ACQUIRING SOCIAL CAPITAL: THE BIOGRAPHICAL TRAJECTORY OF LONG-TERM SURVIVING HIV AND AIDS ACTIVIST FAGHMEDA MILLER

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DECLARATION

This is my own work. No part of this work has been previously submitted in whole, or in part, for the award of any degree. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

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ABSTRACT

Despite criticism from relatives, religious leaders and her Muslim community, Faghmeda Miller publicly disclosed her HIV status on World AIDS Day in 1996. She became the first Muslim woman in South Africa to do so. Her story of courage in the face of the unknown, stigma and discrimination echo the complex social context in which HIV is experienced nationally and globally. It places emphasis on the fact that HIV affects all humans, irrespective of religion, race, gender, sexuality or socio-economic status.

Using life trajectory as a method of enquiring into Miller's social and religious meaning making regarding her infection and HIV and AIDS activism, this research presents her challenges and victories in her journey with HIV and AIDS. The biographical study examines how she became the face of a Muslim woman with HIV in society. In speaking up for the infected voiceless and taking a lead in creating awareness about a highly stigmatised disease, Miller shows how personal agency was used to change attitudes, save lives and offer support to the suffering. Mass media in the 1990s—television, radio and print—played a crucial role in her trajectory. This study argues that Miller acquired social capital through the declaration of her HIV status, increasing her public profile, and co-founding the Muslim HIV/AIDS organization, Positive Muslims. The analysis focuses on turning points in her life trajectory, including traumatic experiences, transformative reflections on Islam, and activism. Through her personal and social challenge with the virus, she ultimately embraces an inclusive Islamic theology of compassion.

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CHAPTER 1: INTRODUCTION

Introduction

Sub-Saharan Africa is at the epicentre of the global HIV and AIDS[1] pandemic, with South Africa the country with the highest rates of HIV infected people. Approximately 7.1 million of the country's population currently live with the devastating disease (UNAIDS 2018). Former South African president, Nelson Mandela, stated about the epidemic: "This is a war; it has killed more people than has been the case in all previous wars; we must not continue to be debating, to be arguing when people are dying and I have no doubt that we have a reasonable and intelligent government, and that if we intensify this debate inside, they will be able to resolve it" (*Sunday Times*, 10 August 2003)**.** Indeed, the national government in 2016 was spending an estimated ZAR23 billion towards combating HIV/AIDS - 80% from state funds and 20% from donors (Nkosi 2016).

The high rates for HIV and AIDS in South Africa are varied and debatable. One contributing factor has been inefficient leadership response to the epidemic. 'HIV/AIDS denialism' by President Thabo Mbeki between 1999–2008 at the height of the pandemic was the most notorious instance (Mbali 2003; Nattrass and Kalichman 2009). Also, HIV as a predominantly sexually transmitted disease (STD) renders it a taboo topic in many communities, making awareness-raising for safe sex practices difficult. Other factors that contribute to the spread of HIV include poverty, gender inequality, sexual violence, high levels of STDs and limited and

[1] AIDS is the acronym for Acquired Immune Deficiency Syndrome, caused by the human immunodeficiency virus (HIV). By damaging the immune system, HIV interferes with the body's ability to fight disease causing organisms. Symptoms of HIV infection include, amongst others and depending on the progression of the virus: fever, headache, fatigue, diarrhoea, weight loss, rash and mouth sores. AIDS occurs at an advance stage of immune damage and dysfunction, causing opportunistic infections and diseases that can lead to death. At the beginning of the pandemic there was only an AIDS diagnoses as medical science only afterwards discovered the HI virus as the primary and prior cause (AIDSinfo 2019).

uneven access to quality medical care (Jewkes 2009, Leclerc-Madlala et al. 2009). Furthermore, stigma, fear of rejection, socio-economic factors, and religion influence the impact of the disease on South African society, including health care and nutrition in citizens' daily lives.

Local religious institutions often serve as spaces for members of faith communities to seek answers to life events, traumas and other phenomena impacting their lives. Admonishment from the pulpits of mosques and churches and from religious leaders in other faiths contributed to the myth that HIV/AIDS is God's punishment for immorality and sin, leading to public perception that the disease is shameful. This impacts disclosure, health treatment and social support (West 2011, 135). Within Muslim communities, in particular, tensions exist relating to strong cultural and religious taboos linked to the topics of sex, sexuality, STDs, HIV and AIDS. Since HIV/AIDS is predominantly associated with sinful sexual conduct, Muslims remain focused on the ideal of sex as confined to marriage and ignore the reality of sex occurring outside of marriage.

The silence around extramarital sex is a form of HIV/AIDS denialism, of not acknowledging its existence and ignoring its devastating impact. Thus, religious and cultural 'silences' have contributed to the spread and treatment of the disease (Long 2009). In South Africa, in the 1990s, especially, denialism about HIV/AIDS and its prevalence within the Muslim community saw the disease becoming a silent killer—physically, mentally and emotionally—to those infected or affected by it, with countless Muslim sufferers remaining faceless.

The pattern of silence, denialism and unacknowledged suffering was powerfully disrupted in 1996 in South Africa, when a Muslim woman publicly declared her HIV status on World AIDS Day. Faghmeda Miller announced her disclosure: "I have decided to disclose my status not only for myself but also for all the other HIV positive Muslims who suffer discrimination,

stigmatization and disrespect in our community" (Haddad 2011, 398). Her story of courage in the face of the unknown and her experience of stigma and discrimination in the local Muslim community echo the complex social context in which the HIV epidemic is experienced globally. Miller has since become well known for her HIV activism and the leadership role she undertook as the first Muslim woman in South Africa to publicly disclose her HIV status, against criticism from relatives, religious leaders and others in the Muslim community. Through her HIV activism and agency over the past decades, she has created a space for acceptance of and compassion towards HIV infected and affected Muslims where there was none. Following her public disclosure, she continued to support HIV survivors and went on to co-found the Non-Profit Organization Positive Muslims in 2000, a faith-based organization providing psycho-spiritual support for people infected and affected with HIV and AIDS, and promoting Islam as an inclusive theology of compassion. By publicly disclosing her HIV-positive status, Miller used her agency and voice to create awareness and to educate others not just about the disease but also about Islam as a religion of compassion and care. In the process, she has become a beacon of hope and courage for marginalized and stigmatized sufferers. She showed that finding meaning within the Islamic faith supports a marginalized identity through a theology of compassion.

Living long-term with HIV

Few studies exist that trace the experiences of long-term HIV survivors in South Africa, let alone in its Muslim community. This research study will contribute to this deficit by providing a biographical trajectory of Faghmeda Miller as a long-term HIV survivor and activist who is living with HIV for more than a quarter of a century. It will thus add to the growing body of knowledge about HIV and AIDS that is aimed at creating a better understanding of the disease and syndrome. Long-term survivors of HIV have the unique experience of having been

expected to die but, unexpectedly, living a long life. They represent a diverse range relating to ethnicity, gender, sexuality, socio-economic status, culture, religion and nationality. Published research on their long-term existence is limited. Despite the growing number of long-term HIV survivors, they thus appear to have been "forgotten." Yet, the experiences of long-term HIV survivors can contribute significantly to better understanding the disease, especially how support for infected individuals may be promoted beyond current efforts. It is their life trajectory as long-term survivors that gives them a particular 'expert' status in the area of living life with HIV (as well as possible insights to support further treatment in the future) that forms the basis of my study.

Research indicates a greater level of stigma attached to HIV compared with other illnesses that are stigmatized, such as cancer, leukaemia and herpes (Lee et. al. 2002)**.** Stigma is hence profoundly experienced by people living with HIV and AIDS. While research shows that the level of stigma associated with HIV infection has dropped considerably in the United States and other parts of the globe, seropositive individuals still experience high levels of stigmatization (see, for example, Lee et al. 2002, Ciambrone 2003, Deacon et al. 2009, Daniel and Squire 2009). Four reasons are identified in the literature for HIV/AIDS still being highly stigmatized: (i) the disease is considered to be to the result of irresponsible behaviour; (ii) it is currently incurable and eventually fatal; (iii) it is contagious, and (iv) it has physical conditions that are clearly visible or apparent when the HI virus eventually progresses to full blown AIDS. The HIV/AIDS body is thus a highly stigmatized body.

HIV and AIDS related stigma is further layered with stigma associated with homosexuality, drug use and sexual promiscuity. The experience of stigma, based on society's negative views of HIV infected people, leads to HIV-positive individuals not only being prone to harmful feelings towards themselves, but also exposes them to harm from society. For example, South

Africa witnessed, first-hand, the extreme effect of stigma and discrimination in 1998 when Gugu Dlamini, a young black woman, who disclosed her HIV-positive status on a local radio station was murdered three weeks later, the reasons emerging as the double shame she was perceived to have brought upon her community not only for being HIV-positive but openly lesbian (Deacon et al. 2009, 105). In response to this event, and subsequent murders in South Africa, on the African continent and elsewhere, the United Nations Agency for AIDS (UNAIDS) chose stigma as its campaign theme for World AIDS Day in 2003. As Faghmeda Miller states about the serious impact of the social stigma associated with HIV, "I would often tell people that it is not HIV that is killing us. Look, I am living proof that you can live long with the virus. What is killing the people is the stigma and discrimination attached to the virus."[2]

Social disclosure of HIV was a contentious issue for those living with the HIV virus, as highlighted in a Slomka et al. (2013). Rejection was experienced by some while others chose to disclose only to a significant other. Most of the participants indicated being selective in sharing their HIV status, even though they desire to give back to society by sharing their personal experiences and knowledge about HIV as a means to educate the public about coping with the disease. Research elsewhere shows that coping emotionally with HIV over the long-term involves patients' resilience in overcoming the challenges of living with the virus on a daily basis (see, for example, Jue 1994; Turner and Kelly 2000; Siegel and Schrimshaw 2000; Slomka et al. 2013). A change of perspective, though, is generally identified as necessary to manage negative emotions and attitudes towards the diagnosis, self-care and medication. Researchers recognize the need to include the experiences of older, long-term HIV survivors

[2] Interview with Faghmeda Miller, Cape Town 2018.

as volunteer navigators to initiate newly diagnosed HIV-positive individuals into the complexities of living with HIV.

The role of spirituality and religion to support coping with HIV and AIDS and its related medical and physical conditions is demonstrated in numerous studies (see, for example, Arrey et al. 2016; Caimbrone 2003; Hasnain 2005; James et.al. 2009; Kaplan 2014; Maman et al. 2009; Obermeyer 2006; Ridge et al. 2008). It is evident from such studies that religion is a source of hope and support for many people living with HIV and AIDS, despite the prevailing negative attitude shown by religious institutions and religious leaders towards the virus and the disease. According to Ridge et al. 2008, in a study conducted in the United Kingdom, places of worship represent a sense of belonging for black African immigrants living with HIV, in which they feel they can obtain emotional and material support in the form of counselling, prayers for their well-being, networking for various forms of social support, and assistance for financial and asylum needs, regardless of the dominant narrative of sin attached to an HIV diagnoses among the community there. Similarly, sub-Saharan African migrant women living in Belgium, in a study by Arrey et al. (2016), were seen to ascribe a positive faith in God for their survival. Although they did question God for their having contracted the virus, they still find refuge in Him through prayer and religious activities. The refugee women believe strongly that it is only through the grace of God that they were able to be in Belgium, which afforded them a "second chance" to life by being able to access free HIV antiretroviral and other medical treatments (Arrey et al. 2016). The World Health Organization (WHO) reported and recognized, in 2007, the great role played by faith-based organizations regarding HIV and AIDS related care and treatment in Sub-Saharan Africa (WHO Report 2007).

In a study of three HIV-positive South African women from townships near Cape Town, Marian Burchardt (2010) explores the meaning of the uncertainty embedded in the strategies

these women employ to navigate daily life with HIV. According to Burchardt, within the historical context of HIV/AIDS denialism in South Africa, biography as a mode of reflecting self-construction has been adopted by local AIDS activists for publicly speaking about their experiences and awareness-raising about the disease. Burchardt hypothesizes that uncertainty felt by an individual ensuing from an HIV diagnosis is often reflected in individual biographical perspectives. Hence, the need, as I argue in the current study, for including in our understanding about the disease the biographical narratives of long-term HIV survivors because they have first-hand knowledge via experience of living with the virus for a long time.

Life Trajectory of HIV and AIDS

In South Africa, biographical narrative emerged against the backdrop of the historical struggle against apartheid. HIV and AIDS activism follows in this post-apartheid fighting tradition for a human rights-based approach to the pandemic to prevent more people dying. The HIV and AIDS struggle began locally because people were being denied access to HIV medication by the same government for which they had fought and sacrificed in the cause of liberation and democracy. Historically privileged as white and being able to access the expensive Highly Active Antiretroviral Therapy (HAART) drugs, South African High Court Judge, Edwin Cameron, spoke out against this injustice in *Witness to AIDS* (2005). In 2000, at the Global AIDS Congress in Durban, the emotional personal story of Nkosi Johnson, an eleven year old HIV-positive boy by birth, shook the country and the world. The co-founder of the Treatment Action Campaign (TAC), Zachie Achmat, rose to prominence for the campaigns and activists he inspired and rallied towards accessible and affordable antiretroviral treatment for all infected South Africans; the TAC took the government to court for not taking preventative steps against mother-to-child transmission (MTCT) during pregnancy and breast feeding. These are but a few examples of the prominent voices that emanated with courage in the South African context

of HIV and AIDS activism. The common thread of the activist in these narratives, like Faghmeda Miller, is the lived realities of ordinary South Africans, their positive responses and resilience in the face of a life-threatening disease they and others face. Haddad concurs and demonstrates in her work that "it is the voices of those who are HIV positive, as well as those who work in the communities that need to be recovered and recognised in setting the agenda for any future research" (Haddad 2011, 4).

An individual life and the role it plays in the larger community can be greatly understood through story. Biography as a qualitative research method will thus be used to conduct this study, as biographical narrative represents human life from a lived perspective. The focus of my study is to highlight not only the challenges that one woman experienced in her journey with HIV and AIDS, but to integrate these with the victories in her life trajectory that resulted from her choosing to openly live an exemplary life with HIV. Her biography became allegorical of a community and HIV and AIDS.

According to Ann Oakley, all biographers must be their subjects' advocates, if only in the sense that they must regard the story of this particular life as one worth telling, either for its own intrinsic interest or because of its external impact (Oakley 2010, 430). Rachel Morley recognizes the emotional and personal connection between the biographer and the subject as central to the production and interpretation of the narrative (Morley 2011, 965). Oakley and Morley's observations resonate with me at the personal level and my motivations for choosing Faghmeda Miller as my research subject. First, I am connected to my research subject at a personal level as she is my biological sister. I thus have an intrinsic love for and affinity to her. I have been deeply touched by her trauma and inspired by her triumphs. Second, I find great pedagogical value in her life story as it is still highly relevant in the fourth decade of the global HIV and AIDS epidemic. As a researcher and biographer, I am faced with the challenge of

presenting Faghmeda Miller as a research subject, while also being constantly aware of my subjective relationship to her. Thus, the strong biological and social bond I share with my research subject will serve to aid rather than hinder my task of focussing on the biographical trajectory study of Miller as a long-term survivor of HIV.

Potential limitations

A possible limitation to this research study could be the size of the sample, which is based on the life of one person only. I decided to interview three more people in addition to my primary subject in order to obtain more textured and in-depth data. I could possibly have interviewed more people who have known my subject during the course of her life, but this would have taken up much more time than was available for the fulfilment of a master's thesis. As this is a minor dissertation, both the time and length of this research study is restricted. I am also cognizant of the fact that my personal relationship to my research subject and that knowing her intimately could be perceived as limitations to the current study. However, I choose to rather see these as advantages. The prior knowledge I hold in this relationship with my subject before even attempting a biography places me in an advantageous position of already being familiar with many aspects of her life, thus allowing me to more fully engage with and interpret the data to produce a richer biographical narrative of the subject than I would otherwise have done. Indeed, biography as a form, is replete with narratives by persons closely and intimately connected to the research subject precisely because of the biographer also serving as an informant about the subject even while allowing the subject to speak her story. Another shortcoming could be my own bias to the critical interpretation and analysis of the data for the very reason of close proximity to the subject. I am aware of this possible bias. While I will eventually let the reader decide the impact on my thesis, I will also include some discussion on my interaction with the subject and its possible influence on the research. I will share my

personal reflections in my research notes and analysis with the reader. This should mitigate possible limitations regarding the relationship between me and my subject.

Outline of chapters

The central research questions of this thesis are elaborated in five chapters on the following questions:

- What are the biographical experiences and the HIV activism of Faghmeda Miller in her life trajectory?
- How did she challenge prevailing stereotypes and cope with her illness to become an impactful long-term HIV survivor?

The main argument covered by these questions points to the social capital she acquired in the process of publicly disclosing her HIV status and subsequently co-founding the Muslim HIV/AIDS support group, Positive Muslims.

Chapter 1: This chapter introduces the study's rationale. It focuses on the context of HIV and AIDS in South Africa and the response to the virus and disease by society, in general, and the Muslim community, in particular. It declares the main subject of the study.

Chapter 2: The theoretical framework of this study is informed by the following four concepts: (i) long-term HIV survivor studies, (ii) life trajectory as research method, (iii) the theory of memory anchors and (iii) the theories of social capital. The first point to note is that Miller is a long-term survivor of HIV which has begun to attract attention in the literature. Based on this recognition, the concept of life trajectories is presented as a method of choice in producing a biographical narrative, as it allows for a complex phenomenon to be studied over time. This study makes use of Aleida Assmann's (2001) theory of memory to show how trauma, emotional affect and symbolic interpretations are recollected by the research subject in dealing

with her HIV-positive trajectory. Pierre Bourdieu's (1986) theory of social capital is finally used as a lens for analysing the social capital gained by the research subject through her agency and activism in the field of HIV and AIDS.

Chapter 3: This chapter explores the life trajectory of Faghmeda Miller, offering a narrative of her early life, adulthood, marriage and HIV trajectory. It sheds light on her social and religious meaning making over time. It focuses on identifying key turning points and defining moments in her lifespan.

Chapter 4: The analysis of the data in this chapter draws upon the theoretical concepts of life trajectory, memory anchors and social capital to analyse the experiences of Faghmeda Miller. The aim of the analysis is how key turning points, identity and agency contributed to the acquisition of social capital for her. In this chapter, I also provide some brief discussion on reflexivity in the research process and use extracts from my research diary to engage the impact of retelling and memory as therapeutic process for both the research subject and the researcher.

Chapter 5: This chapter provides a summary of the thesis, including key conclusions that can be made about the value of biography narratives of long-term HIV survivors to better understand the AIDS syndrome. It celebrates Faghmeda Miller's activism in the field of HIV and AIDS as one of the long burning candles who shines her light brightly on this path. In the face of ongoing stigma and discrimination relating to HIV and AIDS, she embraces the notion that "there is still much work to be done." It is with this challenge and spirit that she supports the longevity of life for herself and others infected with by the virus, and those affected by it too.

CHAPTER 2: THEORY AND METHOD

> The intent of biographical research in its various guises is to collect and interpret the lives of others as part of human understanding (Roberts 2002, 15).

Introduction

A biography is the narrative of a life lived by one person and written about by another (Petrie 1981, 5). We write about the lives of others because we have the sense that their lives matter, and further, that they matter beyond their own lives or deaths, and have value for others, other lives and other lives in other times. Moreover, a crucial aspect of the social sciences is awareness of the social and cultural dimensions of an individual life, which reflects broader societal conditions. A life story, by focusing on or inquiring into the personal life of an individual, is therefore never independent of the political and socio-economic conditions in which it is or was lived.

The biographical trajectory of HIV and AIDS activist, Faghmeda Miller, in the current study offers a window into her social and religious meaning-making in the wake of the HIV/AIDS pandemic and the societal shifts it necessitates and produces. While her life and her living is personal to her, the story about how she dealt with her HIV infection lends itself to more general inquiry. It suggests an examination of the making of meaning for herself and others when an HIV diagnosis signifies social rejection, isolation, chronic illness and the threat of imminent death. I explore the application of the biographical method and trace some of its historical developments within the twentieth century, in which biography as a narrative form is seen as an important source of social, not just personal, knowledge. Sometimes called microhistory, is the personal history or story of an individual person that is valued for its merit in advancing individual life story as an "allegory" for the culture as a whole (Lepore 2001, 133).

Thus, according to Roberts (2002, 5):

> The appeal of biographical research is that it is exploring, in diverse methodological and interpretive ways, how individual accounts of life experience can be understood within the contemporary cultural and structural settings and is thereby helping to chart the major societal changes that are underway, but not merely at some broad social level. Biographical research has the important merit of aiding the task of understanding major social shifts, by including how new experiences are interpreted by individuals within families, small groups and institutions.

In the case of my research subject, it is the context of HIV and AIDS—its impact on her at the personal and individual level and how she interprets this, and the expansion and resonation of that personal to the broader society - the local Muslim community of which she is a part, in South Africa and beyond.

Life trajectory is a valuable method of inquiry in the personal narrative, allowing for identification of turning points, defining moments, struggles, challenges and meaning making as well as the identity and agency of the research subject in moments of triumph and tribulation. Tayob insightfully employs the life trajectory method in the field of religious studies to reveal the complexities of a religious life with its unfolding "journeying and destinations" (Tayob 2014; 2015). Aleida Assmann's concept of "three memory anchors" offers valuable insights into the experiences of trauma and memory, and their relevance in biographical narrative (Assmann 2001, 43). The integrated meanings and symbols located in a "chain of emotions" (Assmann 2001, 48) and operative within a biographical trajectory become the experiences that form the bond of social and personal relations and networks. The generation of social capital—a by-product of social relationships, networks, and personal educational investments—which is accumulated over a period of time has also a useful theoretical lens. Social capital brings out social relationships and linked aspects of recognition, respect, gratitude and friendships in a life, etc. for the person whose story is being told. The social capital concept in this study is primarily informed by Pierre Bourdieu's (1986) definition.

Biography, history and culture

Biographical methods of inquiry have become increasingly attractive to social scientists as they attempt to account for both individual actions and social and cultural changes. 'The biographical turn', a phrase coined by Chamberlayne, Bornat and Wengraf (2000), refers to a significant shift and trend in the social sciences, with the emergence of biographical research as an accepted critical scholarly method of investigation since the late 1990s. The 1990s is characterized as an intensive period of search for a research method to "prise open the different dimensions of lived totality" (Gottfried 1998, 452). The biographical turn is generally identified by a "subjective" or "cultural" turn, in which personal and social meanings are brought to the fore with the aim of understanding an individual's life within its social or cultural context, or to investigate phenomena therein (Wengraf et al. 2002). Biographical research seeks to understand the experiences of individuals in their daily lives, what they see as important and how to provide interpretations of the accounts they give of their past, present and future, in particular, as regards moments or contexts of change. In sum, the method reflects an increasing concern about "lived experience", and how to best express and reveal this within the broader practice of qualitative research methodology.

Denzin argues that, as regards social texts, biographical methods must be brought in line with critical theories in structuralist and poststructuralist developments linked to hermeneutics, semiotics, feminist theories, cultural studies, Marxism, postmodernism and deconstructionism (Denzin 1989, 25). Further, the validity, reliability and generalizability in the biographical method must be set aside in favour of meaning and interpretation (Denzin 1989). This key debate of "realism" versus "constructionism" in the biographical method merits some attention.

Realism maintains the view of objective knowledge about reality, which is claimed to be reflected in individual narratives and experiences. Proponents of realist narrative tend to focus on a textual analysis that "feeds upon interpretation in a swirl of language and symbols" (Roberts 2002, 7). Realists use language as objective reality and claim the interpretation thereof as solely the author's. Constructionists, on the other hand, view life stories as "biographic illusion"—the illusion of writing a story about the reality of another person—that is devoid of reality. Their main critique of realism is that life stories are not instantly or directly referential of experience; furthermore, that realism lacks historical input, political context and sociological perspectives on institutions and structures, from both the written and reading point of view.

The tension in the debate is resolved in a sort of postmodern vein through recognition of the critical interpretation of the story as the researcher's, in contrast to arguing the latter as subjective acceptance. In other words, the compromise is to elide insistence or requirement of objective reality as the criteria by which to judge the validity or worth of a text or story. Central to the outcome of this debate is that a constructionist view is useful and valid as a form of inquiry, knowledge and representation of the subject. It is now a given that stories or narratives inform different methodological or theoretical purposes, hence the need for the element of "reflexivity" in research, as identified by Giddens (1991). Reflexivity refers to the process by which the researcher reflects upon the research data collection and interpretation. Furthermore, tracing reflexivity in the interview process, involving oral history or biographical work, is often the result of exposure of raw emotions, misconceptions and traumatic memory, and resembles a therapeutic process (Wengraf et al. 2002, 250). As such reflexivity as an aspect of the healing processes will be critically reflected upon in the analysis and concluding chapters of this research.

The debate regarding the relationship between history and biography is not a new one. Historically, it was argued that traditional biography tends to place too much emphasis on the individual at the expense of wider historical processes and nuances in society. Biography, in the past, tended to be seen as easier than writing history; the rationale for this view was that coming to terms with one individual did not require complex and sophisticated analyses of social, political and economic structures (Caine 2010). The focus on the individual, it was argued, diverts attention away from the broader and important questions about underlying social and economic causes and political developments, which resulted in the relegation of biography to the margins of historical study (Caine 2010). Ostracized and dubbed the "unloved stepchild" of academia (Nasaw 2009, 573), biography was generally accepted as a narrative form, but looked down upon as an inferior historical form. Nevertheless, since recorded history, the lives of prominent individuals has never ceased to interest biographers and historians. Classical biography, as a genre, continues to shed light on the significant contributions of particular individuals in history, whilst still largely feeding the "great man theory", reflecting gender and other types of social biases.

Historical developments at the close of the twentieth century, moreover, including the decline of Marxism and the collapse of the Soviet bloc, called into question the idea of the "grand narrative" that privileges monolithic views, in particular, perspectives of dominant groups at the expense of silencing, subordinating and marginalizing others. In this new context of historical and social change, individual lives began to gain increasing importance as a method of illustrating the effect of difference - wealth, power, class, ethnicity, gender, and religion on historical experience and understanding. From a feminist standpoint, biography, as Virginia Woolf, long ago wrote in *A Room of One's Own* (1929), has been "too much about great men." The field of feminist oral history, though, only emerged in America in the 1960s and 1970s to

give voice to black women's[3] experiences of political and social marginalization through the recording and sharing of their oral accounts and experiences as valid representations or social texts. "The personal is political" or "the private is political" is a concept coined as a rallying call by second-wave feminists and feminist movements[4] to emphasize the connection between personal experience and larger social and political structures (Hanisch 1969).

Whereas "classical" biographies of the past focused more on prominent individuals in history, the rise of new micro histories reflects wider acceptance of the capacity of the individual to reflect broad historical changes and more localised social histories or microhistories like women's histories, black histories and post-colonial histories (Caine 2010). In line with this shift towards the individual, and the extent to which a single person may be distinctive and influential in a socio-cultural context, the concept of microhistory emerged in the late twentieth century. Micro-historians probe for personal clues as a means to explore the culture and the ordinary lived experiences of persons within it. Unlike "classical" or "grand narrative" biography, the value of microhistory is located in the individual life story as "allegory" of broader issues affecting the culture as a whole (Lepore 2001, 133). The exemplariness of one person's life within the context of changing societal cultural phenomena allows for a relatively ordinary or unknown individual life to reflect the greater meanings in a society at the time, in which that life is lived and/or is written about. It could, perhaps, be argued that the study of one life might be rather limiting. The advantage, though, of conducting case study research is that it allows for a "complex phenomenon" to be researched over time (van Lier 2005, 195).

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[3] See, for the example, the work of Audre Lorde, a leading black African-American writer, poet, feminist and civil rights activist. Her classic book, *Sister Outsider* (1984), is a collection of her most influential non-fiction prose that has had a ground-breaking impact on the development of contemporary feminist theories.

[4] Second-wave feminism is a period of feminist activity and thought that began in the United States in the early 1960s and lasted roughly two decades, until the 1980s. Third wave feminism is an iteration of the feminist movement that began in early 1990s in the United States and continued until the rise of fourth wave feminism in 2000s.

Religion and life trajectories

The emergence of life trajectories as a theory for studying a life over a period of time is advanced and applied by Tayob within the field of religious studies. Tayob explores the religious meaning making of ordinary Muslims in South Africa through the life trajectories of members of the Muslim Youth Movement (MYM) "over several decades" of religious activism (Tayob 2014; 2015). The life trajectories of the subjects studied shine a light on their religious and activist paths over a period of time, concluding that religious engagement cannot be confined to singular moments of activism but are imbricated in the daily lives of the subjects as Muslims, and experienced in diverse ways within their trajectories. The narratives of those studied reveal that they are motivated by a search for meaning and coherence in pursuit of an "authentic Islamic life" (Tayob 2014, 12). In this construct of the self, "narratives are windows into the real worlds in which people live, allowing us to get a bit closer to the operative religious meanings by which they live" (Roof 1993, 303). In the case of Tayob's study, the daily experiences of the activists under apartheid oppression and the impact of the anti-apartheid struggle shares the understanding that "Islam needs to be re-introduced in some way in all aspects of life" (Tayob 2014, 13). In the context of South Africa, the religious path was for the MYM activists inextricable from the injustices they and others experienced, so activism towards social, political and economic justice became a key component of Islamism for them.

Like the youth in Tayob's study, it is through religious expression that many people find meaning and purpose in their everyday existence. According to Tayob, "life trajectories and autobiographies contribute to our deeper understanding of religions, and how they are lived by men and women in a particular time" (Tayob 2015, 157). Religious conversions and turning points are transitions imbedded in the living trajectories of the people who give them distinctive form and meaning.

Further, Tayob notes:

> Life trajectories capture the dynamic nature of religious traditions and phenomena. They can complement and challenge what we know about religions based on rituals, myths and beliefs. Life trajectories bring out the individual experiences of the latter, in their embodiment over a period of time (Tayob 2015, 154).

Tayob uses the frameworks of James (1929) and Al-Ghazali (1058–1111) to interpret the religious trajectories of the men and women yearning for an authentic way of life while simultaneously dealing with the political context of apartheid in which they found themselves. Their search for inner peace and justice within a political and religious life conflicted and intersected with their everyday life challenges. Tayob finds useful the terms "conversions" (used by James) and "confusion" (used by Al-Ghazali) to locate their agency, activism and search for meaningful social and religious identities as South Africans *and* Muslims. The life trajectories traced by Tayob reveal how activism and agency progress from conversion, periods of intense political activity interspersed by reflection, doubt, change of heart and, sometimes, change in direction.

Tayob's life trajectory approach contributes significant value to my own research, with regard to its specific insights into how Muslims approach and understand their faith on a daily basis. Tayob convincingly substantiates life trajectory as a useful method that can be used to magnify understanding about the major turning points and events over a life course. Trajectory is a life observed as it unfolds over time, rather than focus on one particular moment or a general "snapshot" of a life. This understanding of the dynamism at play in the life lived of an individual, and the processes that are entailed therein, is the core of Tayob's focus on "journeys" and "destinations."

> I … interviewed activists who had been involved in Islamism over decades. Rather than taking a snapshot of their lives as engaged in a ritual, a practice, a video message or a book, I focussed on destinations and end-points that unfolded over decades (Tayob 2015, 163).

Life trajectory, as applied by Tayob offers an opportunity in the current study to include the various turning points, moments of trauma, triumph and religious meaning making in Faghmeda Miller's life. Although Islam is explicitly embedded in my research subject's trajectory, the socio-political context of Islam is different from the Islamic activism studied by Tayob. Thus, Tayob's theories of conversion and confusion, even though closely related to my research subject's experiences, are not wholly suited to my case study.

The interviews I held with Miller reveal a number of traumatic memories brought to the fore in the process of telling her life story and over the course of her life journey. Hence, my use of memory anchors as identified by Assmann include not only the experiences of trauma, but also that of emotional affect and symbolism in the theoretical framework.

> …the stories that trauma unwittingly tells, is that trauma seems to be much more than a pathology, or the simple illness of a wounded psyche; it always has the story of a wound that cries out, that addresses us in the attempt to tell us of a reality or truth that is otherwise not available Caruth (2016, 4).

Caruth points to the wider resonance of trauma in the time and space in which it is experienced by the individual, or its socio-historical context or location. Defining trauma, Sigmund Freud (1856–1939), argued that "any experience which calls up distressing affects—such as fright, anxiety, shame or physical pain—may operate as trauma" (Freud and Bauer, in Brandell 2012, 42-43). The effect of an HIV positive diagnoses in itself is a stressful experience that brings about much anxiety and, possibly, shame for the person living with the virus; hence it is traumatic, according to Freud's definition. A theoretical framework that includes trauma informs my analysis of a life trajectory.

Memory anchors

Memory has particular relevance in biographical accounts, including bringing into question the reliability of recollection, especially in relation to the presence of trauma. Memories of traumatic events are often a primary source of distress for trauma survivors. At the other end of the spectrum, is the phenomenon of the absence of any memory of a traumatic stressor or significant life event (Berliner and Briere 1999). This raises concerns about how to treat memory mechanisms that operate within traumatic experiences. Aleida Assmann reviews the "false memory debate" that calls into question the reliability of personal memory (Assmann 2001, 44). Contemporary debates hold opposing views on the issue of memory homeostasis or changes in psychological recall of an event experienced in the past, with trauma therapists and cognitive psychologists disagreeing on the preservation of memory. The former argue that memory can be stored over a period of time and reactivated, whereas the latter criticize this. According to Assmann, however, "memories operate under the pressure of present circumstances, but […] are reconstructed in specific institutional frames that determine their selection and sculpt their contours" (Assmann 2001, 58). In other words, memories are reconstructive in nature rather than being a faithful representation of what was seen, heard or experienced. This means that the memories of the same event constructed in a different institutional frame (legal, therapeutic, historiographical, autobiographical or ecclesiastic) can have marked social and political differences and consequences, depending on the given institutional frame. Denoting institutional frames or discourse can influence how a memory is told or reconstructed, the interpretation differing to the context in each instant of recall.

Assmann argues that three different memory anchors operate within memory recollection: affect, symbol, and trauma. With regards to trauma, she draws on the work of literary critic, Lawrence Langer, who denotes the term "unheroic memory" as characteristic of a "diminished self", referring to those who have been deprived of any and all control over their environment

and completely subjected to the fate of those in authority as in the case of World War Two Holocaust victims (Langer 1991, 177). Trauma is defined as the result of experiences that exceed the limit of psychosomatic assimilation, which destroys the individual's capacity for self-integration and self-representation. To illustrate, Assmann uses the example of metaphorical language in the experience of a child abuse victim: "throughout such memories I am here, not here… reliving something clearly not understood, not given meaning—just lived and recorded, as if in amber, now suddenly cracked open" (Assmann 2001, 57). It is the "bringing to life" by recall through language that Assmann is getting at here and the paradoxical position of space (here and there) versus time (then and now) that is the location for re-construction and un-reliability. Hence, trauma is experienced in such an instance of abuse through memories of an overpowering situation that had created an original feeling of being overwhelmed, with the resulting inability to give expression to something not properly comprehended at the time in which it occurred. The theoretical implications of Assmann's memory anchors in trauma offer invaluable insight into life trajectory research, as it reveals the processes or journeys undertaken by the individual of suffering, victimhood and resilience.

According to Assmann, the affectual quality of individual memories is beyond our control; their emotional activation in certain instances cannot—and this is the point—be deliberately instigated (Assmann 2001, 48). In other words, one's feelings and emotions about a memory are involuntary; but action (agency) taken to deal with memory is voluntary. Thus, emotional affect plays a pivotal role as a memory anchor. Memory tends not to be stimulated by the ordinary, everyday happenings but rather seems to adhere to something that has been seen or heard that is out of the ordinary. For Assmann, if the experience has been "exceptionally base, dishonourable, unusual, great, unbelievable or ridiculous" (Assmann 2001, 47), we are more likely to remember it for a long time due to the emotional affect linked to the event. The value of affect then, according to Assmann, is precisely located in the "chain of emotions" that gives

the memory legitimacy, that is, the emotions linked to personal experiences that create the feelings (Assmann 2001, 48). The truth claim in autobiographical memory is hence supported through the value of emotions and feelings: "I can accept factual inconsistencies, dismiss reality from my mind, or misread evidence, but *I cannot deceive myself about what I have felt"* (Assmann 2001, 49).

Symbol, as a memory anchor and its related social conditions, functions as an anchor to stabilize collective and individual memories. Assmann refers to pioneering research results of studies conducted on memory which indicate that "every individual, and every historical occurrence, is indeed transformed into a doctrine, concept, or symbol when appropriated by the collective memory; it acquires a social significance, it becomes an element of a given society's ideational system" (Assmann 2001, 52). For Assmann, the notion of "collective memory" is equally applicable to individual memory. In contrast to the emotionally charged anchor of affect, symbolic memory is rooted in the individual, with collective reactions to the historical occurrence, personal reinterpretations of the memories, and the resulting meanings ascribed to the experiences. Latent memories exist in an intermediate state from where they may either be recalled or forgotten, depending on the symbolic representation acquired. According to Assmann, "a memory acquires the force of a symbol if it is incorporated into the process of retrospective self-assessment, and thereby positioned within a given configuration of biographical meaning" (Assmann 2001, 54). In other words, the symbolic societal structures (family, childhood, community, nation, religion, etc.) operating within a biographical trajectory are accessed through the narratives and experiences of the individual, together with personal integrated meaning.

While trauma and memory are central experiences of a life trajectory on the individual level, it is imperative for a study of life trajectories to be located within a given social context. Shared

experiences - positive or negative—often form the basis for social relations. It is through social integration that direct and indirect ties and networks are formed. I now turn to the value of social capital as a way of interpreting a life trajectory on the social level.

Social capital

The term "social capital" has achieved recognition through pioneers in the field, James Coleman (1926–1995), Pierre Bourdieu (1930–2002), and Robert Putnam (born 1941). Social capital is broadly defined as the resources available to actors embedded in social structures, through which members can profit. It is a way of conceptualizing the intangible resources of a community, shared values and trust, upon which members of society draw in daily life (Field 2003). As a resource, social capital is generated by creating and maintaining social ties. Both Bourdieu (1986) and Coleman (1988) emphasize the intangible nature of social capital in relation to other forms of capital; financial, political, cultural, or human.

Social capital, and its various forms and contexts, has emerged since the 1980s as one of the most salient concepts in the social sciences. Since its emergence, a steady, growing interest in the term is apparent. There is now adequate evidence to confirm that the turn of the twentieth century witnessed a great interest and familiarity with this term and phenomenon, thus, "we can safely speak of an explosion of scholarly interest in social capital" (Field 2003, 4). At the heart of social capital theories is the fundamental notion that relationships matter. Social capital consists of resources embedded in social relations and social structures, which can be mobilized when an actor intends to increase the chances of success in a resolute action taken. Like cultural or human capital, social capital is an investment, on the part of the actor, to increase the likelihood of success in decided actions (Lin 2001, 192-193).

Within social capital theory, a micro-macro perspective debate flourishes amongst its protagonists. A micro-perspective view of social capital focuses on the resources available to

an actor embedded in social structures. Available resources are used by actors to achieve their personal interests. From this perspective, the focus of social capital is on the benefits to an individual through group participation and on the deliberate construction of sociability for the purpose of creating the resources sought (Bourdieu 1986, Coleman 1988). The macro-perspective, on the other hand, emphasizes the benefit of social capital to the society as a whole and not only to a few individuals. Putnam, the proponent of the macro perspective, stresses that cooperation and mutual benefit must be the outcome of organizational networks, norms and trust (Putnam 2000). Most scholars, however, agree that individual social relations as well as institutional social relations with embedded resources are beneficial to both the collective and the individual (Lin 2001).

French sociologist, Pierre Bourdieu defines social capital as:

> the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance and recognition—or in other words, to membership in a group—which provides each of its members with the backing of the collectivity-owned capital, a 'credential' which entitles them to credit, in the various sense of the word (Bourdieu 1986, 248-249).

According to Bourdieu's definition, social capital can be divided into two elements: (i) the social relationship itself that allows individuals to claim access to resources possessed by their associates, and (ii) the amount and quality of those resources. Bourdieu goes on to show how social capital can be used practically to gain access to powerful positions through direct and indirect employment of social connections.

Bourdieu is concerned with three forms of capital: economic, cultural and social, each operating in a different field. Capital, which is "accumulated labour" in its materialized form enables its agents to appropriate social energy in the form of living labour ((Bourdieu 1986, 241). According to Bourdieu, "it is in fact impossible to account for the structure of the social world unless one reintroduces capital in all its forms and not solely in the one form recognized

by economic theory," that is, economic capital (Bourdieu 1986, 242). This implies that although cultural capital and social capital are defined as non-economic, in the capitalist sense, they nevertheless have an exchange value that is dependent on the field within which they function.

Cultural capital exists in three forms: (i) the embodied state (educational qualifications), (ii) objectified state (cultural goods), and (iii) institutionalized state (or symbolic capital, a term coined by Bourdieu) that can be converted into what he similarly deems "social capital" (Bourdieu 1986, 243). Cultural capital in its embodied state is distinctively connected to the individual person and may require an economic investment to obtain academic qualifications, skills, and competence. It can exist independently of monetary holding and can compensate for lack of money as part of a strategy to pursue power and status, that is, social capital. Displaying cultural capital enables acceptance and status into society and, hence, acquisition of social capital.

Social networks can provide additional opportunities for economic capital, which can be re-invested into cultural capital, thus creating a cycle that affects social capital and its related networks and investments. In this regard, religious organizations present its members with opportunities for sociability. It is within the gatherings and meetings of members sharing a common faith and course that new loyalties and trusts are built and recreated. Opportune moments, experiential learning, and sharing in spirit and faith are all elements that enhance social cohesion and cooperation. It is within these common spaces shared that networks are formed. Bourdieu refers to this expenditure of time and energy, direct or indirect, where real connections are made, and skills gathered and used within social settings as the nuts and bolts of social capital.

Methodology

This qualitative research study makes use of a combination of semi-structured face-to-face interviews and unstructured narrative interviews with open-ended questions to explore the effect of HIV on the biographical trajectory of Miller. The interview questions in Robert Atkinson's book (1998), *The Life Story Interview*, were used as a guide to cover the main life themes. All the interviews were conducted in Cape Town. The English language was the interviewee's choice of language, although she and I are both equally comfortable with Afrikaans. The interviews followed a thematic scheme with main questions and some follow-up questions scheduled ahead of time. I have, throughout, this study, and including during the interviews, remained fully aware of the relation between the interviewer and interviewee. I thus made a conscious effort to treat my research subject as the expert in the HIV/AIDS field without losing sight of my aim to obtain rich and nuanced data from the interviews. I also recorded my observations and feelings in this regard in a research diary specifically kept for this purpose to remain fully cognizant of myself as an active participant in the research and interpretive process. The diary serves as an important source to discuss the issue of reflexivity in the research process and analysis in chapter 4.

As this is a single case study, most of the material quoted in my prime sample is written without referencing in order to enhance flow of thought and reading by avoiding unnecessary distraction by repetitive use of quotation marks. I believe this has been vastly supportive in writing a clear biography of my research subject. Thus, it should be noted that, with the exception of Miller, all other sources quoted are referenced in accordance with the Chicago style of referencing as required by the Religious Studies Department of the University of Cape Town.

Conclusion

This chapter has shown that biographical research as a scholarly practice has gained more ground in the social sciences since the 1990s. The shift in focus from society towards individual experiences and narrative had emerged as a method to more deeply inquire into the means by which people give meaning to their lives in the context of social, historical, cultural and religious changes. One of the major challenges with the biographical method is the issue of subjectivity versus objectivity at the epistemological level, which may be resolved via reflexivity, a necessary requirement in the biographical method. In the debate between history and biography, the latter has traditionally been regarded as an inferior form of scholarship. The rise of new histories, that is, the concept of microhistories, has had the effect of settling the impasse by arguing for the importance of individual narratives and experiences as ultimately "allegorical" of the society as a whole. Through the interpretation of personal experiences and voicing of narratives, the biographical method traces the personal trajectories of individuals over their lifespan and offers a peek through the window of social and religious meaning making over time, encompassing lived reality in its entirety. The current research study aims to chart a life course and will apply the theory of life trajectories as it allows for the tracing and identifying of changes, turning points, major decisions and defining moments in the life span of my research subject. The interviews reveal traumatic events experienced by the research subject and consequent emotions that engaged her in a journey of deep reflection and religious meaning making through which she, as well as those she influenced by her activism, came to re-evaluate and find new understandings and interpretations of Islamic symbols and values in the context of the HIV/AIDS pandemic. The lens of memory anchors in constructing a life trajectory will also be examined, as well as Miller's gaining of social capital via her journey as person living with HIV and an HIV and AIDS activist.

CHAPTER 3: LIFE TRAJECTORY OF FAGHMEDA MILLER

> A biography maps the social architecture of an individual life (Manning 2012, 479).

Introduction

In dealing with the data from the interviews held with Faghmeda Miller and other interviewees, the life trajectories framework helped me understand her life choices, turning points and religious commitments within the prevailing cultural, religious and social context of South Africa. Her memories of early life and childhood guided me to understand her memories of trauma in tracing the trajectory of her HIV illness. They also show the resilience and religious meaning making in her adulthood. Her life story reveals how Muslims living with HIV/AIDS at the beginning of the pandemic were stigmatised and stripped of all social capital because of lack of knowledge and inaccessibility to treatment. Publicly declaring her HIV-positive status challenged the then prevailing social attitude that silenced this existence. The tragedy of Muslims being stigmatized, excluded from the community and denied access to faith-based support as a result of an HIV positive status served as the catalyst for the establishment of an inclusive HIV/AIDS Muslim Support Group. Miller's life story will be presented with a focus on three major periods in her life: (i) early life, (ii) marriage, and (iii) living openly with HIV.

Early life - illness, schooling and Muslim identity

Faghmeda Miller was born on 31 October 1967 in Cape Town, the third of four children to Abduragmaan and Galima Miller. Her mother had experienced complications in pregnancy and was hospitalized at eight months up until the baby's birth. Miller remembers being told she had been sickly at birth and in childhood, and spending much time in hospital for a bronchial asthmatic condition: "I remember they always had to drain fluids … [and] phlegm [from] my lungs … a very painful procedure." Miller traces these memories to around the age of four

years. She was also partially deaf in her left ear, and regularly attended the ear, nose and throat (ENT) hospital clinic. Her doctors had warned her mother of a possible short lifespan for her daughter, to which Mrs Miller had responded with her faith in God as the giver of life and death, and devoting her attention to her daughter's wellbeing.

Miller's earliest recollection was periods of hospitalization, the two or three days in which she missed school and her friends. These moments of isolation and sadness from ill health later helped her with accepting her HIV illness. "From a very early age, I just accepted what happened to me … I knew there is a Higher Being and someone protecting me." Miller remembers feeling secure in her sense of a higher being in her healing processes, her first inklings of personal spiritual connection.

Her illness made her withdrawn as a child. Although she had siblings, cousins and friends, she recalls spending a lot of time by herself, reading. Reading was an escape into her world of imagination, especially during the painful medical procedures she underwent.

Despite her illness, her parents had treated her as they did her three siblings, never allowing her to feel limited by her illness. She thus experienced a normal way of life, for example, sharing house chores with her siblings. Her mother, Galima Miller, enforced strict discipline in the household: "I remember my mom would lay down rules and regulations. My dad was the one who would overlook things and was more flexible." Domestic chores were assigned to all, irrespective of age or gender. Miller enjoyed a close relationship with her siblings. Ighsaan, her eldest brother, would often offer her puny bribes to do his chores, and Faslie, her youngest brother, enjoyed teasing and annoying her. Najma (the researcher), Miller's older and only sister, was always caring towards her, and they both share a close bond despite their different personalities. "My sister is talkative while I am the quiet one." Miller remembers both her parents as loving and caring towards them, but she shared a special bond with her father.

Abduragmaan Miller played a pivotal role in Miller's child and adult life. Her childhood memories include him bathing her and her sister. She also remembers that her father never refused to chauffeur his teenage daughters to their friends' homes and back, later teaching all of them to drive and allowing them to drive his car when they got their drivers' licence. Talking about him in the interviews made Miller very emotional, for he had passed away from a sudden heart attack just before the first documentary about her HIV journey was released. He had played a large role in supporting her when she began proactively dealing with her HIV diagnoses. Her memories of him are affirmative and related with affection: "My dad was very compassionate and showed great empathy towards people. I think that's why later in life when other things happened to me, I regarded him as my rock, and role model." Miller attributes her own qualities of caring towards others, especially in times of hardship in their lives, to him.

Miller does not consider her family to have been overtly religious. For example, she does not recall herself or her siblings as children having to performing the five daily prayers, but remembers them observing Ramadhan and celebrating Eid, the two main Islamic festivals: "As a child I grew up knowing that during the month of Ramadhan I had to fast. I was not excused even though I was a sickly child!" She recalls the daily breaking of the fast (*iftaar*) as special, replete with delectable sweet treats reserved only for Ramadhan, and the atmosphere at the dinner table being jolly and religious at the same time. A special prayer was said solemnly for a day of successful fasting before the meal was enjoyed. *Eid al Fitr*, the celebration after Ramadhan, she remembers as happy occasions with new clothing for each of them, visits to the extended family, and tables laden with special Eid treats shared by family, neighbours and friends. Miller remembers her delight at receiving a one-rand coin from her father for having fasted the full month, that coin was their magical incentive or "bribe" for them to observe the next Ramadhan! Sharing food with others had always been important to her mother, who sent

them to deliver steaming, carefully covered plates to their neighbours in Elsies River. The food were offerings of *barakah* (blessings) symbolizing the wish to receive blessings in return.

At the age of twelve, in 1979, a turning point occurred in Miller's life when the family relocated from Elsies River to Belhar when they were allocated a municipal house. This was considered by the then apartheid government a form of compensation for the family home confiscated in Goodwood, in the Cape Town Northern suburbs under the Group Areas Act.[5] The land and properties of Miller's paternal and maternal grandparents had been expropriated. In essence, the entire Goodwood and broader Northern Suburbs community had been broken up by the forced removals. Miller's family resettled in the sub-economic residential area of Elsies River. She had not yet been born but learnt about the eviction from oral history accounts of her parents and other family members.

The move from to Belhar was not just a physical relocation for Miller but also a step in an inner religious awakening. Next to their new home was a primary school which Miller and her youngest brother attended and where they completed their primary education. Miller and her siblings joined the *madrassa* classes that were held in the afternoons at her primary school premises. "I loved to learn about the history of our religion, and I tried to excel in it… especially … [at] quiz time between the boys and girls…, I usually did well." Two years later Miller began high school in Belhar at Excelsior High and recalls her religious awareness: "When I started high school and met and befriended other Muslim girls we started to talk about religion and prayers. That is also when I started to wear the headscarf and being aware of God in [my] life." Zaida Hamza became her bosom friend and the two of them approached their high school

[5] In 1950 the Group Areas Act was passed by the apartheid government of South Africa to forcibly segregate people based on race. The Act was repealed and re-enacted in 1957, granting the government the mandate to forcibly remove blacks (black Africans, Indians and coloureds) from areas designated for white settlements.

principal with the request for a space on the school premises to perform the midday prayers. They also asked for permission to wear a headscarf to school. Other Muslim pupils at the school joined them in performing midday prayers and wearing the headscarf when their request was met with favour. Miller signals this as the period when she understood religion as not only being conscious of a divine reality, but also displaying it through moral actions: "My life really changed at high school because I started to be more God-fearing."

During the 1980s, the Muslim Students Association (MSA) had been active in high schools in the country.[6] Inspired by the Islamic activism of the Muslim Brotherhood in Egypt and the Iranian Revolution in the 1970s, the MSA organised itself as a political movement among Muslim students to challenge the oppressive apartheid regime by emphasizing the value of justice in Islam (see Tayob 1995, 148). Miller ascribes her religious turn at the time to her sister, who had joined the MSA and later the Muslim Youth Movement (MYM). However, Miller herself had not taken an active role in the MSA, but she was inspired to become more God-conscious, which she undertook through performing daily five-time prayers and adopting a modest dress code. Miller remembers a highlight in this regard when she and Zaida attended their Matric ball: "Being Muslim does not mean you have to go sit in a corner and just pray… all the time. You are a normal human being, you have challenges, you can also have fun, and you can live your life." She attended the ball with a headscarf. Miller recalls this idea as an important realization for her about the Islamic way of life.

[6] The Cape-based Muslim Students' Association was launched nationally in 1974 and became the chief recruiting agent for the Muslim Youth Movement (Tayob 1995).

Marriage and Malawi

Miller had dreamt of marriage, including a grand wedding, and raising a family of her own. Growing up as a teenager and young adult in the 1980s in a traditional Cape Malay Muslim home, meant marriage and family were important aspects of her cultural identity and worldview: "I never even thought of studying further. I just wanted to get married and have a family and continue life." After graduating from high school, she worked as a pharmacy assistant for which she later trained. At the age of twenty-six, she became assistant manager at this pharmacy.

Miller met and married Abdullah Juneja, a Malawian businessman, who was visiting his younger brother, Abdulkader Lehman, in South Africa in January 1994. Apart from being an acquaintance and employee of Miller's brother-in-law, Lehman was also a family friend and neighbour of the Millers. Juneja was visiting for an operation for his haemorrhoids in Cape Town. Miller and her family met Juneja out of courtesy as neighbours. She recalls that when she had walked over to honour her neighbour's guest, she had first heard his attractive voice as he conversed with someone in an adjacent room:

> I basically fell in love with his voice before I physically met him. And when I saw him, there wasn't really that head over heels attraction or love with this person. I just liked him… his personality. Me being a shy person, somehow, we just hit it off …and could talk about anything. I asked him about the operation he was going to have so I could help him with painkillers he might need from the pharmacy I worked at and I also advised him about treatment of the wound… We just liked one another.

Juneja spent a month at his brother's home, recuperating. Miller and Juneja communicated via his young nephew, sent across the road between their homes, bearing hand-written letters to each other. "I still have some of the letters until today," Miller informed. They also sneaked out occasionally to spend some time together. Miller grew to know him better. She learnt that

he worked as a commercial pilot for Air Malawi and had been a political prisoner[7] for opposing the totalitarian regime of Kamuza Banda in Malawi at the time. She had been impressed by his involvement in resistance movements and had admired his stand against the oppressive system in his country. They talked about his family and Miller learnt that Juneja and his brother, Abdulkader, whom he was visiting, while both Muslim and Malawian, were ethnically considered 'coloured' because their father was a Pakistani who had settled in Malawi and married their mother, a Muslim woman from the local Ngoni tribe.

Juneja also revealed that he had been married previously but was now divorced from the mother of his four children, aged twelve, eight and five. Before returning to Malawi, he sent her a marriage proposal by letter. Miller decided she wanted to marry him. Abduragmaan and Galima Miller, at first, did not approve of Juneja as a potential husband for their daughter. Besides being nine years older than her, he was also a divorcee with four young children who lived with him. Miller remained resolute in her decision and perceiving this and wishing for their daughter's ultimate happiness, her parents reluctantly conceded to the match. This was not exactly the fairy tale romance of love at first sight, but for Miller, her wedding day, when it happened, was everything she had dreamt of.

On 27 April 1994, a public holiday celebrating South Africa's transition to democracy and three days after their *nikaah* (wedding celebration), the couple flew to Malawi to start their new life together. "I didn't know what to expect. I was both excited and nervous," Miller recalls as she had only known her husband for a little over three months. It was also the first time she had travelled abroad, and here she was leaving the soil of her native South Africa to make a

[7] Miller was not able to provide any further information about her late husband, nor the activities he was involved in other than what is mentioned here. It is interesting to note, though, that all political parties and groups were banned under Kamuza Banda, their activities forced to go underground, often with fatal consequences if members were caught by Banda's secret police force that spied on Malawian civilians (McCracken 1998).

new life for herself with a husband and children. Her concerns, however, were laid to rest when Juneja's mother and extended family welcomed her warmly when they disembarked in Blantyre. Miller also remembers feeling safe and secure with her husband at her side to guide and protect her in Malawi, 'the warm heart of Africa'.

The newlyweds spent three days at the home of her mother-in-law in the village of Zomba before proceeding to Balaka, their new home in which Miller would live with her new family. Bonding with Juneja's children had been easier than she had expected, which she attributes to her natural affinity with children and youth: "We became an instant family; I adapted to their life and also tried to teach them my way of doing things." The extreme tropical heat, however, was a real challenge, and her first walk alone around her new neighbourhood ended in a bumpy wheelbarrow ride home by kind neighbours who came to her assistance when she suffered a severe bronchial attack due to the extreme humidity. Miller recalls having felt panic initially at the time as she could not speak Chichewa and was alone amongst people who were still strangers to her. She had been pleasantly surprised when her village neighbours rushed to her aid, including a group of teenagers who helped her into a wheelbarrow to quickly transport her home. Recalling the incident, the joy she felt in this acceptance from people she had just met is palpable:

> At that moment, an overwhelming sense of relief replaced my panic and chest pains; happiness—knowing that I was surrounded by caring and loving people. The young energetic teenagers raced through the village shouting 'Give way! Give way!' and my body received blows as the wheelbarrow stomped over bumps and ditches; but those blows did not matter.

Even though Miller adjusted quickly to her new life and role as wife and mother, she had become homesick. After four months, she visited Cape Town in August. Juneja had not been able to take time from work, and she began to miss him and her family. She returned, "I could continue with life again," but back in Malawi two weeks later, she found Juneja very ill.

This was the beginning of a fraught time for Miller in her personal life and her own health. As a young woman of twenty-six, the ill health of her thirty-five-year-old husband did not immediately strike her as alarming:

> He developed tuberculosis (TB), and because it was a third world country, they didn't have the tablets like we have here in South Africa. He needed to be injected every day for his TB. Luckily, we stayed near the clinic, and every morning we would take a walk there to get his injections. And then I noticed that he started to lose weight, it was too much in a short period of time. And I also became ill; my chest acted up and I was tired. I also started to lose weight.

Juneja did not recover; in the next three months, he became worse. The couple made plans in November to travel to South Africa to seek medical treatment for him. However, it was not to be. It is apparent from Miller's description of Juneja's worsening condition that, even though not aware of it at the time, this was Miller's first encounter with full blown AIDS. The virus' impact on his body was not recognised as a disease known to any of them, including the health workers who attended to him at the clinic.

The Friday [before they were due to fly to Johannesburg on the Saturday] Juneja's stomach started to run with diarrhoea and he couldn't keep anything down and just wanted to sleep: "I too was not well, but, you know, as a wife you don't worry about yourself when you need to take care of your husband." Her mother-in-law and other family members arrived to take care of the children, and friends, seeing her husband's weakened state, advised moving him from home to the clinic cum hospital. An ambulance had to be called to fetch him as he collapsed and could not even walk the short distance to the clinic across the road from their house.

He had been given an intravenous drip by a nurse there, and Miller assumed he would be discharged that evening, in time to make their flight the next day. "He was getting weaker, so the nurse did not want to take the drip off… saying he would have to stay overnight. I stayed with him as was the local hospital custom for family members to keep vigil at the patient's bedside and care for them during the night." Her mother-in-law also slept in the ward that night.

Miller relates that she was physically and emotionally exhausted by that point and had dozed off to sleep just after midnight for a few hours: “When I woke up, [Juneja] was lying flat on his back and his head was rolling. I realized with shock he was dying; he kept looking at the ceiling. I jumped up and began screaming for his mother.” Her mother-in-law awoke and ran out to call for help. A short moment later, the nurse and doctor rushed inside but he had already passed on: “I had just recited the *kalima* (declaration of faith) for him and was sitting there with him in my arms.” Miller became visibly sad as she recalled her husband’s suffering and death in front of her in the early morning hours of Saturday, 18 November 1994. It was just seven months into their marriage. Juneja was buried that same afternoon; they had waited only for his brother to arrive from Cape Town to lead the burial procession. “When the *mayyit* (corpse) left, then I cried… I broke down… collapsed.”

The following day the children’s mother arrived to take away the children, against their will and with much resistance. Miller expressed sadness at losing her new children and not being able to support them as they grieved for their father. She left a few days later for Cape Town to receive medical treatment, as her own health was worsening too. Her plan was to receive medical care and return to Malawi, which did not materialise as her illness trajectory unfolded beyond her own comprehension.

Return to South Africa and HIV diagnosis

Her parents and siblings had been shocked at the amount of weight Miller had lost when they received her a week later at Cape Town International Airport. She was a widow, merely seven months after her wedding. She felt inexplicably exhausted, constantly nauseous and vomited all the time. A rash of fine pimples broke out all over her body. Her parents took her to their local family doctor. Assuming that she was dehydrated from the tropical heat she had not been used to and suffering from nervous tension at the shock of her husband’s death, he treated her

accordingly, However, her condition kept deteriorating rapidly, and she was admitted to a hospital, where she was administered an intravenous drip for dehydration. Miller was surrounded by many doctors who were all baffled by her symptoms, until one of them casually asked, “Have you tested her for AIDS?” The hospital staff, without requesting her permission or providing her with any pre-counselling, drew a blood sample from her and sent it for HIV testing, telling her only they would inform her of the results in two weeks’ time. By then, she had stabilized enough to be sent home. Miller recalls that moment that HIV entered her consciousness, for it also seemed impossible that it might already have entered her body:

> I did not know much about this disease, but I felt highly insulted that they could even assume that I had AIDS! … At that time people really discriminated against people with AIDS. So I thought not to tell anyone that I was being tested for AIDS.

In the early 1990s in South Africa, and elsewhere globally, people did not speak openly about AIDS or HIV. The early identification in the 1980s of AIDS amongst white gay men in the West, particularly in the United States, had resulted in a tendency to blame “outsiders” for the disease, that is, people not seen as “normal” in their sexual habits or not part of the majority heterosexual population (Petros et al. 2006). At this point, Miller herself believed that her being tested for AIDS was not only a mistake but a grave insult to her identity as a married Muslim woman and a widow:

> I believed that AIDS, as it was called back then, was just for a certain group of people and that surely I did not fall under those groups, that is, either, a promiscuous black person or a gay person—you know, someone who sleeps around. And I did not fall under that group!

It had been a tormenting two weeks for Miller, and nothing prepared her for an HIV-positive result. She was so unprepared for the diagnosis. She did not remember how she had managed to drive home from the hospital where she had gone to receive the results. At home, her mother had immediately bombarded her with questions about her visit to the hospital. But Miller had brushed her off with lies about just needing to rest and to increase the dosage of some or other

medication she had been on at that time: “Then I went to my bedroom and I sat down. I could not cry. I was still in shock.”

She recalls the first thought that rose in her mind: “Why is God punishing me like this?” Miller remembers feeling immediate anger towards God, based on the perception that people with AIDS were experiencing a curse from God for some sin they had committed. Her anger grew:

> I was angry with my late husband. I was angry with my God. I was angry with the world. I decided that I would just die and that no one would know what I had died from.

She ceased performing her ritual five daily prayers, because in prayer she faced God and as she would not face a God that was punitive towards her. Surely, she had all the while tried her best to be a good Muslim who followed the Islamic faith righteously. She was also consumed with deep feelings of guilt that that she had brought shame upon her family. Miller’s thoughts at the time reflected the prevailing attitude by the Muslim community towards the pandemic and those suffering from the disease (Esack and Chiddy 2009).

She resigned herself to a death sentence which she waited to descend on her, reasoning that since her husband had died within two weeks of becoming ill, she herself would also die two weeks from the time of receiving her diagnoses. Finding herself still alive after the two weeks were up, Miller returned to consult the doctor who had diagnosed her, realizing that her shock had prompted her to just walk away without asking any questions about the disease or even allowing her to explain what the prognosis was. The doctor explained that she was HIV-positive and that the disease had not yet progressed to full-blown AIDS, and that that she could expect to live between five to ten years with the virus in her body, provided she took good care of herself and followed a healthy diet. Miller remembers this new as a pivotal moment in which she reassessed her choice: “I then decided that I was not ready to die yet. I wanted to live.”

The doctor suggested that Miller join a support group through the hospital counsellor to learn how to live with the disease. More importantly, it would help her accept her HIV-positive status, and cope with the illness. She was further tested for tuberculosis (TB),[8] the results showing a co-infection of HIV/TB. She was given a daily dose of antibiotics for four months. A fortunate side effect of the TB medication was increase in appetite, the nourishment aiding her body to heal naturally. She gained weight and felt relieved she had no physical signs of HIV or AIDS.

Miller's session with the counsellor had benefitted her in two ways. Firstly, the counsellor placed importance on forgiving the person who had infected her in order to free her mind to cope with surviving the diseases and healing. Secondly, the counsellor introduced Miller to the Christian HIV/AIDS support group, Assemblies of God Fellowship (AGF) operating at the time in Bellville. It was at this Christian support group that Miller began to learn more about the virus, its transmission, and the disease it becomes. She also began to understand the circumstances of her own infection. As she learnt about the symptoms of AIDS, she realized that it had been full blown Aids that caused her husband's death—the sudden weight loss and diarrhoea preceding his death. Naturally, Miller wondered if her late husband had known he had HIV and knowingly infected her when he married her: "It was in the support group that I started to share my story about how my husband had infected me, how I felt, and the trauma that I was going through." Miller believes that Juneja had not known that he had contracted the virus. She suspects that this had happened when he was exposed to contaminated needles while he had been a political prisoner, as Juneja had related to her the torture he had been subjected to, including being injected with chemicals to force him to reveal information about those

[8] TB is a leading cause of death among people with HIV; hence it is routinely tested for following an HIV-positive diagnoses (AIDSinfo 2019).

opposing the regime of Kamuzu Banda.[9] She is certain that Juneja, the person she knew and loved, would not have passed on the infection to her, or anyone else for that matter, had he known he had it.

Miller not only acquired knowledge about living with HIV, but also began to understand the importance of acceptance and forgiveness as vital for her emotional healing. She began to experience that through acceptance, forgiveness and compassion a constructive relationship with the virus can be established, first for the person with a positive diagnosis and also for others. Daniel and Squire (2009) also observe that the process of coming to a place of acceptance of an HIV infection requires being in a supportive dialogue with members of the medical profession and the broader community, including community organizations and family members.

> In the support group I learnt that AIDS was not a curse from God. In fact, you must see it as a blessing. Slowly but surely, I did what the counsellor advised me to do—I forgave my late husband. It was not easy, but I had to do it. And I started to pray again and realized that I had actually missed that! I had missed my prayers, because when I sit on my *musallah* [prayer mat] I have the opportunity to really pour out my heart. And that was what I began to do, all the time, asking God how I could overcome this disease. But how was I going to tell my family? I needed guidance. I needed support, and I could not find anything, it seemed. The support group gave me the strength I needed, the wisdom that knowledge about HIV is the courage one needs to continue to live and to live healthily.

Her account gives important insight into her spiritual attitude, which she applied towards healing and facing the challenge of an HIV-positive diagnoses. Her process resembles a disclosure of her HIV-positive status to the Divine.

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[9] Kamuzu Banda (1898–1997) was the prime minister and later president of Malawi (1964–1994). In his first year as prime minister, Malawi achieved independence from the British protectorate of Nyasaland. Two years later, Banda declared himself president of the country, in 1970, pronouncing himself Life Long President under the ruling Malawi Congress Party (MCP). His totalitarian regime ruled Malawi with an iron fist, making it one of the most oppressive African countries, post-independence. The MCP's political opponents were regularly imprisoned, tortured and killed (McCracken 1998).

It was also in the support group that Miller heard the story about Saleem (pseudonym), a young gay Muslim man who had been rejected by his family for being HIV positive. Saleem was homeless, alone, ill and dejected, but upon entering a hospice for the terminally ill, he was surrounded by caring people who were Christians, which led to his decision to renounce his Islamic faith. He died a Christian. His family had finally begun to enquire about him but found only his ashes, as his dying wish was to be cremated as a Christian and not buried as a Muslim. Miller recalls the impact of Saleem's story: "I was shocked when I heard this story… I thought that this could not be! That was when I decided that I would not let this happen to another Muslim, ever!" The moment is telling; there was clearly a gap that Miller identified between Islam and Christianity regarding the issue of compassion and the mercy and forgiveness of God regarding issues of HIV, AIDS, sex and sexuality. Through the Christian support group, she came to see and name the harsh, judgmental attitude of Muslims towards people living with HIV/AIDS, exemplified in the cruel rejection and circumstances of Saleem's death.

However, she was still longing for guidance and connection from the Muslim community. Her soul searching and experience were generating questions that begged answers directly from her faith and religion, which she did not for once entertain renouncing. What does Islam and the Qur'an say about people like her and others who suffer from a disease that is stigmatised but is no fault of theirs? Moreover, she longed to be among other Muslims for support, and to share her knowledge of HIV and AIDS to support them as well. This was the 1990s, before internet search engines were available to assist people with accessing information easily. Miller began to search the telephone directories and to contact Islamic organizations dealing with health and medical issues.

> I would call them up and ask if they accommodated Muslim people who are infected with HIV, if there was a support group, and where HIV positive people could go for help. The responses were not at all satisfying to me. First, they would

> demand to know who I was and whether I had HIV. Those were not the questions I wanted them to ask me.

Miller was looking for help, support and guidance from the Muslim community as a safe space where she could feel accepted without being judged. She identified the HIV/AIDS counselling within her community as a dire need. If she needed it and felt like this, others would have this need and feeling too. At this point, Miller made a commitment to herself: if she decided to disclose her HIV status, she would establish a support group for Muslims that would be founded on principles of non-judgement, non-discrimination, and compassion towards HIV/AIDS infected and affected people. What she was not finding to support her in overcoming her trauma of a positive diagnosis, she would build and provide for others.

All the while, Miller struggled with disclosing her HIV-positive status to her parents. She decided to approach a close family friend, a frequent visitor to their home. “Muslims don’t get AIDS!” was his first response to her when she confided her HIV status to him in private. He excused himself, left and did not visit the Miller home for weeks. His absence and her family’s noting this increased her anxiety. When he did finally appear, he had taken her aside and confessed his shock at her disclosure, saying he had needed time to digest such information. Miller’s friend’s behaviour reflected the dominant attitude to HIV and AIDS among Muslims during the 1990s, a sort of communal denial of the disease, based on an assumption that because Islamic law prohibits premarital, extramarital and homosexual relationships, Muslims thus should be impervious to HIV/AIDS.

Research reveals a lower prevalence of HIV and AIDS amongst Muslims than for other religious groups (Gray 2004, Hasnain 2005, Obermeyer 2006). However, there is increasing evidence that Islamic values regarding sexual conduct are not an adequate defence against HIV/AIDS. A comparative study was conducted in Cape Town in 2004 to determine HIV infection rates among the Muslim population in three predominantly Muslim residential areas

in the Cape metropole. The results indicate a 2.56% prevalence of HIV infection in the sample of 352 Muslims. Compared to the entire national population, the rate is low, but the researchers were concerned that the low prevalence still requires adequate awareness and strategies to prevent the spread of the disease amongst the Muslim community. The study made it evident that Muslims had to stop denying that HIV affects them and needed to begin addressing prevailing risk behaviours and attitudes to stop its spread (Kagee et al. 2004).

In 1995, about a year after her original diagnosis, Miller mustered the courage to disclose her HIV status to her parents. Disclosure is generally a very difficult process for people living with HIV/AIDS as they fear rejection, abandonment and discrimination, and is thus highly stressful for them. Miller had experienced these fears and emotions, and it was only at the fourth attempt that she managed to actually disclose her HIV-positive status. Her mother had voiced suspicions that her daughter was lying about her condition, although offering no actual reasons for Miller's apparent untruth other than her motherly instinct. Her father, on the other hand, accepted the news about her infection immediately, stating it as a test from God, in whom he advised his daughter to take refuge and guidance. Despite their mixed reactions, shock, and pain, both her parents were nonetheless immediately supportive of Miller. Her mother had informed her siblings, all of whom straightaway contacted Miller to assure her of their unconditional love and support for her. Miller was greatly relieved as her worst fears of rejection were not realized. She was pleased when her sister suggested they all go for counselling together as a family to learn how to best support her. Counselling was helpful to them all and dealt with their anxieties, for example, sharing crockery with their affected daughter and sister. Her mother, as the primary carer, undertook to become fully informed about all aspects related to the virus so as to give her daughter optimum care, especially during her bouts of illness. The family thus became proactively involved in Miller's challenge of living with HIV.

The issue of disclosure did not end there for Miller, "as time went by, I realized that I could no longer keep it quiet. I still belonged to the Christian support group, but I felt there was something crucial still missing in my life. I needed to do something about it." That something was the healing and educating conversation with the Muslim community, which necessitated further disclosure of her HIV-positive status.

Public disclosure

Miller recalls that in 1995 South Africans were only beginning to become aware of the presence of HIV and AIDS in the general population and its growing pandemic status. Later only, towards the end of the 1990s, South Africa would be identified as the most impacted country regarding infection rates. According to the United Nations' AIDS report, South Africa had the largest number of people living with HIV/AIDS globally, with 4.2 million (19.9%) of its population infected (UNAIDS Report 2000, 9). People then referred to the virus and the disease with a great deal of ignorance. Miller reports having felt silenced, frustrated and unsettled when she heard ignorant and uncaring comments from the members of public and her extended family. The final straw came at a family gathering.

> We were all sitting at the table having a meal with my uncles, aunts and cousins. One of my cousins asked me to pass her a slice of bread. Before I could reach out for the plate, she nudged me in my side and said: 'Ugh, just take it with your hands, or do you have AIDS?' … I knew that even if I did have HIV, touching food with my hands would not infect her, but she did not know any better. I was upset because I could not say anything back to her.

She had not yet disclosed her HIV status to members of her extended family, and the off-hand comment, meant as a joke, nonetheless rankled. Miller identifies this as the decisive moment to publicly disclose her HIV status in order to educate her family and community about the facts and myths about the disease, to shift them towards more caring and supportive attitudes.

She and her parents attended the 1996 Annual General Meeting of the AGF Church's HIV/AIDS Support Group, which was open to the general public. Here she came into contact with Ashraf Mohamed, a researcher at the Islamic Medical Association (IMA) on TB and HIV/AIDS. As a medical researcher, Mohammad was aware of the Muslim community's vulnerability to the virus due to its deadly silence about it and discriminatory attitudes towards those infected. He attended the meeting of his own accord, but later disclosed he had a specific motif in mind. People attending were also invited to mingle with the support group members to learn how they were dealing with their HIV diagnoses. Mohamed had struck up a conversation with her father who informed him he was there to support his daughter, and the former expressed appreciation for the family support they were offering. When Miller joined the conversation, Mohammed expressed interest in her story, saying that his wife was a presenter at Radio 786, a Cape Town based Islamic radio station, that was interested in interviewing an HIV positive Muslim on the station's health program, planned for airing on the upcoming World AIDS Day on December 1.[10] The programme producers had been unable to find anyone willing to be interviewed on the programme let alone publicly disclose their HIV-positive status. He asked if she would consider being interviewed. Miller, having for some time then been contemplating public disclosure, had even discussed this with the support group's counsellor and immediate family members, but still feared rejection by her extended family and community. She informed Mohamed of her negative experience with the Islamic Medical Association when she had inquired from them about any available support for HIV

[10] Established in 1988, it is the first health day observed globally. Accessed 21 January 2020. (https://www.worldaidsday.org/about/)

positive Muslims. Mohamed assured his full support should she take the leap to do the interview. True to his word, Mohamed remained loyal to her, and was the first vital link in Miller's network when embarking on her public HIV trajectory.

The opportunity had presented itself and Miller had a decision to make.

> I knew that my uncles, aunts and cousins all listen to this particular radio slot, because at family gatherings we usually discussed the topics that had been on air. So 'should I or shouldn't I?' On the other hand, it was a good opportunity as my whole family would be listening in, but, on the other, I still feared their rejection.

She decided to do the interview, and drove with her mother to the radio station studio for the live interview. Two years after her initial diagnosis, she was going to publicly share her story as a Muslim woman living with an HIV diagnosis. Miller recalls that Sunday morning on

1 December 1996:

> I went on air. I gave my name and said I was HIV-positive. Amina Mohammed, the presenter, started asking me questions-how had I contracted the virus, for how long was I positive now with HIV, how did I feel.

Up until that moment, most Muslims in South Africa had been mainly silent about the existence of HIV/AIDS in their communities. Others were in utter denial and believed that only a certain "unsavoury" group of Muslims was susceptible to the disease. They believed HIV and AIDS concerned these "others" and not them.

The interview was followed by a call-in session. Immediately, the telephone lines began buzzing with listeners calling in with comments and questions. Contrary to Miller's fears, the feedback from those who had listened to her public disclosure on air about her HIV positive status was mostly constructive and encouraging. Many callers shared stories of having lost family members to the disease, and the associated trauma and pain that came from lack of communal support for those infected and affected. Some with family members diagnosed with

HIV requested Miller's telephone number to further engage with her to deal with their situations that overwhelmed them.

Miller was surprised and grateful for the supportive reception of her disclosure. However, she was not prepared for the painful rejection from some members of her extended family, none of whom called in to acknowledge their relationship with her. At the very least, she had expected some to call in with the simple assurance of their support. Throughout the interview, she had been keenly aware that they were tuned into the radio program and listening to her. She returned home from the station with the dreaded feeling of rejection, and, for the first time since her diagnosis, shed tears for having HIV. She later learnt that her extended family had remained silent because they disapproved of her public disclosure, preferring she remain quiet and private about her HIV status. Miller's disclosure impacted family relations:

> For about the next five years, there were family members who no longer came to our home to visit. Their withdrawal and disapproval was hurtful, but the situation made me determined to continue with what I had started. I realized I needed to do more, be more vocal about my HIV status, so that more people, my family especially, could learn more about the disease. They were clearly very ignorant regarding HIV.

Following the radio interview, many people began calling Miller at home to seek support in dealing with HIV/AIDS. She listened to their stories with deep respect but felt unsure she was helping them adequately. "I realized I needed more information myself in order to help them with the queries they had, and with issues that I had not myself thought about regarding the disease and its impact. So I took a basic counselling skills course as a first step in knowing how to help other people." The counsellor at the HIV/AIDS support group gave her a practical 'crash course' to deal with HIV positive people and those affected. Later she enrolled for a formal counselling course at Cape Peninsula University of Technology, and received a certificate for it when she was employed by the institute in 2004. It was mainly Muslims who

sought her support, convincing her of the need for the Muslim support group she had vowed to establish when she had heard Saleem's story months before.

Miller found herself speaking about HIV and AIDS on different platforms and to different people of all religions and races. She no longer attended the Christian support group, feeling strong enough, to support others too through public appearances in which she shared her personal story about how she had contracted and was dealing with her HIV diagnosis. She was increasingly invited to give talks at schools, churches and synagogues, and at a Bahai AIDS conference. Her message was deeply spiritual even if her engagements were not aimed at Muslims only: "I wanted people to know that it does not matter what your religion is—whether Christian, Jew, Muslim… HIV affects everyone." She echoes the urgency of the moment to raise awareness about the reality of the transmission of the virus, as Runions wrote at the time, "this is not a virus that consumes only the 'untouchables' of society. By going public, you tell the community that AIDS is everyone's problem. Maybe if more 'regular' people come forward, others will begin to see that they are not bullet-proof" (Runions 1996, 66).

But it saddened Miller that Islamic religious leaders were neglecting this responsibility. In fact, she had faced backlash from local *imams* (mosque leaders) and the Muslim Judicial Council (MJC)[11] for openly talking about HIV and encouraging other Muslims to do the same. Their response was basically to regard sex as a private matter and a taboo topic for the public, especially for Muslim women. Faced with their censure, Miller's resolve to speak up strengthened. She called a meeting with the MJC to directly state her position and educate them about the disease and their leadership responsibility to support and protect Muslims facing the pandemic. She told them that they needed to know that Muslims were vulnerable to the disease

[11] The MJC is one of the oldest and most influential Muslim organizations representing religious leaders.

that does not discriminate who it infects. In this effort, she received important support from Christo, a Christian priest who had been infected through a blood transfusion. He welcomed her request to accompany her to the meeting. Interestingly, at the meeting, she learnt that it was the first time the MJC learnt she had contracted the virus through marriage. They listened and gave her their 'blessings' to continue her activism in the community. Miller was still disappointed at their severe judgement and lack of compassion towards those who contracted the disease outside of marriage. The meeting had aimed to change the MJC's perception about AIDS and encourage their following a different approach that considered the lived realities and experiences of Muslims living with and vulnerable to HIV and AIDS.

As mentioned, sex, sexuality and sexual mores are sensitive subjects in the Muslim community, neither easily spoken about nor listened to. Sex outside marriage is considered *haram*—forbidden, unlawful and punishable by God. Thus sex, and everything related to it, is treated as taboo at the public level even while engaged with at the private level. According to Toefy (2002), divorce statistics obtained from the MJC itself show that 20.83 % of women applying for divorce via the organization cite the cause as infidelity by their husbands. At the time, and based on her own experience, it was precisely such women that were vulnerable to infection through their husbands that Miller was also fighting for. It was her duty as a Muslim to show compassion and support to those suffering and in need of protection. As Miller recalls:

> People led us to believe that AIDS was a curse from God, so I had questioned why my Lord was so angry with me? Why was He punishing me like this? But I came to understand that this is not fact but a myth; it is not a truth. One must be compassionate towards others at all times, as you do not know what another person is going through.

Throughout, through faith and prayer, Miller navigates the difficult and uncertain terrain of living with HIV:

> You need to be strong in your faith in order to overcome the daily challenges of life. I turned my back, then made peace again with my faith. I realized that in fact

> I could not continue my life without my faith at the centre. This understanding is what basically keeps me going. The fact is I do not and should not see my challenge with HIV as a punishment, but rather as a kind of blessing.

Miller's belief that HIV is not a punishment is based on seeing a practical life challenge as a spiritual blessing that allows one the opportunity to shape one's spiritual attitude to oneself and others, enabling closer proximity to God and others. Thus, in her worldview, religion and spirituality are an effective means towards physical and emotional wellbeing of those infected or affected by the disease. For many of those infected, this spiritual attitude is a source of hope and support, even amidst negative attitudes associating sin with the virus (Ridge et al. 2008; Ciambrone 2003).

Miller draws strength from the Qur'an and the belief that Allah (God) will not place a person in a situation they cannot handle, nor abandon them. This is a core message she believes Muslims should have about Islam relating to any concern, including HIV: "Even though mankind will turn their backs on you, He will not turn His back on you. And it might seem like a dark patch, but Allah will always be there for you." Miller also respects atheists, and those who might not share her views about faith but who find their own constructive coping mechanisms. She nonetheless encourages those with spiritual beliefs and an HIV positive diagnoses to make practical their belief, "because prayer is very, very powerful." She shares that when she feels lonely or depressed, she sits on her *musallah* (prayer mat) and talks directly to Allah about her feelings, challenges, failings, fears and intention to try to do better, requesting support, guidance and strength. She embraces the idea that God is unconditionally merciful and compassionate.

Public life and recognition

Miller describes herself as generally an introvert. As a child, although she had some friends, her favourite pastime was staying at home to read. Speaking up and expressing herself were

not in her nature, let alone sharing her life in public. But after publicly disclosing her HIV status and living openly with the virus, she increasingly found herself called upon to share her knowledge and experience on HIV and AIDS. Every public appearance is for her an encounter with the lived reality of the pandemic among South Africans from all walks of life. People approach her to interact with her and to share their own stories, to seek advice or even to disclose their positive status. Some request counselling or personal support while others want follow-up speeches. This is a key aspect of her HIV activism since she became a public figure.

The year 1999 was especially significant for Miller when she was approached by a local commercial television station, e.tv, to make a documentary about her, her life story of living with HIV and AIDS. Akiedah Mohamed was commissioned by filmmaker and director Zulfa Otto-Sallies to produce the documentary for e.tv. Mohamed was keen to use her creative writing and filmmaking to express her inner turmoil and issues of her community, in the process giving voice to those marginalized, stigmatized and silences within it.

As a film director and Muslim woman, Mohamed was acutely aware of the tensions linked to AIDS in her community. She had personal experience of having lost an uncle to the disease amidst a community's silence about his illness. Paradoxically, even though it had not been voiced, people were not oblivious to HIV being the cause of his death; it was just too shameful to be uttered. Mohamed's uncle had been openly gay. Mohamed also knew of heterosexual people in the Muslim community who also had the virus and faced a deadly silence in the community. Through the medium of film, she was eager to initiate engagement and educate the Muslim community and general public about the virus.

The documentary, *The Malawian Kiss,* was first screened in August 1999. It contains actual footage from Miller's wedding, the radiant bride, attired in a white fairy-tale bridal dress, her

head adorned with a splendid *midoura*.[12] Beside her is the happy groom, smart in a Western style suite, proud at his new wife and her family, whose members had ensured that the wedding looked and felt special in its Cape Malay tradition that Miller had been dreaming of since a girl. The story is about an ordinary young Cape Malay woman and Malawian businessman who fall in love and seal their union and desire to build a life together through Islamic practice: a formal proposal, followed by a *nikaah* (marriage ceremony) and wedding feast in which the newlyweds are blessed by family and friends. Viewers see the wedding and entourage, the rituals of religious commitment between the couple and the merging of two families from different countries and communities into a new, larger family. It is in many ways the dream coming true of the new South Africa in which love triumphs over the past hurt of race and other exclusions under apartheid, ushering in the future in which people can just be human beings together. The tragedy that ensues from the reality of HIV and AIDS in this union of love and marriage, and a heterosexual one at that, was emotional and educative for the Muslim and broader South African community. The documentary was screened eleven times on e.tv by public request.

The following year, 2000, Miller was presented with the Woman of Courage Award by an international women's magazine, *Femina,* for her outspokenness as a Muslim woman on the topic of HIV/AIDS. Nominees of the award are identified as achievers in various walks of life, inspirational, courageous for breaking gender barriers, and contributing meaningfully to others in their communities. Miller remembers arriving at the magazine's offices expecting a request for an interview, and being surprised and touched when informed she had won this award from among the seven nominees. The recognition spurred her HIV and AIDS activism towards

[12] A gold embroidered cloth that is stylishly draped to cover the hair of a Cape Malay bride.

further steps in the fight. As Miller's public profile increased, she was contacted by a university student, Abdul Kayum Ahmed, who interviewed her for his research study on the impact of HIV/AIDS on the Cape Muslim community (Ahmed 1999). Ahmed expresses enthusiasm to support her in her aim to establish a support group for HIV-positive Muslims, undertook to do this after his studies. Upon completing his research, Ahmed sent Miller a copy of his dissertation and expressed his gratitude for the interviews with her:

> Subsequent to you having read my paper, I would like to set up a meeting with you to discuss your views on a way forward and then arrange a larger meeting together with yourself and people like Abdulkader Tayob [UCT professor in Religious Studies], Rashid Omar [the imam at Claremont Main Road Mosque], Esack and Ashraf Mohamed to concretize these suggestions.

Ahmed introduced Miller to Professor Farid Esack, a well-known academic who intended writing a book that developed an Islamic theology of compassion to address the HIV/AIDS pandemic, which he too felt was seriously neglected by Muslims in South Africa (Esack and Chiddy 2009). Miller's dream to establish the support group for HIV positive Muslims began to materialise.

In June 2000, Positive Muslims was formally launched by the three founding members, Miller, Ahmed, and Esack. Miller remembers meeting Esack for the first time, and the three of them holding further meetings to discuss the objectives of the organization: "We first operated from Farid's [Esack] house because we were looking for premises and at the time did not have the actual support group. I was still doing one-on-one support with people." A few months later, they moved to proper offices, with Miller playing a crucial role as the only executive member who was HIV-positive. Her physical presence, public profile with HIV and AIDS activism and networks contributed to the organization's credibility; she became its face and ambassador. Miller spearheaded the support group while Esack sourced funding and Ahmed managed the administration. From the very beginning, Miller insisted that Positive Muslim's approach be non-judgemental: "We believed that, firstly, HIV/AIDS is not a *balaah* (curse) from Allah

(God). And secondly, we did not ask people how they had contracted HIV." Capturing this attitude in its name, Positive Muslims placed emphasis on Allah's love and mercy, epitomized in acceptance of and compassion towards those infected.

Miller's own HIV-positive diagnosis was key to the leadership role she played in the support group: "For example, we had a psychologist working with the support group, but people would not 'listen' to her." The challenge for members of the support group was identifying with someone who was not HIV-positive; they felt they could better relate to someone actually living with HIV. This initially caused tension between the psychologist and Miller. Miller's knowledge and first-hand experience of living with HIV as a Muslim appealed to and helped the members to more proactively deal with their psychosocial and psycho-spiritual needs. The support group members simply trusted her more, seeing her as better able to empathize with them. The challenge needed to be dealt with constructively, however, as both her skills and that of the psychologist were needed for the intervention:. "What we then did, was that the two of us would co-facilitate and do consultations with the group and individual members. I would speak from a personal point of view and she from a psychological point of view." Thus, the rift between "qualifications" and "lived reality" was negotiated and resolved.

In reflecting on the value of the support group, Miller mentions that many members related socio-economic conditions as linked to their HIV infection. Most members were women of colour, living in marginalized communities, economically dependent and socially vulnerable, common to the general South African context in which the majority of those infected continue to be the poor and women. The apartheid legacy contributes to lack of social and economic opportunities, high unemployment, poor education and poverty amongst the majority black population (Jewkes 2009). Cloete et al. affirm and highlight these socio-economic concerns relating to people living with HIV and AIDS in Cape Town. They cite a research participant:

> People come because they are HIV-positive, they came to the support group but many times the HIV status is almost secondary in the support group; it's like a whole lot of other issues that come out about poverty, about unemployment, about domestic violence, about child support, just everything else but the HIV status (Cloete et al. 2010, 6).

Positive Muslims noted similar economic conditions amongst members of their support group, which created strain on their limited resources.

Travelling for work related to Positive Muslims took Miller all across South Africa. She served as the organization's key spokesperson and resource person regarding HIV and AIDS. To name a few, she was the keynote speaker for the First All Africa Muslim Youth Conference in Durban (October 2000), and at the Consultation on Islam and HIV & AIDS in Johannesburg (26–30 November 2007). Her speaking commitments also took her abroad, to Sudan in North Africa, the Netherlands in Europe and the United States, including an event at the Whitehouse. Her mission and role centred on being a Muslim spokesperson for people living with HIV and AIDS and challenging related norms and stereotypes. Miller reflects that

> most of the engagements involved conferences, sometimes as a guest speaker to share my story with the people of the country I was visiting. Sometimes, the hosts would also make documentaries of me…; I would go on air and people would come to rally around me and ask questions.

She relates that Europeans expressed awe at a Muslim woman in hijab (head-covering) talking openly about living with HIV.

Miller remembers, in particular, a trip to Holland in 2008 when Positive Muslims was commissioned by the ethnic minority Muslims there to conduct a training workshop on HIV and AIDS awareness-raising. The workshop, arranged by humanitarian organization Oxfam/Novib, was attended by approximately fifty participants, mainly Muslim refugees from different countries and cultures, including religious leaders (imams) and teachers (*alims*). Miller, Esack and another colleague, Fatima Noordien, facilitated the workshop, designed with Miller's slot sharing her story at the end of the programme. The four-day workshop got off to

a poor start, with the facilitators struggling to get through to the participants, especially the religious leaders who insisted that "Muslims do not get AIDS!" Miller intuitively intervened to break the "deadlock." She calmly stood up, requested the facilitator's permission, and shared her story, immediately changing the dynamic of the workshop. The fact of her lived reality with HIV created the breakthrough with the participants. It is not just Miller's knowledge about HIV and AIDS but the lived experience she embodies that reshapes the landscape for meaningful and constructive conversation to occur. For the Muslims in Europe in the Oxfam/Novib group, as with their African counterparts, denial is easier than actually facing HIV/AIDS and its plethora of related social issues. By sharing her experiences in her own voice and narrative, Miller embodies the fear, shame, stigma and intolerant social attitudes associated with the virus. At the same time, her courage to speak up against the stereotyping transmutes these negative aspects into constructive effort which creates a flicker of hope for those struggling with coming to terms with the disease.

In 2010, Positive Muslims, was closed down by the executive board due to lack of funding. However, there remain some questions about the closure shared with me.[13] For Miller, reflecting on the closing down of the organization, after ten years of existence: "even today, although the organization is no longer there, people still associate me with Positive Muslims."

Career as an HIV and AIDS activist

Miller's career as an HIV and AIDS activist demonstrates what Burchardt refers to as "a typical example of how HIV infected people and AIDS sufferers in South Africa skilled and

[13] In an interview (4 October 2018) with Fatima Noordien, director of Positive Muslims, 2007–2009, she revealed that when she left the organization, it was financially viable: "By then, the budget had grown to four million a year and they had enough money in their kitty for five more years. I really don't know what happened after that… to those donors who had pledged because the contracts and everything were in place."

‘expertified’ themselves, thereby transforming themselves into leading AIDS activists and their illness experience into a vocation” (Burchardt 2010, 15). From 2000–2004 Miller poured her energies into Positive Muslims, especially the support group about which she was passionate. The small stipend she received from the organization from its inception barely sustained her. Thus, when she was presented with an employment opportunity in the same field of HIV and AIDS that would earn her a better income, she resigned from Positive Muslims. She, however, continued to be an integral part of the support group, and had volunteered her services there until the organization closed in 2010.

In 2004 Miller began work at the Cape Peninsula University of Technology (CPUT) as a Health Promoter in the Student Wellness Centre. She received further training in HIV and AIDS support, and also applied her personal experiences, knowledge and skills relating to counselling for students infected or affected by the disease. Miller’s main task was providing pre- and post-test counselling services to students, and related training for HIV peer educators. The CPUT programme had been initiated by the World Health Organization (WHO) and implemented by the South African government in 2004, with the aim to establish and provide HIV and AIDS related services in targeting those identified as high-risk for infection and who would benefit from knowing their HIV status. Students in tertiary institutions were an identified group in this regard. Engaging people living with HIV was a crucial component of this pioneering government and global health initiative towards providing quality HIV and AIDS related services to reduce stigma and discrimination associated with the disease. Ashraf Mohamed, already mentioned, head of the Department of Community Health in the Faculty of Applied Science at CPUT, had offered Miller the position. When the government and global health community began HIV and AIDS intervention in the country, he identified her as the person for this pioneering position that had opened up at the tertiary institution. Miller, content that

Positive Muslims had found its footing, and continuing her work with the support group, took the university position, which she held until 2008.

A similar position as HIV and AIDS Health Promoter became available at the University of the Western Cape (UWC) in 2009. Miller moved there to provide skills to yet another tertiary institution in the Western Cape. All the while, her personal and organizational networks in the HIV and AIDS field kept growing. Her work at the UWC Students Wellness Centre included organizing the annual Carols by Candlelight event to observe World AIDS Day at the institution. Miller was required to arrange a noteworthy guest speaker to address the audience. In December 2012, unable to recruit such a person, she decided to address the audience herself. She recalls: "my story is the same every time, but the audience is different; that is why I sometimes adapt my story for the audience—so they hear the message in it."

Dorian Basson was in the audience, attending the event with his partner, a colleague of Miller. Dorian was HIV-positive and suffering from severe depression; he would later inform her that listening to her life story saved his life. Basson left the function with a vision to establish an organization for people living with HIV so activists like Miller could more widely share their inspiring life stories to accelerate the fight against the pandemic. In 2015, he established the Red Ribbon Foundation, and in 2016 the organization honoured Miller with the Faghmeda Miller HIV/AIDS Activist Award. Basson's story is one amongst many of the impact of Miller's narrative on people's lives. Her job at UWC ended due to lack of funding when Donald Trump took office in 2017 and cut back US funding for HIV and AIDS in Africa.

In September 2018, Miller was approached by the National Association of People Living with Aids (NAPWA) to manage and run workshops for their stigma and discrimination campaign, which was funded by a private US donor. She designed and implemented the programme over

four months in the Western Cape for NAPWA's head office in Johannesburg. At the time of writing, Miller is still actively involved in the field of HIV and AIDS.

Miller's involvement in HIV and AIDS extended beyond Positive Muslims, her own HIV career and the institutions in which she works. The positions and contracts she undertakes in her HIV and AIDS activism might end or an organisation close down, but her involvement in the lives and lived realities of people living with HIV and AIDS continues. Miller is currently ambassador to the following HIV and AIDS organizations: Brothers for life, LifeLab, Living Openly, The Aids Consortium, NACOSA, NAPWA, Red Ribbon Foundation, and Women Living Positive.

Conclusion

This chapter has narrated the life trajectory of Faghmeda Miller, offering a window into her social and religious life over her life span to date. I focused on three major time periods in her life: early childhood, marriage and living with HIV. It was seen that her parents, especially her mother, played a crucial role in her early life, providing loving and supportive role models for her for dealing with life's challenges, including childhood illness. The second phase of Miller's life focused on and relates to her adulthood, marriage and the tragedy that ensued for her from the HIV/AIDS pandemic in the early 1990s.

Miller returns to her family seven months later as a widow, having lost her husband to an unknown cause, and discovering her status as HIV positive. She came to terms with her diagnosis by joining a Christian HIV/AIDS support group, the Assemblies of God Fellowship (AGF), and connecting deeply with her own Islamic faith through prayer over a period of two years. This helped her disclose her HIV diagnosis to her immediate family, and then more widely on World AIDS Day in 1996. Despite persistent misgivings from extended family, Muslim religious leaders and community members, her public disclosure earned her much

support from the public and those infected and/or affected by the virus. She rapidly became a spokesperson for Muslims living with HIV. She was recognized both locally and abroad as the first Muslim woman in South Africa to publicly declare her HIV status to the fight against the pandemic by encouraging awareness, challenging myths about the disease and promoting support for those infected and at risk.

Miller co-founded Positive Muslims, becoming the "face" of Muslims infected and affected by HIV/AIDS, and travelled widely, locally and abroad, to share her knowledge and first-hand experience of the disease. Her agency and activism inspired Muslim communities and other South African communities and people in many other countries. The conservative position of religious organizations at the beginning of the HIV/AIDS pandemic has since changed because of efforts by her and other activists. Positive Muslims became the support group she dreamed of to fight the deathly silence around the disease. Miller's popularity and ongoing work in the field of HIV and AIDS continues to date.

In the next chapter, I will apply the theory of social capital to discuss more closely Miller's trajectory from a shy young girl to well-known woman with a cause. Notwithstanding the difficulties and rejection she encountered initially in the 1990s, the following chapter shows how the social capital she acquired and used to raise awareness about the disease amongst the public, including in her Muslim community, transformed her moments of darkness and challenges into agency and authority towards personal and social well-being.

CHAPTER 4: LIVING WITH HIV: MEMORY, SYMBOLS AND SOCIAL CAPITAL

> Individual life trajectories are fascinating for the experience they share about themselves, and for their part in a larger movement and tradition in the culture. Life trajectories have been put in the foreground, without losing sight of the context in which they have embarked on their journeys. (Tayob 2017, 2)

Introduction

The last chapter mapped the biographical trajectory of Faghmeda Miller, offering a window into her childhood, early adulthood and experience as an HIV and AIDS activist. This chapter draws on the concepts developed by Tayob (2014; 2015), Assmann (2001) and Bourdieu (1986) to analyse the significant events in her life trajectory. More specifically, it focusses on the "symbols" recollected (Assmann) and "reconstructed" (Tayob), and then turns to the social capital acquired as long-time survivor of HIV.

In the absence of internet and social media availability during the 1990s, mass media in the form of radio, television and print, played a crucial role in broadcasting Miller's story. I highlighted the key persons who facilitated her access to personal and social networks that spurred Miller's public recognition and development as a long-term survivor of HIV. Bourdieu's theory of social capital helps with focusing and framing the development of Miller as a public personality. But first, I will begin discussing her life trajectory using Assmann's and Tayob's insights on the process of memory in shaping and reshaping her understanding of family, marriage, community and religion. As already mentioned, this chapter also looks at the issue of reflexivity on the part of the researcher, given her close connection as a sibling to the research subject. I will discuss the particular engagements made by me as researcher with reference to the observation by Wengraf et al. (2002) that the oral process (by means of interviews in the data collection stage) and the writing up of the biography as well as the analysis of the main themes that emerged in Miller's story also evoke and contribute to aspects of memory and trauma in relation to the therapeutic process for the researcher.

Emotions and symbols

According to Assmann, people tend to forget details of the events in their life, except for those that have the greatest emotional impact on them. Individuals, hence, reconstruct their memories based on emotions evoked by the past. Such memory is connected with key symbols in the process of telling the past. Such symbolization takes multiple forms, ranging from the concrete to the abstract, and can include architecture, scripture, rituals, recitation, religion, family and community. Assmann argues that it is critical self-reflection that configures new "biographical meaning" through symbolization. Apart from physical growth and maturity, the dynamism of a life trajectory includes mental, emotional and spiritual development in contexts and times of both harmony and discord. In other words, over time and with various life experiences, people can develop new or different ideas, challenge themselves and others, and change their perspectives on life matters. My analysis of Miller's biographical trajectory focuses on two symbols that stand central in her recollection: (i) family and marriage, and (ii) community and religion. These two symbolic areas reflect her recollections, and my analysis will specifically discuss the meanings and interpretations she recollected with regard to her HIV-positive status.

Family, marriage and community

Family is a major symbol around which she remembers her life, and the challenges she has faced as a long-time survivor of HIV. Miller's family dynamics provided her stability and cohesion, which she harnessed when she learned about and was challenged by her HIV diagnosis. She projects a supportive role for family and community in her life trajectory, but relates some challenges to conceptualization and expectations.

The gentle nature of her father was complimentary to the tough love approach of her mother. Together, her parents bestowed upon her an attitude of solace, acceptance and resilience when she disclosed her HIV positive status to them. This was a reflection of an experience of an

illness earlier in her childhood. This helped to her to develop an 'accepting' attitude, and paved the way for her to deal with her HIV-positive status. She acknowledges that living with an HIV-positive diagnoses requires acceptance as the first step towards emotional healing and physical wellbeing.

She portrays the usual rivalry between siblings, but felt overprotected by them as a the result of her childhood illness. Sharing of food with neighbours during Ramadhan and Eid exemplified the bond with her siblings that was strengthened through acts of kindness and generosity towards neighbours. Later, Miller was influenced by her sister's involvement with the Muslim Youth Movement (MYM), becoming aware of the demand to fight injustice through Islamic activism. Her marriage and emigration from South Africa to Malawi also shows her the strong symbolization of family. Stepchildren brought instant motherhood, which she attributes to her natural affinity for family and young people. Her first experience of her new land was acceptance from this new family. In her bumpy wheelbarrow ride, she felt joy in her misfortune - what mattered most was being surrounded by a caring community.

Miller's marital life and happiness was short lived when Juneja became ill in the last three months of their seven-month marriage. After his death, his ex-wife reclaimed the children, leaving Miller alone with neither offspring to live with as family nor an inheritance to support her. Widowed under these circumstances, she was disappointed and let down by her late husband. In Cape Town, Miller's first thought when she received her blood test was that she had brought "shame" to her family and community. She believed that her positive diagnosis was the result of having sinned. She found it difficult to disclose her positive status to her parents. She tried in vain to share her status with a family friend. Fear, withdrawal and rejection were not the responses she had expected. This feeling was short-lived as the generally constructive reaction of parents and siblings restore her faith in family.

Miller related a strong sense of family in her recollection. She presents the family as a set of relations and shared practices that sustained a life. This was challenged by the death of her husband, and by her discovery of her HIV status. She had anticipated these reactions from family, as she had witnessed in her interactions with the Christian HIV/AIDS support group. With time, persistence and educative engagement about HIV and AIDS in her immediate circle, extended family members who had at first rejected her eventually changed their attitudes. They came to accept her HIV-positive status and restored her sense of family. Family bonds had been challenged, but she eventually found renewed comfort in the family, which signalled unconditional acceptance and love.

Reflexivity challenges the view of knowledge production as independent of the researcher producing it and knowledge as objective (Berger 2015, 220). As the researcher, this means taking responsibility for one's situatedness within the research project and the possible effect it may have had on the research process. According to Widdowfield, "not only does the researcher affect the research process, but they themselves are affected by this process" (Widdowfield 2000, 200). In reflecting on my own relationship with my sister as my research subject, I must acknowledge that the research study and process was quite emotional for me at times. For example, I was particularly affected when Miller related to me in an interview how she had struggled to gather the courage to inform our parents of her HIV status. In my research diary, I had pondered my reaction during this particular moment in the interview process, as well as in general: "the field was a bit blurred today as part of me relived Faghmeda's journey; another part was present to that of being a researcher and interviewer."[14] Here, my own subjectivity in the interview process and moment in the study became noticeable. My own

[14] Research Diary entry dated 9 September 2018 at 3.35 pm.

emotions were of concern and I too needed to deal with them. The "therapeutic process" that Wengraf et al. (2002, 250) identify in the interviewing phase of oral history or biographical work, was brought to the fore. My emotional response indicated my own unexpressed pain lying latent within my being, which had now been "cracked open" through the research I was undertaking.

Although I was familiar with my sister's journey, her story nevertheless evoked my own emotions during the interviews and the writing up of chapter three, her biography. In my diary, I had written, "This is such an emotional moment for me right now… Tears are flowing and I am crying for my sister having HIV!"[15] The traumatic memory and emotions it evoked in me were related to my own circumstances at the time Miller was talking about due to my own family commitments. I had left the country in 1995[16] with my husband, Sheikh Saad Altalib and our four young children and could not be physically by my sister's side to comfort and support her at the early stages of her disclosure of her HIV status when she had faced scorn from the family and Muslim community. Her memories triggered my own emotions of separation and pain at not being there at her side. Thus, being the researcher, the research became something of a healing for me too, just as it had been for Miller and her community when she began to directly inform and educate them by disclosing her HIV positive status in 1996. The healing aspect for me has been located in retelling Miller's story to others, particularly those in academia; bridging the gap thus between 'lived reality' and knowledge

[15] Referring to an entry in my research diary, dated 28 January 2019 at 11:40 am.
[16] In 1995, My husband and I, together with our four children relocated to Malawi from Cape Town for him to continue his work there. This was made possible by Malawi becoming a multiparty democracy in 1994. An Iraqi national and missionary worker in Malawi since 1982, my husband had been deported shortly after our marriage by Kamuzu Banda in 1988 for his Islamic activities, which the president perceived a threat to his autocratic rule.

has greatly helped me in processing my own trauma too, for nobody is left unaffected by the HIV and AIDS pandemic, especially if it is one's own sister.

Religion and community

Closely related to family, religion through the Muslim community in Cape Town became another symbol recollected and reconstructed in Miller's trajectory of illness and survival. During her childhood illness and consequent feelings of loneliness, Miller had found inner support through her conviction in God. A close look at her experiences and recollections regarding religion shows this as a major symbol in her life.

Miller never felt alone. She attributes this feeling of constant support to the presence of a Higher Being in her daily life: "I don't think I was really God-conscious, but I knew that there was a Higher Being and someone protecting me." The *Allah* that Miller 'knew' through her illness and sadness has remained central to her life.

Islam, for her, was more than religious and spiritual belief. If in childhood, religion and community took root in Miller's identity - the cultural ritual of sharing food during Ramadhan and Eid - then a deeper engagement with the political and social aspects emerged in her teenage years. Attending *madrassa* after school with her friends created strong bonds with other Muslim students with whom she shared religious beliefs and practices. But it was her decision to attend the Matric Ball wearing her headscarf that embedded in her trajectory the idea of religious activism and a strong sense of identity. Religion was about family but also commitment to identity in public life.

Miller's understanding of religion was challenged when she learnt of her infection with HIV. At first, she believed that HIV was a punishment from God. This was a depressing belief and turned her into a restless seeker with more questions than answers. She went beyond her Muslim community, and joined a Christian support group that guided her towards

understanding and accepting that the disease is not a curse from God. Although contrary to the dominant Muslim discourse at the time, Miller embraced this view, and eventually found a similar theological interpretation in Islam. Her faith in *Allah* was restored. Being HIV-positive became an opportunity for her to live with more consciousness of God. Miller gave new meaning to her experience of religion and the disease by seeing her HIV experience as a "blessing" and "a second chance to life." She not only rejected an interpretation of HIV as God's "curse," but replaced it with a paradigm shift towards God as Merciful.

Gender constitutes a major component in the construction of religion in Muslim communities. It angered Miller that members - all male - of the Muslim Judicial Council (MJC) criticised her for openly talking about issues of sex and sexuality as related to HIV and AIDS. Also, they could not accept that a Muslim woman was taking a leadership and public role. She found support from other leaders in the Muslim community. The imam of Claremont Main Road Mosque, Rashid Omar, and his congregation were and remain supportive of Miller. She also mentioned Ghairunisa Johnstone, founder and director of Mustadafin Foundation and the late Moulana Ighsaan Hendricks as exceptions in the general attitude of the Muslim clergy.

Miller was also supported by the Muslim Youth Movement (MYM) following her public disclosure, recognising the value of her contribution and, spurred by her sister's prior involvement in the movement. A major breakthrough for the Muslim community addressing its HIV/AIDS denial occurred in 2000 when the MYM organised The First Africa Muslim Youth Conference: The Role of Muslim Youth in Developing Africa in South Africa, bringing together youth and Muslim clergy to discuss the need for a 'positive' Muslim response against the pandemic. She gave the keynote address at the conference. Importantly, she has paved the way for a compassionate response to those infected and affected by the pandemic. Although

Miller was rejected by many mainstream religious leaders and their congregations, she was supported and applauded by the majority Muslim community.

Some of the Muslim clergy accused her of promoting promiscuity for adopting the use of condoms to prevent the spread of the disease. She believed that a pro-condom stance is permissible in Islam because of its value in saving lives. Miller had requested the *ulama* (religious leaders) to advocate HIV testing as mandatory for couples wishing to marry prior to solemnizing their marriage. Her personal activism continued institutionally through the organisation, Positive Muslims, established six years following her initial diagnosis.

While Miller received crucial support from a Christian group, she still expected Muslims to support her. The rage she felt by the general rejection of her community catapulted her into HIV and AIDS activism. It was her outspokenness and audacity that attracted the public's attention. Eventually, Miller herself became that which she found wanting in the Muslim community. She became a model for Muslims who challenged a Muslim identity that rejected those infected with HIV. Paving the way for transforming attitudes towards HIV positive persons, Miller became a symbol of hope and compassion.

In applying a methodology of reflexivity, as discussed in Chapter 2, I conclude this section on the memory anchors by reflecting on Miller's recollection as well as my subjective relationship with her, attending to my affectedness as a researcher, bridging the gap between 'lived reality' and academia all the while processing my own trauma too. Family, community and religion evoked strong emotions in her narrative. Miller is remembering the negative responses vividly, accurately displaying Assmann's theory of effect in memory anchors. The recollections of family, community and religion demonstrated Miller's symbolization as argued by Assmann. In each case, we see how her recollection demonstrate some challenge to her previous

expectations. Most notably, religion was symbolized in a new way through her encounters with the disease, Christian support group and religious leaders.

Social capital

In this section, I turn to the social capital acquired by Miller in becoming the face of Islam. My analysis of social capital will focus on four major events in her life that played a major role. I will examine how each of these events contributed social yields such as personal development and investment, personal characteristics, institutional networks, social relationships and acknowledgments.

Public disclosure of HIV status

Miller began to accumulate social capital when she was diagnosed with HIV. During this period she learned how to live with HIV rather than dying of AIDS. The Christian HIV/AIDS group provided her with much needed information, guidance and psycho-spiritual support to deal with the virus. This group enables her to start building her first activist networks. Ashraf Mohamed is the key link between her and the public at the start of her journey of public activism two years later. He and his networks played a pivotal role in her public disclosure that prompted her activism, her participation in the documentary film about her life as a seropositive HIV survivor, and later in her career as an HIV and AIDS counsellor at tertiary institutions.

Miller's public disclosure earned her widespread recognition as an HIV and AIDS activist amongst Muslims. Talking publicly about a sexually transmitted disease was a weighty subject at the time and demonstrates the social and cultural barriers she had to challenge. Giving voice and testimony to her experience with HIV on radio signals Miller's entrance into the arenas of the public and the social. This turned her into a recognizable figure in her community, hailed as a heroine for showing fortitude and bravery. Miller shared her contact details on the radio

so people could reach her personally or via telephone regarding information about the virus. For many Muslims, she became their private counsellor.

She took cognizance of the need to invest in herself—her health, education and networks regarding HIV in order to be more effective in helping and counselling others. In these ways, she acquired social capital which Bourdieu says is "made up of social obligations" (Bourdieu 1986, 243). Her first-hand experience of living with the virus became a means of helping others to manage the disease. By becoming an HIV and AIDS counsellor, she grounded herself in the field and became an authority on the subject.

Social capital through networks and publicity

Bourdieu refers to one of the means of gaining social capital as the "existence of a network of connections" (Bourdieu 1986, 249). Film director and producer, Akiedah Mohamed, consulted with Ashraf Mohamed about an HIV/AIDS awareness documentary she was planning to make. Ashraf Mohamed referred her to the only Muslim person he knew who was living openly with HIV. Miller's story was the perfect match for the plot of Mohamed's film, exposing the fate of a normal love relationship ruined by the fatal virus through *The Malawian Kiss,* released in 1999. The electronic media network contributed to Miller's growing public image.

Miller's childhood dream was realized of appearing "like the actors on the big screen." More importantly, family, community and clergy feature in the documentary, sharing their opinions about Miller that formed an integral part of the Muslim community's responses towards HIV/AIDS. The narrative of the film suggests a shift in perception around the disease through Miller's lived experience. The visual power of the media attract wider attention to Miller's personal story and the lived reality of HIV and AIDS amongst South Africans. Miller became an important stakeholder in the field of HIV and AIDS activism. Her appearance on national television saw her becoming a public figure in South Africa.

Miller also acquired social capital through a public award she received from a popular woman's magazine in South Africa, *Femina*, as mentioned in Chapter 3. Patricia de Lille, then Pan African Congress Member of Parliament, had been one of the finalists nominated for her courage in exposing corruption in government. The choice of Miller above de Lille is significant in social capital she acquired, as argued by Bourdieu:

> the relationship of appropriation between an agent and the resources objectively available, and hence the profits they produce, is mediated by the relationship of competition between himself and the other possessors of capital competing for the same goods, in which scarcity—and through it social value—is generated (Bourdieu 1986, 246).

Shortly after receiving this award, Miller was nominated for the 'Women that Make a Difference' award by another magazine whose name Miller could not remember. But these awards and nominations from prominent, national South African media sources added to her social capital.

Miller's investment in social networks was an important part of her development as an activist. These public appearances and awards contributed to her public recognition as a spokesperson and activist for people living with HIV within the Muslim community.

Social capital through activism

Positive Muslims symbolized her wish that she developed in the Christian support group. The main focus of the organization was to provide counselling and support for Muslims living with HIV/AIDS, regardless of how they had contracted the virus. As the leader of the support group, Miller's leadership style was typically that of a servant leader. In supporting group members, she was a pillar of strength. The relationship with the organisation and its members further enhanced her social capital as counsellor and symbol of bravery and commitment.

Miller's lived experience helped her to establish rapport with the support group and create special bonds with the members. Her non-judgmental attitude and empathy towards all those

infected and affected in the support group served as a catalyst and cementing element in the organization. Members of the support group displayed an affinity for her due to her validation of them and their health condition. She took a personal interest in the wellbeing of each member and thus gained their trust and loyalty towards her personally, and to the organization. One of her former colleagues recalls her value:

> If you look back now, after so many years, you see the regard and the respect that she still gets from all of her people. But it was because she was there for them at a time when it was critical and she was also very giving. She always put the other person above herself, which was one of the things people appreciated! It is the action. It is the caring call. It is the availability. When someone sits in the middle of the night and can't sleep or is struggling with night sweats and feels as if death is on his or her doorstep… they can call her! That is what people appreciated! It is the fact that they could send her a message at that time and she would reply and be accessible to them. She would even know what they were going through and would tell them, 'expect this or that to happen still'… and that was brilliant! (Fatima Noordien, Interview, 4 October 2018).

Through Positive Muslims, Miller gained additional respect, recognition and authority in the field.

Miller's HIV-status served her not only with the support group, but also with funders and the general public. Her travels locally and abroad to represent the organization at conferences and workshops enhanced her status as the 'face' of Positive Muslims. Her membership and presence influenced donors to support the organization and its programmes. Funders often requested meeting with her directly, recognizing her experience and also seeking assurance that she formed part of the leadership of the organization they intended funding.

Miller's social capital placed her in the ideal position as co-founder of Positive Muslims to gain and expend social capital. Religious or faith-based organisations are recognised as significant providers of social services linked to valuable social, behavioural and health outcomes, enabling religious involvement in producing social capital (Yeary et al. 2012).

Positive Muslims provided Miller with personal connections and organizational capacity through which she earned and expended social capital in her HIV and AIDS trajectory.

Miller's agency as an HIV and AIDS activist continued after the organisation closed down in 2010. She went on to represent South Africa at the White House in 2012 and, similarly, at the South African Parliament in 2013, representing Muslims with HIV in engagements with senior state officials in both countries. She was honoured in 2016 with a life-long award created in her name, the 'Faghmeda Miller HIV/AIDS Activist Award' in recognition of her HIV and AIDS activism by the Red Ribbon Foundation. Currently, Miller serves as ambassador for many HIV/AIDS organisations and has an online presence on YouTube. Driven by a belief that "there is still work to be done," she ran a project on stigma and discrimination reduction for the National Association for People Living with Aids (NAPWA) from September to December 2018.

The social networks and recognition that Miller has accumulated in her HIV and AIDS journey over 25 years are notable achievements. The capital contributed to cultivating her expertise and carved a role for her as an authority in the field. Her lived experiences, accessibility and compassion have made her a sought-after HIV and AIDS counsellor. The knowledge she has acquired, and continues to acquire, represents a capital that she gained in the process of coming to terms with and dealing with her HIV positive diagnosis. She expends her social capital towards supporting others to deal with and live constructively with their HIV diagnoses.

Conclusion

I discussed the trajectory of Miller's life in terms of the recollection of her life story through the symbols she employs in telling it and her acquisition and expenditure of social capital. Her recollections were interrogated through the lens of the memory anchors of emotion, symbols and social capital. The interpretative symbols of family, marriage, religion and community

were the anchors I identified for best analysing her life trajectory. The emotions of anger and rejection weighed heaviest for her, especially regarding community and religion. Her anger at the Muslim Judicial Council for turning a blind eye to the HIV/AIDS pandemic and contributing to the Muslim community's ignorance fuelled Miller's determination to speak up and create awareness about the disease. Discussion of this symbolization shows how family, God, religion, identity and theology shaped and were reshaped in the course of her life and life trajectory. She confronted prevailing negative attitudes by appealing to her own experiences and challenges she encountered in efforts to conscientize members of the Muslim community and the broader public, both locally and abroad. As a Muslim woman, Miller became a controversial figure for speaking up and taking leadership in creating awareness around a highly stigmatised disease. But her expending her social capital changed perceptions and practices towards people living with HIV.

CHAPTER 5: CONCLUSION

> To be told that you have a disease and might live only for a certain period of time gives you a totally new perspective on life. You appreciate the smallest things that others may not even take note of ... a flower blooming on a pavement ... the sunrise … the sunset … You appreciate life! Because you do not know if you are going to wake up tomorrow morning. (Faghmeda Miller 2018, Interview)

In 1994 an HIV/AIDS diagnosis was a death sentence and signified social rejection and isolation. In South Africa, the situation was exacerbated by the government's failure to act promptly to save the nation from the impact of the deadly virus that was spreading unchecked amongst its citizens. But now long-term survivors are a more common phenomenon as advancement in HIV antiretroviral therapy has transformed the disease from an apocalyptical death sentence to a manageable chronic illness. However, not much is known about long term survivors, especially about Muslim women, with a religious orientation towards combating the disease.

This study of Faghmeda Miller's life trajectory has been shown to reflect her life of living with a stigmatised disease in the Muslim community in particular, and South Africa in general. The Muslim community responded first with indifference, deeming Muslims impervious to HIV infection, and then with silence and shame as members of the community became infected. The myth that 'Muslims do not get AIDS!' was exposed when Faghmeda Miller publicly disclosed her HIV-positive status on a local Muslim radio station in 1996 on World AIDS Day. Speaking up and taking the lead to create awareness about a sexually transmitted disease took courage. The gravity of the denialism and complacency moved Miller out of her naturally shy and introverted personality to become an outspoken woman on a mission, travelling locally and abroad, for Muslims and all people in general living with or at risk of HIV and AIDS.

This study has traced Miller's life trajectory spanning fifty years. The complexities of her life, with its major turning points, defining moments, choices and decisions are captured. Life trajectories (Tayob), applied in this study as a method to better understand Miller's journey, enabled deeper insights into her religious and social meaning making. The life trajectory was constructed through memory recalled (Assmann) and social capital acquired and expended (Bourdieu). The analysis focused on the turning points and emotions experienced in her trajectory that contributed to her decision to speak up and embark on a life of HIV and AIDS activism. The study showed that Miller gained social capital by publicly disclosing her HIV status and transforming herself as an HIV activist in South Africa.

The study also showed the researcher's own subjectivity, in the sense of the impact the interview, writing and analysing processes had on her own being, which led to her reflecting on her emotions for her own therapeutic process. The issue of reflexivity in the research was shown to be importantly linked to the researcher's close relationship as a sibling to the research subject and situatedness in the research. Thus, while the major focus is Miller, the researcher too becomes implicated in the research, especially with regard to consciously signposting possible limitations, processes triggered and advantages by being closely connected to and impacted by the research, as such disrupting notions of objective research.

Miller's journey became a long burning candle, shining brightly on the path of HIV and AIDS dimmed by stigma, discrimination and shame aimed at victims, survivors and those affected by the pandemic. Recognizing this critical challenge, her life of activism for Islam and HIV became an allegory for how South Africa in general eventually came to terms with the epidemic. Her trajectory may be compared, amongst others, with prominent personalities like high court judge Edwin Cameron, the late Nkosi Johnson and Zackie Achmat, who emerged in

the HIV/AIDS struggle. But there are many others who, like Faghmeda Miller, were transformed, and whose life trajectories may tell us more than the headlines about the epidemic.

Faghmeda Miller remains optimistic about life with HIV in the wake of being seropositive for twenty five years. She has achieved most of the goals she had set for herself at the beginning of her journey, including a pilgrimage to Mecca, and becoming close to God and her Islamic faith. A daily dose of antiretroviral (ARV) medication helps her to manage the disease. But key to her prolonged existence has been living with purpose—being supportive of others infected and those affected with the virus has become her calling in life. Ultimately, it is Miller's ability to empathize with others like her and her availability when they are in need of support that earns her the highest accolades and social capital as an HIV and AIDS activist making a valuable contribution to South African society and humanity in stemming the spread of the deadly pandemic. It is hoped, and recommended, that the story of Faghmeda Miller will inspire others to invest time and effort in similar biographies and life trajectory narratives of ordinary people who take on responsibilities towards the vulnerable in social justice struggles.

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