points out, "more pressing needs" (2008: 191) were high on Mbeki's agenda. The latter's insistence on the ineffectiveness of drugs to delay the implementation of South Africa's public roll-out of medicines and the establishment of an HIV/AIDS infrastructure led to Mandela's first and only foray into South African politics, when the former leader supported AIDS activists in South Africa openly. Cameron recalls that encounter with Mandela in positive terms, where he suggested to Mandela that Mbeki could also backtrack on his denialist position and make life-saving drugs available to South Africans:

During [Mandela's] presidency I had criticised his leadership on the issue. Now it was plain that, at age 83, he was deliberately assuming responsibility for an entirely new and unforeseen task – to assert the need, within the ANC and more widely, for antiretroviral treatment to form part of the government's overall response to AIDS. It was clear that his intervention would be momentous. Perhaps it would be he who could set right the anguished debate about AIDS in our country. (2005: 128)

In the same meeting with Mandela, Cameron describes Mandela's becoming personal when the latter remembers that moment when he was diagnosed to be a cancer sufferer.

The diagnosis gave rise to a dispute among different urologists in South Africa to decide the best option for medical intervention. Significant differences in the diagnosis urged Mandela to make a choice between two opposing medical procedures:

He went on to describe how he had taken the treatment despite the risk that ‘doctors can make a mistake’. And yet now, as a result of treatment, he was clear of cancer: the medical intervention, supported by non-dissident medical science, had triumphed. Madiba’s parable was personal and powerful: when life is at stake, trust medical science, even when the debate may rage; *ignore dissidents*; choose reason and hope above scepticism. It was powerful and suggestive advice. (2005: 129, emphasis added)

Mandela’s words clearly contradict the path taken by his predecessor. Why Mbeki opted for this path, despite the advice and evidences provided by established medical science, still today remains a mystery. However, Gumede’s work on the life of Thabo Mbeki sheds some light on the reasons that may have pushed Mbeki to take sides with dissidents. The scandal over the production of the anti-AIDS musical, called *Sarafina II*⁵⁷, that was to tour the country with the objective of raising awareness on AIDS among illiterate South Africans, had something to do with Mbeki’s decision. Mbeki had been then appointed the head of a ministerial AIDS task team when the scandal erupted in the national media:

The resulting scandal strained the bond between government and AIDS activists. Opposition parties, the media and many NGOs unleashed a barrage of attacks on the health minister, who withdrew into a defensive shell. Government and Ngema [the playwright] claimed the criticisms were anti-government, anti-black and racially inspired [...] greatly angering both Dlamini-Zuma and Mbeki [...] Acutely sensitive to criticism, especially when it emanated from the ANC camp, political home to most of the AIDS activists, the government lashed out in anger. (2008: 191)

Hereafter, Mbeki’s denialism acquired a great moral significance in South Africa. I contend that one possibility behind this assumption might well be the successful management of the disease in other countries, where the epidemic was under control

⁵⁷ Source: <https://www.nytimes.com/1996/10/08/world/south-africa-scandal-over-sarafina-spotlights-corruption-in-the-anc.html> Accessed: 18th of October 2020

almost on a global scale. The fact that South African authorities still refused to commit themselves to a national treatment plan for HIV/AIDS ended up infuriating the country's leading AIDS activist, Zackie Achmat. In the course of Cameron's Harvard lecture, as escalating tensions between Mbeki's cabinet and civil society grew steadily, the former publicly endorsed Achmat's analysis of the South African government's policies, which the renowned AIDS activist labelled as "a holocaust against the poor" (2005: 137). Taking up on Achmat's statement, Cameron's judiciary role in pursuing accountability for sufferers' deprivation of human rights and health democracy has seen him breaking the impartiality of a judge. His participation in public debates on contentious topics with the government's AIDS policy has made him question whether or not he was in full capacity to step in and raise his voice against the inadequacy of certain decisions being made to stop AIDS. He recalls:

My public stand as a person with AIDS who owes my own life to the benefit of treatment is that everyone should have a right to life through access to antiretroviral treatment. So strongly and clearly have I expressed this view that my stand has, I believe, disabled me in my judicial capacity from considering with the necessary dispassion legal questions that may arise in this context. (2005: 150)

These words reveal a lot about Cameron's ethics of conscience and superlative work ethic⁵⁸ when one considers how he too was a citizen affected by the inaction of policy makers. Additionally, it was also in his hands to instigate an ideological revolt against Mbeki's cabinet from within the system and with the support of civil society and AIDS organizations. Crossing the blurred line between the personal and the public is just a question of will and reparation. However, his insights into this sensitive topic show his self-controlled nature, which seeks, in turn, to keep alive the spirit of the transition to democracy through a strategy of bridge making among the different public and private

⁵⁸ Source: <https://www.dailymaverick.co.za/article/2019-08-20-justice-edwin-cameron-urges-fight-for-constitutional-values-as-he-steps-down-from-the-bench/> Accessed: 18th of October 2020

actors. This type of statement also functions as a testament to the government's socio-political stance on the use of public roll-out of medicines to combat the health crisis as Cameron's words anticipate what was yet to come: confrontation and social unrest in post-apartheid South Africa. Good governance underlines the major duty of government to live up to the expectations of its citizens, and the HIV/AIDS crisis in South Africa has seen civil society facing global capital to call for respect for the right to life and for public institutions to grant the most vulnerable members of society an opportunity to thrive in life.

7.4 Conflicting Views: Pro-Treatment Movements, Drug Multinationals and Good Governance

Although all the auto/biographies under analysis in this dissertation deal, to a greater or lesser degree, with Mbeki's denialism, *Witness to AIDS* offers Cameron's insights into this particular issue from within the legal system. His functions as a judge render Cameron a voice of authority, taking in mind that he is well acquainted with the legal quandaries arising from the capacity of South Africa to put HIV/AIDS sufferers on treatment or not. One of the major focuses of attention in the memoir is thus the problematic relationship between multinational drug companies, with the blessing of Mbeki's cabinet, and HIV/AIDS sufferers. In approaching this controversial issue, Cameron also relies on the expertise of the HIV/AIDS activist Nathan Geffen, with whom he co-authors chapter six, "'We Are Not the Red Cross' – Patents, Profits and Death From AIDS", and chapter seven, "Poor Treatment – Justice for Poor People". Geffen's collaboration with Cameron responds to the need to integrate the legal and social dimensions of the epidemic into the national strategies and targets. This collaboration seeks to promote the provision of medicines in the context of the participation of sufferers in public life and decision making.

The debate about patents and intellectual property protection in South Africa has energized the public concern about the role of health research in saving the lives of South Africans dying of AIDS unnecessarily. The enforcement of patent rights on antiretrovirals has been the subject of intense contestation, leading to popular unrest⁵⁹. Cameron and Geffen elaborate further on the long-running dispute between those who plea for the provision of drugs for poor people, considering that “knowledge [cannot] be transformed into a limited resource” (168), and those highly placed in national and supranational institutions, who defend the idea that “drug companies must recoup their research and development costs so as to have an incentive to continue to develop new life-saving medicines (169). In this context of litigation, activists have called into question the inaction of the South African government to issue a compulsory licence by which the country was entitled to produce cheaper generic drugs on the grounds of the public health emergency exception. This possibility offers promising prospects to the most vulnerable, which is something that Cameron and Geffen welcome. Price reduction increases the chances of average South Africans to be put on treatment and also overturns the government’s conviction that universal treatment would be a burden on national finances. The ethical debate around this issue has been multivocal, with medical and legal considerations raised from different perspectives about the role of health authorities in safeguarding integrity and humanitarian concerns.

The growing discontent of HIV/AIDS sufferers with the preservation of the rights of pharmaceutical companies, and with the influence of the latter over making-decision spheres, has given rise to pro-treatment movements marching on the streets to expose corporate abuse. The emergence of these movements, namely Zackie Achmat’s Treatment Action Campaign (TAC), has challenged the legitimacy of patent rights,

⁵⁹ Source: <https://www.theguardian.com/world/2001/jun/12/aids.chrismcgrear> Accessed: 4th of November 2020

questioning not only the excessive pricing of life-saving medicines, which act as an impending barrier, but also the lack of cooperation among the different public actors in the struggle against the virus. This situation has compelled sufferers to find the shelter of the legal system to redress the existing inequality between the rights of civilians and the rights of corporations in a matter of acute national emergency, as was the case of the epidemic. In this context, AIDS activists geared their efforts towards stopping mother-to-child transmission of the virus in their bid to build a HIV-free South Africa. In this regard, the sentence of the court was an added boost to activists, as the court ordered the government to step in so as to make medications available to pregnant women with HIV:

‘The magnitude of the HIV/AIDS challenge facing the country calls for a concerted, coordinated and cooperative national effort in which government in each of its three spheres and the panoply of resources and skills of civil society are marshalled, inspired and led. This can be achieved only if there is proper communication, especially by government.’ The court continued: ‘We consider it important that all sectors of the community, in particular civil society, should cooperate in the steps taken to achieve this goal [of achieving access to treatment].’ (2005: 175-6)

This call for increased cooperation in the area of health assistance continued to find the opposition of the government which continued to uphold the belief that HIV does not cause AIDS and that universal treatment was not cost effective. In his memoir, Cameron makes explicit reference to the cases of Brazil and Thailand, whose per capita gross domestic products (GDP) is similar to that of South Africa⁶⁰, and of their landmark achievements of their local and national pro-treatment movements. These achievements are the mirror in which South African activists have tried to find a model in their bid to urge the members of Mbeki’s cabinet to reconsider their position.

⁶⁰ Source: <https://countryeconomy.com/countries/compare/brazil/south-africa> Accessed: 4th of November 2020

In relation to the latter, Mark Gevisser has documented in greater depth Mbeki's motivations to take sides with HIV/AIDS dissidents, and these views have shaped Mbeki's opinions and policies since then. As a result of this union, Mbeki has become caught up in a loop of confrontational events with ANC-aligned segments of society and in one squall after another⁶¹. Gevisser's broader analysis of Mbeki's positioning raises an essential question: "[is] the state really willing to condemn society's most vulnerable to death in the name of a balanced budget?" (2009: 280). Protests have revolved around two fundamental issues: the need to move beyond the policies based on austerity and awareness campaigns, and the maintaining of an open exchange with the government. The exact reason why Mbeki turned a blind eye to HIV-positive people in the past still remains a mystery in the present. However, some voices (Gevisser 2009; Nattrass 2012) push in the direction that Mbeki rejected anyone to filter information on HIV/AIDS for him after the *Sarafina II* and the Virodene⁶² scandals. Additionally, Mbeki also decided to gear actions towards the design of an economic plan for the African continent to be self-sufficient and to reduce the global capital's interferences in economic policies. In Mbeki's view, as seen in chapter two of this dissertation, the age of globalization has widened the gap between rich and poor countries and produced ideologically repressive movements promoted by big multinationals. More specifically, this desire for economic self-sufficiency stems from Mbeki's suspicion that a

⁶¹ Source: <https://www.nytimes.com/2001/11/04/opinion/thabo-mbeki-and-aids.html> Accessed: 4th of November 2020

⁶² In *A Legacy of Liberation: Thabo Mbeki and the Future of the South African Dream*, Mark Gevisser contends that after South Africa's failed attempt to produce a homegrown antiretroviral in 1998 Thabo Mbeki changed his mind about both AIDS drugs and policies. Mbeki himself was accused of becoming the patron of the development of the antiretroviral to finance the ANC. The scientific community rejected Virodene AIDS trials on the grounds that it could activate AIDS in HIV patients. This scandal was a turning point in Mbeki's positioning, who had been appointed by Mandela to lead South Africa's response to HIV/AIDS. The scandal also involved the former health minister, Dlamini-Zuma, the former wife of former president of South Africa Jacob Zuma. p. 278.

worldwide conspiracy against black people, with a strong racist component, was already in progress to decimate African population⁶³. This view is shared by some of the sufferers in the memoirs, namely Sizwe in *Three Later Plague* and Fana Khaba in *Khabzela*. As Mark Gevisser notes, Mbeki was willing to concentrate on the question of why AIDS, if it truly existed, turned out to be unstoppable and a serious threat to the national interests of South Africa:

Reverting to a racist image of Africans as being unable to control their sexuality, the world wanted to dump expensive and toxic medicines on unsuspecting Africans while ignoring the real causes of AIDS: Africa's ongoing poverty and underdevelopment. Mbeki emphasized repeatedly that Africans had to find African solutions to African problems. But his thinking derived, almost exclusively, from American dissidents – particularly the ideas of Gesheker, a historian. Gesheker had tracked the way that colonial medicine had traditionally pathologized Africans; once AIDS exploded across Africa, he applied this understanding to the way scientists spoke about it. (Gevisser 2009: 284)

Thus, the idea that political economy was responsible for the spread of AIDS gained ground in Mbeki's mindset. And consequently, it was poverty, the illustration of the sustained failure of economic policies on the continent over past decades, the area that required urgent action to curb the epidemic. One way or another, Mbeki has found his way to contest AIDS science, and this shift has left to one side the issue of medical treatment, which is something that Cameron overtly considers a mistake.

In Cameron's autobiographical memoir both the author and Geffen put a human face to the struggle for life-saving medicines and the problems that have arisen on account of excessive pricing. The actual case of Nontsikelelo Zwedala, a terminally ill patient without access to adequate treatment, captures the anxieties of an individual whose situation portrays the agony of life combined with the outward expression of death looming on the horizon. Her waning life appears to be in stark contrast with her

⁶³ Source: <https://www.independent.co.uk/news/world/africa/south-africa-apartheid-aids-saimr-plot-infect-hiv-virus-black-cold-case-hammarskjold-documentary-a8749176.html> Accessed: 6th of November 2020

enthusiasm for living, carrying out personal projects and realizing her dreams in the company of her near ones despite losing her husband due to AIDS-related complications.

Cameron and Geffen's engagement with Nontsikelelo's case responds to the wrong assumption, in the eyes of Cameron and Geffen, that the demands of antiretroviral treatment are an obstacle to people like Nontsikelelo who live in shanty towns under difficult conditions and without running water or electricity. In fact, Cameron and Geffen prove right the belief that the strengthening of the social fabric, mostly through TAC's activism and demonstrations, can be effective and promote significant changes in the lives of individuals like Nontsikelelo, who have nearly given up hope. In the case of Nontsikelelo, her plight takes a turn when she manages to secure a place on a pharmaceutical trial for the development of a new life-saving medicine. In this light, Cameron and Geffen observe:

Nontsikelelo's life and health –and her recovery from near-death– are a rebuke to those who have argued that it is impractical or impossible to introduce antiretroviral treatment for poor Africans who have AIDS. Many arguments have been made that treatment in these settings is not 'sustainable': that Africa lacks the infrastructure necessary for the drugs to be used effectively; that the cost of treating Africans is too high; that efforts should rather be concentrated on prevention. (2005: 188)

Nontsikelelo's successful recovery thus proves wrong the government's assumption that poor people would eventually be unable to take responsibility for their treatments. In lieu of this, pro-treatment movements have encouraged health authorities to widen AIDS might be perhaps an excuse to cynically deal with the problem, especially once spending constraints disappeared. Both Cameron and Geffen insist on the government's "damaging and erroneous notion that 'prevention is better rather than cure' in AIDS programmes" (2005: 192) to adopt a different strategy.

In *The Moral Economy of AIDS in South Africa*, critic Nicoli Natrass criticizes the risks that the concept “constrained optimisation”—mostly endorsed by economists—entail in the long run for the economic development of South Africa. The critic argues that disparities might increase if the allocation of resources concentrates only on healthy individuals. She notes:

Such strategy [constrained optimisation] may include giving HIV-negative people preferential access to welfare, education and health services and even confining HIV-positive people to ‘sanitoria’ (as in Cuba) or the equivalent of leper colonies. The problem with this line of logic is obvious: if you concentrate resources on the ‘most productive members of society’ in order to maximise growth, you sacrifice the ideal of equal treatment and respect for persons. It conjures up a vision of a brutal (and brutalising) society in which the HIV-positive are shunned and discriminated against in an effort to ensure a greater share of income for those who survive the pandemic. (2004: 36)

It is noteworthy that the aim of the TAC’s campaign is twofold in the sense that by recovering individual’s health one is also promoting the restoration of dignity and, in turn, human agency. Therefore, one of the areas of concern of pro-treatment movements has to do with the ethical and moral question of health investments in South Africa. In particular, Cameron and Geffen suggest that the choices of the South African health system are immoral because these prioritise the prevention of new infections over dealing with existing infections. In this context, as Cameron and Geffen point out, HIV tests are only death sentences. They contend:

Why get tested if the only ‘benefit’ is to gain knowledge of one’s own premature death—with the added likelihood of discrimination and stigma? By contrast, when treatment is offered as part of a voluntary counselling and testing programme (including a safer-sex discussion and condom provision), there is a real incentive for people who suspect that they may have HIV to come forward. (2005: 194)

One of the key aspects of *Witness to AIDS* lies precisely in both its historical and historiographic value. This is so because the current welfare state of South Africa has extended protection to HIV/AIDS sufferers thanks to the relentless work of pro-treatment movements, working closely together with the NGOs that implemented,

against all odds, the roll-out of antiretroviral programmes for the most vulnerable. Their firm belief in a fairer society, upholding the idea that what is truly unsustainable in South Africa is, in fact, opposition to treatment and denialism.

7.5 Conclusion

Witness to AIDS provides a full sweep of the social, cultural, historical, legal, political and economic context in which the need to fight for the preservation of human rights is presented as a must. Cameron proposes the simple choice of decency versus indecency, where an understanding of decency is configured as a non-conflictive vision of a progressive conceptual landscape enshrined within the Constitution of the Republic of South Africa. The very driving force for social change and development in South Africa, as attested in the text, resides in the articulation of mechanisms that promote equality and true social mobility. Cameron's commitment to these values shows a high-level backing to fuel the momentum created by a chorus of progressive voices and forces to end the questionable approaches of authorities to the epidemic. Fighting indecency is thus tantamount to facing the demands of global capital and the inconsistencies of denialism and its partakers by building bridges with the aim of ensuring social cohesion in a country formerly divided by racial prejudices.

This autobiographical memoir fosters respect for the most vulnerable and promotes good governance in the field of health practices. The promotion of social harmony, both wisely and benevolently, seeks to reduce the impact of privilege on the less favoured individuals of South African society, who are in most cases facing difficulties in adapting to the changing political and economic situation of the country. Cameron's role in teaching society how to exercise their rights and harness their powers is best exemplified by the gradual process of the socialization of medicine in South Africa, which is the commendable task of a dedicated professional in the field of human rights.

Conclusions

The HIV/AIDS life narratives produced in the first decade of twenty-first century South Africa are a faithful reflection of the anxieties of post-apartheid society. They express new forms of state violence and oppression over disabled individuals, and, more importantly, of what is happening in the hearts and minds of HIV/AIDS sufferers. The construction of these life narratives, namely how sufferers and memoirists compose the AIDS experience, far exceeds the capacities of HIV-negative people to fully imagine the daily struggles of suddenly finding out the extent to what a virus, for which there is no cure known, can determine your whole life once their paths cross. This simple fact dictates the lives of HIV/AIDS sufferers until the end of their days, and this suffering can be mediated through the different manifestations of trauma, namely: abuse, violence, and displacement, especially when institutions pretend nothing happened, as Sarah Schulman (2012: 155) states, has occurred. In this dissertation, I have provided distinct focuses on trauma through the work of theorists such as Caruth, Craps, Fassin, LaCapra, Laub, Roth or Schulman, amongst others, to illustrate the evolution of trauma theory from its initial point of departure. This starting point, namely the account of the Holocaust, considered traumatizing events as unrepresentable, but as we have seen the expression of trauma, through life-writing, becomes retrievable and, thus, symptomatic of the emergent agency that has arisen in the life narratives of each of the AIDS sufferers portrayed in this doctoral dissertation. The complex, nuanced, and sometimes even elusive style in which the emotional realm of HIV/AIDS sufferers eventually comes to the fore stand as key features for our understanding of sufferers' conceptualization of their corporeal and psychological experience with HIV/AIDS. Such an element transcends any type of barrier, be it ideological, physical or emotional, and subverts the construction of any moral order, national integrity and dignity, the

nature of political action, and any symbol of power operating under the guise of either the global capital or African nationalist aspirations that are deployed in South African public policies and spaces.

The booming of illness memoirs in the post-apartheid period is the confirmation that literature performs a crucial safeguard role for fundamental rights in sync with these pressing needs. This aspect generates new sensibilities regarding disability, foregrounds the role of mediation not just as a conflict resolution mechanism but as a tool for raising awareness and generating public discussion. The circulation of these testimonies gives value to a body of non-fictional forms of knowledge that calls into question policies whose end goes into social outrage and abuses of sufferers' basic rights. As is known, scientific knowledge has the ability to cause and unleash disease but also has the power to heal or alleviate pain. Therefore, this doctoral dissertation also seeks to demonstrate that the targets of scientific progress must revolve around two fundamental issues: good service to global citizenship and commitment to strong ethics, the accumulation of strategic gains in the field of equality, the improvement of public and global services in areas as delicate as HIV/AIDS. What we have witnessed in South Africa with the HIV/AIDS crisis does no credit to the production and application of scientific knowledge, and this still happens today with COVID-19 vaccines outside of the limits of the rich western hemisphere when science aims to please its economic and political creditors over the fulfilment of its original purpose when, arguably, the lack of the independent exercise of scientific duties opposes the interest of the majority of the citizens of the world.

Nobody is exempt from contracting an incurable disease or developing a rare disease that needs to obtain the broader support of national public services. The invisibility of HIV/AIDS disability and trauma justifies the intensification of

cooperation through concerted efforts between all the parties involved in this enterprise, namely civil society and organizations, politics and the scientific community. HIV/AIDS memoirs examine the multifaceted manifestations of trauma through the testimonies and instantiations of the lives of diverse generations of South Africans. These range from relevant public figures in the socio-political landscape of the country, such as Zackie Achmat, Edwin Cameron, or Fana Khaba, to ordinary citizens, all of whom contributed, by sharing out their intimate experiences with the disease, even at the cost of losing their lives in some cases, to the achievement of the universalization of treatment in South African public hospitals and clinics when this measure was not even planned to come into effect.

In this doctoral dissertation I have spoken at great length about the implications that AIDS sufferers' testimonies entail in terms of the construction of democratic foundations of South Africa in view of the limited resources available for a long while to combat the spread of the HIV/AIDS life-threatening virus. Hence, each of the testimonies comprised in this dissertation prove that the HIV/AIDS sufferers' critique of the redemptive discourse of nation-building policies in South Africa is an integral component within the need to contest any attempt on behalf of official public discourses and narratives to contain the AIDS experience merely to marginalized, abjected and otherized identities. The protective umbrella of AIDS life-writing creates a normalizing context for sufferers to open themselves up to their own examinations of AIDS, trauma, and the value of their testimonies in terms of historiography and metanarrativity. Although AIDS is a global issue, we have seen in this dissertation that its development, dynamics and consequences play out with substantial differences on South African soil due to the politicization of the disease. This central aspect of the HIV/AIDS crisis in South Africa calls on us to assess the extent to which the convergence between unity

and integration has truly come into effect, giving way to a solid and unified nation around any central aspect that is needed to bring people together in pursuance of the same objective: inclusion and restoration of dignity and integrity. The exclusion of HIV/AIDS sufferers has been a reminder of the new forms of oppression that emerged in the post-apartheid days, especially considering escalating tensions around treatment and the management of the health crisis.

The transformative spirit of AIDS life-writing has been essential in fighting off the largest obstacle in this battle: AIDS denialism and political inaction. The political engagement of sufferers and their coming together has resulted in the unprecedented mobilization of South Africans, who exercised pressure on institutions to highlight the importance of good governance. The nation, again, as it did in the apartheid days, raised its voice for the accomplishment of a noble end: HIV/AIDS sufferers cannot fall into oblivion. Every rally, every demonstration, every testimony, and every little advance that has been made in the struggle for visibility and for recognition of the rights of AIDS sufferers to signify has not been in vain. This dissertation wishes to place value on the testimonies of sufferers who were socially and historically disinvested, and whose experiences resisted being homogenized when, in fact, their stories were rife with rich nuances and coloration, showing the entire South African nation their lives are teeming with possibilities, passions are dreams. The uniqueness of their experiences cannot be replaced with the official and monotonous narrative of the epidemic. The privileged cannot speak for the sufferers; hence, the importance of literature to memorialize and to document the AIDS experience out of the artificial comfort zone created by the West and their representatives in the southern tip of Africa.

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