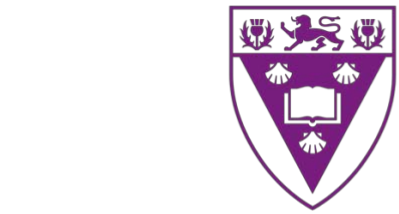


RHODES UNIVERSITY

Where leaders learn

Lifting the Veil on the 'Untouchable': A Study of Muslims Living with HIV in Durban, South Africa.

by

SHABNAM SHAIK

G21S2704

A thesis submitted in fulfilment of the requirements for the degree of a Doctor of Philosophy.

In the

Department of Anthropology

of the

Faculty of Humanities

at

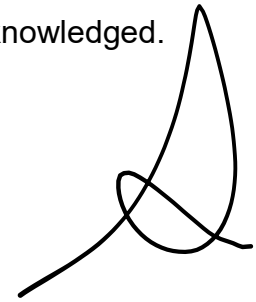
Rhodes University

Supervised by

Dr Susan de la Porte

DECLARATION

I, Shabnam Shaik, declare that the work produced and presented in this dissertation is my original work and that all sources of information have been cited and acknowledged.



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Shabnam Shaik
G21S2704

"*All we have to decide is what to do with the time that is given to us*" – Gandalf the Grey

For Fred and George,
For my Peanut buttercup,
But mostly,
For Mum.

ACKNOWLEDGEMENTS

"*Nevertheless, she persisted*" – Senator Elizabeth Warren (2017)

This has been an incredible journey of self-discovery, pain, passion, and truth seeking. There have been numerous points throughout this PhD journey where I thought I would never make it to the end. I give thanks to Allah for the strength that I have received, for it has only been through prayer and perseverance that this dissertation has come to be.

Firstly, to my research participants, who let me into their lives, and gave me such rich information about their lived experiences, I am forever grateful. I thank you for trusting me with your life story and being an incredibly valuable and vital source of information for this project. Without you, this would not have been possible. Your voices are heard and my hope is that it may lead to awareness, education, and change in our community.

Mum, I am grateful for the strength that you have shown in bringing up three children as a single parent, and facing the stigma that came with being a divorced Muslim woman in the 1980s. The fact that you will not see me walk across that graduation stage hurts immensely. The faith that you had in me persevered. My achievements are your achievements. I could not have gotten to this point without the freedom and independence that you ensured I had. I could not have asked for a better mother.

My ride-or-die supervisor, Dr Susan de la Porte. Sue you have been my rock throughout and I cannot find the words to express how much appreciate all that you have done for me. A student could not ask for, nor find, a better supervisor and mentor as I have in you. You went toe-to-toe with me on this, spending even your vacation reading my work, something that is absolutely unheard of from an academic. Your strength and support has been immensely valued from the moment we first sat down, over a decade ago, to a cup of coffee to talk about research, when I just an Honours student in Anthropology. There have been so many more cups of coffee since, and there are still more to come. More than a supervisor, you have become my close friend. You have guided me along the way ever since, giving me the freedom to make my own choices for my research, never stifling, always encouraging. You are a blessing in my life and I know that I would not be the academic that I am today without your positive influence. Thank you will never be enough to express my gratitude for

your wisdom and guidance in all the time we have known each other. Here's to less stressful ventures!

Des Bekker, my dearest and nearest in Makhanda. You and your family are my family in this little town, in the middle of nowhere. You took me in, the little 'stray' as Thys likes to call us, and you made this town and Rhodes University a home for me. The best part of my day has been our coffee and smoke 'work' sessions. It's a miracle the stone wall doesn't have our bums imprinted into it! Thank you for your love, strength, and constant support!

Trianne Amarchund, 'started at the bottom but now we're here'! Look at us now! Thank you my friend for your encouragement and support over the years. We bonded over food, shewhoshallnotbenamed, and eventually over dissertation drama, and look at us now! We made it through, and here's to bigger and better things in the future. I couldn't ask for a better friend and fighter to be in my corner.

I have been incredibly lucky to have been surrounded by students who care about my academic career and who have supported and pushed me when I needed it. I had never envisioned that I would be writing my PhD alongside my Master's students, but Rinisa Naidoo, Paige Sarah Norman, and I found ourselves doing just that. The brainstorming, masses of coffee, and orange slices have all come to an end but it is not THE end. You turned a lonely journey around for me and your constant presence and support continues to be very much appreciated. Ntokozo Sibisi your virtual encouragement and passion has always been a force to be reckoned with, and I am grateful to have you in my corner, cheering me on. Kelsey Nebbe, thank you for your encouragement and your cheerfulness through it all. Thank you to all of you for taking a chance on me and trusting me with your academic growth. I have learnt so much from all of you which has added so much value to this thesis. I am so proud of all you, and what you have achieved, and I look forward to the great things to come.

Melusi Dlamini, my partner-in-thesis, my sounding board with brilliant ideas and feedback, and soon-to-be-Dr, I am ever so grateful that you came to Rhodes. After a very lonely post-graduate journey, it has been such a pleasure and relief to have someone with me who understood exactly what I was going through. Your encouragement has been so valued as well as your wise and kind words throughout.

Dr Nokuthula Cele, I am finally here my friend. I am sad that I achieve this milestone without you, but I know that your spirit is watching and cheering me on, as you always have. Drs Delarise Mulqueeny and Gerelene Jagganath, and Prof Mariam Seedat-Khan, thank you for your advice, assistance, and encouragement and mentoring over the years. You have all been a valuable part of my academic journey, you have walked so that I could run. Prof Aswani, we may not have talked about my research much, but I have learnt so much about Anthropology from you over the years, you have shown me a side to this discipline that I had never thought about and I am very much grateful for that. Profs de Wet and Palmer, and Dr Henderson you have all been so encouraging about my work and you have always shown interest and asked questions which made me think about my work in a different way. I know that without those questions, my work would look very different. You all introduced me to anthropology in different ways and have made me value this discipline much more.

Saskia van Geuns, Lola Hallowes, and Bongiwe Tenze, you have been such cheerleaders and I am so grateful for your support and encouragement over the years.

To my NTEU Rhodes Exec, thank you for all the encouragement over the years, and especially towards the end as it has been such a trying time. Thank you for all the advice and for the support that you have given me, more so now that ever.

To my family who has been with me from the very beginning, thank you for putting up with my crankiness and mood swings as I navigated the waters of academia. Nani, you always told me to make my own decisions and make sure that I ‘get an education’ so that I would not need to rely on finding a rich husband to provide for me. Nani, I have become my own rich husband and I know you would be proud of me. Sumz, Auntie Foz, and Uncle Baboo, your support has been incredibly valued. You guys have been cheering me on for years, now we have something else for you to cheer about! You guys have always shown interest in my work and listened to me ramble on about it. Your love and encouragement is appreciated.

ABSTRACT

HIV and AIDS has been prominently studied, by both biomedical and social scientists, since the 1980s. Despite the extensive research that has emerged globally, Muslims have largely been absent in much of the discourse on HIV and AIDS. While the disease is said to be under control in many parts of the world, hidden populations pose a risk to increase in prevalence. Muslims living with HIV are one such hidden population and are only recently gaining representation in studies on HIV and AIDS. Quantitative studies reflect a sharp increase in HIV prevalence in countries with significant Muslim populations, however, more in-depth qualitative studies are needed to garner an understanding of the nature of the disease among Muslims. Muslims have a long history in South Africa, beginning with indentured slavery in Natal (now KwaZulu-Natal) in 1860. There are no specific HIV and AIDS prevention campaigns directed at Muslims in Durban, KwaZulu-Natal, South Africa. Muslims in Durban do not regard HIV is a significant concern for them due to religious doctrine, which they believe if followed will keep them safe from infection. My findings suggest that there is cause for concern over the spread of HIV and AIDS amongst Muslims in Durban. The hidden nature of the disease in the Muslim community has created challenges to curbing the spread of the disease due to the concealment of its presence and the marginalisation of Muslims living with HIV and AIDS. This study conceptualises the HIV and AIDS lived experience amongst Muslims in Durban, South Africa, and uncovers the social and cultural context of the disease. The qualitative study used life histories with ten Muslims living with HIV and semi-structured and unstructured interviews with ten caregivers, five health care professionals and two religious leaders to gain a detailed understanding of the lived experiences of Muslims in Durban. Through the lenses of Purity and Danger, Stigma and Spoilt Identity, and Social Death, this study found that religion [Islam] and its strong moral code influences understandings and perceptions of HIV and AIDS which, in turn affects diagnosis, treatment, care, social identity, and the social well-being of Muslims living with HIV who face stigma, discrimination, shame, and ostracisation from their own community. This study highlights the gaps in the literature on Muslims living with HIV and by providing insight into the lives of participants, the study draws attention to the plight of Muslims living with HIV and AIDS (MLWHIV) and encourages more qualitative studies to be conducted so that a multifaceted understanding of Muslims living with HIV can be created.

Keywords: HIV and AIDS, Muslims, South Africa, ethnomedicine, socio-cultural-religious challenges

GLOSSARY OF TERMS

TERM	MEANING/ EXPLANATION
UMMAH	Muslim community
IMAM	Religious leader and scholar and one who leads a congregation in prayer
MENA	Middle east and north Africa region
HIV	Human immunodeficiency virus
AIDS	Acquired immunodeficiency syndrome
WHO	World Health Organisation
HADITH	A collection of authenticated proverbs by the prophet Muhammad (PBUH)
PBUH	Peace be upon him (this term is always stated and written after a prophet's name
ART	Anti-retroviral therapy
MALAMAI	Muslim scholars who are trained in the application of prophetic medicine Singular: malam
RAMADAN	The 9th month of the Islamic calendar, which is spent in abstention from food and drink, from dawn until dusk
ALLAH	God
ZAKAT	Alms. Charity that is given specifically from one Muslim to another Muslim
MASJID	Place of worship
MSM	Men who have sex with men
PMTCT	Preventative mother to child transmission
STD	Sexually transmitted disease
IC	Islamic care-line

MAP	Muslim aids programme
HAZRAT	Honorific. Generally used for followers of the prophets (peace be upon them)
RA	'Radi allahu anhu': honorific used for the companions of the prophet (PBUH) and translates into "may Allah be pleased with him/ her". Male: anhu Female: anha
JANNAH	Heaven/ paradise
TAWHID	Unity
IMAAN	Faith
SALAH	Prayer
SAWM	Fasting
QUR'AN	Muslim holy book
SUNNAH	Practices and traditions performed by the prophet Muhammad (PBUH)
MAHRAM	Family member of the opposite sex whom one cannot marry
NON-MAHRAM	Any person of the opposite sex whom one may marry (where there is no marriage taboo)
NAFS	Self (literal translation from Arabic to English). The term, however, is used in the same manner as 'ego' and relates to desires
HIJAB	Head scarf
BURQA	Outer garment which covers the entire body, including veiling the face and eyes of a woman
NIQAB	A covering which veils the face from view, however, the eyes are uncovered

ABAYA	A loose-fitting Arabian garment that covers the body of the woman wearing it from the neck to the feet, as well as the arms up to the wrists
MUT'AH	Temporary. Used in reference to temporary marriage practiced by Shia Muslims
HALAL	Permissible
HARAM	Forbidden
WALI	Legal male guardian
IDDAT	'Waiting'. A three-month period of waiting that a woman performs after she has been divorced or widowed
NIKAH	Marriage
ZINA	Adultery
KHAMR	Intoxicants: substance that intoxicate the mind, for example, alcohol, and recreational drugs
IRHAM	A state of purity during Hajj, that is marked by wearing white clothes from a specific material
TAWAF	'To surround': The act of tawaf is moving around the kabah in an anti-clockwise direction seven times.
MUHARRAM	The first month of the Islamic calendar, during which Ashura (day of commemoration in Islam) is observed.
ARV	Anti-retroviral
JAMIAT	Assembly of people used to describe groups of men who travel, locally and globally, to spread the word of Islam. Similar to a Christian missionary
MOULANA	Scholar and leader in the religious community in Islam
ASTHAGFIRULLAH	I seek forgiveness from Allah
JAHILIYYAH	Ignorance, one who acts ignorant or who goes against the norms of Islam

GAFOOR UR RAHIM	All forgiving
EM	Explanatory model
CAM	Complementary and alternative medicine
NAZR	Evil eye
MUHAJIRRUN	The first Muslim believers
FAHISHAH	Lewdness, perversion, or indecency
TA'UN	Epidemics/ plagues
ULAMA	Learned ones
WUDHU	Ablution for prayer
NAPAK	Unclean
PAK	Clean
HAKIM	A Muslim who has strong knowledge of Prophetic medicine. Similar to a malam
DUA	Non-ritualised and non-routine prayer
ZAMZAM	Holy water that originates in Makkah (Mecca)
MAZAAR	Mausoleum of a Saint
ALHAMDULILLAH	Praise be to Allah
ISTHIGFAR	To repent, seek forgiveness from Allah
MADRASSAH	Islamic school
DAWAH	Acts/behaviours which serves to promote Islam and to convert non-Muslims to Muslim

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CHAPTER ONE: INTRODUCTION TO THE STUDY

*"To this day, I have never come across someone like me and it's incredibly lonely… Now I have got to the point in my life where I'm proud to say who I am: I'm British-Pakistani, Muslim, gay and living with HIV. I just want to say to someone, 'You understand, right? How difficult it is as a Muslim and being HIV positive?'" (*Shamal Waraich, BBC, 2018*)*

1.1 Introduction

Public health innovations in the last two hundred years have led, more or less, to either the eradication or control of communicable diseases. Barnett and Whiteside (2006) explain that medical innovation in vaccines and medication has greatly assisted in the improvement of health and healthcare. Despite the obvious gains, communicable diseases have recently become a cause for global concern and certain diseases have become drug resistant, for example tuberculosis, whilst others, like HIV[1], evolve so fast that it is difficult for scientists to develop effective treatments or find a cure. Currently the only effective treatment for HIV and AIDS[2] lies in anti-retroviral treatment which is also being used to lower risk in transmission.

The earliest and most substantial evidence of the existence of HIV, which subsequently causes AIDS, dates back to 1959 (Iliffe, 2006; Epstein, 2007; Abdool Karim, 2008). In the 1980s a blood specimen, belonging to a group of malaria blood samples taken in 1959 in equatorial Africa, was tested and identified positive for HIV. This Leopoldville specimen, believed to have been drawn from an unnamed male in 1959, has allowed epidemiologists to create a probable timeline of disease progression for HIV and AIDS and to understand how the virus potentially spread across the world. At the time of the 1959 specimen the region was sparsely populated with a low movement of people and it is believed that the disease did not have much avenue to spread (Iliffe, 2006). Colonisation and modernisation, however, saw the rise in the occurrence of rapid urbanisation, migration, liberation wars and development taking hold in various African countries, meaning that HIV had the perfect environment in which to spread (Iliffe, 2006).

[1] Human Immunodeficiency Virus
[2] Acquired Immunodeficiency Syndrome

In 1979 and 1980 doctors in the United States of America (USA) observed, in an increasing number of mostly homosexual male patients, clusters of what were previously extremely rare diseases. These included pneumocystis carinii pneumonia and Kaposi's sarcoma[3] (Barnett and Whiteside, 2006; Iliffe, 2006; Epstein, 2007; Abdool Karim, 2008). As a result, according to Parker (2001), HIV and AIDS was initially believed to be a disease that affects primarily homosexual males. In 1983 and 1985 HIV-1 and HIV-2 were identified respectively. Drs Luc Montagnier and Francois Barre-Sinaussi and their colleagues at the Institute Pasteur in France called their initial finding, in 1983, lymphadenopathy associated virus (LAV). In the USA Dr Robert Gallo from the National Cancer Institution labelled his discovery the human T-lymphotropic virus type III (HTLV-III). After thorough investigation into both scientists' work the two viruses were found to be the same and both doctors were credited for the co-discovery of HIV (Abdool Karim, 2008). HIV-1 and HIV-2 both cause AIDS, however, it is important to note that the two viruses are genetically distinct (Motomura et al, 2008). As such, as Motomura et al (2008) state, the test needed to determine the presence of each type of virus is different and the treatment regimens for each differ as well. HIV-2 is predominantly prevalent in West Africa (for example in Guinea-Bissau, Mali, Sierra Leone and Nigeria), however, it also occurs in other regions of the world including the USA, parts of Europe and India (Abdool Karim, 2008; Campbell-Yesufu and Gandhi, 2011). Lemey et al (2003) note that the first indication of HIV-2 in a human being dates back to the early 20th century, although HIV-2 was only officially identified in 1986 by Francois Clavel. It is important to note that HIV-2 is less virulent, slower acting and more difficult to transmit than the dominant HIV-1 and so the spread of HIV-2 internationally has been less pronounced (Barnett and Whiteside, 2006; Abdool Karim, 2008).

HIV originates from a virus that jumped the species barrier to human hosts. It is a zoonotic disease which Armelagos and Barnes (1999) explain as a disease in which the primary hosts are non-human animals and infect humans incidentally. In most cases the original host animal is barely affected by the disease it carries and can live with it comfortably, yet when that disease spreads to another species it can be detrimental, as is the case with HIV and AIDS. Scientists have found HIV to be closely related to various Simian Immunodeficiency Viruses (SIV) found in various monkey

[3] A previously rare cancer.

and ape groups across Africa. HIV-1 is linked to an SIV found in chimpanzees (*Pan troglodyte troglodyte*[4]) living in the forest of Central Africa and HIV-2 is linked to a SIV found in the sooty mangabey (*cercocetus atys atys*) from West Africa (Lemey et al, 2003; Barnett and Whiteside, 2006, Gouws and Abdool Karim, 2008; AIDSInfo, 2016). The initial jump across the species barrier to humans, and its mutation into HIV, could have resulted from any number of activities that required direct contact with an infected primate which led to the mixing of blood between the two[5] species. As a retrovirus, HIV specifically belongs to the lentivirus genus which explains the characteristically slow or long period of development and disease progression[6], resulting in slow symptomatic experiences to the infected, with the disease affecting the immune system and brain of the host (Barnett and Whiteside, 2006; Williamson and Martin, 2008). Barnett and Whiteside (2006) and Gouws and Abdool Karim (2008) explain that HIV-1 mutates rapidly and has two major strains, groups M and O. Group M has eleven subtypes (labelled from A through to K) and causes 99% of infections worldwide. Subtype C, from Group M, is especially infectious and is the strain widespread in Southern Africa (Barnett and Whiteside, 2006; Gouws and Abdool Karim, 2008; Morris and Cilliers, 2008; AIDSInfo, 2016).

When HIV and AIDS was first identified in the early 1980s, Margaret Heckler, then Secretary for the United Nations Health and Human Services, boldly declared in 1984 that there would be an HIV vaccine within two years, yet, in the more than thirty years that followed, there has been limited success (Shilts, 1987; Barnett and Whiteside, 2006; Williamson and Martin, 2008a). The very nature of the virus and its ability to continuously evolve has meant that the creation of a vaccine to target a particular structure has been problematic. Classical vaccines have the ability to mimic natural immunity which occurs against reinfection and, to date, there have been only two cases recorded where patients have recovered from HIV and AIDS (Pollard and Bijker, 2021).

The southern region of Africa's first sign of HIV came from rural Karanga in Malawi which borders Tanzania and Zambia (Iliffe, 2006). The virus, it is believed, moved through Zambia, Botswana and Zimbabwe before finally reaching South Africa (SA).

[4] Central chimpanzee or tschego (Pika, 2019).
[5] This includes through hunting, butchering, and preparation of contaminated meat.
[6] The window period of HIV is several weeks to several months (Barnett and Whiteside, 2006).

Malawian mineworkers, who were tested in South Africa in 1986, were found to have a prevalence rate of 4% (Iliffe, 2006; Epstein, 2007; Abdool Karim, 2008). The main sites of transmission were found to be towns and cities and major roads that saw numerous truck drivers and migrant movement (Iliffe, 2006). Statistics only provide one piece of the puzzle, and it was found that in some areas sex workers and urban to rural migration saw high prevalence rates, whilst in others prevalence rates remained low (Iliffe, 2006). The modes of transmission for HIV were varying and therefore a one solution fits all preventative measure would not work.

Since the 1980s, as a global epidemic, HIV and AIDS has impacted the lives of people regardless of class, caste, colour, religion or sexual orientation and, as such, is a well-researched area of study, both biomedically and socially. It must be noted, however, that some segments of the population are disproportionately more affected than others, for example, poorer socio-economic groups, men who have sex with men, sex workers and intravenous drug users, while race and age disparities also reflect that young black women are more susceptible to HIV than other groups, which is often tied to low socio-economic status and patriarchal norms (Campbell, 1997; Campbell, 2000; MacPhail and Campbell, 2001; Selikow et al, 2002; Campbell, 2003; Leclerc-Madlala, 2003; Leclerc-Madlala, 2008; Selikow et al, 2009; HIV.gov, 2022; KFF, 2023). This does not, however, mean that every aspect of HIV and AIDS has been researched and hidden and/or unrepresented groups are cause for concern for disease transmission. In South Africa the primary focus of study has been on the poor and, due to the racial demographics of class in South Africa, this has meant that much focus has been placed on black South Africans. From the 1980s studies have centred on mineworkers, sex workers and youth in rural and urban areas, as well as on immigrants, truck drivers, and sugar daddies in the major cities of Durban, Johannesburg and Cape Town (see for example Campbell, 1997, 2000; MacPhail and Campbell, 2001; Selikow et al, 2002; Campbell, 2003; Leclerc-Madlala, 2003, 2008; Selikow et al, 2009). What remains clear through the vast body of research since its discovery in the 1980s, is that HIV and AIDS has been a highly stigmatised disease, with blame being ascribed to particular ‘categories’ of people for both its origins and its spread. Despite the widespread, global nature of the disease it continues to be stigmatised in many sectors of society.

1.2 Background and Focus of Study

The Joint United Nations Programme on HIV and AIDS (UNAIDS, 2021b) latest estimated global statistics for HIV and AIDS prevalence stands at 37.7 million people living with HIV (PLWHIV). This is an increase from the 2018 statistics which placed global prevalence at 36.9 million PLWHIV (UNAIDS, 2018). The fact sheet further states that there were 1.5 million new infections and that a further 680 000 people died from AIDS related sicknesses in 2020 (UNAIDS, 2021b). Infections, as well as deaths from AIDS related sicknesses in general, appear to be on the decline (UNAIDS, 2021b). A comparison of the UNAIDS 2021 statistics and the estimated seven billion global population indicate that while mass hysteria surrounding HIV and AIDS may be over (especially since the advent of COVID-19), the HIV and AIDS epidemic has more far-reaching consequences than merely being a challenge to health and health systems. HIV and AIDS, as noted, affects people across gender, sexuality, class, race, socio-economic status and religion and in so doing, has economic, political, production, environmental, familial and societal repercussions (Oramasionwu et al, 2011).

The population of South Africa stands at 60.14 million people and KwaZulu-Natal (KZN) is the second largest province in terms of population size with 11.5 million people or 19.1% of the country's population (StatsSA, 2021). South African Muslims make up 3% of the total population of the country and as such Islam is a minority religion in South Africa (Isilow, 2021). Despite this, Muslims have a rich history in South Africa. The first wave of Muslims who were brought to the country from 1652 – 1800s were from Asia and other parts of Africa through involuntary migration, i.e., as slaves, political prisoners and political exiles (Mahida, 1993). The second wave of Muslims entered the country from 1860 – 1911 mainly as indentured labourers from British India, and some entered as a merchant class during that time. In the post-apartheid period, an estimated 100 000 African Muslims crossed South Africa's borders to enter the country (Mahida, 1993). Islam has also been considered the largest religion of 'conversion' in South Africa and one of the fastest growing religions in the world (Lipka, 2017). In South Africa many reverts[7] to Islam are black Africans

[7] Revert is the appropriate term used by Muslims for those who convert to Islam from other belief systems. Dodge (2018) explains that the reason for the use of revert instead of convert is that Muslims believe that everyone is born into the natural faith of Allah (God), that all babies are "born with an innate sense of submission to God, which is called *fitrah*". A hadith from Sahih Muslim strengthens this argument with a saying

and particularly women and youth (Haghnavaz, 2014). Thus, whilst the population of Muslims in South Africa may be relatively small in number, they are present and active in South African society and are affected by the same issues as other South Africans. One example of this was the presence of Muslim South Africans, for example, Ahmed (Kathy) Kathrada, Ahmed Timol, Adbullah Heron, Rahima Moosa, Ismail Ahmed Cachalia, Fathima Meer and Yusuf Dadoo, in the apartheid struggle (Sicard, 1989; and Vahed, 2021).

In the Middle East the refugee crisis has resulted in a mass migration of people, mainly Muslim Arabs, moving to countries in Africa (mainly North African countries), Europe, and North America (Lynch and Brand, 2017). The political turmoil and wars in the Middle East have resulted in major instability in the region and in a refugee crisis. According to the UNHCR (2021) formal records reflect that South Africa does not have refugees from the Middle East. Refugee migration, in particular, brings with it concerns over economic survival and recent studies have shown that there has been an increase in HIV and AIDS within this context (El Feki, 2012; Setayesh et al, 2014; AVERT, 2019; and Oraby, 2021). Muslims, however, are understudied in the area of HIV and AIDS and the lack of clear statistics, especially in predominantly Muslim countries (in the Middle East and Asia), is telling. Researchers are increasingly looking into this area of study; however, qualitative studies remain scant (Kagee et al, 2005; Todd et al, 2007; Isilow, 2009; Kamarulzaman, 2013; Lipka, 2017).

Given that Muslims living with HIV, as a whole, are particularly under-represented in current research, through this study I aim to provide some insight into the lived experiences of Muslim people, living in Durban South Africa, who are infected with and affected by HIV and AIDS. It is hoped that the representation of the lives discussed in this dissertation will promote other Muslims to come forward about their own experiences so as to create a transparent conversation around issues of sex, sexuality, and HIV and AIDS amongst Muslims. Through highlighting the lived realities of Muslims living with HIV, awareness of the realness of HIV and AIDS among Muslims is created. One argument that I put forward is that an increase in the number of Muslims testing and disclosing their HIV-positive status may assist with not only

from the Prophet Muhammad (S.A.W) which states that "No child is born except upon *fitrah* (i.e. as a Muslim). It is his parents who make him a Jew or a Christian or a polytheist".

prevention strategies but with the de-stigmatisation of HIV and AIDS, which can then, in turn, benefit in the improvement of care and quality of life for HIV+ Muslims. The following sections of this chapter draw attention to HIV in the South African context, Islam, sex, sexuality and HIV and AIDS.

1.3 South Africa's HIV Epidemic: A Closer Examination

Although HIV and AIDS is a global pandemic, structural inequalities have resulted in low-and-middle-income countries (LMIC) being hardest hit by the HIV pandemic (Shao & Williamson, 2012). South Africa is a LMIC and according to Simbayi et al (2019) the HIV pandemic hit its peak in South Africa in 2006 and made up 40% of all deaths in South Africa at the time. In 2002 the number of people living with HIV was estimated to have been 4.25 million and by 2018 this had increased to approximately 7.25 million with an estimated 13.5% of South Africa's population marked as HIV+ (StatsSA, 2018; KFF, 2021). The figures go on to reflect that approximately one-fifth of females between the ages of 15 – 49 (referred to as the reproductive ages) are HIV positive and prevalence amongst youth aged 15 – 24 declined to 5.5% in 2018 from 6.7% in 2002 (StatsSA, 2018; KFF, 2021). UNAIDS (2021a) reflects that from 2010 to 2020 new infection rates in South Africa decreased from 420 000 to 230 000, therefore figures dropped by a staggering 45%. AIDS-related deaths, in South Africa, are down by 50%, declining from 160 000 in 2010 to 83 000 people in 2020 (UNAIDS, 2021a).

The first case of HIV in South Africa was reported in 1982 when the South African Medical Journal evidenced two cases of AIDS in male homosexuals and so, just as with the USA, the disease was initially associated with the homosexual population (Abdool Karim, 2008). The early years of transmission therefore focused on men who have sex with men and people who (unknowingly) received unsafe blood transfusions (Abdool Karim, 2008). In the absence of testing at the time, haemophiliacs were at high risk due to their need for blood transfusions. By 1989 the cases of homosexual males who were admitted to HIV clinics plateaued while the numbers from the general, heterosexual, population rose. By the early 1990s heterosexual sex was thus the dominant form of transmission in South Africa (Abdool Karim, 2008). Perinatal transmission from pregnant women was also a concern. A blood test for the detection of HIV was created in 1986 and today blood is routinely screened for the presence of

HIV and blood donors are made to complete an extensive questionnaire on their sex related activities. The Blood Safety Policy was adopted by South Africa in 1999 and there has subsequently been a significant drop in the prevalence of HIV in blood collections (Abdool Karim, 2008).

The scientific and biomedical understanding of the disease as well as its epidemiology, requires robust explanation to understand the social aspect of the disease. The socio-political history of South Africa plays a prominent role in the transmission of HIV and AIDS within the country. South Africa has a unique past in relation to other African countries in that while most African countries that were colonised fought for their liberation directly from the coloniser, this was not the case in South Africa. Instead, South Africa experienced intermittent wars between the Afrikaner and the British settlers culminating in the British colonisation of the country, followed by a post-colonial era in which the Afrikaner National Party assumed control resulting in the apartheid regime from 1948 to 1994 (SAHO, 2016). The socio-economic structures of apartheid laws were built on the foundation laid down by the British for the acquisition of cheap labour from the indigenous populations of the country. Such laws created a situation that was almost perfect for the spread of HIV and AIDS in South Africa (SAHO, 2016). The beginning of the epidemic in South Africa coincided with the township revolts of the 1980s and the epidemics peak occurred later during the political transition to a democratic state (Iliffe, 2006). The subsequent changes at the forefront of the democratic dispensation took place during the economic, political, and social upheaval of the country and ordinary citizens were compelled to concentrate on survival. As such both the outgoing and incoming regimes were distracted from making HIV their chief priority (Iliffe, 2006).

The black African population in South Africa has been the hardest hit by HIV and AIDS. Migrant labour was a major role player in the transmission of HIV and AIDS as many men (at first) were forced to leave the contrived colonial ‘homelands’ to seek employment in urban areas due to the cash economy that they were forced into (Campbell, 1997 and 2000; SAHO, 2016). Women, who subsequently moved to urban areas due to the absence of the male breadwinner in the home, were often forced into sex work to support their families (Campbell, 1997). The structural nature of colonisation and apartheid resulted in the majority of black people being unskilled and with little decent formal education, coupled with stringent race-based laws, were

mostly relegated to the lowest socio-economic strata of society with many black people, especially women, living in abject poverty.

Foster (1996) argued that cases of HIV spread quickly on the mines, and consequently HIV and AIDS spread to the rural areas. Foster (1996) stated that, in the early 1990s, estimates for prevalence amongst miners stood at 10 – 20% which was a concern for mine owners as it meant a high turnover of labour and labour shortages which could potentially affect the prosperity of the mines. In the 1990s, mine workers were considered to be more at risk of contracting HIV than being in an accident (Heywood, 1996). Mine workers are largely black males, either South African or from neighbouring African countries. In the 1990s Gencor LTD estimated that around 30 of their workers were dying of AIDS-related diseases every month (Heywood, 1996). Many early studies on HIV and AIDS in South Africa were, thus, conducted around mine workers and sex workers near mining compounds, thereby shaping the early focus of research on HIV and AIDS in South Africa (Selikow et al, 2002, 2009; Campbell, 1997, 2000, 2003; Corno and de Walque, 2013).

Research in South Africa has been extensive on a biological as well as on a social level. The focus, as stated, has been largely on the poor and by extension black South Africans. Research has, as noted, included primarily studies on mine workers, migrant labourers, sex workers, men who have sex with men, transactional sex, sugar daddies, low-income population groups, prevention of HIV transmission from mother to child (PMTCT) and AIDS orphans (Nattrass, 2003; Campbell, 1997, 2000, 2003; Selikow et al, 2002, 2009; Abdool Karim, 2008; Peltzer et al, 2015).

The political history of HIV and AIDS in South Africa is a complex one. The South African government's engagement and response to HIV and AIDS has been characterised by disorganisation, mismanagement of funds, and denialism (Chigwedere and Essex, 2010; McNeil, 2012; Simelela et al, 2015). The National Party (NP), which was in power in pre-democratic South Africa, made minimal effort to engage with the disease and McNeil (2012) notes that in the early 1990s, prominent white parliamentarians blamed the spread of HIV and AIDS on the 'promiscuity' of homosexuals and black South Africans and there were claims made that promoted weaponizing the virus as a tool to reduce the black population of South Africa (Fassin and Schneider, 2003; Chigwedere and Essex, 2010; McNeil, 2012; Simelela et al,

2015). When the democratic government, led by the African National Congress (ANC), assumed power, HIV and AIDS was positioned as one of twenty-two lead projects that formed part of the Reconstruction and Development Plan (RDP). President Nelson Mandela's government focused on prevention programmes to educate the public about the disease. The Sarafina II project raised concern over its R14,27 million budget and the mismanagement of funds allocated to fighting the disease (McNeil, 2012). The project lost funding in 1996. Civil society was critical of the government's actions, especially the lack thereof, which did nothing to reduce the spread of the disease (McNeil, 2012; Simelela et al, 2015).

President Thabo Mbeki's government was characterised by denialism, and President Mbeki publicly and vociferously claimed that HIV did not cause AIDS (Fassin and Schneider, 2003; Chigwedere and Essex, 2010; McNeil, 2012; Simelela et al, 2015) thereby resulting in the refusal to make ARVs accessible to the public and organisations like the Treatment Action Campaign (TAC) were formed with the purpose of pressuring government to take action against the disease. The TAC played a prominent role in organising protests and in March 2003 launched a civil disobedience campaign to heighten pressure on government (McNeil, 2012). The TAC had a proactive agenda and campaigned for improved access to essential medications and ART[8] and promoted the need for accurate information dissemination to the public about HIV and AIDS (Achmat, 2004a; Heywood, 2009; Geffen, 2010; Sabi and Rieker, 2017). The TAC was vociferous in challenging the South African government on their HIV and AIDS policies, as well as the lack of accountability from government and pharmaceutical stakeholders, whilst simultaneously advocating for the human rights of PLWHIV (Achmat, 2004a; Gaffen, 2010). In addition to the fight for access to medication, the TAC also worked to reduce AIDS-related stigma and discrimination (for example in hospitals, workplaces, and schools) and advocated for government to address the socio-economic factors that play a significant role in the transmission of the disease, and for comprehensive sex education to promote awareness of the spread of HIV and AIDS and promote behaviours not deemed to be risky (Gaffen, 2010; Sabi and Rieker, 2017).

[8] Anti-Retroviral Therapy.

Zackie Achmat co-founded the TAC in 1998 and has been a prominent activist against HIV and AIDS. Achmat is Muslim, openly HIV+, a member of the LGBTQI+ community and an anti-apartheid activist. In campaigning for universal access to ART for South Africans, Achmat declared that until ART is accessible to the South African public, he would not take the medication himself (Achmat, 2004b; Robins, 2004; Powers, 2017). Achmat (2004b) noted at the start of the campaign that he understood that the necessary medication that an HIV+ individual is required to take is expensive. The TAC was not campaigning for the entire medication regime, but rather for access to affordable medication (Achmat, 2004b). Achmat went to Thailand in October 2000 and secured 5 000 capsules of fluconazole[9] and this was publicised, resulting in an "international public outcry against the pharmaceutical giant, Pfizer" (Robins, 2004: 667). This drew attention to the inflated prices of branded medication, and as a result Pfizer made some of its drugs free of charge to state clinics (Robins, 2004). The TAC and Achmat have been pivotal in the fight against HIV and AIDS and Robins (2004: 667) highlights this by noting the chant of members of the national TAC conference, "Long live Zackie, long live. Long live, TAC, long live!" The South African government won a lawsuit in 2001 that allowed for the production of generic ARVs which would cost less than the international medication, however, there was no movement on public access to the drugs. In 2002, the South African government was ordered by the South African High Court to make available to pregnant HIV+ women, Nepravine (an antenatal drug), yet despite this ruling, the government did not move forward with public access (McNeil, 2012; Simelela et al, 2015). A further point of contention during President Mbeki's reign was the controversy surrounding Dr Mantombazana Tshabalala-Msimang's approach wherein she was openly sceptical of ART and advocated strongly for the use of alternative treatments (Davis, 2014; McNeil, 2020). The then Minister of Health was opposed to the HIV+ pregnant women receiving ART. Instead, she promoted the use of garlic, African potato, beetroot and alcoholic drinks as treatment (Davis, 2014; McNeil, 2020). This was met with local and international outrage. Dr Tshabalala-Msimang maintained her stance, stating that side effects of ART were problematic and advocated rather to address the underlying socio-economic factors which plagued the spread of the disease (McNeil, 2020).

[9] Fluconazole is an anti-fungal prescription medication.

Finally, in the mid-2000s, and following significant pressure from international and local activists, antiretroviral programmes were implemented which had a marked impact on South Africa's HIV+ population (Chigwedere and Essex, 2010; McNeil, 2012; Simelela et al, 2015). Under President Jacob Zuma, prevention efforts were intensified, HIV and AIDS education programmes were pushed, condom usage was promoted and there was an increase in testing and counselling services (McNeil, 2012; Simelela et al 2015). In 2016, South Africa adopted the 90-90-90 target proposed by UNAIDS – the aim of which was to diagnose 90% of all HIV+ individuals, provide 90% of those diagnosed with antiretroviral therapy (ART), and finally to achieve a 90% viral suppression rate in those already on treatment – to be reached by 2020 (Rajasuriar et al (2022).

As noted above, activism has played an important role in the fight against HIV and AIDS. In as much as literature about MLWHIV is scarce, it does not mean that there has been total silence. Zackie Achmat is one of many Muslim HIV and AIDS activists. Fanta Ongoiba, an HIV+ Muslim woman from Toronto, Canada, is noted to have said, "HIV/AIDS doesn't discriminate. The way women are wearing the veil, hijab, to cover themselves, HIV can also be covered this way" (Eastwood, 2013). Ongoiba uses her position to educate Muslims about the importance of safe sex practices in Toronto and in her home country, Mali (Eastwood, 2013). Ongoiba has also drawn Imams[10] from the communities she works in to speak about the dangers of HIV and AIDS and to educate their congregation. Ongoiba has spoken out about the stigma that exists within Muslim communities in relation to HIV and AIDS. She has pointed out that preaching abstinence is not realistic because "how long can somebody abstain", and as such she advocates for condom usage not only to prevent HIV, but also sexually transmitted diseases (Eastwood, 2013).

Waheedah Shabazz-El is a Philadelphian HIV+ Muslim woman whose activism work began in the Philadelphia penal system to reduce medical neglect in prisons (McTighe, 2017). Shabazz-El had a history of drug abuse and considered herself "a believer who had strayed and returned" (McTighe, 2017). She is the founder of the U.S. based Positive Women's Network which aims to empower women living with HIV and AIDS in the USA. In 2006 she spearheaded a campaign to make condoms accessible in US

[10] An imam is a religious leader and also one who leads others in prayer.

jails through the commissary system[11], she also writes an advice column in the Prison Health Newsletter and has been a community representative on a US protocol which targets women at risk through the HIV Prevention Trials Network (McTighe, 2017). Shabazz-El also works to promote reproductive justice and to draw attention to the intersections between domestic violence and increases in HIV prevalence (McTighe, 2017).

Khadijah Abdullah, based in Washington D.C. in the USA, is the founder of Reaching All HIV+ Muslims in America (RAHMA). *Rahma* is also the Arabic word for mercy. Abdullah's HIV and AIDS activism began when she met an HIV+ Muslim in college (Montague, 2016). Abdullah worked with the individual in her capacity as a healthcare professional and found that he had no support from the Muslim community and he told her that he felt isolated and alone (Montague, 2016). It was her interaction with him that prompted her to create RAHMA and actively work towards reducing and eradicating HIV and AIDS stigma and discrimination amongst Muslims, and to create a safe space for MLWHIV (Montague, 2016). RAHMA provides youth education, workshops and training in relation to HIV and AIDS to provide factual information about sex, sexual health and HIV transmission and advocates for the rights of PLWHIV (Montague, 2016).

Abdul-Aliy Muhammad is a black, queer, HIV+ Muslim who felt disillusioned at the organisation he was working for that provided HIV testing. He discovered that the organisation had monitorised HIV+ results (Williams, 2020). Muhammad was also fighting against the racist culture in the organisation and organised a 'med strike' where he and others refused to consume their HIV medication resulting in the resignation of the organisation Chief Executive Officer (Williams, 2020).

In South Africa, Zackie Achmat's sister is another prominent HIV activist. Taghmeda (Midi) Achmat is also a co-founder of the TAC, co-founder of the Association of Bisexuals, Gays, and Lesbians (ABIGALE), and founder of Unveiling the Hijab which is a Facebook group for queer Muslim women (Jungar and Oinas, 2010).

Faghmeda Miller co-founded Positive Muslims in Cape Town after being diagnosed with HIV. She is the first Muslim woman in South Africa to disclose her HIV+ status

[11] This is a store in a prison or correctional facility which inmates can make purchases from.

and her activism focuses on the South African Muslim community (McTighe, 2017). Miller, who was infected by her late husband, has been open about her feelings of shame in relation to her diagnosis and uses her organisation to assist MLWHIV (McTighe, 2017). Miller runs a support group through the organisation, does counselling and runs HIV and AIDS awareness and education programmes (McTighe, 2017). Miller has noted in the past that it is a 'lonely road', and she continues to strive to raise awareness and education about HIV and AIDS in the Muslim community (McTighe, 2017). I communicated with Faghmeda early on in my research process and she provided me with important insight for my study.

Minority groups have been ignored for a long time in the study of HIV and AIDS in South Africa and thus there was a dearth in data and in social research in particular segments of the country's population. There has, however, been a changing landscape in the social science study of HIV and AIDS with literature becoming more widely available on white, coloured, and Indian populations (Dilraj et al, 2007: Naidoo, 2010; Kenyon and Zondo, 2011; Brown, 2016; Naidoo et al, 2016; Mabaso et al, 2019). South Africans of Indian Descent and Muslims, in particular, are a very conservative group and documenting their experiences with HIV and AIDS has not been an easy task. Muslims (including South African Muslims), in particular, have 'othered' HIV and have long believed that it is a disease for homosexuals and for 'wayward' members of society lacking in 'moral' integrity (Hasnain, 2005; Saltmarsh, 2012; Kamarulzaman, 2013; Oraby, 2021). Understanding how HIV affects Muslims, through transmission to living with and caring for those with HIV is, therefore, an important undertaking so as to ensure that realities are met with care and understanding.

Table 1: Mid-year population estimates for South Africa by population group and sex (StatsSA, 2021)

Population group	Male		Female		Total	
	Number	**% distribution of males**	**Number**	**% distribution of females**	**Number**	**% distribution of total**
Black African	23 761 051	80,9	24 879 278	80,9	46 640 329	80,9
Coloured	2 578 930	8,8	2 716 038	8,8	5 294 968	8.8
Indian/Asian	790 412	2,7	754 810	2,5	1 545 222	2,6
White	2 257 654	7,7	2 404 805	7,8	4 662 459	7,8
Total	**29 388 047**	**100,0**	**30 754 931**	**100.0**	**60 142 978**	**100.0**

1.4 Motivation and Study Rationale

During the conclusion of my Masters, in 2013, I came across an advertisement for an online support group for Muslims in the USA and it jolted something in my mind. I had been reading about HIV and AIDS for quite some time as an undergraduate and post-graduate student, and yet had not come across any discussion related to Muslims and HIV. I thought to myself “why are you so surprised, knowing what you know about Muslim youth (in particular), that HIV and AIDS is a reality in the Muslim community too?” As a result, I began a preliminary literature review and, at the time, information available on HIV and AIDS in relation to Muslims in various parts of the world was scant. Quantitative studies referred to statistics found in North African countries that are predominantly Muslim and statistics for the Middle East, a traditionally Muslim area, indicated an extremely low HIV prevalence rate. Qualitative studies were, however, extremely limited and it became clear that this was an area of study within the field of HIV and AIDS that required attention. The qualitative studies that have been done on HIV and AIDS and Muslims in South Africa have tended to focus on a theological response to the disease and very few studies have engaged directly with HIV+ Muslims (see Ahmed, 2000, 2013; Amod, 2004; Haddad, 2011; Kamalie, 2019).

IslamicHealth (2009) points to the stigma attached to people living with HIV in revealing their HIV-positive status to another for fear of rejection and/or being

ostracised. This hints at the silence that surrounds Muslims in addressing HIV and AIDS. Providing insight into Muslims living with and being affected by HIV is a relatively new area of study within the social and human sciences research arena and currently minimal research exists on the actual lived experiences of Muslims living with HIV. Studies on the physical, emotional, financial, and psychological aspects of HIV and AIDS, as well as the way in which Muslims cope with the disease, and the coping strategies which they employ, are limited.

Additionally, despite rigorous increases in HIV and AIDS awareness and outreach programmes, HIV-related stigma continues to exist in the third decade after the first HIV-infection was reported in South Africa (Mulqueeny & Taylor, 2017 and 2018). Stigma is still very much present in HIV and AIDS discourse and this will be discussed in more detail in Chapter Seven. Further, HIV infections span the intersections of race, religion, class, and gender divides, yet there is silence surrounding South African Muslims living with HIV. This is cause for concern and warrants research. To gain an understanding of HIV and AIDS within the South African Muslim population, the drivers of the disease, the social and cultural factors that play a role in disease transmission and the inside worlds of those infected and affected by HIV, it is crucial to engage in detailed, qualitative, research. Through an anthropological lens, this study explores the lived experiences of South African Muslims who are affected by and infected with HIV in Durban[12], KwaZulu-Natal, South Africa.

1.5 Research Problem: Towards an Understanding of The Lived Experiences of Muslims Living with and Affected by HIV and Aids in Durban

South African Muslims have, much like Muslims in the global HIV and AIDS context, until recently, largely fallen outside both biomedical and social science research and as a result not much is known about HIV and AIDS within this group. Esack and Chiddy (2009) state that entwined within cultural norms are religious viewpoints which impact on the openness of individuals about their behavioural actions and their HIV status. Accordingly, little is known about the drivers of HIV infection amongst South African Muslims and, as a result, there is limited understanding of HIV prevention needs,

[12] eThekwini District. A city located on the east coast of South Africa.

opportunities, challenges, and priorities faced by Muslims infected with HIV and AIDS and by those affected by the disease such as family members and caregivers. Although a number of groups have formed to provide support to Muslims living with HIV and AIDS, especially in Cape Town and Johannesburg, such as Positive Muslims, Islamic Careline and the Muslim AIDS Programme (MAP), there remains a dearth of research, especially qualitative research, on the actual lived experiences of Muslims living with HIV. This problem was identified at the outset of the study and culminated in this investigation. Through providing insight into Muslims living with and affected by HIV and AIDS in Durban, South Africa, the study, in the broadest sense, addresses some of the gaps in the existing literature. The study, moreover, provides an in-depth analysis of perceptions, attitudes, and experiences of Muslim individuals in Durban who are infected with and affected by HIV and AIDS and unpacks the hidden nuances of the lives of HIV+ Muslims. Furthermore, the study explores the coping strategies they adopt and the support mechanisms they rely on as well as the fluidity of their relationships and interactions with family members and with their broader social networks. The research, through creating awareness and understanding of Muslims living with and affected by HIV and AIDS in Durban, unpacks the stigma that HIV+ Muslims face and indicates how this stigma transforms an individual into a being regarded as ‘polluted’ and unworthy of community affiliation, relegated instead to the fringes of society.

1.5.1 Key Research Questions and Objectives of the Study

Key questions for the study included:

a. What is daily life like for Muslims living with HIV and AIDS in Durban?
b. What are the emotional, psychological and physical needs of Muslims living with HIV in Durban?
c. What were the perceptions and understandings of HIV and AIDS prior to and after diagnosis of Muslims living with HIV in Durban?
d. What are the coping mechanisms and strategies that are utilised by Muslims living with HIV in Durban?

e. What community structures are in place and how do these structures play a role, either positively or negatively, in the lives of Muslims living with HIV and AIDS in Durban?
f. How have significant others (family members, community members) responded to a positive diagnosis of Muslims living with HIV in Durban?
g. What is the response to HIV and AIDS amongst Muslims living in Durban?
h. How have the various stakeholders involved with Muslims living with HIV perceived or understood HIV and AIDS prior to and after their work in this area?

The central aim of this research was thus to explore and, therefore, understand the experiences of South African Muslims in Durban living with HIV and AIDS and the ways in which they cope with their experiences. Anthropology seeks a holistic understanding of phenomena and in terms of an analysis of how HIV and AIDS impacts upon those affected by the disease, Anthropology offers a unique perspective both on how to approach studying the disease and on its effects on those directly and indirectly affected. Kleinman (1976) explains that Anthropology, and Medical Anthropology in particular, can reveal the ways in which people interpret, understand, and experience their conditions, thus enabling the design and implementation of appropriate and relative interventions. This is especially important for a hidden group of HIV+ people, as their needs may be unique, and programmes need to be cognisant of this.

1.6 Methods of Data Collection

Anthropology is a discipline that straddles the sciences and humanities and medical anthropology is a field which exemplifies this. This research is framed within a wholly qualitative schema. Qualitative research, as described by Babbie et al (2006: 270) is the attempt to "study human interaction from the perspective of the social actors themselves". Anthropologists, in particular, refer to this as the *emic*, or insider, perspective. The *etic* perspective is referred to as the outsider perspective. Participant observation is the hallmark of anthropological research, however, for the purposes of this particular research, participant observation was not possible to employ. A specific study site could not be found and participants, whilst open to discussing their lived experiences, were not open to having an 'outsider' in their homes. As an HIV-negative

Muslim female, I could not be an insider nor gain insider access to the social worlds of my participants. The *etic* perspective was thus employed in this research; however, the perspective of the participants is emphasised throughout (both during the data collection phase and in the write-up process). The methods relied on for this study thus include in-depth semi-structured interviews, unstructured interviews[13] and detailed life histories. Gaining in-depth (thick) description and understanding my participants' experiences and key life events from their own perspectives was regarded as pivotal throughout the data collection period, whilst it was simultaneously deemed as crucial to ensure that participants felt and remained safe and respected. Interviews were carried out in spaces that were neutral or ordinary for participants so as to ensure their comfort and not bring attention to the research. These spaces included coffee shops, rooms at a faith-based Muslim NGO[14] where some participants regularly visit, homes where possible[15], and for religious leaders', at their places of worship.

Research participants were sought through a (national) non-governmental organisation (NGO) that is run by Muslims and also through the use of personal contacts and leads from participants. A small network was thus created resulting from the snowball effect of the investigation. Snowball sampling is especially useful when researching a difficult to reach population (Bernard, 2006; Neumann, 2014). Through support networks participants were able to pass my information on to people they know who could then contact me if they were interested in being interviewed. This approach aimed at ensuring that privacy was maintained and that only willing participants were engaged with. Participants included Muslims living with HIV, health care providers/ professionals, care-givers, as well as religious leaders.

Okely (2012) notes that through direct experience we give culturally specific authoritative knowledge and this guides and influences the manner in which we navigate everyday life. As anthropologists, she argues, it is important for us to be "fully aware and grounded" in self-awareness so that we are able to notice and understand difference (Okely, 2012: 36). This is especially so when a researcher is embedded in

[13] These unstructured interviews took on the nature of casual and open conversation with various stakeholders throughout the research process and would be characterised as occurring during 'hanging out'.
[14] Non-governmental Organisation.
[15] Some of my participants were fine with being interviewed in their homes for privacy and comfort, however, they did not want me to be in their space outside of the interviews.

research within their own community of origin, as has been the case for me. Through acknowledging one's positionality in the field, self-awareness around gender, ethnicity, class, and education must be addressed as the positionality of the researcher has immense significance in the encounters one has in the field and in the manner in which knowledge is created via these encounters (Okely and Callaway, 1992; Okely, 2012). I found that I had an interesting position in the field as I was neither insider nor outsider because I embodied both perspectives. My position was a researcher first and foremost, and then a Muslim woman. I believe that it was important for me not to wear the 'hat' of Muslim first so that I could engage with and maintain a sense of naiveté whilst collecting data. In doing so, my interlocutors were able to speak to me without interruption or risk of correction and tell me about their experiences and beliefs as I aimed to understand their experiences from their point of view. As a Muslim female, I held an emic view because I share religious beliefs, practices, and values with my interlocutors and as such, I held insight into the Muslim community, the socio-cultural norms, and ways of thinking within the community. Simultaneously, I held an etic position because I am not HIV+ and thus am not in a position to fully comprehend the experiences of my interlocutors and immerse myself in their experiences. I was very reflective going into the research process and during it and, although I did not conduct traditional anthropological fieldwork, I kept a fieldwork diary as I have previously found this to be extremely helpful in acknowledging, engaging with, and understanding my thoughts and feelings during research.

A very strong part of this introspection was my engaging with my own experiences in relation to my participants so that I could understand the place of privilege that I held, particularly in relation to my female participants. I grew up in a non-conventional Muslim household. Had my parents not divorced when I was three years old, I do believe that I would likely have been pushed to or forced to get married as soon as I had completed my secondary education. My reasoning for this is because all of my paternal female cousins have been married young, most of whom are homemakers and have little to no independence, especially financial, from their spouses. My parent divorced in 1988 and I remember celebrating my fourth birthday at my maternal grandparents' home. My mother became a single mother to three children (I have two older brothers) and we lived with my maternal grandparents when my parents separated. My father was absent from our lives growing up and provided very little to

no financial support and his custody rights were terminated after a particularly violent incident when my brothers and I were in his custody. I was brought up with the mindset that abuse is wrong and that I should not allow myself to be in a position that enables a man to have financial or social control over me. Independence, and especially financial independence, was always the goal for me.

My mother had to 'go back to school' and she earned a diploma indicating her proficiency in operating a computer and in being au fait with relevant office related software. This certification enabled her to obtain an office job which she held until she retired in 2018. My maternal grandfather (Nana) earned his living as a charter fisherman (which he was well known for) and my maternal grandmother (Nani) was a homemaker. They owned their own home, which provided us with the stability that we needed. Due to my mother's experiences, and what my grandmother saw as her [my grandmother's] failings in not allowing my mother to pursue higher education, it was always 'drummed' into me that I needed to be financially independent and the way to achieve this was to earn a degree and get a good job. Marriage was never the main concern that it was for so many young Muslim females that I knew growing up. Whilst many of my female cousins were learning how to be good wives, I was learning how to be self-sufficient. We did not shy away from discussing female issues in my home, and my Nani would tell my brothers to purchase sanitary products when I needed them. Her reasoning was that they would have wives and daughters one day and they needed to be aware of what women's needs are. My mother was shocked at these situations because she and her brother were not brought up in the same manner, and my Nani noted that she realised where she went wrong in certain instances and did not want to make the same mistake again. There was no gendered division of labour in our home. My brothers and I had table duties, dish duty, and laundry duty that we took turns completing or did them together. My second brother learned to cook full meals before I did and my Nani never saw it as a priority for me to learn how to cook, rather she focused on teaching me how to wire a light bulb and other small DIY tasks in the home. My Nana would take me and my brother to *pump for white crackers* (bait for fishing) and would have me help fix fishing rods and his boat motors. For me marriage was a choice, and I knew that I would not be forced to remain in a marriage that was less than ideal for me. I learnt sex education at school and my mother never had a problem with that. We had a very transparent relationship and if I was going out,

she was well aware of it and would stress that I need to be safe. I wasn't much of a clubber (attending night clubs regularly) but my brothers were, and it wasn't something that they hid from her. My mother firmly believed that it was better knowing where her children were should they need her help than to have any of us lie to her and feel like we could not turn to her for help when we were in trouble. I mainly had male friends, and I worked in a predominantly male environment at my part-time job, and there were often situations when an 'auntie'[16] would see me out with a male friend or a group of male friends and immediately tell my mother who would merely respond by saying, "*I know where my daughter is every night, and who she is with. Do you?*". These, and many more experiences, are very different from the experiences of most female South African Muslims and non-Muslims of Indian descent, and it did make it difficult at times to comprehend the experiences that I was entrusted with during interviews. I struggled with feelings of anger for my participants, especially my female participants who had entered marriages without knowing their potential spouses and the way they were treated post diagnosis, being held accountable for actions that were not their own. I was angry with my male participants and how their behaviour was largely excused because "boys will be boys" and because it was deemed to be the job of their wives to set them on the *'right path'*. I worked through these emotions with my therapist, and I used my field diary as a point of reflection when I was analysing and writing up my findings because it was important for me to find objectivity and maintain it throughout the research process. When conducting interviews, I had to be conscious of my facial expression and body language so as to ensure that my anger did not show and that I mirrored my participant's emotions and portrayed a sympathetic stance. As a *Muslimah* (female Muslim) some of my male participants struggled at first to be open about their experiences, however, after we spent a few sessions together, sometimes talking about sport and general topics, a good sense of rapport was built, and they were more comfortable with expressing themselves.

The term *ummah*[17] is commonly used to refer to Muslims as a collective. *Ummah* is the Arabic word for community (Abdul-Wahid, 2017). At its core, Islam promotes a

[16] Colloquial term for a woman known to the family but not necessarily a relative
[17] Collective term used to describe Muslims and refers to Muslims as a community.

sense of brotherhood/sisterhood and Muslims tend to see themselves as a community, regardless of the wider society of which they are a part (Abdul-Wahid, 2017). For the purpose of this study the term community (in keeping with the concept of *ummah*) has been used in relation to Muslims living in Durban, South Africa.

1.6.1 Gaining Access to Research Participants

At the outset of this study, I knew that it was going to be a long and arduous road. Through conversations with people whom I know who work in this field I was told that it would not be easy to find people willing to speak openly about their experiences. This was in relation to Muslims living with HIV and people who provide care, either professionally or through volunteer work. In order to obtain ethical clearance for my study I was expected to find an organisation to work with so as to access participants. This took a year to achieve despite the fact that I sent numerous emails to various organisations and drove all over the greater Durban area visiting NGOs I was directed to by people who had volunteered with them (and had informed me that these NGOs work with and provide care for Muslims living with HIV), yet I was continuously turned away. The answer was always the same, "*we do not know any HIV+ Muslims*". After a visit to one particular organisation, I was leaving the office feeling dejected when a staff member, who was on her way out, stopped me and told me in no uncertain terms, "*don't bother, no one will admit to HIV+ Muslims*". This, however, is not a countrywide phenomenon. The Durban community is particularly silent on the matter of HIV+ Muslims, yet in Cape Town there is more open conversation taking place. A prime example of this is the organisation Positive Muslims. Positive Muslims was co-founded by an HIV+ Muslim woman, Faghmida Miller, whom I contacted for advice and a general overview on her experiences since her diagnosis. Faghmida was very supportive of my endeavours and, at the time, had I the funding, I would have changed the base of my study to Cape Town. Had that happened, however, it would have kept the silence and secrecy around Durban intact and some silences need to be broken for the greater good. I eventually located a nurse at a clinic in Durban who told me that should I follow the correct applications through the Department of Health, I could do my research at the clinic at which she is based. With this letter in hand, I was finally able to apply for and receive ethical clearance for my study in 2015. This initial

research site, however, did not pan out. The silence and secrecy around the existence of HIV and AIDS in the Muslim community is so strong that it took me a total of two years before I was able to find an organisation willing to disclose that they provide services to HIV+ Muslims in Durban. The organisation was extremely valuable in getting me started on my data collection by introducing me to two HIV+ Muslims, and I was able to form more connections through these initial contacts. The organisation was the site for four of my interviews, however, the organisation did not play any further role in my research.

1.6.2 Interviews: Semi-Structured and Unstructured

At the outset of the study informal, unstructured, interviews were used to garner a sense of perceptions surrounding HIV and AIDS within the Muslim community in Durban. I had unstructured interviews with health care workers and care-givers whom I know privately as well as with friends who are connected through personal and academic relations to Muslims and HIV and AIDS. The use of unstructured interviews was helpful in creating a network of people whom I believed I would be able to rely on when the data collection phase of the research began.

Bernard (2006) describes unstructured interviews as often taking the form of everyday informal conversations whereby the researcher gains insight into the world under study, allowing for the establishment of networks and stronger rapport with relevant stakeholders to be built. The use of the one-on-one unstructured interview was a valuable research tool for this particular study because it allowed for free-flowing conversations between myself and my participants, ensuring ease and comfort (Bernard, 1994; Bernard, 2006; Neumann, 2014). This was useful, in the absence of a fixed research site, to learn about the social context of HIV and AIDS in the Muslim community in Durban. Preliminary unstructured interviews assisted with the creation of semi-structured interview questions and life history schedules for the later, more formal discussions. These conversations also aided in my getting to know who the key players in the area of HIV and AIDS and Muslims in Durban are and in my discovering the extent to which the disease remains hidden. The use of unstructured interviews, moreover, helped me in forming connections with relevant parties who were then able to assist me with finding research participants.

Denscombe (2007) speaks to the nature of semi-structured interviews which allows participants to develop their ideas and speak freely and widely on issues which they believe to be of importance. This is especially relevant in that participants are not limited in any way through the use of rigid, inflexible and directing questions, allowing the researcher to glean information on "opinions, feelings, emotions and experiences" (Denscombe, 2007: 175). This allows for detailed responses from participants, thereby providing more holistic outcomes as opposed to posing questions that elicit one-or two-word answers. Semi-structured interviews are created with a clearly defined set of issues that need to be addressed, however, as Denscombe (2007) reflects, they also ensure flexibility in the interview process as the participant is allowed to develop her/his own thoughts and ideas on the topic of discussion and furthermore may draw upon other aspects of the research which may not have occurred to the researcher. The focus is thus on the participant as opposed to the question being posed.

During this study semi-structured interviews were carried out with five health care professionals, ten caregivers, and two *Imams*, on a one-on-one basis at the place of my participants' choosing. My participants were thus assured of being in a space in which they felt comfortable and were able to have privacy throughout the interview process. Most of my interviews were, with the permission of my participants, recorded on a Dictaphone. The use of the Dictaphone was helpful as is allowed me to focus on the interview rather than being distracted by writing notes. Once the recorded interviews were complete, the recordings were transferred onto a personal hard drive and deleted from the Dictaphone. The audio was then transcribed in order to sieve through and extract valuable and pertinent information. Some of my participants refused the use of the recording device and, as such, I wrote notes during the interviews.

1.6.3 Life History Interviews

The key method of data collection used for my research with Muslims living with HIV was the life history interview which allowed me to gain deep insight into the lives of my key informants.

The life history interview allows for what Neumann (2014) refers to as a biographical style of information gathering which overlaps with oral history. Delving into the lives of my key participants enabled me to garner material about their lives in a documentary

style, ranging from my participants' earliest childhood memories to their present life situation. I became fully immersed in their diachronic experiences through the use of life histories which led to a better understanding of the people I was working with.

Usually, according to Bernard (2006), life history participants are older people, however, my participants ranged in age from 21 to 65 years of age. Whilst I had prepared a structured interview schedule, the interview was very open, and my interlocutors were asked to identify key moments in their lives and people of significance. The discussion moved, from there, into their earliest childhood memories, family and community life, and continued through education, adolescence, and adulthood. The life history method allowed me to learn who my participants are, what their values and beliefs are, the family life they have experienced and further helped me to gain rapport as we spent extended time periods together. I shared some of my own life experiences to make my participants feel comfortable and reduce barriers to communication.

It was understood, at the outset, that there is the possibility of inaccuracy with life histories as the nature of the interview relies on the accuracy of the participant as well on their openness and honesty. The process of the interviews was long[18] and time was spent with each participant over a number of days to create a relationship with my participants and, as such, I believe that I was able to glean information that was true and honest. In most instances it was possible to correlate some of the information garnered through the life history interviews with information from other participants, (for example, a nurse or social worker who worked with my participant), to check for accuracy. In total, ten life histories were carried out with five female and five male research participants.

Through the use of a combination of these methods I was able to compare and contrast information I received from my various participants during the informal and unstructured interviews with the information gleaned through the more detailed semi-structured interviews and the life histories, in the absence of participant observation.

[18] Each interview session lasted between 1 to 2 hours depending on how my informant was feeling and when they decided to stop.

This cross referencing of information assisted with ensuring the reliability and validity of data collected (Barnard, 2006; Neumann, 2014).

1.7 Problems Experienced: Prior To Entry and Once in The Field

My study began with the registration of my PhD in Anthropology in late 2013, however, the road to meeting relevant participants was long and taxing. I had anticipated, at the outset, that entering this particular field of study would be difficult. This proved so in trying to find a research site where I would be permitted access to participants for my research. Early talks with fellow academics, organisations, family and friends encouraged my research idea and the importance of and need for it. This, however, did not lead to easy access to participants and those involved with Muslims living with HIV expressed the extreme difficulty I would face in gaining access to participants.

I contacted faith-based NGOs that are Muslim run and who, on their websites, stated that they offer services to HIV-positive individuals (regardless of faith), however, I was informed that they had not worked with Muslims living with HIV. I tapped into personal contacts and spoke to a family friend actively involved in community affairs and found that she works directly with Muslims living with HIV. She immediately told me that I should give up because no one would talk about being HIV positive because there is "*just too much stigma around it*". This did not put me off as I was determined to delve into this world and learn about HIV and AIDS amongst Muslims in Durban. I contacted government hospitals and received a positive response from one, however, there was no guarantee that there would be HIV positive Muslims (although the hospital is located in an area with a large Muslim population) attending the clinic. Obtaining permission from the Department of Health would also have been a lengthy process that I was unsure I had time for.

I sent out numerous emails, made phone calls and physically went to organisations that I was directed to, or had found information about online, and met a dead-end each time. During this time, I constructed a full proposal for my study, as per university requirements, however, I had to have a gatekeeper's letter in order to proceed with obtaining ethical clearance. This proved so difficult that I was set back by a year before I was able to receive some form of go-ahead from an organisation. I finally received

my ethical clearance in mid-2015 and I was able to begin my search anew. The person I had contacted initially, who was to be my gatekeeper at the hospital she worked at, retracted her assistance for my study. I was not given a reason but this meant that I had to begin my search for an organisation and/or for participants again. I was on the verge of giving up with my project at this stage as I only had one participant whom a close friend had put me in touch with. After much door knocking at various Muslim non-governmental organisations in Durban, I was put in contact with a former medical nurse who currently works at an NGO and she offered her assistance. Through the NGO I was able to access a sample population for my study, and my participants were able to refer me to other contacts, and so my pool of participants increased.

Whilst these difficulties had been expected I had not anticipated the difficulty that would come with trying to access caregivers of Muslims living with HIV. Through my family friend I was able to contact a number of people, mainly female, who work in various capacities with Muslims living with HIV. During informal interviews some people were forthcoming, however, a significant number stated openly that they were not willing to speak about the care they provide for fear of being stigmatised by their family and communities, even with the promise of complete anonymity and confidentiality. As noted, some participants refused to have their interviews recorded for fear that the recording would be found, and their voices recognised. This made me realise that the stigma within the Muslim community in Durban affects more than just Muslims living with HIV and that it extends to anyone linked by association.

1.8 Moral And Ethical Considerations

The Anthropology Southern Africa (2005) Ethical Guidelines provide an outline of the expectations, roles, and responsibilities of anthropologists in the field. At the outset of the study, which was self-funded, I was aware that this is a sensitive subject, involving vulnerable people, and that the utmost care would need to be taken to ensure that my participants' identities were kept private. This was achieved through the use of pseudonyms, in order to ensure anonymity and confidentiality for my interlocutors. Other than stating the city that my participants reside in, no other information relating to place has been identified. HIV+ Muslims are a vulnerable group of people and I took care to ensure that I treated my interlocutors with the utmost respect at all times. All

of my participants in the study were provided with an informed consent form which explained the nature of the research, and all were asked for their permission to take part in the study and to have their interview recorded. Some participants opted not to have their interviews recorded and I abided by their wishes, and simply took notes as we spoke.

My research participants were also informed that they may withdraw from the interview at any time and that they were free to decline answering any question that they were not comfortable with. In instances where a research participant mentioned another person or child in an interview, a pseudonym has also been provided to ensure the respect and privacy of the respective parties. I explained to my participants my reasons for wanting to interview them and the purpose of my research, and that ultimately my work would be published in the form of a thesis for a Doctoral degree, and that there would be subsequent journal publications based on the study as well. Whilst my participants needed their privacy, which was achieved, as mentioned, through the use of pseudonyms, they were also excited to have their stories told. In this way, being part of the study was cathartic for my participants because it provided them with a chance to speak openly about their experiences without fear of judgement. In all aspects of my research process I maintained openness and transparency with those who were involved, and I tried my best to uphold the reputation and dignity of my discipline and profession through my practice.

1.9 Structure of The Thesis

Chapter One: Introduction to the Study

Chapter One introduces the study. It includes the background, the study rationale, the research problem, the study aims and objectives, the key research questions, the research methods and the structure of the thesis.

Chapter Two: Literature Review and Theoretical Framework

Chapter Two begins with a review of relevant literature surrounding Muslims living with HIV. Every endeavour to include the most current anthropological studies on HIV and AIDS and Muslims, both globally and locally, has been taken. The theoretical and conceptual frameworks that have been applied to the ethnographic data are briefly introduced in the second half of this chapter, however, more detail on these frameworks is provided in the relevant chapters that follow.

Chapter Three: Islamic Religion and Muslim Culture as a Mechanism for Protection Against HIV and AIDS

Chapter Three aims to introduce the reader to the key tenets of Islam and how these tenets guide the manner in which Muslims navigate day-to-day life and especially sickness. The chapter provides contextual information concerning Muslims in South Africa and explores the various Muslim responses to HIV and AIDS.

Chapter Four: Participant Information: MLWHIV, Healthcare Professionals, Caregivers, and Imams

Chapter Four introduces my research participants according to their groups. My key interlocutors, Muslims Living with HIV, are introduced first. They are followed by healthcare professionals, caregivers, and Imams.

Chapter Five: Explanatory Models of HIV and AIDS: The Muslim Perspective

Chapter Five provides a description of how HIV and AIDS is understood and experienced by Muslims in Durban and the various practices that are engaged with as forms of treatment for HIV and AIDS. The chapter explores the ethnography through the application of the concept of explanatory model as a conceptual framework.

Chapter Six: Purity and Danger as a Framework for Understanding HIV and AIDS in The Muslim Community in Durban

Chapter Six draws on the work of Mary Douglas (1966), specifically her work on purity and danger and links this to understandings and experiences of Muslims living with HIV in Durban, South Africa.

Chapter Seven: Social Stigma and The Spoiled Identities of Muslims Living with HIV in Durban

Chapter Seven centres around the presence and application of stigma and discrimination in relation to Muslims living with HIV in Durban. The chapter explores the ways in which HIV+ Muslims are stigmatised and discriminated against in their community and how they navigate the stigma. The ethnographic information is framed upon Goffman's (1963) notion of the spoiled identity.

Chapter Eight: HIV and AIDS, Social Death, and Muslims in Durban

Chapter Eight brings the reader to the culmination of lines drawn from purity and danger, through stigma and spoiled identity and finally ends with the social death experienced by HIV+ Muslims. The concept of social vitality is also explored through the formation of a new community via support groups and the activism that can stem from the experiences of Muslims living with HIV in Durban, South Africa.

Chapter Nine: Conclusion and Recommendations

Chapter Nine rounds off the dissertation by concluding the preceding discussions and draws the inter-related components of the dissertation together. Through the study certain recommendations become apparent and these are explored in this chapter.

CHAPTER TWO: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 Literature Review

2.1.1 Anthropological Contributions to the Study of HIV and AIDS

Since the 1980s anthropology has made major contributions to the study of HIV and AIDS worldwide. Ramin (2007) splits the anthropological camp into two schools of thought[19], namely, what he terms, traditional anthropologists and political economy anthropologists. According to Ramin (2007), the 'traditional' anthropologists believe that their role is to provide a socio-cultural perspective to build onto epidemiological and biomedical knowledge of HIV and AIDS, while the political economy anthropologists, Ramin (2007) maintains, advocate that the primary factor in understanding HIV and AIDS is not anthropology's unique perspective of society, but the political and economic systems at play that influence behaviour of individuals. Paul Farmer (2010) has been a major contributor in this regard and has written extensively on the concept of structural violence in the arena of HIV and AIDS, stating that societal structures, (e.g., racism, sexism, and inequality), are what directly and indirectly harm individuals. Political economy anthropologists have provided a significantly important perspective to understanding HIV and AIDS and specifically the broader structural forces at play, however, they have not capitalised on the advantageousness of 'traditional' anthropology's comparative method and have thus risked ignoring the importance of understanding the local cultural context.

In contributing to the study of HIV and AIDS, anthropologists have been involved in international healthcare programmes. Manderson (1998) asserted that the involvement of anthropology in the discourse on HIV and AIDS has ensured that local knowledge, structural barriers to health, and cultural influences on patterns of illness have been accounted for, to some extent. Ramin (2007) identified three phases of anthropological research into HIV/AIDS in Africa since the beginning of the epidemic. The first phase, the Handmaiden Phase, found anthropologists supporting biomedical research without challenging the traditional public health approach (Ackeroyd, 1997;

[19] Ramin (2007: 127) acknowledges that these are not true classifications in anthropology and is rather attempting to represent a "stylised representation of two dissimilar approaches to anthropological understandings of HIV/AIDS".

Bond and Vincent, 1997). The focus at the time was heavily on biomedical and individualistic explanations of HIV and AIDS. The second phase, the Cultural Experts phase, involved a shift towards understanding the epidemic in a broader socio-cultural context and it was recognised that social, structural, and cultural factors played a significant role in shaping the risk of infection (Parker, 2001; Schoepf, 2001). The focus, during this phase, was on interpreting cultural meanings of sickness and designing prevention programmes that were culturally appropriate (Parker, 2001; Schoepf, 2001). Phase Three, the Political Economist Phase, saw anthropologists exploring the links between socio-cultural processes and the global political economy (Farmer, 1996; Farmer, 1999; Castro and Farmer, 2005; Farmer, 2010). During this phase, there was a growing emphasis on how structural forces, for example, racism, sexism, political violence, and inequality, contribute to the transmission of HIV. The gendered aspect of HIV transmission is argued, for example, to stem from women's vulnerability to infection due to their low socio-economic status, which places them in positions of vulnerability as they try to survive economically by exchanging sexual favours for financial security (Castro and Farmer, 2005; Farmer, 2010). Structural violence, therefore, was proposed as a conceptual framework to understand the epidemic (Smith, 2003; Castro and Farmer, 2005; Farmer, 2010) as political economy anthropologists argued that societies are shaped by large-scale social forces which are rooted in historical and economic processes, which define structural violence and influence the distribution and outcome of HIV and AIDS transmissions (Ramin, 2007; Farmer, 2010). In this respect, poverty has been described as a critical factor in the transmission of infectious disease (Farmer, 2010). Anthropologists like Farmer (1996; 1999; 2010) believe that linking structural forces like poverty to HIV and AIDS is crucial for intervention, prevention, and treatment strategies and, as such, poverty reduction came to be emphasised by political economy anthropologists as a prominent means to reduce disease transmission.

In the early stages of the epidemic, including the 1990s, non-anthropological literature on HIV and AIDS made generalisations about 'African' sexuality which were Eurocentric in nature as these understandings were based on marriage patterns in Europe (Schoepf, 1993; 2001). The focus was hinged on the differences of polygamy in African societies and monogamy as practiced by most Europeans. This led to the suggestion that the epidemic was linked to multiple sexual partners (Schoepf, 2001).

Anthropological research into the link between sexuality and HIV and AIDS revealed that the construction of sexual realities is complex and is not always determined by individual agency (Campbell, 1997; 2000; Schoepf, 1997; MacPhail and Campbell, 2001; Selikow et al, 2002; Leclerc-Madlala, 2003; Gilbert, 2016). Rather, sexual realities are influenced by a range of structural factors beyond individual agency, shaped by socio, political, economic, and religious forces, among others (Farmer, 2010). Anthropological research highlighted the crucial role of political and economic structures in influencing the dynamics around the spread of HIV and AIDS and has been instrumental in reshaping the understanding of populations are risk from HIV and AIDS (Ramin, 2007; Leclerc-Madlala, 2008; Selikow et al, 2009; Farmer, 2010; Gilbert, 2016; Stadler, 2021).

In addition to studying the links between sexuality and HIV and AIDS, anthropologists have contributed greatly to the understanding of what it means to be 'high-risk' and have redefined the concept of 'risk group' (Ramin, 2007). Mainstream public health discourse identified certain groups of people to be at risk for contracting the disease, namely, sex workers, migrants, drug users, and truck drivers, however, this labelling resulted in blame being placed directly at their door (Seidel, 1993; McGrath, 1993; O'Neil, 2004; WHO, 2004; Ramin, 2007; Farmer, 2010; Gilbert, 2016). Anthropologists stressed that essentialist understandings of risk are problematic, that there are no empirically bounded risk groups and that it is unprotected sex, rather than specific groups and types of relationships, that places individuals at risk (Ramin, 2007; Farmer, 2010). Anthropologists worked toward highlighting the poor definitions and stigmatisation associated with categorisations and shifted the discourse towards concepts such as 'vulnerable groups' and 'risky behaviour' (O'Neil, 2004; WHO, 2004; Ramin, 2007; Farmer, 2010; Gilbert, 2016). This shift in discourse highlighted the notion that everyone is susceptible to infection.

Anthropology, both 'traditional' and political economic anthropologists, has contributed significantly to understanding the gender dimensions of the epidemic (Ramin, 2007). In the past, women were traditionally blamed for the spread of HIV, in particular sex workers, and this led to stigmatisation and blame (O'Neil, 2004; Leclerc-Madlala, 2008; Selikow et al, 2009; Gilbert, 2016). Anthropological studies revealed that, in general, women have limited power in sexual negotiations with men, making them

relatively powerless and vulnerable to being in 'risky' situations (MacPhail and Campbell, 2001; Leclerc-Madlala, 2003; Hunter, 2010; Henderson, 2011; McNeil, 2011; Gilbert, 2016). Cultural assumptions about gender relations and the subordinate status of women contribute to the sexual abuse and vulnerability faced by women. The structural violence approach (see Farmer, 2010) has made significant impact on studying the link between gender and HIV and AIDS. By understanding the deep vulnerabilities of women due to economic, social, political, and religious factors and the need of support for their survival it can be seen how these factors aid in the spread of HIV and AIDS. Anthropologists have advocated for the empowerment of women, and reducing poverty and women's dependence on men can have long lasting positive effects on the reduction of the transmission of the disease (Beshemera et al, 2013; Anugwom and Anugwom, 2016; Gilbert, 2016).

In light of the above information, the most significant contribution that anthropology has provided is the importance of non-reductionist and essentialist understandings of HIV and AIDS. Anthropologists have promoted the cruciality of promoting culturally appropriate awareness and education campaigns and understanding that behavioural change does not benefit from a one-size fits all intervention approach (Ramin, 2007; Selikow et al, 2009). Anthropologists have shown that cultural determinants strongly influence health behaviours and can serve as barriers to behaviour change and that being knowledgeable about the biomedical aspects of HIV and AIDS does not automatically translate into behavioural change (MacPhail and Campbell, 2001; Leclerc-Madlala, 2008; Selikow et al, 2009; Farmer, 2010; Kamarulzaman, 2013; McNeill, 2011; Gilbert, 2016; Neihaus, 2018). Anthropologists have further explained that merely making condoms accessible does not equate to condom usage. Condom use, in particular, has faced numerous socio-cultural, economic, political, and religious barriers. Attitudes toward condom use vary widely, ranging from cultural arguments against condom use as being non-African or as promoting promiscuity in religious arguments, to beliefs that condoms are harmful and hinder social interaction (MacPhail and Campbell, 2001; Selikow et al, 2002; Leclerc-Madlala, 2003; Hasnain, 2005; McNeill, 2011; Gilbert, 2016; Niehaus, 2018). Behavioural change strategies must engage with local cultural understandings and structural factors which shape individual behaviours.

Anthropology has a long history of engagement with the socio-cultural, economic, and political forces that surround the discourse on HIV and AIDS and the contributions to healthcare initiatives have been important in creating public awareness about the disease and programmes which work toward the reduction of HIV and AIDS around the world.

2.1.2 Anthropology, AIDS, and South Africa

As noted in Chapter One, literature on HIV and AIDS in South Africa has focused primarily on the black majority, primarily in relation to mine workers, sex workers, the youth, and the rise of the 'sugar daddy' phenomenon (Foster, 1996; Heywood, 1996; Campbell, 1997, 2000, 2003; MacPhail and Campbell, 2001; Selikow et al 2002; Selikow et al, 2009; Leclerc-Madlala, 2003, 2008).

Studies have shown that pushing public health education on HIV and AIDS has not had any meaningful measurement of success in reducing the rates of transmission of HIV in South Africa (Campbell, 2003; LeClerc-Madlala, 2008; Selikow et al, 2009). Stadler (2021), for example, from his research in Bushbuckridge, challenged the homogenising discourses present in public health and biomedicine and argues that socio-cultural discourses must be included in education programmes. Similarly, Henderson (2011) explored the strained relationship between biomedical discourse and practices and local healing traditions in Okhahlamba in KwaZulu-Natal and argues, exploring the equal place that both have to play in society, that the modern and traditional need to reconcile. Similarly, Hunter (2010) argues that prevention and treatment programmes by biomedical practitioners could be improved if there was better understanding of the meanings of love, sexual practices, and sexual identities and how these intersect at the local level. As a point of reference, Hunter (2010) points out that condoms tend to be used with secondary or more casual sexual partners, while with the main lover (where the possibility of marriage may lie) there is no condom use (Campbell, 1997; Selikow et al, 2009). Free access to condoms as a strategy commonly promoted by public health is therefore not like translate into uptake when the underlying subtleties of relationships inter-woven with the structural forces of society are ignored. Mark Hunter (2010), from his data collected in Mandini in 2006, explored gender and intimacy and how these complex concepts are important in understanding the spread HIV and AIDS in South Africa. In his ethnographic works,

Hunter (2010) states that love and intimacy in relation to HIV and AIDS have historically been left out of the discourse yet this impacts notably upon behaviour and prevention.

McNeill (2011) investigated the silence surrounding HIV and AIDS amongst the Venda people of South Africa, the associated stigma, and the perceived absence of a lack of behavioural change. One of the arguments put forward by biomedical scientists and epidemiologists is that the lack of behavioural change is a result of a lack of biomedical knowledge about the disease and its transmission (KFF, 2008). McNeill (2011), based on his research, argued that this is not the case and expressed that the reason for the lack of success in relation to behavioural change is due to cultural frameworks and practices of a community and their interpretation and reception of information. One example provided by McNeill (2011) is that when engaging in casual sex encounters men will use condoms, however, condoms are not believed to be necessary in long-term partnerships or marriages. McNeill (2011) argued that the community holds the relevant biomedical knowledge, however, speaking openly about HIV and AIDS is stigmatised because it is believed that if one shows that they hold the relevant knowledge about the disease then one must be infected. Silence surrounding the disease then acts as a protective mechanism against stigma. Songs that are directly about HIV and AIDS, condoms, ARTs, prevention and the vectors of HIV and AIDS are frequently met with violent opposition because of the belief that to have such knowledge one must know the disease intimately, i.e., have first-hand experience and must be HIV+. McNeill (2011) explained that females in the area face much of the associated stigma and that female peer educators who speak openly about the disease, as an important aspect of their job, are stigmatised. That said, NGO's recruit female volunteers who are or have been sex workers and often are infected with HIV, which speaks to the notion that those who have extensive knowledge of the disease are HIV+ (McNeill, 2011).

Whilst condoms are promoted by public health as a means to prevent transmission of the disease, anthropological research indicates that the belief in some communities stands in strong opposition to this measure as many people regard condoms as a way to transmit the disease (McNeill, 2011; Stadler, 2021). Stadler (2021) provides an example of young boys, from KwaBomba, who told him about worms that would

appear in condoms which meant that HIV was present in the condom. The proof for this was in an experiment whereby the condom was filled with water and placed in sunlight and subsequently ‘worms’ would appear in the water in the condom (Stadler, 2021). This belief tied in with the notion that black people were being purposefully infected with HIV (Stadler, 2021) resulting in negative consequences for peer educators who were working in the arena of prevention. This results in silence as a response and, quite possibly, as an aversion to biomedical knowledge so as to avoid stigmatisation. The concealment of HIV and AIDS is linked to the reduction of exposure to what is considered dangerous knowledge (Stadler, 2021).

In relation to music, McNeill (2011) juxtaposes guitar-playing minstrels (male) to peer educators (female) and states that the minstrels' songs are valued and given more social esteem because they are connected to ancestral authority. There is a strong gendered component that comes through in McNeill’s (2011) work as he describes the songs by the minstrels placing the blame on young women who act against the community’s cultural traditions, laws, and moral values. These acts include the use of contraception (for example condom use, which as has been mentioned is believed to transmit the disease), and having abortions (McNeill, 2011). In addition to this, menstrual blood is considered polluted, and HIV is transmitted in this ‘dirty blood’ from women to men during intercourse (McNeill, 2011). McNeill’s (2011) work also adds to the notion that black women are more vulnerable to infection because of their socio-economic status and reliance on men. Sexual relationships between men and women, in certain contexts, include a strong material component and it is a way for unmarried women to achieve some sense of financial income and in some instances stability (Campbell, 1997; LeClerc-Madlala, 2003, 2008; Hunter, 2010; McNeill, 2011; Niehaus, 2018). Masculine identities on the other hand reflect that respect is linked to multiple sexual partners, conspicuous consumption and the ability to provide for their sexual partners (Hunter, 2010; Niehaus, 2018). In attempting to gain economic freedom, women become peer educators, however, they are then stigmatised because of the knowledge they hold of the disease which, in turn, affects their ability to work and adds to their vulnerability. McNeill’s (2011: 236) work reflects the importance of intersectionality as he argues that “the politics of tradition; an anthropological approach to knowledge; and health-related interventionism” must be engaged with in

tandem. This sentiment is echoed by other anthropologists (Hunter, 2010; Niehaus, 2018; Stadler, 2021).

Stadler (2021) argues that South Africa's history of colonialism and apartheid created structural, spatial, and systemic violence in African communities and biomedical regimes were placed at odds with traditional healing practices (Hunter, 2010). The segregation, forced migration, migrant labour, breakdown of the black family and gender norms that were caused by colonisation and enforced further by apartheid laws created the perfect situation for the rapid spread of HIV and AIDS amongst black communities in South Africa (Stadler, 2021). In the Bushbuckridge area, Stadler (2021) explores the socio-cultural beliefs that people hold in relation to HIV and AIDS and argues that these challenge biomedical and public health discourses. He explores the complex understandings of the disease which encompasses suffering, grief, misfortune, jealousy, morality, and witchcraft. In all this, however, Stadler (2021) has shown that people have resilience and agency and find ways to support each other. Anthropological research also indicates that witchcraft has featured prominently in understandings of HIV and AIDS in South Africa with research documenting beliefs that PLWHIV have been cursed by enemies or people who are jealous of them (LeClerc-Madlala, 2003, 2008; Selikow et al, 2009; Stadler, 2021). HIV and AIDS in South Africa is typically a disease that is shrouded in secrecy (Niehaus, 2018; Stadler, 2021). Witchcraft is practiced in secret and has been blamed for the transmission of HIV and AIDS in certain communities (LeClerc-Madlala, 2003; Stadler, 2021). Witchcraft is used as a way to understand and explain illness and misfortune and as a result it lends to understanding the immense suffering that HIV and AIDS has caused in peoples' lives (Stadler, 2021). Rumour and gossip have also played a role in how the disease is spoken of because they allow for secrecy and for local frames of reference to be utilised to talk about the disease and understand it (Stadler, 2021). Rumour can be used negatively to accuse someone of being HIV+ or positively to provide information on the disease in a manner that is locally acceptable.

Klaits (2010), McNeill (2010), Niehaus (2018), and Stadler (2021) also bring to the fore that whilst there is suffering and pain there is also care, love, and attention that is part of the HIV and AIDS discourse which cannot be ignored. The community bonds of caring have a place in caregiving for PLWHIV and communities pay attention to how

people live and what they need (Henderson, 2011). Niehaus (2018) explains that even though there is stigma, family members will try to assist their loved one in whatever way they can. HIV and AIDS is a complex social and biological disease, and the authors express the importance of understanding the socio-cultural beliefs that surround sickness and disease in different communities and how these beliefs affect prevention, treatment and quality of life.

2.1.3 HIV and AIDS in the Muslim World

UNAIDS (2021b) states that there are 37.7 million people living with HIV worldwide. Of this number, there are currently 25.4 million people on treatment and new infections have reduced by 23% in the last decade (UNAIDS, 2020). In eastern and southern Africa there has been a marked decline in prevalence (43%), however, it has been noted that there has been a severe increase in prevalence in the Middle East and in the North Africa (MENA) region where there has been a growth of 7% and the figure is rising (UNAIDS, 2021b). Kamarulzaman (2013) noted an increase in incidence rates of 25% (since 2001) in the region, most specifically in five countries which have a predominantly Muslim population, namely, Bangladesh, Indonesia, Guinea-Bissau, Kazakhstan and Kyrgyzstan. In addition to this, Kamarulzaman (2013) stated that there was a 35% increase in the number of newly infected people in the MENA region. Statistics provided by UNAIDS (2020) reflect that there has not been much change since Kamarulzaman's study. UNAIDS places the incidence-prevalence ratio at 8.2% which illustrates that the disease is not under control in the MENA region.

Cochrane and Nawab (2012) estimated that in 2012 there were 1.5 billion Muslims worldwide. In 2013 Ahmed (2013) pointed out that, at this stage, there was no complete data set that could aid in the study of incidence, spread, or mortality of HIV and AIDS amongst Muslims. Recent statistics have put the number of Muslims worldwide at 1.9 billion people, making up 24.7% of the world's population yet, despite this, there is still a dearth of qualitative literature with respect to Muslims and HIV and AIDS (Countrymeters, ND). A prominent reason cited for the lack of studies in relation to HIV and AIDS amongst Muslims is that HIV and AIDS was not prevalent in Muslim regions and communities around the world in the early 2000s (Desai, 2004; Hasnain, 2005; Todd et al, 2007; Ahmed, 2013; Mahomed and Laher, 2015). Hasnain (2005), Esack and Chiddy (2009) state instead that the lack of statistics and literature in the

past has often been due to the stigma and denial that surrounds HIV and AIDS and the beliefs that a ‘good’ Muslim should not engage in premarital sex, extramarital affairs, homosexuality nor imbibe intoxicants of any form. Stigma and denial, Esack and Chiddy (2009) therefore maintain, played a pivotal role in Muslims being under-represented in studies on HIV and AIDS. Whatever the case, Muslims have, until recently, been largely absent from the literature on HIV and AIDS.

Recent studies, however, suggest that new infections in the MENA region, occur predominantly among men, with the main causes cited being intravenous drug use (IVDUs) and men who have sex with men (UNAIDS, 2020). Furthermore, women are noted as being particularly vulnerable to infection and as having limited access to basic services (UNAIDS, 2002). A collaborative study by LEARN MENA in 2018 brought together researchers from multiple countries in the MENA region and it was reported that stigma, discrimination, and violence against women are the main factors that place women at risk of infection (LEARN MENA, 2018). An estimated 46% of women surveyed stated that “violence or fear of violence” affected their ability to protect themselves from HIV and AIDS and additionally, impacted their ability to manage their HIV status if infected (UNAIDS, 2020: 293).

Despite the increasing incidence and prevalence rates, the MENA region remained an understudied area in the first decades of HIV and ADS research. The region has, however, become a focal point for HIV and AIDS research in recent years considering that just a decade ago literature on HIV and AIDS in predominantly Muslim regions and countries was markedly scant. At the time of doing my initial research and writing my proposal for this PhD it was difficult to find any literature on HIV and Muslims. The political turmoil and subsequent economic and socio-cultural upheaval that has taken place in the MENA region has, however, allowed researchers access to a previously understudied and underrepresented group of people. The increase in refugees and refugee camps has led to non-governmental organisations (NGOs) and other organisations offering their assistance and, subsequently, it has become possible to research the nature and scope of HIV and AIDS. Whilst this is important, it is also crucial to understand the nuances and experiences of people in relation to HIV and AIDS from a qualitative perspective. While literature has become available in MENA and in the predominantly Muslim regions of Asia, namely, Pakistan, Malaysia and

Indonesia, much of the literature has been quantitative. In recent years a number of qualitative studies have begun to emerge, yet many of these do not focus directly on the experiences of HIV+ Muslims, but rather, tend to focus on how HIV+ Muslims are perceived by other groups, for example biomedical healthcare professionals and how such perceptions affect treatment and care (Lawless et al, 1996; Todd et al, 2007; Alavi-Naini, 2012; Bocci, 2013; Kamarulzaman, 2013; Labra and Thomas, 2017; Yuvaraj et al, 2020; Attum et al, 2021; Oraby, 2021).

In Africa, HIV and AIDS literature tends to focus on black Africans, on sex workers, migrant labourers, and on people with low socio-economic status (Dekker, 2015). While such research is pivotal, it is important to understand the implications of this narrative as the limited (and somewhat skewed) research focus has meant that other groups remain outside of the radar with low reporting and limited research focus. As Mabaso et al (2019) state, this results in intervention and treatment not reaching underreported groups, such as South African Muslims, because of a lack of awareness.

In colonial Africa, Dekker (2015) explains, officials blamed African 'traditional cultures' for what colonial officials considered to be the existence of 'social problems', namely, homosexuality, premarital sex, and female promiscuity. Dekker (2015) notes that Muslims similarly stigmatise the above behaviours, but associate them with colonisation, westernisation, and modernisation. Dekker (2015) and Rhine (2015) argue that westernisation and modernisation in African countries resulted in changes in cultural conceptions of life and marriage which led to new types of romantic partnerships and expressions of love in the twentieth century. Sex, in Islam, is a "powerful secret" and secrecy is strongly featured in HIV and AIDS discourse (Dekker, 2019: 4). Dekker's (2015) study, conducted in Nigeria, focuses on the secrecy around HIV diagnoses and the declaration of one's status among Muslims which, Dekker (2015) asserts, leads to many questions being asked of the HIV+ Muslim. Dekker (2015) and Rhine's (2015; 2016) work reinforces the reasons for non-disclosure of HIV+ status among Muslims as being linked to fear of stigmatisation and ostracization due to the strong negative connotations attached to so-called 'risky' behaviours. As a result, Dekker (2015) emphasises the importance of research in understanding concepts of sex and love in Islam, as these concepts tend to inform sexuality and

sexual practices and ideas around intimacy which, Dekker (2015) argues, are important when facilitating intervention and prevention programmes.

Rhine (2015), in one of the few studies produced from the perspective of an HIV+ Muslim, explores the role of transactional sex between young females and older males as a key driver of HIV transmission amongst Muslims in Northern Nigeria. When these young women eventually go on to marry, Rhine (2015) asserts that it is common for them to infect their husbands. Rhine (2015) cites socio-politico and economic shifts as key influencing factors for shifting courtship practices, sex and marriage norms, rather than intentional violations of Islamic religious principles. It is common, Rhine (2015) notes, for men in Nigeria to be unaware of the HIV status of their girlfriends or casual sexual partners. Men, Rhine (2015 and 2016) asserts, also tend to have multiple partners whom they provide gifts to in exchange for sexual favours. Rhine argues that this is a "public secret" and it is believed that this is a naturally acceptable occurrence because men lack the ability "to control their sexual impulses" (Rhine, 2015: 92). Building on the works of Staler (2003) and Butt (2005), Rhine (2015) describes situations in which HIV+ Muslim women hide their status and seduce men, knowingly infecting these men, as a form of revenge for how society has treated women. Rhine (2015) further explains that it is relatively common practice that if a woman's parents suspect that she has been, or is, sexually active prior to marriage, that they take her for an HIV test. If the woman tests positive for HIV, her parents are very likely to disown her, which leaves the woman homeless and destitute. The solution to this, Rhine (2015) explains, is for the woman to look for a man or men (without disclosing her HIV+ status) who will be able to provide economic assistance for her in the short term through engaging in transactional sex, or the long-term, through marriage. Women, in many parts of Africa, have limited socio-economic power and rely on men to provide for them economically, thereby making them susceptible to HIV infection (Campbell, 2000; Leclerc-Madlala, 2003; El Feki, 2012; Haghnavaz, 2014; Lynch and Brand, 2017).

Studies in Muslim parts of Africa further illustrate that when it comes to treatment, there is a hindrance to adherence as a result of faith-based healers (Beckmann, 2013; Rhine, 2016; Tocco, 2017). Tocco (2017) explains that Islamic Prophetic medicine was common as treatment for health and well-being prior to the introduction of western

biomedicine, anti-retroviral therapy (ARTs) and public health measures. Tocco (2010 and 2017) and Dilger et al (2016) have written about the *malamai*[20], who insist that they are able to facilitate the curing of an HIV+ person. The *malamai* have been responsible for spreading misinformation, for instance that they can cure HIV and AIDS, that HIV+ Muslims do not need to rely on biomedical treatments (i.e. ART) and that HIV+ Muslims should rely on the *malamai's* herbal treatment which, they argue, would serve the HIV+ Muslim patient better (Dilger et al ,2016; Tocco, 2017). This, Dilger et al (2016) and Tocco (2017) note is extremely dangerous and has resulted in the health of many formerly healthy patients deteriorating to the point where the patient has full-blown AIDS. Tocco (2017) explains that the *malamai* rely on receiving an income through consultations and as the introduction of biomedical treatments reduces their chances of earning, they spread misinformation in order to retain their client base. The argument that the *malamai* use to insist that there is a cure for HIV and AIDS is a *hadith*[21] which states "There is no disease that Allah has created, except that He also has created its treatment" (Sahih Bukhari, 1966). According to Tocco (2017) and Musharraf and Arman (2018) this is taken to mean that under Islamic discourse on disease, HIV is a disease which can be cured, as opposed to the biomedical model which states HIV is a chronic disease requiring lifelong adherence to treatment.

Other literature from Dilger et al (2016), Tocco (2010; 2017) and Musharraf and Arman (2018) indicates how religious practices also deter adherence to ART. The authors' works reflect that HIV+ Muslims, in various parts of Western and Northern Africa, have a strong desire to fast during the month of *Ramadan*[22] and this negatively impacts their ART intake. Medication needs to be taken at specific intervals, and with fasting hours sometimes being longer than twelve hours, this means that HIV+ Muslims find it difficult to fast and adhere to their medication regimes. Fasting in the month of Ramadan is one of the five pillars of Islam and the spiritual reward during this month is considered to be immense. HIV+ Muslims, Tocco (2017) explains, do not want to lose out on the spiritual rewards (especially that of forgiveness) that are possible

[20] The malam (singular) or malamai (plural) are scholars who are trained in Prophetic healing.
[21] Hadith are a collection of authenticated sayings by the Prophet Muhammad (Peace Be Upon Him).
[22] Ramadan is considered to be one of the most spiritual months in the Islamic calendar. It is the ninth month of the Islamic calendar and is spent in abstinence of food and drink for 29 or 30 days, from dawn until dusk each day.

during this time. When fasting, Muslims refrain from ingesting food and water from dawn until dusk. A sick person is under no obligation to fast, however, when a Muslim is found to not observe the fast, the individual is often questioned by other Muslims, which then raises suspicion as to why the Muslim is not fasting. In trying to maintain secrecy and privacy in terms of their HIV+ status, Tocco (2017) notes, Muslims may pretend to fast which means that they are not eating or drinking if they are in front of others which may be for lengthy periods of time. As such, Tocco (2017: 78) argues that "patient's 'local moral worlds' extend beyond and may inhibit treatment adherence", as social concerns and the desire for normalcy overshadow biomedical expectations of adherence to treatment.

Research in relation to HIV+ Muslims in west and north Africa has focused on two broad categories which include (1) how Islamic tenets (such as male circumcision, prohibitions of substances such as alcohol and drugs, and prohibition of pre-and extra-marital sex) and social practices affect the transmission of HIV in Muslim communities, and (2) the manner in which Islamic tenets such as fasting and pilgrimage affect adherence to ART (Habib et al, 2009; Tocco, 2010; Yakasai et al, 2011; Tocco, 2017; Musharraf and Arman, 2018).

Hasnain (2005) states that social stigma that is often closely linked to HIV and AIDS is deeply entrenched in Muslim societies and HIV+ Muslims tend to be rejected and shunned by both their family and community. According to Kamarulzaman (2013) and Ahmed (2013) ideas about the contraction of HIV as being associated with promiscuity and drug usage has led to the heavily stigmatised nature of HIV and AIDS in the Muslim context. HIV and AIDS has been posited as a punishment from *Allah*[23] or as God's wrath on the promiscuous and unfaithful (Badri, 2008; West, 2011; Alavi-Naini, 2012; Bocci, 2013). Hasnain (2005) further points out that the response of policy makers to HIV and AIDS in Muslim countries has focused primarily on individuals abstaining from sexual practices prior to and outside of marriage as well as on drug usage. This is linked to the theology of retribution where the belief is that if a person has acted in a way deemed to be wrong or immoral and has strayed from their religious path, then the blame of contracting a disease such as HIV is placed squarely on the individual (Esack and Chiddy, 2009; Siddiquee, 2009; West, 2011). Siddiquee (2009:

[23] God.

59), for example, refers to the notion that HIV and AIDS is divine retribution "brought upon those who have sexually transgressed" and how it is attributed to a particular *hadith*, but only in partiality. The problem is that the *hadith* in question is a five-part verse and when one part is read alone it lacks important context and the meaning changes drastically. It is also not a particularly authoritative *hadith* and yet it is heavily cited in Muslim discourse on HIV and AIDS. Siddiquee (2009) problematises the notion of divine or collective punishment and brings up an important point in this regard; she questions why the so-called 'innocent' are punished for the wrongdoings of others. Siddiquee (2009) notes that it is due to this stigma that those who are at risk are prevented from seeking assistance in the form of counselling and testing as well as treatment because this would involve the individual having to disclose 'risky' or what Hasnain (2005), Cochrane and Nawab (2012) and Kamarulzaman (2013) refer to as 'immoral' behaviours.

Hasnain (2005) further states that changing the behaviour and lifestyles of individuals is necessary to break the chain of transmission and to contain the HIV and AIDS epidemic. Hasnain (2005: 1) specifically notes that "the disease is therefore largely avoidable by changes in personal behaviour, in other words by voluntary choice. Containment of the AIDS epidemic thus depends on effecting change in behaviour and lifestyle to break the chain of transmission". According to Hasnain (2005) and Todd et al (2007) it is important to take into consideration the social and cultural variables in Muslim societies that affect so-called 'risky behaviour' as these variables are crucial to an in-depth understanding of the epidemic in Muslim societies. The Asia-Europe Institute (AEI) Newsletter (2005), Hasnain (2005) and Todd et al (2007) all state that while the World Health Organisation's Global Health Atlas does show the threat of an HIV and AIDS crisis in Muslim countries on the whole, data on incidence, prevalence and mortality for Muslims in the MENA and Asia regions is still limited. Todd et al (2007) further state that whilst prevalence rates in the region are argued to be low, there has also not been much evaluation concerning seroprevalence, behaviour, and knowledge regarding HIV and AIDS in the MENA and Asia regions. This is due to either under-reporting or non-reporting of statistics in these regions which can have serious consequences for disease surveillance and may, ultimately, result in the continuous spread of HIV and AIDS in regions that have high Muslim populations.

In the 1980s, when the disease was in its early stages, religious leaders called for compassion towards people living with HIV and AIDS. Part of this response was because of the belief that the disease does not affect the religious[24] (Frederiks, 2011). These beliefs and statements were coupled with moralistic perspectives surrounding the abstinence of sex prior to marriage, faithfulness within the marriage (whether monogamous or polygamous) and no deviations from religious norms, such as acts of prohibition, and/or homosexuality (Hasnain, 2005; Todd et al, 2007; Frederiks, 2011). It soon became clear, however, that HIV and AIDS did not only affect those labelled as so-called 'deviant' or 'immoral' and could infect anyone. In South East Asia addressing the disease from a religious standpoint has been collaborative and inter-religious (Frederiks, 2011). Inter-faith networks, which include Buddhist, Muslim, Hindu, and Chinese leaders, have been established, for example the Asian Inter-Faith Network on AIDS (AINA) which was launched in 2005. The Asian Muslim Network appeals for *zakat*[25] from the Muslim public to assist with treatment and core programmes (Frederik, 2011). The messages sent out, however, stressed the need to adhere to religious rules – to be faithful and not to engage in premarital sex – and did little to address the existence, and cause, of so-called at-risk behaviours (Desai, 2004; Frederiks, 2011; Kamarulzaman, 2013).

There has been much speculation about the spread of HIV and AIDS in Muslim countries and according to Hasnain (2005: 4), "Islam places a high value on chaste behaviour and prohibits sexual intercourse outside of marriage" and there is also the belief that a 'good Muslim' abstains from behaviours that are prohibited. Saltmarsh (2012:32) explains that some Muslims lead a 'double life' and find the expectations of being a devout Muslim to be "daunting … unrealistic and unattainable by the average human being". Saltmarsh (2012), in conversation with three presenters from the U.S. Conference on AIDS (2011) held in Chicago, discussed the 'double life' led by gay Muslim men and the difficulties they experience. The internal struggle explained one presenter, that comes with being Muslim and gay led to him breaking away from religious practices and entering a spiral of drug addiction. The lack of discourse around sex and sexuality in Muslim communities is stark. The presenters further stated that

[24] i.e., 'practicing' Muslims who follow the principles of Islamic guidance strictly, e.g., praying regularly and fasting.

[25] Alms. Zakat is one type of charity and must be given from one Muslim to another Muslim.

"Muslims are hardly ever mentioned in either the HIV community in general or in any of the goals set by agencies to reach out to communities of colour" (Saltmarsh, 2012: 33). One of the reasons for this has already been stated, Muslims (globally) do not recognise HIV and AIDS as a disease that affects them; it is a disease of the 'other' (Desai, 2004; Hasnain, 2005; Esack and Chiddy, 2009; Saltmarsh, 2012; Kamarulzaman, 2013; Azhar, 2015; Mahomed and Laher, 2015). Desai (2004) further points out that religious scholars have referred to the epidemic of HIV and AIDS as God's vengeance upon the immoral and sexually promiscuous and views HIV and AIDS as a form of punishment for the sins committed by such amoral people. Hasnain (2005) states that it is simply that Muslims engage in so-called 'risky behaviours' that contributes to the spread of HIV and AIDS, yet this is accompanied by a great sense of denial by Muslim governments and by religious scholars alike regarding the increasing threat of HIV and AIDS. This is echoed by Todd et al (2007: 151) in that the lack of research and data on Muslims is due to the notion that the "strong proscriptions" that exist in objection to risky behaviours reduce any concern for the spread of HIV and for public health concerns (Mahomed and Laher, 2015). Hasnain (2005), Todd et al (2007), and Kamarulzaman (2013) further add that prevailing social, cultural and religious structures surrounding Muslims do not create an environment that is conducive to individuals 'at risk' feeling safe for disclosure. Saltmarsh (2012) adds to this in saying that Muslims are closed off and not interested in getting tested due to the related judgement and stigma. Saltmarsh (2012) further asserts that there are little to no resources within Muslim communities, specifically in the USA, that offer testing, treatment and counselling specifically for Muslims and thus that Muslims must rely on non-Muslim service providers. According to Hasnain (2005), religious scholars and leaders need to foster a safe environment for individuals at risk such as those seen in Uganda and Senegal involving Muslim religious leaders. In Senegal HIV and AIDS prevention is discussed regularly in *masjids*[26], during the important Friday prayer sermons and on television and radio (UNAIDS, 2001; Alkaiyat, 2014).

Literature indicates that efforts have been implemented in certain Islamic States to curb the prevailing stigma associated with HIV and AIDS. The AEI Newsletter (2005) states that in Iran, in 2001 and 2002, an HIV-positive employee could be dismissed and patients with the virus could be refused treatment. There has, however, been

[26] Plural of *masjid,* which is a public place of worship for Muslims.

progress and although stigma is still rife, HIV education has been implemented in government schools and prior to marriage couples are encouraged to attend classes on how to prevent HIV and AIDS transmission. In Bangladesh, the AEI Newsletter (2005) further states that awareness programmes have been implemented in *masjids* drawing religious leaders into programmes. Similarly, in Malaysia, according to Kamarulzaman (2013), harm reduction programmes have been implemented targeting drug users only whilst female sex workers and men who have sex with men (MSM)[27] have been largely ignored.

It becomes clear that Muslim communities, around the world, are conservative in nature and that sex is a taboo topic (Chabilall, 2011; Todd et al, 2012; Azhar, 2015). This is even so within the more 'liberal' households. Azhar (2015) states that when sex is brought up it is in relation to procreation and that any and all sexual urges must be dealt with within the confines of marriage. Young women are not encouraged to further their education for a sense of independence and economic freedom. Young women are 'allowed' to pursue tertiary education, but the understanding is that she will 'settle down and get married' once she is done and the role of primary economic provider will be her husband, whilst she tends to the home and children (Azhar, 2015). This leaves women with little agency of their own. Young men, on the hand, are expected to become the primary breadwinner of the family which translates into being able to pursue a tertiary career into graduate school in order to improve the household income (Azhar, 2015). In many instances, Azhar (2015) argues that males tend to be a few years older than their wives and settled in their careers upon marriage whilst their wives are in their early twenties and have not really engaged in 'life activities'. Another issue which Azhar (2015) raises is of young men who do strictly follow Islamic principles and who are involved in drug use or who engage in homosexual acts and are encouraged to get married to 'good' girls who are then tasked with changing and/ or transforming their husbands into what is deemed to be 'good' Muslim men. This places young women at high risk of infection and without community support as the expectation is that one's marriage is private and that it is the responsibility of the couple to resolve any problems or conflict. The risks pertaining to women, as a result

[27] Men who have sex with men

of their economic oppression, are often made worse with the threat of food insecurity, poverty, and gender inequalities (Root and Whiteside, 2011).

Chabilal (2011) focusing on Muslim youth points out that Muslim youth are influenced by their family and school culture in relation to their knowledge about HIV and AIDS. Imam Karmani states that it is important to know and understand what is allowed sexually within the confines of religion and what is not so that informed decisions may be made (Azhar, 2015). Chabilal (2011) points out that in South Africa, Muslim youth are confused by the contradictory messages that they face in relation to HIV and AIDS. Schools tend to focus on intervention programmes which are responsive in order to create an understanding of safe sexual behaviour (Kelly, 2002; Chabilal, 2011). Sex education in schools and other public forums focus on the use of condoms as a means for preventing transmission of sexually transmitted diseases (STDs) and HIV in particular. The discussion is not around abstinence which is widely stressed in terms of Islamic religion. It thus becomes confusing for Muslim students because in the home, if sex is talked about, parents tell their children to abstain (Chabilal, 2011). Educators have been able to provide accurate information on HIV and AIDS but parents, through their own misconceptions, undo the work done by the school by pushing their own perceptions, which generally focus on abstinence (Chabilal, 2011). The problems faced by Muslim youth in relation to sex education and HIV awareness are the same regardless of whether they attended segregated or non-segregated schools (Chabilal, 2011). Geertz (1973) furthermore notes that schools are an extension of the community they are in and so the cultural practices of the community are the cultural practices of the school. Schools that are in conservative areas then, are likely to not address sex education in a meaningful way which leaves youth looking for answers elsewhere (Chabilal, 2011; Azhar, 2015). Chabilall's (2012) work shows that communities have become a little more open to sex talks at schools but there is still more work to be done in this regard.

HIV and AIDS is gendered in nature and as noted earlier, Muslim women are more susceptible and vulnerable to infection (Hasnain, 2005; Alavi-Naini, 202; Azhar, 2015). Azhar (2015) stated that according to Imam Karmani women need to be made aware of their rights within a marriage. This notion is directly in opposition to Badri's (2009) claim of the marriage contract being solely for economic purposes and that a woman is under obligation to have sex with her husband whether she wants to or not (Azhar,

2015). Marital rape is becoming more and more recognised and the Imam states that women have the right to say no to sex in a marriage without repercussions from her husband (Azhar, 2015). A principal in Chabilall's (2012) study wanted the young females at school to be aware of the patriarchal stance of the religion in relation to polygamous marriages. The principal wanted to ensure that females are aware of their rights and the conditions under which polygamy is acceptable and may be practiced in Islam (Chabilal, 2011).

Alavi-Naini (2012) paints a different picture of HIV and AIDS in the Muslim world. She argues that the urging and insistence on reducing so-called 'risky' sexual behaviours, in line with religious principles, has resulted in the decline of HIV infections within Muslim populations. Alavi-Naini (2012) addresses evidence to prove this point, whereas statistics offered by global organisations, such as, UNAIDS, WHO, and AVERT, seem to paint a different picture of the prevalence of HIV and AIDS in Muslim regions. Alavi-Naini (2012) points to particular Islamic practices and rules, namely, no sex before marriage, no extramarital relationships, no homosexual acts, no drug use and no alcohol intake (which she argues may lead to poor decision-making) as the avenue to reducing prevalence of HIV in Muslim communities. Circumcision and compulsory ritual ablution after sex is also touted by Alavi-Naini (2012) as important in HIV and AIDS reduction amongst Muslims. What is not addressed is the socio-cultural nuances that exist in different Muslim communities across the world. Alavi-Naini (2012) relies on studies that have been carried out in sub-Saharan Africa where findings have shown that the prevalence of HIV and AIDS seems to be lower amongst Muslims than non-Muslims. This is not significant enough though, as other studies have shown a rise in prevalence in other Muslim dominant regions. Male circumcision may play a role in the reduction of transmission and infection and has been encouraged in South Africa with the promotion of male medical circumcision, but it is far from a cure or a mechanism for preventing people from engaging in so-called 'risky behaviours' (Wamai et al, 2011; Kalichman et al, 2018).

2.1.4 Muslims and AIDS in South Africa

Kagee et al (2005) and Positive Muslims[28] conducted a significant community-based HIV prevalence study that targeted a predominantly Muslim population in South Africa. The study, the first of its kind, was conducted in three residential areas in Cape Town (South Africa) that have high Muslim populations. The prevalence rate in Kagee et al's (2005) study was 2.56%, as espoused by Isilow (2009), which is regarded as a relatively low percentage. Alarmingly, however, none of the infected persons had been tested previously and thus, Kagee et al (2005) argue, this could lead to an increase in the spread of HIV and AIDS. Amongst the findings of the research study it was established that from the six hundred couples who were interviewed, 57% stated that their reasons for marriage was pregnancy and when looking at divorce rates 20% stated the main reason for divorce was spousal infidelity. This relatively early study on Muslims in South Africa provides insight into probable 'risk' factors in the transmission of HIV and the risk for HIV infection and spread amongst Muslims in South Africa. Kagee et al's (2005) study is significant in that it highlights the need for further studies to be done so as to ascertain prevalence of HIV and AIDS amongst Muslims within a wider context of South Africa.

A later study conducted by Mahomed and Laher (2015) focused on the relationship between one's religious orientation and the perceived risk of contracting HIV. Carried out in Johannesburg, South Africa, through the use of surveys, the study found a positive correlation between one's reliance on Islamic principles for guidance and personal gratification and one's awareness of the risk of contracting HIV (Mahomed and Laher, 2015). According to Mahomed and Laher (2015) if one adhered to Islamic doctrine and followed the laws of Islam then one would be at a low risk for contracting the disease because one would be protected as much as possible. The study is in line with the notion that Muslims around the world do not see themselves as high risk for the contraction of the disease and this is put down to religious affiliation and the notion that 'good' Muslims do not contract HIV (Mahomed and Laher, 2015). Respondents did not see any risk of contraction from sexual or drug taking activities because they answered that they were not involved in such activities. In essence, respondents

[28] Positive Muslims: a faith-based organisation in Cape Town (no longer in existence) that assisted Muslims living with HIV and AIDS.

believed that any risk to contracting the disease was external and outside of their control (Mahomed and Laher, 2015). The study found that those people who were intrinsically more religious and vehemently followed the teachings of Islam were least likely to contract the disease through perceived 'risky' behaviours. The study also found that females who cover themselves, i.e., dress modestly, perceive themselves to be low risk because they feel that they are not inviting the stares of un-related men. This study is, however, problematic because it relies on the honesty of an individual when completing the survey. Regardless of the anonymity that was involved, many Muslims do not want to disclose their personal behaviours to the public in general, even if they will not be pointed out specifically, and this signifies the importance of establishing rapport when conducting research in this sensitive field. The reputation of the religion is also perceived to be important and so responses must be further questioned. Qualitative studies that speak directly to the experiences of Muslims are thus needed in order to ascertain real behaviours, attitudes and perceptions.

Although there is widespread stigma relating to HIV and AIDS within the Muslim community there are groups who aim to assist Muslim individuals living with HIV and AIDS by using a de-stigmatising approach. According to Cochrane and Nawab (2012) IC and MAP approach HIV and AIDS prevalence in the Muslim community as being indicative of wider social issues, namely violence against women and drug abuse and, therefore, choose not to limit their responses to promoting faithfulness in relationships and abstinence before marriage. The approaches utilised by these organisations replicate both Islamic principles as well as international good practice. Cochrane and Nawab (2012) state that the services provided by MAP include life skills training, education and development that addresses issues of information on disease, assertiveness, sex, sexuality, death and dying and is aimed mainly at the 'high risk age group' of 14 – 29. The belief is that these discussions will enable youth to make more informed decisions in the future. Further initiatives have also been taken to assist in areas of violence against women and children and with other social issues that plague South Africa.

As stated in Chapter One, the decision to undertake research in this field of study came about during an online discussion on an international forum for Muslims concerning the availability of support groups for various medical conditions, including

HIV and AIDS. At this point, when HIV and AIDS was mentioned the discussion reached a standstill. I realised that open discussion on the topic was taboo and something almost unheard of within the Muslim population. Upon further investigation into the South African scenario, I found that there are care groups that exist in Durban although these tend to be operating covertly. Despite the work of such groups, on the whole there remains a dearth of literature from the perspective of Muslims infected with and affected by HIV and AIDS in general and in South Africa specifically. Research that exists is predominantly quantitative and has sought, as a starting point, to establish incidence and prevalence rates through quantitative data gathering techniques. Qualitative studies have largely focused on theological approaches and responses to HIV and AIDS. Rich qualitative analyses, offering insights from the insider's perspective remain limited and there is thus a dire need for such research if we are to move beyond a surface level understanding of HIV and AIDS in the Muslim population.

2.2 Theoretical framework

This study drew on a number of theoretical paradigms to aid in the analysis of the data gleaned. Grounded Theory was proposed at the outset as the research study was exploratory in nature and I believed that the application of grounded theory would be useful in focusing and foregrounding data collection and subsequently drawing suitable themes from the data itself as opposed to imposing theoretical ideas on the data. The study is the first of it's kind in South Africa as it draws information directly from MLWHIV as primary sources of information and as such it was important to let the data drive the analysis. Through applying the cross-comparative method of grounded theory, the following theories emerged as useful for the study; Erving Goffman's theory of stigma, Mary Douglas' purity and danger framework, and social death. The application of these theoretical frameworks to the data has been incredibly insightful and meaningful. The theories are briefly mentioned in this chapter and will be expanded on in the resulting ethnographic chapters.

2.2.1 Grounded Theory

Due to the scarcity of research relating to Muslims living with HIV, the type of data that could potentially emerge from an empirical study such as this could not be wholly predicted. As such, Grounded Theory, first proposed by Glaser and Strauss in the 1960s, was deemed to be the best approach to this particular study as it provides a framework for understanding and analysing the data that is collected throughout the research process (Walker and Myrick, 2006; Khan, 2014; Chun Tie et al, 2019). In addition, Grounded Theory helps the researcher to generate theory from the data itself without being confined by pre-existing models of analysis or, in other words, it advocates "developing theories from research grounded in data rather than deducing testable hypotheses from existing theories" (Strauss and Corbin, 1990: 4; Khan, 2014; Chun Tie et al, 2019). The use of grounded theory thus permits researchers to look at their work in new ways, as by being simultaneously involved in data collection and analysis, Strauss and Corbin (1990) argue that researchers are able to control the research process. This increases the analytical power of their work and is therefore considered to be an excellent method of social analysis in the field of medical studies (Thomas and James, 2006; Walker and Myrick, 2006; Sbaraini et al, 2011; Khan, 201; Chun Tie et al, 2019). It was in the social studies of health that grounded theory was first conceptualised.

According to Strauss and Corbin (1990) human beings are not passive recipients of larger social forces, they are in fact active agents in their own lives. Human agency is important to acknowledge because the way in which people react to phenomena determines the direction which research takes, which in turn, impacts upon the development of the subsequent theoretical framework (Khan, 2014; Sbaraini et al, 2011). Whilst society may teach its citizens to react in a certain way to people with diseases such as HIV and AIDS, the way in which people in close contact with those who are HIV+ act and react is likely to be affected by a host of individual as well as societal predicators and one should not therefore pre-suppose or hypothesise what these actions and reactions might be. At the same time, while individuals are arguably active agents in their own right, one cannot negate the possibility that 'society, reality and self are constructed through interaction' and that "interaction is inherently dynamic and interpretative" (Strauss and Corbin, 1990: 7). Symbolic interaction, a key aspect of grounded theory, is therefore a crucial component of this research as it

acknowledges that people do not respond in an automated fashion to external stimuli, but rather, that thinking and reasoning shape interaction. Anderson and Taylor (2009) point out that the symbolic interaction approach looks closely at the finer details of individual interactions between people. Symbolic interactionism specifically looks at and addresses the subjective meanings that are enforced over objects, events and behaviours by people. These subjective meanings are then afforded primacy as it is believed that people's behaviours and responses to others are based on what the individual believes to be true rather than what is objectively true (Khan, 2014). Symbolic interactionism will be used to understand the way in which HIV+ Muslims respond to their disease medically, socially and psychologically.

2.2.2 Erving Goffman: Stigma

In addition to Grounded Theory, Erving Goffman's theory of stigma has been applied. The reason for this can be linked to what Cochrane and Nawab (2012) refer to as the 'hidden' statistics for HIV and AIDS and Muslims and therefore Goffman's theory of stigma is beneficial to the study. Individuals who have been infected with HIV and AIDS have traditionally faced stigma from society, although this has since changed somewhat due to HIV and AIDS awareness programmes and drives by governments and NGOs. The isolation of the infected (in this case the HIV+ Muslim individual) from those who are non-infected can be linked to Goffman's (1969) notion of the *spoilt identity*. Isolation does not necessarily refer to the physical isolation of stigma but can also refer to psychological isolation whereby the individual is cut off emotionally and psychologically from society as a result of his/her disease in the form of being unable to share status for fear of rejection. Goffman (1969) looks at stigma and social identity in relation to medical conditions in terms of both physical and cognitive disabilities (Davis, 2017; Hannem, 2022). Stigma, Goffman (1969:11) argues, originally referred to physical signs on the body that serve to "expose something unusual and bad about the moral status" of the person, for example being a criminal or traitor. Goffman (1969:11) describes the person as being "blemished, ritually polluted, to be avoided, especially in public places". Stigma can still be applied in the same sense today but does not necessarily need the outward physical alterations of the body to mark social stigma and shame. Instead, society places people into categories of what is deemed

ordinary and natural and consequently ‘different’ or ‘unnatural’ (Goffman, 1969; Ros et al, 2013; Holleman, 2020; Hannem, 2022).

My research reflects that sexual morality plays a role in stigma against MLWHIV and one’s moral status in the Muslim community is important. Kleinman and Hall-Clifford (2009: 419) state that anthropological contributions to the study of stigma have focused on “stigma as embedded in moral experience and on the stigmatised as a person with a moral status”. Power, in this instance, moral power, affects the manner in which stigma is distributed within a social environment. Yang et al (2007) refer to moral experiences, which are those phenomena of day to day live and practical interactions which define what is deemed important for ordinary people within a local social setting. Yang et al (2007) and Kleinman and Hall-Clifford (2009) note that the local social world, in this case the Muslim community in Durban, determines the moral standing of the community and individuals within it. Social norms, values, and obligations are set by the local social group and the moral status of the individual (which feeds into the moral status of the group) is maintained through alignment (Yang et al, 2007; Kleinman and Hall-Clifford, 2009). Therefore, those individuals who are unable[29] to maintain or meet the standards of the social norms and values are stigmatised and ‘othered’. Kleiman and Hall-Clifford (2009) argue that there is a relationship between those who stigmatise and those who are stigmatised. Yang et al (2009: 1524) hypothesised that the concepts of “moral experience, or what is most at stake for actors in a local social world” provide anthropologists with a new lens to interpret and understand both the stigmatiser and the stigmatised. The authors further note that the core effects of stigma threaten the individual with the loss or diminution of what they value and their own personal value within the local social world. Within society individuals seek to be part of a group and if they do not share common characteristics and attitudes with the larger group then they often fall outside of the group dynamic and become an ‘outsider’ or ‘the other’. When a person becomes sick they are often cut off physically, in some way, from those around them because, if it is something contagious, others do not want to get sick as well. When a person is diagnosed with a life-threatening disease it further separates the individual from those around him/her as well as from wider society through both his/her experiences and through society’s understanding of that particular condition. With respect to HIV and

[29] This may be through perceived inability or by evidence of the individual’s inability to maintain norms.

AIDS and how society has traditionally responded to the disease, the response has been largely negative with individuals often being discriminated against due to the nature of the disease, thus separating those who disclose their status from those around them. Jackson (2002) and UNAIDS (2008) argue that this is because HIV and AIDS has moral undertones. Stigma is a universal phenomenon but exists and is experienced within a specific local social world context. In South Africa, for example, Niehaus (2018) reflects that his research in the Bushbuckridge Municipality sexual morality was not a stigmatising factor. For this community, it was the liminal 'between death and dying' that caused fear and stigma. My research reflects the opposite. For Muslims in Durban, South Africa, any 'deviance' in sexual morality (perceived or not) results in stigma because the local social world of Muslims in Durban emphasises the values of sexual morality in Islam. Core lived values affect the lived experiences and moral lives of stigmatised people and this is perpetuated by the type of illness, social setting and social networks (Yang et al, 2009). Within the Muslim community stigma surrounding HIV and AIDS is widespread and this leads to those who are infected not disclosing their status for fear of being ostracised from their families and communities (Cochrane and Nawab, 2012). This will be expanded upon in Chapter Seven.

2.2.3 Mary Douglas: Purity and Danger

Mary Douglas' work involves studying human beings in society and making meaning through a symbolic lens and, as such, has provided an important framework for this study. Douglas's (1966) work *Purity and Danger* has been used to conceptualise the experiences of HIV+ Muslims living in Durban, South Africa. Douglas's work on beliefs and societies reflects that people believe and behave in ways that they are taught (Zaloom, 2020). For example, the language a person learns growing up is taught to them by their primary caregivers. Douglas (1973) argued that people's understanding of their reality has social origins and that social experiences are the phenomena that inform what people find acceptable and palatable in their societies and by extension their worlds. People in a society share culture, i.e. ways of knowing and ways of being, and social life depends on these shared understandings of the world (Spickard, 1990; Simpson and Hughes, 2020; Zaloom, 2020; Powell, 2022). All societies, no matter how simple or complex, must share beliefs. This is important to ensure that social

cohesion, interaction, and communication is sustainable and continuous. Social cohesion and interaction are often centred around notions of what is considered to be real, right, and wrong (Spickard, 1990; Simpson and Hughes, 2020; Zaloom, 2020; Powell, 2022). Douglas's (1966) Purity and Danger is founded on this. Ideals of what is 'right' and acceptable in a society are directly linked to what is considered to be 'pure' and 'good', whereas as ideas of 'wrong' and unacceptable actions are directly linked to 'impurity', 'dirt', and 'bad'. Purity and Danger reflects Douglas's (1996) concern with symbols, which ties in with symbolic interactionism (a key feature of Grounded Theory). The application of concepts such as purity and danger, clean and unclean, help people in a society to create and enforce order in their worlds (Douglas, 1966; Spickard, 1990; Zaloom, 2020). Douglas (1966; 1973) argues that that which is considered 'pure' is valued and holy, whereas that which is considered 'impure' is dangerous, taboo, and has no value in society. Behaviours are symbolic and may be connected to notions of 'pure' and 'impure', which becomes useful when theorising about the social implications of a disease like HIV and AIDS.

Culture shapes and develops the foundational inclinations of people who make up the community of a local social world, and the resulting incorporation of 'disgust' is a fundamental aspect of human interaction in the world (Rozin et al, 2000; Duschunsky, 2016). Thus, the moral undertones of HIV and AIDS stem from ideas within a community about what behaviours are considered acceptable, valued, and thus 'pure' when compared to behaviours that are perceived as unacceptable, dangerous and thus 'impure'. The meanings assigned to symbols and the resultant categorisation are an important part of social control which are enforced by the community (Zaloom, 2020). Muslims are socialised with the inclination of particular behaviour being 'bad' and sex taboos shame people. What is considered sexual immorality in Islam is engrained into a Muslim as a sin, as shameful, and disgusting behaviour. It shapes how Muslims engage in the world and with people around them. A friend, who has since left the fold of Islam, told me about the time he first had sex. He said that once he had undressed and was in front of his partner, he felt ashamed and wanted to have the lights in the room turned off. Sex acts out of the desired norm of sexual morality are clandestine. Muslims, therefore, must be 'good' so as to attain spiritual rewards for a better afterlife. These categorisations inform the social order that exists in Muslim society and result in people being associated or categorised as 'good' or 'bad'

Muslims. Duschinsy (2016) notes the importance of understanding that there is a relationship between the individual and the community of their local social world. This has a number of ramifications for MLWHIV in their social worlds, which comes through stigma and discrimination, and ultimately social death. Douglas (1970, 2004) was her own critic and noted that some of the examples she tried to fit through the lens of purity and danger did not entirely work out, specifically the example of Leviticus. *Purity and Danger*, however, tells us that humans classify phenomena in their local social worlds and that classifications are set according to criteria (Fardon, 2016). Douglas (2004) has noted that the broader social world is dynamic and classifications can become unruly. This can be seen in the spread of Westernisation and changing beliefs. At one point in time, Western societies believed that homosexual relationships were 'wrong' and that adultery was 'wrong', however, these beliefs changed over time as society changed. Muslim communities, although living in secular societies, however, do not have such shifting beliefs. Wider society has somewhat changed the way it views homosexuals and sex outside of marriage, but in Islam the fundamental principles concerning sexual relationships have not changed. *Haram* does not become *halal* because other communities accept it. As such, Muslim beliefs are firm and continuous. Douglas (2004) has espoused that where parts of the world do not fit the classification, these parts become anomalies (Fardon, 2016). Anomalies which cross boundaries can be "reclassified, physically controlled (exile or extermination), avoided, labelled dangerous or used to enrich life" (Fardon, 2016: 26). Muslims do not see those who have acted in 'sexually immoral' ways as anomalies. Those Muslims who have not engaged in what is deemed 'sexually immoral' acts, who have contracted HIV in *non-haram* ways, (e.g. through birth or from a marriage partner), are anomalies. This does not change the fact that they are considered 'dirty' and they are still avoided and labelled as dangerous. Douglas's (1966) theory on Purity and Danger will be engaged with in more detail in Chapter Six through the analysis of ethnographic data that has been collected.

2.2.4 Social Death

Social death, a conceptual framework which ties in with grounded theory, stigma and purity and danger, is another tool that has been used to analyse the data which has

been collected throughout the research process. Social death is a concept that was first introduced in the 1960s, by Barney Glazer and Anselm Strauss (Gilleard and Higgs, 2015). Glazer and Strauss (1965) conducted observations in hospitals in the USA and found that some patients, prior to physically dying, experience death socially. Glazer and Strauss (1965) wanted to explore whether or not a person could die socially before they died clinically or biologically, and from this the authors aimed to explore what this would mean for human interactions and relationships. Mulkay and Ernst (1991:178) define social death as "the cessation of the individual person as an active agent in other's lives, acknowledging that individuals may be dead for some parties, yet socially alive for others". In the past, the term social death has been applied to the elderly, specifically elderly people who suffer from dementia or Alzheimer's disease and people with disabilities which restrict social interaction, such as severe cognitive disorders (Sweeting and Gilhooly, 1991 and 1997; Gilleard and Higgs, 2015; Ransom et al, 2021). Social death involves the loss of self or personhood of the individual in question, by people around them (Sweeting and Gilhooly, 1991; Rabinow, 2007; Ransom et al, 2021). For the purpose of this study, this means the HIV+ Muslim and their family and friends (i.e. their community). Social death concerns the "termination" of one's "social existence", whereby an individual or group is removed from society, generally due to factors outside of their control (Mulkay and Ernst, 1991: 173). Erving Goffman's work on the 'non-person' has been an important cornerstone to Glazer and Strauss' (1965) work. A person's social existence is not continuous, and is reliant on whether they are able to relate to and communicate with other people in their community (Rabinow, 2007; Rosa and Diaz, 2019; Ransom et al, 2021). For a person to continuously live socially, they must be able to offer something of value to the community, however, when the person is regarded as no longer having anything of value to contribute they are phased out of active social interactions and experiences (Mulkay and Ernst, 1991). This may take place immediately or slowly over a period of time. Whilst social death has its conceptual origins in the studies of biologically and clinically dying hospital patients in the USA, this has shifted and has been applied in diseases like HIV and AIDS. An HIV+ person may live a long and healthy life, with the body deteriorating very slowly if they adhere to their treatment regimes. Due to the moral undertones of the disease, HIV+ people (and in the context of this study, HIV+ Muslims) experience stigma and discrimination which impacts their social relationships negatively. Social death is well placed to frame the experiences of HIV+

Muslims who have disclosed, or have had their positive status disclosed. Whilst laws exist to minimise the discrimination against HIV+ people, for example in the workplace and healthcare system, on an informal social level stigma and discrimination are difficult to police and address. Social beliefs that are shared by a community are difficult to change, especially when those socio-cultural beliefs are strongly tied to religious tenets; i.e. Muslims and Islamic guiding principles. Koka et al (2013) state that negative perceptions of HIV+ people, combined with stigma and discrimination, lead to ostracization and result in social deaths due to HIV+ people being 'othered' in their communities. HIV+ people, accordingly, lose their social status, and experience social rejection and social isolation which ultimately leads to social death (Koka et al, 2013). Koka et al (2013: 235) poignantly express that "if you have AIDS you 'die' twice because the first thing that kills you is being lonely when everyone discriminates against you long before your biological death", which may be many years after diagnosis. Social death has been applied as a conceptual framework to the data gleaned in this study and will be expanded on through analysis in Chapter Eight.

The application of these frameworks together provides a useful theoretical basis in understanding the experiences of HIV+ Muslims living in Durban, South Africa. In the chapter that follows, concepts and beliefs about Islam and sickness will be explored in relation to HIV and AIDS. The chapter outlines Islamic responses to HIV, speaks to how Islamic principles serve as preventative tools for the transmission of HIV and finally Chapter Three provides background and contextual information about Muslims in South Africa.

CHAPTER THREE: ISLAMIC RELIGION AND MUSLIM CULTURE AS A MECHANISM FOR PROTECTION AGAINST HIV AND AIDS

"The Messenger of Allah (ﷺ) said, "*Verily, Allah, the Exalted, and Glorious will say on the Day of Resurrection: 'O son of Adam, I was ill, but you did not visit Me.' He would say: 'O my Rubb*[30]*, how could I visit you and You are the Rubb of the worlds?' Thereupon He would say: 'Did you not know that such and such a slave of Mine was ill, but you did not visit him? Did you not realize that if you had visited him (you would have known that I was aware of your visit to him, for which I would reward you) you would have found Me with him*?" (Al-Bukhari, 6:3:896).

Islamic religion and Muslim culture provide a stringent set of moral rules which act as a barrier against Muslims engaging in behaviours regarded as morally and culturally reprehensible and/or as placing individuals 'at risk' of ill health. The purpose of this chapter is twofold. In the first instance, the chapter unpacks the key cultural and religious practices that seek to uphold the moral fibre of individuals and Islamic society at large as these are regarded as crucial in acting as a mechanism against HIV and AIDS amongst Muslims. The second part of the chapter focusses on the Islamic diaspora in terms of the South Africa context and indicates how certain Islamic beliefs and practices, derived and adapted from Hindu culture,[31] are upheld in South Africa, albeit in a changed form, and continue to shape and define understandings of the way in which society 'should' be ordered as well as beliefs around sickness and health.

3.1 Islam as a Holistic Way of Life in Regulating Behaviour

According to Amod (2004: 33) "Islam is a comprehensive way of life because its values, principles, rules, and regulations deal with every facet of life". Accordingly, Islam has a strong place in the mental, physical and spiritual aspects of the lives of Muslims as the system of rules offers guidance in all aspects of a Muslim's life and in everyday experiences. Islam, however, does not have an officially recognised and

[30] Lord.

[31] Most Muslims in South Africa are descendants of the indentured labourers brought to KwaZulu-Natal in 1860, who were predominantly Hindu.

organised theological body (Sachedina, 2008). As the youngest of the Abrahamic religions, Islam spread fast throughout the world. The Qur'an was first revealed to the Prophet Muhammad (PBUH[32]) in 7th century Arabia and upon the Prophet's death the Muslim *ummah* was divided on the basis of leadership with one group pledging allegiance to Hazrat[33] Abu Bakr (RA)[34] and the other to Hazrat Ali (RA)[35] (Kamalie, 2019). This divide is widely known as the Sunni[36]/Shia[37] divide (Chitwood, 2017; Iqbal, 2020). There is, thus, a plurality of sorts in Islamic beliefs and practices with the power and authority of interpretation and decision-making falling into the hands of religious experts (Siddiquee, 2009). Whilst Sunnis (majority) and Shias (minority) agree on the fundamental aspects of Islam and its teachings, there are key differences which relate to practice, historical events, leadership, politics and ideological heritage (Chitwood, 2017; Iqbal, 2020). This is important to note because there are implications on what is considered acceptable Islamic practice and what is not depending on the sect that is followed. Whilst religion and culture are not synonymous, they are inextricably linked and with Muslim populations residing in different parts of the world the Islamic faith has become "infused with multiple and differing cultural and social practices" (Kamalie, 2019: 35). This stated, many of the central tenets of Islam cut across the various sub-religious sets that have developed and the core, fundamental tenets of the religion are shared.

According to Haddad (2011) religion is very important for followers because it provides guidance, explanations, comfort and a framework for perceiving, experiencing, and engaging with the world. Amod (2004) refers to modern secular societies as being materialistic, lacking in spirituality and as placing great emphasis on self-gratification. Secular law, in general, Amod (2004) argues, tends to be divorced from religious law in that secular law leads to more liberal lifestyles where people are prone to focusing upon self-satisfaction at the expense of the broader community (Badri, 2000). Amod (2004) further states that in secular society there is regarded as being no need to curb

[32] Peace Be Upon Him.
[33] Honorific. It is a term of respect.
[34] Abu Bakr was the father-in-law and a sahabah (companion) of the Prophet (PBUH) and was the first recognized Caliph (successor of the Prophet Muhammad [PBUH]).
[35] Ali ibn Talib was a sahabah, cousin, and son-in-law of Prophet Muhammad (PBUH). He was the fourth Caliph. Some of the sahabah believed that Ali ibn Talib was designated by the Prophet (PBUH) as his successor.
[36] Sunni: followers of the Sunnah (way) of Prophet Muhammad (PBUH).
[37] Shia: those who believe that Ali ibn Talib was the rightful successor of Prophet Muhammad (PBUH).

or restrict one's wants and desires outside of the realm of a codified legal framework. Islamic teachings, on the other hand, Amod (2004) states, aim to foster a balance between the spiritual and the material, with the spiritual taking precedence because the ultimate goal of a Muslim is to attain *Jannah*[38]. The Islamic way of life not only seeks to integrate the spiritual and the physical, but also aims to integrate the moral, aesthetic and intellectual aspects of human personality with the aspiration being the achievement of a balanced, coherent and practical lifestyle (Amod, 2004). *Tawhid*[39] can be regarded as a significant manifestation of this principle. Moreover, the overarching emphasis of attaining balance and unity within the religion is evidenced in the act of *salah*.[40] With respect to *salah*, prayer is the physical act of worship, and this is carried out according to specified rules which have a strong spiritual dimension attached to the physical act (Amod, 2004). The physical act of *salah*, Amod (2004) maintains, serves to create God-consciousness and a strong connection to Allah in the same way as fasting does during the Islamic month of *Ramadan*.

Moderation is regarded as being essential in Islamic cosmology and Islamic teachings have built-in mechanisms for safety and protection of Muslims. In order for the mechanisms to be effective, however, it is important that Muslims adhere to all aspects of the religious code and invest in all components of the individual persona as to neglect any one aspect of the persona, or any one part of the religious code, is tantamount to neglecting all. In the pursuit of perfection on an individual level, as well as the pursuit of harmony on the social level, all factors of developing the persona and social order are stressed including (but not limited to) *imaan*[41], *salah, sawm*[42], the avoidance of substances such as alcohol and drugs as well as prohibitions against engaging in behaviours deemed to be morally reprehensible, for example, extra-marital sexual relations. Thus, Amod (2004: 33) argues, for a Muslim to "attain the full benefits of Islam's protection from all social ills, including HIV and AIDS, we have to practice all its aspects in totality". Thus, living one's life according to the holistic Islamic teachings is regarded as crucial in terms of maintaining health and wellbeing.

[38] Paradise or Heaven.
[39] Unity.
[40] Prayer
[41] Faith.
[42] Fasting.

3.2 Islamic Understandings Surrounding Sickness and Health

Islamic approaches to health and well-being likewise focus on the spiritual health dimension as well as on the physical dimension and any deficit in one domain is regarded as negatively impacting upon all aspects of the individual (Kamalie, 2019). It follows then that suffering is regarded as being connected to Allah's will and as a test of faith. According to Siddiquee (2008: 14), "It is the Almighty Creator who causes it and He [is the one] who answers the constrained when he calls out to Him, and removes evil". Suffering in terms of the Islamic worldview, therefore, is not framed as an ethical dilemma from a God who is just and compassionate and who requires vindication, rather it is framed in the manner of a "divinely ordained temporary situation" (Siddiquee, 2008: 14). There is, however, a differentiation between natural disasters and personal harm that a human being experience's (e.g. sickness, injury or death). In this sense, Siddiquee (2008) argues that personal harm draws attention to Allah's presence in one's life and the position and status of the individual's faith. If Allah is regarded as knowing all, and has ordained everything, then this includes failure, sadness and punishment alongside joy and success (Siddiquee, 2009). Whilst Allah is viewed as being responsible for all, human beings are believed to be provided with guidance to assist them in their daily life. This alludes to the *Qur'an*[43]*, Hadith,* and *Sunnah*[44] which are considered to provide knowledge in relation to health and well-being. Included in these teachings is the importance of caring for the sick and bereaved, and it is believed that one who provides care for the sick will be rewarded immensely (Siddiquee, 2008; Esack and Chiddy, 2009; Saltmarsh, 2012). When it comes to HIV and AIDS this notion, however, does not always carry through and the stigma that is associated with the disease often affects the care that sick individuals are able to get, as will be shown in the chapters that follow.

[43] Islamic Holy Book.

[44] These pertain to the practices of the Prophet Muhammad (PBUP) during his lifetime. Muslims are encouraged to emulate these practices.

3.3 Islam as a Mechanism of Protection Against HIV and AIDS

3.3.1 Morality as a Mechanism for Maintaining Health in Islam

The ultimate goal for Muslims is perfection so that a healthy and harmonious society may be created and maintained, and a healthy, moral personality is regarded as being central to this (Amod, 2004). Morality and well-being are thus seen as being inter-linked or as Amod (2004: 35) states, "spiritual development is inextricably bound to moral development". There is thus an overarching emphasis on upholding the moral order according to religious ideals. Amod (2004) argues that morally healthy individuals will create a healthy and moral society, and, in turn, a moral society will enhance the development of morally healthy individuals. With the holistic emphasis of Islam, where spiritual health is strongly linked to a rigid moral code, spiritual ill-health, Kamalie (2019) asserts, can consequently be experienced as a crisis or loss of faith, a questioning of one's faith or as failure to follow the prescribed moral order. Kamalie (2019) thus argues that the ideal of synchronicity between the two domains of spirituality and physical health can be upset by an individual being afflicted by serious sickness which can, in turn, be perceived as either retribution for sinning or as a test of faith to absolve any sins (Kamalie, 2019). As such, according to Islamic cosmology, the sick individual must seek forgiveness and repent for sin. On the flip side of the coin, sickness is also regarded as an opportunity to purify one's body and soul/spirit by accepting Allah's will, thereby, in terms of the Islamic world view, resulting in one being rewarded for their patience and endurance (Kamalie, 2019). Sickness and healing on earth therefore means the possibility of being afforded a higher status in the afterlife in that it is believed that a person pays for their sins through sickness and that it is better to do so while alive, as opposed to in the afterlife. Due to the moral undertones of HIV and AIDS, this has not been the experience of my interlocutors, and according to information gleaned from the interviews, HIV and AIDS is a disease that, for Muslims living in Durban, is firmly located within the realm of punishment, both on earth and in the afterlife. Rahele noted that her mother would tell her that her prayers would not be answered because of her disease, "*She didn't want me to pray for her and she would always tell me that Allah won't listen to my prayers and forgive me, that I would still go to hell when I die because I did wrong things*". Tasneem expressed similar sentiments. She had a patient, a few years ago, with whom she did home visits. Tasneem said that she spoke to the person's family about praying with

and for him but the family of the HIV+ Muslim did not respond positively. Tasneem noted that the family blamed him for his own disease and felt that they were at risk because they lived in the same home and, additionally, did not believe that prayer would be useful. Tasneem said, "*They made it seem like they were doing Amar a favour by letting him live at home with his parents, and that he was a lost cause. His father said that it was his [Amar's] own fault that he was in the situation that he found himself in and that because Amar committed a major sin he would go to hell and so praying for him wouldn't help".*

While sickness and suffering are normally construed in Islam as providing the perfect setting for reflection on one's life and for improving one's future attitudes, behaviours, and practices this is not the case for HIV+ Muslims (Kamalie, 2019). Rather, in terms of dominant Islamic beliefs, the emphasis is placed on HIV- individuals receiving Islam's full protection from HIV and AIDS by adhering to all aspects of Islamic practice in its entirety. It is within this framework that the Muslim response to HIV and AIDS can be explained.

3.3.2 Regulating Sexual Relations in Islam as a Mechanism Against HIV and AIDS

In line with such notions of morality, Amod (2004) argues that Islamic teachings offer solutions to problems and diseases and specifically to HIV and AIDS given the fact that the disease is primarily transmitted through sexual intercourse. A significant aspect of prevention through an Islamic framework is thus sexual regulation. Amod (2004), like Badri (2000), asserts that if Islamic ruling around sexual intercourse is followed, this will prevent the spread of HIV drastically. Interactions between men and women within the Islamic context are rigid and are strictly bound by rules and regulations. Islamic guidelines regulate sexual behaviour primarily through the prohibition of sexual intercourse outside of marriage (this includes pre- and extra-marital sex) as well as through the prohibition of free mixing between *non-mahram*[45] males and females so as to avoid situations that may lead to sexual 'impropriety' and

[45] Not an immediate blood relative; for example, a male who is not a woman's father, brother/s, nephew/s, or parent's brother/s. A non-mahram is a man whom a woman is socially able to marry.

promote temptation based on sexual desires (Badri, 2003; Amod 2004). As such, the concept of 'dating' is also not a term that is associated with Islam. Huda (2017:1) cites a *hadith* which states that "Not one of you should meet a woman alone unless she is accompanied by a *mahram*[46]" and "Whenever a man is alone with a woman, Satan is the third among them". These scripts conscientise and promote feelings of guilt which disallow people from engaging with the opposite sex and prohibit any sexual behaviour or act outside of marriage. Hence, most Muslims marry young to avoid the temptation of sex or, in other words, so as not to fall victim to one's *nafs*[47] (Hasnain, 2005; Alavi-Naini, 2012; Bocci, 2013; Azhar, 2015; Huda, 2017). In situations where it is necessary for males and females to interact there are clear guidelines that govern the interaction including lowering one's gaze so as not to look directly at a person of the opposite sex. There are also specific *hadith* and verses in the *Qur'an* which speak to the importance of avoiding the gaze, for example:

> *"O 'Ali, don't follow up your first [unintentional glance at a woman] with a second glance, for you will not be sinful for the first [unintentional] glance but you will be sinful for the next"* (Sunan Tirmidhi, Hadith: 2777).

> *"Say to the believers that they should lower their gazes and (thereby) protect their chastity. That is better for them. Allah is well aware of what they do"* (Surah Nur, Ayah: 30).

In Islam emphasis is also placed on modest attire so as to avoid "unnecessary excitement or temptation" (Amod, 2004: 35). Modest dressing, it is stressed, "embodies the qualities of reserve, respect and restraint as these are played out" (El Guindi, 1999: 96). There are codes of dress for Muslim men and women, however there are stricter dress requirements for Muslim women than there are for Muslim men. Modesty is mentioned in the *Qur'an* but there is contention over whether this means the entire body or simply for women to cover their breasts and pubic area (El-Ali, 2022). This stems from differences in interpretation of a verse in the *Qur'an*, from Surah An-Nur[48]. El-Ali (2022) argues that there is no specific set of rules that govern

[46] Immediate blood relative; for example, a woman's father, brother/s, nephew/s, or parent's brother/s. It is socially and religiously unacceptable to marry a mahram.
[47] Nafs literally translates from Arabic to English as the 'self'. When the term is applied, it is done so in relation to the concept of 'ego' and relates to one's desires.
[48] The Light.

dress in Islam beyond the need to cover the genitalia. Muslim females around the world, however, grow up with the assumption that when a female experiences puberty, she must begin to cover her head with a headscarf and wear loose fitting clothing that covers her entire body (El-Ali, 2022). What is taught in Islamic schools is that a Muslim female must be covered almost completely, from head to foot, arms to the wrist and that the only parts of the body that are allowed to be seen are the face, the hands and the feet (El-Ali, 2022). A Muslim male is expected to cover himself from the navel to his knees in loose fitting clothing and as such he is allowed to not wear a shirt in public (Hansen, 2004). Clothing is an important symbol of the embodiment of Islam (Rugh, 2002; Hansen, 2004) and El Guindi (1999) goes on to state that by dressing modestly, and veiling oneself, a Muslim woman thus carries with her, her privacy and sanctity (Rugh, 2002). A Muslim woman can be easily identified if she is wearing a *hijab*[49], a *burqa*[50], a *niqab*[51] or an *abaya*[52], items of clothing which serve to keep the body hidden from other people. Clothing such as this aims to ensure that the modesty of the woman is protected and that she is likewise shielded from the gaze of men so as to avoid 'sexual temptation' on both sides (Hansen, 2004). Muslim women, in private spaces and with other women present, may take off their coverings and reveal themselves. Clothing is, therefore, a veil between the public and private.

Arranged marriage is another mechanism for regulating sexual relations in Islam. Arranged marriages, whereby parents choose a spouse for their child, were historically the norm in Islam and, whilst seemingly on the decline, are still prevalent today. With arranged marriages, parents' network or use matchmakers to look for spouses for their children. When men and women meet with the intention of marriage, they must be chaperoned by another, preferably older, male family member. The increase of western globalisation, the movement of Muslim diaspora to western countries (due primarily to socio-political upheavals) and the changing nature of societies, Azhar (2015) argues, has led to a shift in experiences. Young people are more often than not now left to find their own spouses, but this is not an easy task when interaction with the opposite sex is minimal and restricted (Azhar, 2015).

[49] Head scarf which covers all the hair on a woman's head.
[50] An outer garment that covers the entire body, even the eyes of the woman wearing it.
[51] A cloth which covers the face of the wearer but leaves the eyes open for other people to see.
[52] A long, loose fitting, dress which covers the wearer from the neck down to below the ankles, and the sleeves cover the arms all the down to the wrist.

In Islam physical desire is acknowledged and whilst sex outside of marriage is prohibited and relationships are closely monitored, sex between spouses is encouraged and Muslims are urged, as noted, to enter into marriage young so as to avoid falling into temptation (Amod, 2004). Marriage, and sexual intercourse within marriage, is thus viewed as an important mechanism in upholding the moral fibre of society. Monasticism[53] does not exist in Islam and celibacy[54] is prohibited (Amod, 2004). The rule of sex within the confines of marriage is regarded as an important mechanism in providing protection against STDs because partners are theoretically monogamous. In the instance of polygamous relationships, which are acceptable in Islam but only if entered into in accordance with Islamic law, sexual intercourse should be between the people within the marital union only. In such cases, it is expected that each person should be tested for STDs, specifically HIV, and if the results are negative, it is believed that the parties in the relationship have nothing to fear (Amod, 2004). Thus, abstinence prior to marriage is encouraged and once married, marriage is viewed as providing protection against HIV and AIDS and other sexually transmitted diseases.

In accordance with Islamic norms and principles, *Mut'ah*[55] marriage is practiced by *Shias*. This has many purposes and a common one is for relieving sexual frustration in an acceptable or *halal*[56] manner (Labi, 2010; Iqbal, 2020). In essence *mut'ah* marriage is a temporary marriage contract with a stipulated time period agreed on by both parties (Iqbal, 2020). Preconditions for *mut'ah* marriage are that the woman must not be married, she must get permission from her *wali*[57], she must not be sexually promiscuous, and she must be Muslim or from the People of the Book, i.e., a practicing Christian or Jewish woman (Abedi, 2017). When the marriage contract ends, the wife must then go into *iddat*[58] whereby the woman abstains from marriage and as such sexual intercourse so that if she is pregnant there is no doubt as to whom the father of the child is (Abedi, 2017). A man may partake in *mut'ah* marriage multiple times a

[53] Also known as monkhood, whereby solitary living and/ or celibacy is emphasised.
[54] A Muslim cannot take a vow of celibacy, and as such do not get married, nor can they practice celibacy within marriage. A hadith stipulates that "When a person gets married, he has completed half of his religion" (IslamQA, 2003).
[55] Temporary.
[56] Permissible.
[57] Legal guardian.
[58] A period of waiting, which is a period of three months.

year, whilst a woman is restricted to three or four times a year given that she must sit the period of *iddat* after every marriage. This type of marriage is not recognised by Sunni Muslims and is considered to be *haram*[59] (Mahmood and Nye, 2013). Parshall and Parshall (2003) note that *Nikah*[60] is long-term, and partners aim to build a life together and have a family. *Mut'ah*, on the other hand, is short-term and is usually purely for sexual gratification (Parshall and Parshall, 2003). *Mut'ah* has also been considered a religiously acceptable form of sex work whereby sexual relations are permitted, are not illegal or immoral by social standards, and are temporary without commitment (Baran, 2011). In the literature, *mut'ah* is not written about in relation to STIs and HIV and AIDS specifically, and this is likely to be because of the denialism that exists amongst Muslims and the belief that they need not worry about contracting the disease. A chat forum, shiachat.com, however, suggested that precautions should be taken in *mut'ah* marriage, and that people should get tested for STDs in general before agreeing to a contract. The comments on the thread, however, indicate that this is not a topic that is raised in general.

Furthermore, with regard to moral norms regarding gendered relations, Badri (2000) and Amod (2004) note that sexual harassment, exploitation, and pornography are forbidden in all forms in Islam with both authors arguing that any deviation from the moral principles and practices of Islam will have dire consequences for Muslims. Another form of prohibition in Islam is against homosexual acts "as this practice goes against human nature" (Amod, 2004: 45). When Muslim authors write about homosexuality and religion, they often refer to the story of Sodom and Gomora[61] (see Badri, 2003; Amod, 2004; Badri, 2008; Alavi-Naini, 2012; Azhar, 2015). Individuals

[59] Forbidden.

[60] Nikah is the Arabic term for marriage, which is used to describe the wedding.

[61] The story of fall of Sodom and Gomora can be found in both the Qur'an and the Bible. Through the story of the Prophet Lut/Lot (PBUH), it is argued that the actions of the people of Sodom and Gomora are used as evidence for the condemnation of homosexuality in Islam (Hendricks, 2010). Sodom and Gomora were wealthy cities in Mesopotamia, and the aristocrats enjoyed lavish lifestyles, while the common people and travellers were "subjected to harsh social and economic treatment" (Hendricks, 2010: 38). One of the major reasons for the destruction of the cities is homosexuality, specifically male-to-male sexual intercourse. Henricks (2010) explains that young men would be coerced into having sexual intercourse with male aristocrats, and with male temple priests who reasoned that sexual intercourse with males was needed for some of their ritual practices to the gods. Young women were also coerced into sexual intercourse with male priests with the ruse that "the virgins may be purified and made ready for marriage" through the ritual sexual intercourse (Hendricks, 2010: 38). For this, and other reasons, God is believed to have sent two angels to destroy the city.

who contract HIV and AIDS through homosexuality are thus seen as being at fault for not adhering to the teachings and guidance of Islam (Badri, 2003; Amod, 2004).

Strong moral codes, therefore, govern behaviour in Islam so as to curb any form of sexual relations outside of pre-defined categories of people and pre-determined moral codes. Any behaviour that may be regarded as tempting an individual to sway outside of these categories and codes is thus strongly forbidden.

3.3.3 Imaan (Faith)

Another key mechanism in terms of protecting oneself against HIV and AIDS as understood in terms of Muslim cosmology is *imaan*. Islamic teachings infer that faith is the total submission to the will of Allah and His absolute power and that this faith translates into self-restraint (Amod, 2004). The values of morality are, as noted, tied to faith and a strong and firm sense of faith means that a person has a strong will to withstand sexual desire and not give in to temptation. The inability to control oneself in relation to one's desires reflects a weak *imaan*. Sexual morality, Amod (2004) argues, is encouraged and promoted within the framework of an all-seeing, all-knowing Allah, and if a person goes against Allah's will, it is understood that the individual will face retribution. Badri (2000) and Amod (2004) argue that a successful HIV and AIDS programme must emphasise faith and God-consciousness in order to bring about any acceptable change in attitudes to sexual behaviour, specifically, they argue, in relation to those Muslims who are prone to, what is considered in terms of Muslim moral cosmology as, deviance. Amod (2004) argues that promoting a strong sense of faith is a useful tool in enhancing self-restraint as having strong faith in Allah would ensure a Muslim's ability to stand against the influence of the western world (Amod, 2004). Accordingly, individuals who succumb to sexual (or other) urges are seen as lacking in *imaan* and as being influenced by western forces.

3.3.4 Prayer (Salah) as a Mechanism of Protection Against HIV and AIDS

Another mechanism that may be regarded as protecting Muslims against HIV and AIDS is *salah* as *salah* is regarded as keeping people closely linked to Allah

throughout the day. *Salah* is one of the five pillars of Islam and is central to Islamic teachings. It is compulsory for a (Sunni) Muslim to pray five times a day and a Muslim is frowned upon if they do not do so. *Salah* is regarded as beneficial for the development and maintenance of one's *imaan* (Amod, 2004). Regular performance of *salah,* it is stressed*,* keeps one's mind focused on Allah and *salah* thus acts as a constant reminder of Allah (Amod, 2004). Prayer, it is believed, can have a restraining effect on 'immoral' thoughts which, if left unrestrained, may lead to high-risk behaviours. Thus, in the Muslim world view, if one is conscious of their *salah* they are deterred from engaging in what is deemed to be any morally risky behaviours that may counteract the spiritual reward gained from *salah* (IslamQA, 2003). As Amod (2004) points out, however, performing salah regularly but deviating from the prescribed rules and regulations and sinning in another aspect of life cancels out the good and there will then be no spiritual benefit received. If a Muslim drinks alcohol, for example, which is deemed as taboo according to Islamic norms, their salah is considered invalid for forty days. A hadith stipulates that Prophet Muhammad (SAW) was reported to have said, "whoever drinks alcohol and gets drunk, his prayer will not be accepted for forty days and if he dies he will go to Hell" (IslamQA, 2003). This is repeated on a further two occasions in the *hadith*, outlining that a Muslim may ask for forgiveness three times, but on the fourth occasion, "if he commits (this sin) again, then Allah pledges to make him drink the mud of *khabaal* on the Day of Resurrection… The juices of the people of Hell" (IslamQA, 2003). Regularly praying, in Muslim cosmology, creates a direct link between Muslims and Allah, and encourages Muslims to seek aid and protection from Allah on a constant and ongoing basis. Amod (2004) notes that regular *salah* aids in developing a strong moral personality, which, in terms of Muslim belief, is important in preventing the transmission of HIV.

3.3.5 Sawm (Fasting) as a Mechanism of Protection Against HIV and AIDS

Sawm may be regarded as a further mechanism of protection against HIV and AIDS amongst Muslims. Muslims commonly fast during the ninth month of the Islamic calendar, Ramadan. When Muslims fast, they cannot eat, drink, smoke or engage in any sexual activity from dawn until dusk (Ozalp, 2022). Muslims may also fast outside of Ramadan in order to strengthen their faith which, it is believed, aids in behavioural

change. As such, it is common practice for many Muslims to continue fasting on a Monday and Thursday. Fasting during the month of Ramadan is utilised for more than spiritual strengthening and reward, it is also used as a mechanism to break 'bad' habits, such as, smoking, overindulgence, and poor behaviour (such as rudeness, telling lies, cheating, vulgarity) and to improve oneself (Amod, 2004). Fasting is believed to have psychological and spiritual benefits and is believed to help a Muslim develop stronger willpower and self-restraint, which Badri (2000) and Amod (2004) argue enables a Muslim to fight against the urge to engage in so called 'risky' behaviours. Amod (2004: 41) states that the Prophet Muhammad (SAW) is reported to have encouraged young unmarried Muslims to fast often so that they may protect themselves from the "temptation to commit *Zina*[62], as fasting helps to control a person's *nafs*". Fasting, according to IslamQA (2013) focuses the mind, in much the same manner as *salah*, and also holds the same rule as *salah* that if one commits a sin whilst fasting, the fast is deemed invalid.

3.3.6. Prohibitions Against Alcohol and Drugs in Islam as a Protective Force Against HIV and AIDS

Islamic teachings prohibit phenomenon that are believed to be harmful to the human body, society and the environment (Amod, 2004; Kamalie, 2019). Prohibitions thus exist in Islam as deterrents to harm and danger in the social and physical environment. Accordingly, intoxicants such as recreational drugs and alcohol are prohibited in Islam because, as Amod (2004) states, such substance impair an individual's senses and the ability to form coherent judgement is thus reduced, resulting in poor decision-making**.** Michalak and Trocki (2006) make note of various *hadith* which speak to alcohol consumption, gambling, and drug use. The most prominent of these *hadith*, attributed to *Ibn Majah*[63] states that:

"Truly Allah has cursed khamr and has cursed the one who produces it, the one for whom it is produced, the one who drinks it, the one who serves it, the one who carries it, the one for whom it is carried, the one who sells it, the one who earns from

[62] Adultery.

[63] Also referred to as *Sunan Ibn Majah*. It is a collection of hadith compiled by Imam Muhammad bin Yazid Ibn Majah Qazvini (May All Be Pleased With Him).

the sale of it, the one who buys it, and the one for whom it is bought" (Michalak and Trocki, 2006: 529).

Baasher (1981) explains that in pre-Islamic communities living in the region of the Arabian Peninsula alcohol was brewed from dates, honey, sorghum, and grapes. Baasher (1981: 233) adds that at the start of the Islamic epoch wine was considered a "disruptive social evil and was effectively dealt with". In the pre-Islamic era, alcohol was well known "for its pleasure-producing and euphoric effects" (Baasher, 1981: 233 – 234). In the development of an Islamic religious community alcoholism was perceived to be a social problem and there was a series of holy commandments which would result in negative social and religious implications which were prescribed through revelation to the Prophet Muhammad (PBUH) (Baasher, 1981). The focus on alcohol as an inebriater was because it was an activity that became habitual and dependence was high (Cragg, 1973; Mercier, 1975; Baasher, 1981; Michalak and Trocki, 2006). *Khamr*[64] was revealed, through divine intervention, to the Prophet (PBUH) to be a sin and consuming *khamr* did not have any beneficial use and impact for society, rather *khamr* was noted to have harmful effects. A verse from the Qur'an (2: 219) states, "They ask thee concerning wine and gambling. Say: 'In them is great sin, and some profit, for men; but the sin is greater than the profit'". Punishment was used as a measure of control to reduce and eradicate the consumption of alcohol in Islamic society. In the time of the Prophet Muhammad (PBUH) punishment took on the form of either scolding or lashings (lashing was carried out with palm leaves and the number of lashes were never to exceed forty) (El Wakby, 1979; Baasher, 1981; Michalak and Trocki, 2006). In pre-Islamic times in relevant regions, opium was a commonly consumed drug (Baasher, 1981). Opium was initially used for medicinal purposes to alleviate pain and to assist with sleeping. Consumption of opium also became an issue of dependency, affecting the functioning of the person. In modern times, this has translated into any substance that may cause dependency, intoxication, or inebriation being prohibited (Michalak and Trocki, 2006; Kamarulzaman and Saifuddeen, 2009). Recreational drugs have been added to this, for example cannabis, cocaine, and heroine. It is worthwhile to note that in some instance's alcohol,

[64] Intoxicants – refers to substances such as alcohol and recreational drugs. Khamr is derived from the Arabic word *khamar* which means 'to cloud' and refers to substances that cloud the mind and results in a person losing control of their thoughts and actions (Kamarulzaman and Saifuddeen, 2009).

its derivatives, and certain recreational drugs may be permissible, however, this is specifically in relation to life-or-death situations. Medicinal cannabis may be approved for use if it is absolutely necessary and medication that contains alcohol (for example cough mixture) or other *haram* substances (for example non-halal animal derived gelatine) may be ingested if there is no other *halal* alternative.

Amod (2004) argues in terms of HIV and AIDS that the use of intoxicants reduces inhibitions and increases the likelihood of a person falling prey to thoughts and behaviours that they would not ordinarily fall prey to (such as engaging in so called 'risky' behaviours) and should therefore be avoided so as to provide protection at both the individual and societal level.

3.3.7. Pilgrimage (*Hajj* and/ or *Umrah*) as a Protective Force Against HIV and AIDS

Pilgrimage in the form of *Hajj* and/or *Umrah* is regarded as offering a further level of protection to Muslims. Every year, Muslims from across the globe travel to Makkah and Medina to fulfil their pilgrimage obligations, and Eid-ul-Adha[65] marks the culmination of *Hajj. Hajj* is a series of rituals that take place in Makkah and its surrounding areas. *Hajj* is believed to be the single largest gathering of people in one area on the planet, with two to three million Muslims descending into Makkah from all parts of the world (IslamicHelp, 2019). *Hajj* is a an immensely spiritual journey and a significant ritual that takes place is the 'stoning' of the devil at Mina. There are a number of important rituals that must be performed during *Hajj*. The first is that of *irham*[66], wherein pilgrims change into specially designed white clothing which also serves to break down class barriers by rendering everyone to an equal footing because the type of cloth, the style, the cut and weave of the fabric must be the same (IslamicHelp, 2019). The second ritual is *tawaf*[67] which is the act of moving in an anti-clockwise direction seven times around the *Kabah*[68] (IslamicHelp, 2019). The third

[65] Day of the sacrifice – the event marks a religious day of remembering in that the Prophet Ibrahim/ Abraham (PBUH) was commanded to sacrifice his son, Ismaeel/Ishmael to prove his devotion to Allah, and in the last instance Ishmael was removed by God and replaced with a ram.
[66] A state of purity.
[67] To surround.
[68] A cube shaped building built by the Prophet Ibrahim/ Abraham (PBUH) and his son Ismail/ Ishmael.

ritual takes place between Al-Safa and Al-Marwah where pilgrims run between the two mountains seven times in remembrance of *Hajar* (Prophet Ibrahim/ Abraham's [PBUH] wife) who did the same in the search of water (IslamicHelp, 2019). The fourth is a visit to Mount Arafat which is the site of the Prophet Muhammad's (PBUH) last sermon. This is followed by 'stoning' the devil which is symbolic of when Prophet Ibrahim/ Abraham (PBUH) threw stones at the devil three times when the devil tried to mislead him (IslamicHelp, 2019). The final two rituals involve observing the day of *Eid-ul-Adha* and *qurbani* whereby an animal (for example, goat, cow, or sheep) is slaughtered in remembrance of Prophet Ibrahim/ Abraham's devotion to *Allah*. There is also a belief amongst Muslims that through performing *Hajj*, one's sins are wiped away and attendees will have a clean slate from which to begin after *Hajj. Hajj* and *Umrah* are separate events. Amod (2004) further states that these events could potentially be used to host awareness and prevention campaigns for Muslims who could then take the message from the campaigns back to where they live and thus spread awareness in this way.

3.4 Responses to HIV and AIDS by Muslims

Various responses to HIV and AIDS exist in the literature and in practice. Esack (2004), in a Positive Muslims publication, classified responses to HIV and AIDS by Muslims into five categories including denialism, silence, confusion, rejection and sympathy.

3.4.1 Denialism

Embedded in the first aspect, denialism, is the belief that HIV and AIDS does not happen to Muslims (Esack, 2004). Kamalie (2019) explains that this stems from the belief that Muslims are protected against HIV transmission as a result of religious laws and norms that govern behaviour, that is, rules around sexual activity, sexuality and the use of intoxicants. Moreover, AIDS has been characterised as a Western disease (Badri, 2000; Amod, 2004; Hasbi et al, 2021; Yassin et al, 2021 and western influence is thus blamed for the spread of HIV and AIDS amongst Muslims. Kamalie (2019) argues that this is another form of denialism as blame and accountability of

transmission is transferred to ‘the other’. There is a misconception that if the existence of HIV and AIDS is acknowledged in the Muslim community, this would then translate into condoning actions which increase transmission (Esack, 2004). Additionally, this results in ignoring investigations into drivers of HIV in Muslim societies which would be extremely useful for awareness, intervention and prevention programmes (Kamalie, 2019).

3.4.2 Silence

The second response is that of silence. Kamalie (2019) notes that sex and sexuality are regarded as private matters and they are also taboo to talk about. Sex is embarrassing to discuss in Islamic cultures and social stigma thus affects and entrenches silence (Esack, 2004). Silence is perceived as keeping HIV+ Muslims safe because regardless of the mode of transmission an infected Muslim runs the “risk of being victimised, marginalised, or renounced by their family, as well as by their community” (Kamalie, 2019: 39). Shame is ever present and feeds the silence (Yassin et al, 2021). Silence also leads to HIV+ Muslims not asking for assistance or advice. By this it is meant that in wanting to keep their HIV+ status private, HIV+ Muslims run the risk of hiding their disease to their own detriment. HIV+ Muslims may then choose not to attend a public health clinic to collect medication for fear of being recognised which can then result in deterioration of health. Silence also affects transmission of HIV as if a person is not aware of their HIV status, or if they are but they do not want anyone to know about it, this silence can result in transmission of HIV.

3.4.3 Confusion

The third response is confusion. Confusion, in this sense, is situated around whether or not HIV and AIDS is a punishment sent by Allah or not (Esack, 2004; Kamalie, 2019). The *Qur’an*, like the Bible and Torah, relays stories of *Allah’s* wrath on humanity when *Allah* is displeased. Since HIV and AIDS has been described as the wrath of *Allah* then it is perceived that there must be a reason for the affliction to come to humanity (Badri, 2003). Punishments are regarded as being sent by Allah to make humans reflect on their actions. Such punishments include natural disasters (floods,

earthquakes), plagues and diseases. HIV and AIDS being as widespread as it is, it is believed, must exist for a reason, but there is confusion as to what the reason is, as punishment or a test.

3.4.4 Rejection

The fourth response is rejection. Rejection is rooted in stigma and discrimination. Rejection is a form of discrimination, and is based on fear and ignorance around HIV and AIDS (Esack, 2004; Kamalie, 2019; Hasbi et al 2021; Yassin et al, 2021). Bangstad (2009) makes references to the politics of accusation, whereby the marginalised in society are further stigmatised as they are more vulnerable to infection. Kamalie (2019: 41) states the rejection is based on assumptions that are located in "existing prejudices; shame, blame, fear related sexuality, gender, race/ ethnicity, and class" as well as 'immoral' notions of sexual promiscuity and substance abuse. Rejection may lead to isolation and alienation (Yassin et al, 2021).

3.4.5 Sympathy

The fifth response is sympathy. This is the most difficult response because it requires the MLWHIV to be humanised and for the Muslim community to accept that Muslims are not perfect and make mistakes (Kamalie, 2019). Esack (2004) recounted a story of an HIV+ Muslim woman who was discriminated against by an *Imam* who, without knowing her status, said that PLWHIV should be killed. After discovering that the woman was HIV+, the *Imam* changed his perspective and apologised to the woman. Sympathy is important and much needed in response to the epidemic, but this may only come forth when a person see's the other person as worthy of their sympathy. It is important to shift the narrative around HIV and AIDS and Muslims in order to reduce and remove stigma, judgmentalism, and blame. The five categories of responses to HIV and AIDS by Muslims will be dealt with more extensively in the ethnographic chapters that follow.

The first part of this chapter indicates that Islam, as a religion, has a number of pre-existing mechanisms that serve to prompt followers of the religion to behave within a

framework of what is deemed to be culturally and morally appropriate behaviour and deviation from such behaviour, it is believed, will result in severe consequences for the transgressor. Denial about the realities of shifting behavioural patterns and the contraction of HIV and AIDS is strong in Muslim communities and most older clerics tend to recommend fasting, prayer and repentance as opposed to seeking medical help (Azhar, 2015). The situation that non-subscribers find themselves in is seen as a result of their own wrongdoing, in terms of Muslim cosmology. Accordingly, Islam theoretically acts as a barrier against HIV and AIDS and a person who contracts HIV and AIDS is perceived as guilty of not following a prescribed Islamic way or life. Thus, for any form of prevention programme to achieve any level of success amongst Muslims, it is imperative that it is grounded in an Islamic religious and cultural system. This stated, the second part of this chapter introduces the Islamic diaspora of Muslims in South Africa so as to set the context for the ethnographic chapters that follow.

3.5 Islam and Muslim Diaspora in South Africa

During the conception of this study, the inclusion criteria for HIV+ Muslim participants was only that my interlocutor had to be Muslim and their HIV status positive. I did not restrict my study's demographic to a particular ethnic group because I did not want to limit the number of participants I would be able to find. With this in mind, however, the majority of my participants (eight out of ten) are South Africans of Indian Descent. South African Muslims of Indian descent are part of the history and legacy of Indian diaspora in relation to South Africa. A brief understanding of this diaspora is important to provide context to the discussion. Desai and Vahed (2010) state that the first Indians were brought to South Africa as slaves by Dutch settlers in 1653 and after the Act of Abolishment in 1833 and the banning of slavery in all parts of the British Empire, the system of indentured labour was created to deal with the crisis of labour. In November 1860, 342 men, women and children arrived at the port of Durban aboard the S.S. Truro, the first of many people of Indian origin who were brought to South Africa over a period of 50 years to work as indentured labourers on the sugar cane fields in Natal (now the province of KwaZulu-Natal), (IndianDiaspora, n.d.; Desai and Vahed, 2010). Fewer than 12% of the more than 150 000 people who were brought over via indentureship from India by the British, were Muslim (Shaik, 2017). They brought with them traditions, customs, rituals, and language which they attempted to preserve as

much as they possibly could. In addition to these indentured labourers, 'free passenger Indians' arrived in Natal. IndianDiaspora (n.d.) states that these were so called because they paid their own transport fare to South Africa and were in fact Hindu and Muslim merchants, originating from Gujarat. Mukherji (2011) states that outside of India, Durban is the largest 'Indian' city. Indians in South Africa can be divided according to religion; the most prominent being Hindus, Tamils, Muslims and Christians. Amod (2004) explains that South Africans of Indian descent are a conservative group, and even more so are South African Muslims. There is a strong sense of community amongst South African Muslims of Indian Descent and this, coupled with their conservativeness, is strongly linked to religious beliefs (Shaik, 2017).

Cultural and religious practices that existed within Hindu society have been transformed and repackaged to represent Muslim traditions. One person who is credited with converting many South African Indians to Islam, and who has had a significant impact on the religious landscape in Durban, is Sha Goolam Muhammed Soofie, or more popularly known amongst Muslims in Durban as Soofie Saheb. Derwent (2006) notes that Soofie Saheb came to South Africa in 1895 and passed away in Durban in 1911. In the time that he spent in Durban, Soofie Saheb established eleven *masjids*, thirteen Islamic schools, and numerous cemeteries for Muslims (Derwent, 2006). In order to ease Muslim reverts to Islam into their new religion, practices from Hinduism were maintained and repackaged to fit an Islamic narrative. For example, in the Islamic month of *Muharram*[69] South African Muslims who are of Indian descent gather in various spaces around the city, bring offerings to shrines that have been constructed and some Muslims 'fall' into a trance and as such are able to carry heavy loads, will dance, or have hooks inserted into their bodies in displays of faith. These are remnants of *Kavadi*[70] and no such description for the celebration of Muharram exists in the Qur'an or the Hadith. Vahed (2002) explains that the event that takes place in Muharram, *Ashura*[71], became a pan-Indian festival in South Africa which was a joint venture by Muslim and Hindu Indians. Some Muslims also pray to *Hazrat*

[69] This is the first month of the Islamic calendar.
[70] A ceremonial sacrifice event for the Lord Muruga.
[71] Ashura has two meanings. For Sunni Muslims, Ashura marks the day that Allah divided the Red Sea for Musa/ Moses (PBUH) and his people to cross the sea. For Shia Muslims, Ashura marks the day of the death of Husayn ibn Ali at the Battle of Karbala.

Soofie Saheb or Badsha Peer believing that these saints are able to take the message of prayer to Allah, however, the Qur'an and Hadith clearly state that there is no separation between a Muslim and *Allah, salah* provides a direct link to *Allah*, and the only person who is able to intercede on a Muslim's behalf, is the Prophet Muhammad (PBUH) who will be able to do so on the Day of Judgement when all souls will be resurrected to answer for their worldly acts.

South Africans of Indian descent have maintained many rituals, traditions, social, and religious aspects which originated in India, however, one cultural mechanism that did not become firmly rooted in South African Indian society is that of the caste system (Shaik, 2017). Mukherji (2011) points out that this was, largely because those who made the decision to leave India were mainly from the poorest parts of Indian society and as such the indentured system forced them to interact with and co-exist with people of different castes. This resulted in new ways of relating to one another, the forging of new relationships, and a new identity that was not based on caste affiliation, although it can be argued has links to it (IndianDiaspora, n.d.).

The findings of this study refer to the concepts of 'ritual impurity' which in a sense is an offshoot of 'untouchability'. These concepts are connected to South African Indian Muslims' heritage and the Indian diaspora that brought them here. In order to understand these terms and their applicability, a brief understanding of India's caste system will be provided. Jalali (2000) defines the Indian caste system as having divided Indian society into four varnas, the Brahman, Kshatriya, Vaishya and Shudras. The 'Untouchables', or Dalits, Jalali (2000: 251) argues, are considered to be a fifth caste that resulted from the "polluting contact of Shudra males and Brahmana females". As such, the 'Untouchables' have been heavily excluded from the caste division and have been shunned and scorned by society because they were considered unclean and polluted and as such were involved in work which reflected that status, for example latrine and gutter cleaners and street sweepers (Jalali, 2000). Zelliot (2005) further states that those marked as Untouchables were excluded from almost all parts of Indian society. They were not allowed to access any form of education and as such remained illiterate and so could not, and were not allowed, access to read religious texts, they were denied access to village water sources, (e.g., wells), were forced to live outside of the villages, and were forbidden to enter the

residential areas of upper castes. According to Roy and Kaye (2002), the ‘untouchables’ were considered to be ritually impure and were believed to be polluting to others and this pollution, Jalali (2000) states, was viewed as contagious and so other castes stayed well away from them.

Whilst the caste system has not been directly replicated, divisions still exist within South African Indian society and van den Berghe (1967:44) expressed that “the caste system as a whole subsists, for all practical purposes, only in a tendency towards endogamy which is now anything but strict”. Braziel (2008) states that the displacement of a population group results in the population group putting down roots in a new region, bringing with them cultural ideologies from their region of origin. Diasporic cultural development occurs along different lines from the population in the original homeland. Over time, Braziel (2008) argues, the new community becomes distinct from the community of origin and as a result changes in culture, tradition and language occurs. IndianDiaspora (n.d.) states that in order to ensure their survival and place in South African society, Indian South Africans adopted a more western way of life. This ‘watering down’ of Indian culture has meant that certain aspects of Indian culture have been adapted to the host society. Whilst there is no Untouchable caste per say, this thesis argues that the concept of untouchability and ritual impurity is being applied to those living with HIV and AIDS as a result of the stigma that is attached to the disease. It is with this in mind that this thesis seeks to explore the concept of ritual impurity to the physical and psychological segregation of MLWHIV from society as a result of the stigma associated with the disease.

This chapter has aimed to provide background and contextual information about South African Muslims and about the manner in which Islamic principles guide Muslims in relation to dealing with sickness and ill-health. This information is important as the following chapter, in particular, deals with explanatory models from a Muslim perspective in relation to HIV and AIDS. Subsequent chapters engage with issues of ‘impurity’ and the framing of HIV+ Muslims as such, and how these concepts, through the experience of stigma, shame, and discrimination serve to encourage social death amongst HIV+ Muslims living in Durban, South Africa.

CHAPTER FOUR: PARTICIPANT INFORMATION: MLWHIV, HEALTHCARE PROFESSIONALS, CAREGIVERS, AND IMAMS

This chapter begins by providing the reader with an outline of the key participants involved in the study. The first sub-section provides information on my main key informants, Muslims living with HIV/AIDS in Durban, South Africa. The second sub-section of the chapter introduces participants who provided supplementary information for the study, namely, health care professionals, caregivers and Islamic scholars. These sub-sections aim to give the reader an insight into who my participants are and their role in my study through the provision of a brief profile of each participant.

4.1 Introduction to Participants

4.1.1 Key Informants: Muslims Living with HIV and AIDS in Durban, KwaZulu-Natal, South Africa

The aim of this section is to provide a brief sketch of the MLWHIV who participated in this study so as to give a sense of humanness to the discussions that follow. Each participant has been given a pseudonym and I assured my interlocutors that their anonymity would be maintained. I chose to use names that are Persian, as Urdu-based names are very common in South Africa, and as such, the use of Persian names serves to protect the anonymity of my interlocutors. In my interview schedule I did not have a question related to how the individual contracted HIV, however, through the course of the interview process, my interlocutors gave this information freely. I purposely chose to omit the question because I did not wish to make my research participants feel uncomfortable or judged. I chose, instead, to focus on building a relationship of trust so as to enable them to speak freely about their own experiences and it was then up to person to decide what they wanted to tell me about their contraction of HIV and the extent of the detail they wished to go into. I was initially in two minds about directly asking for this information as I believed, at the outset of the research process, that it would be vital in order to get an understanding of the drivers of HIV transmission/infection amongst Muslims in Durban. In keeping with the anthropological tradition, however, I opted instead to focus on developing rapport and on providing a safe space for my interlocutors to speak openly about how they

contracted the disease if and when they felt comfortable enough to do so. I understand that my sample is small with only ten key (HIV+ Muslim) participants, but I feel that the information is useful in providing an in-depth understanding of the challenges that HIV+ Muslims in Durban face. My interlocutors were very forthcoming about their experiences as Muslim people living with HIV and they expressed the importance of talking about their lives because, as one participant put it, "*we cannot shy away from the reality of our lives and actions and the shortcomings of our* community".

It is important to note that whilst some of my interlocutors were sick during the course of my data collection, there had been no deaths up to the point of writing this dissertation.

4.1.1.1. Dalileh: HIV Positive Female Research Participant

Dalileh is a twenty-one-year-old, married, female, black South African who was born with HIV. Dalileh was diagnosed in her late teens, and this was through a routine blood test administered when she was pregnant with her first child. She is grateful that her husband and child did not contract the disease from her and says that since testing positive she and her husband have been using condoms to protect him against contracting the disease. She is currently on ARV[72] medication. Her husband's family have not been very supportive as they are afraid that he will contract the virus from her. Dalileh is not very close to her own family and believes that her mother may likely have died from an AIDS related disease when Dalileh was very young, although this has not been confirmed to her.

4.1.1.2 Hana: HIV Positive Female Research Participant

Hana is a twenty-eight-year-old, married, female South African of Indian descent. Hana said that her husband of five years was diagnosed with HIV in the second year of their marriage, and she then decided to get herself tested, and received a positive result. Hana and her husband do not have children and have decided that they will not have any children in the future as a result of being HIV positive. Hana made a

[72] Anti-retroviral

conscious decision to remain with her husband and says that she has made peace with their diagnosis.

4.1.1.3. Bijan: HIV Positive Male Research Participant

Bijan is a fifty-two-year-old, single, male South African of Indian Descent who has been living with HIV for almost 20 years. Before he was diagnosed, he was about to get married but when he disclosed his status to his then fiancé, she chose to break off the engagement. Bijan noted that the subsequent fallout between their families was considerable, however, his stepmother has been very supportive of him since. Some of Bijan's family members have accepted his status, although others have chosen to break contact with him. Bijan noted that he suspects he was infected by a needle injection. He said that he was outside a bank when he felt a prick and a few days later he felt sick. A routine blood test showed that he was positive for HIV.

4.1.1.4. Rahele: HIV Positive Female Research Participant

Rahele is a sixty-two-year-old, married, female South African of Indian Descent. During an interview with Rahele, Rahele disclosed that she has had a particularly traumatic life, having been sexually abused by her brother as a young girl. She is the fourth of seven children and said that she cannot recall much of her childhood and that most of her memories are negative. Rahele said that she had a good relationship with her father, while her relationship with her mother has always been fraught with contention. She said that her family was very poor and, as a result, she was forced to leave school when she was thirteen years old. Rahele has been married three times. On the first two occasions of marriage, she was forced to get married by her family, her mother specifically, because they felt burdened by her. She believes that she contracted HIV during her second marriage. She describes her first and second husbands as extremely abusive, both physically and emotionally. Her second husband, she noted, was a drug addict and was very violent. He sold her for sex in order to fund his drug habit. Rahele fell pregnant and found out that she was HIV+ after a visit to a state clinic. She then discovered that her husband, at the time, was HIV+ when he married her and although he knew about his status, he did not inform

her. Rahele has four children and her youngest was still in high school at the time of the interview. She is now married to a supportive older male to whom she has disclosed her status. Rahele views this relationship as very positive and regards her husband as being very caring and understanding.

4.1.1.5. Habib: HIV Positive Male Research Participant

Habib is a thirty-six-year-old, single, male South African of Indian Descent. Habib is a single father of an eight-year-old son. He was diagnosed with HIV five years ago through a routine blood test. Habib was very open about how he suspects he contracted the disease. As a youngster he stated that he frequented night clubs in Durban and acknowledged a *"risky lifestyle"*. He said that he engaged in unprotected sexual intercourse, which included sex with sex workers, however, whilst he did drink alcohol, he did not engage in any drug taking activities. Habib said that his childhood was very mundane, and his parents were very strict with him. He said that when he got to university (he studied at an institute outside of KwaZulu-Natal), it was the first time that he was able to take his own decisions and do as he pleased. He stated that this began a long downward spiral for him into, what he referred to as, *"clandestine"* activities. The freedom that he had being on his own led him to clubbing[73] frequently and drinking alcohol. He said he first had sex when he was eighteen years old with a female he met at a nightclub. He noted that he was quite inebriated at the time but remembers being *"very nervous and self-conscious"*. Habib continued to frequent night clubs and "*pick up women*", which included the services of sex workers, for the remainder of his time at university which was about seven years as Habib's highest qualification is a master's degree. He said that he *"calmed down"* when he moved back home into his parents' home and settled into a job. He got married and his wife passed away due to complications from childbirth. He is not sure whether his wife was HIV+ or not as he was unaware of his status at the time. His son is HIV-.

[73] Attending nightclubs to dance. Alcohol and recreational drugs are available at nightclubs.

4.1.1.6. Shamil: HIV Positive Male Research Participant

Shamil is a forty-two-year-old, married, male South African of Indian Descent. He has been married for twenty-two years and has two children. Shamil has a position as an executive in the company he works for. He said that he used to frequently visit sex workers near his place of employment and believes that he contracted HIV in this way. Shamil said that he infected his wife, and they were diagnosed at around the same time. He and his wife are still married. Shamil said that he told his wife that he was unfaithful but did not go into detail about his activities.

4.1.1.7. Sadira: HIV Positive Female Research Participant

Sadira is a fifty-four-year-old, married, female South African of Indian Descent. Sadira is entirely in *niqab* and was married for thirty years. Sadira stated that she was "*a good and faithful wife"* to her husband and noted that she raised their three children as a stay-at-home mother. Sadira was diagnosed with HIV ten years ago and describes her experience since then as being *"horrendous*". Her husband accused her of having sex outside of their marriage (extra-marital sex), blamed her for their HIV+ status and slandered her to their friends and family. Sadira stated that this was impossible as she does not have a driver's license, was extremely dependent on her husband and did not have either the time or the ability to leave the house without her husband's knowledge so it would not have been possible for her to engage in other sexual relationships. Sadira noted that it eventually emerged that she had contracted the disease from her husband. Sadira stated that her husband used to travel a lot (which included overseas trips) with the local *jamiat*[74] and that on these trips he would engage in sex with men and then come home to her. Sadira is no longer married to her husband and lives with one of her children.

[74] A term which refers to assembly or organization of people. The term is used often to describe groups of Muslim men who travel, locally and globally, to spread knowledge of Islam.

4.1.1.8. Haleh: HIV Positive Female Research Participant

Haleh is a twenty-eight-year-old, divorced, female black South African Muslim. She got married when she was eighteen years old and later found out that her husband at the time had a drug problem and had also been "*pimping himself out*" to make money to buy drugs. Haleh comes from a very conservative family and aside from leaving the house to attend school, she did not have much of a social life growing up. Haleh noted that she was a virgin when she got married and believes that the expectation was for her to "*correct"* her husband's behaviour once they were married. Haleh stated that she and her family had no clue about her husband's drug habit when she got married and that the information that they had received about him was relatively good. Haleh has been living with HIV for eight years. She divorced her husband soon after she was diagnosed and moved back in with her parents. At the time of the interview Haleh was engaged to a man to whom she has disclosed her status. She said that he has been very supportive and understanding of her situation and her experiences. Haleh's family, however, do not know about her HIV status because her (now) husband said that they would not be understanding and would stigmatise her. They plan to adopt children when they are ready.

4.1.1.9. Sami: HIV Positive Male Research Participant

Sami is a fifty-three-year-old, married, male South African of Indian Descent. He is a business owner and noted that he is quite well known in the community. Sami stated that he used to frequent sex workers because he felt that he was not "*getting what he needed sexually*" from his wife. He said that he doesn't blame his wife because growing up sex was a taboo topic in their respective homes and that his wife, as a result, was very reserved when it came to sexual intercourse. He cites this as his reason for going to sex workers where he presumes he contracted HIV and passed it on to his wife. Sami and his wife are still married but the relationship is not amicable. His wife is very bitter towards him but sees no alternative but to remain in the marriage because she cannot afford to support herself financially. Sami noted that he takes full responsibility for his actions and feels that it is his penance for his actions to provide for her. Sami and his wife could not have children and he said that he now sees this as a blessing. Their families do not know about the state of their marriage nor of their

positive status because he believes that they would be very upset and would ostracise them.

4.1.1.10. Narda: HIV Positive Female Research Participant

Narda is a fifty-eight-year-old, widowed, female South African of Indian Descent who contracted HIV from her husband. Narda stated that she was diagnosed in the late 1990s. Narda had a child with her husband, but their child passed away when he was eight years old from what was an AIDS-related sickness. Narda said that this was how she discovered that she was HIV+. Narda further noted that her family are poor and do not have the resources for good medical services and she continues to feel guilty that she did not take her son to a doctor sooner. Her husband has since passed on, and, despite being on medication, Narda said that she is not in a good physical state. Narda stated that her immediate family is aware of her status, and while they assist when she needs help, they are not very supportive of her. Narda survives off a social grant and support from a charity organisation.

TABLE TWO: HIV+ MUSLIM PARTICIPANTS

Name	**Male/Female**	**Age**
Dalileh	Female	21
Hana	Female	28
Bijan	Male	52
Rahele	Female	62
Habib	Male	36
Shamil	Male	42
Sadira	Female	54
Haleh	Female	28
Sami	Male	53
Narda	Female	58

4.1.2 Key Informants: Healthcare Professionals, Caregivers, and Imams in Durban, Kwazulu-Natal, South Africa

4.1.2.1 Healthcare Professionals

This sub-section provides information about the healthcare professionals who were interviewed for this study. This information is useful to understand the background of the individuals and how they came to be working with HIV+ Muslims, and the capacity in which they do so. Healthcare professionals who were interviewed for this study included, two nurses, one social worker and two psychologists, all of whom are female South Africans of Indian Descent.

4.1.2.1.1 Sister Aisha Reed: Retired Nurse Currently Working at a Faith-Based NGO in Durban

Sister Aisha qualified as a nurse in 1972. She has worked in various hospitals in Cape Town and Durban, South Africa, in her active years as a nurse. Early in her career, Sister Aisha worked internationally, from 1974 to 1977, at a hospital in Dallas, Texas, in the USA. Sister Aisha began her work with the faith-based NGO she is currently with in 1985 and has held various roles around KwaZulu-Natal during her tenure. She began working in the field of HIV and AIDS in 1987 when she was an Occupational Health and Safety Practitioner in the textile industry but had not had personal experience with HIV and AIDS prior to entering this field as her profession. In 1986, a friend of hers was diagnosed with HIV and whilst her friend's family rejected her, Sister Aisha provided her with much needed support. This sparked an interest in the field of HIV and AIDS and Sister Aisha thus embarked on a journey of discovery about HIV and AIDS, empowering herself with as much knowledge as was available in the early years of the pandemic. In her almost forty years of experience in the field of HIV and AIDS, Sister Aisha has created and implemented numerous education and awareness campaigns and has introduced voluntary testing and counselling initiatives and programmes. Her approach to HIV and AIDS, and to Muslims living with HIV, is that of compassion, which she says stems from her commitment to an Islamic ethos.

4.1.2.1.2 Sister Rifat: Social Worker Currently Working at a Faith-Based NGO in Durban

Sister Rifat holds a Master of Social Work degree and had been working at the faith-based NGO for six years at the time of her interview. Sister Rifat has been working with HIV+ Muslims since she began working at the NGO. Sister Rifat runs a support group for HIV+ Muslims, provides one-on-one counselling, and is also involved in acquiring resources through the NGO for the people who utilise its services, which includes HIV+ Muslims. Some of the resources that are provided include food, clothing, finding the person a place to live and money for rent if there is a need.

4.1.2.1.3 Haleema: Counselling Psychologist

Haleema is a practicing counselling psychologist based in the greater Durban area who holds a Master of Arts degree in Counselling Psychology. Haleema has been active in her profession for over twenty years and became involved in HIV and AIDS when she did her internship in the 1990s and she was introduced to HIV+ people. Haleema feels that there is a strong need for counsellors in this area and since setting up her private practice, has also offered her services pro bono to various faith-based NGOs in Durban. It is through this relationship that Haleema became involved in counselling HIV+ Muslim patients.

4.1.2.1.4 Shiera: Clinical Psychologist

Shiera is a practicing clinical psychologist based in the greater Durban area. Shiera holds a Master of Arts degree in Clinical Psychology from the University of the Witwatersrand (WITS). Apart from the period of time she was away for her studies, Shiera has lived in Durban all her life and grew up in the township of Chatsworth. Shiera considers herself to be a "*young psychologist, I've only been doing this for about ten years*". Shiera became involved in HIV and AIDS work after a friend disclosed her status to her. She said that prior to this happening, Shiera had never thought about HIV and AIDS and Muslims together. She did, however, note that substance abuse and sex work in Chatsworth is "*worrying*" and "*on the rise*". Shiera

also provides pro bono services to various organisations, including Hospice, and this service is offered regardless of faith.

4.1.2.1.5 Sister Nadia Sultan: Registered Nurse

Sister Nadia is a registered nurse who currently works at a public hospital in a former Indian township in Durban. Sister Nadia has been a nurse for over twenty years and has worked in the cities of Johannesburg, Pietermaritzburg and Durban. Sister Nadia is currently based in the HIV clinic at the hospital she works at and she had been there for six years at the time of her interview. Sister Nadia learned about HIV and AIDS when she was a nursing student and when she worked at a hospital in Johannesburg she was placed in the HIV clinic. Sister Nadia noted that she has seen an increase in HIV+ Muslims attending the clinic since she first began working there. Sister Nadia provided a wealth of information on how HIV+ Muslims navigate the public health sector and attempt to ensure that their status is kept hidden.

TABLE THREE: HEALTH CARE PROFESSIONALS WORKING WITH HIV AND AIDS IN DURBAN

Healthcare Professional	Gender	Background	Reason for working with HIV positive people
Aisha	Female	Retired nurse	Personal experience with HIV and AIDS after her friend tested positive
Rifat	Female	MA in Social Work	Worked at an NGO and became involved in HIV and AIDS care
Haleema	Female	MA in Counselling Psychology	Became involved in working with people with HIV and AIDS through her internship
Shiera	Female	MA in Clinical Psychology	Personal experience with HIV and AIDS after her friend tested positive
Sister Nadia	Female	Registered nurse	Was based at an HIV clinic at a provincial public hospital in Johannesburg

4.1.2.2 Caregivers of MLWHIV

Caregiving, according to Sullivan and Miller (2015) and Hileman et al (1992), occurs when a person assists with the physical and psychological care for a person who is sick and in need of aid. Caregivers may be kin or non-kin of the patient under care, and the caregivers in this study were non-kin caregivers for Muslims living with HIV. All of the caregivers whom I interviewed offered their services to NGOs on a voluntary basis, and received no monetary remuneration for their work, other than travelling expenses. Of the caregivers interviewed nine are female and one is male, all are Muslim, and all are South Africans of Indian Descent. Five of my participants in this category have a connection with a biomedical healthcare professional which influenced their decision to volunteer in HIV and AIDS. Caregivers assist HIV+ patients with various issues which include cleaning, bathing, dressing, cooking, feeding, medication regimes and other daily activities. The social aspect of caregiving was prominent during the interviews and caregivers expressed the importance of social engagement with people living with HIV. The hours given to caregiving varied from caregiver to caregiver and was dependent on their availability as some caregivers maintained full-time jobs.

4.1.2.2.1 Mya: Female Caregiver

Mya is a sixty-two-year-old mother of three. Mya has been married for almost forty-years and during this time she has primarily been a stay-at-home mother. Mya became involved in HIV and AIDS when she took her youngest child to the clinic and noticed that there was a group of people who were separated from the rest of the patients in the out-patient clinic. Mya asked about this and was told that the group of people had HIV and so were in a different queue in order to keep them away from other people. She said that she was curious about the disease and began to do a little research on the subject. Mya has always been involved in community work. She says that when she was growing up there was no focus on young Muslim girls getting a tertiary education and working, instead, the emphasis was on preparation for marriage. Mya noted that if she had had the opportunities that her daughter now has, she would have likely become a nurse. Mya began volunteering with AIDS patients at the Hospice near where she lives. At that time HIV was highly stigmatised and while her husband was

very supportive of what she was doing, they made the decision not to tell anyone outside of their immediate family because they were concerned about how people would receive it. Mya says that her mother-in-law was "*particularly ignorant. She had very backward views and would say very horrible things about HIV+ people when she saw something on the news, or in the newspapers. If she knew what I did she would have made a big fuss and accused me of bringing the disease into my home*". Mya is connected to some of my other participants who, outside of her immediate family, are the only people (apart from the organisations she has worked with) who know the details of her volunteer work. Mya has provided home-based care and care at a hospice for many people living with HIV, and particularly for MLWHIV. She feels that it is important for MLWHIV to have a Muslim caregiver and to encourage the person and keep a sense of community.

4.1.2.2.2 Azhar: Female Caregiver

Azhar is a forty-two-year-old homemaker, and a mother of two teenage boys. She is married to a surgeon and her first real interaction with HIV and AIDS was when her husband told her of an incident whereby a surgeon had accidentally 'nicked' himself during an operation and had to be placed on a regimen of post-exposure prophylaxis (PEP) in order to reduce the chances of transmission. She began to be concerned about her husband due to his profession and she noted that she was afraid of the disease and what it could do to a person. Azhar says that her husband assured her that every measure was taken to keep the operation theatres sterile and to reduce the possibility of transmission to healthcare staff. Azhar began researching the disease and realised what a significant presence stigma has in relation to HIV and AIDS. She asked her husband if he knew any HIV+ patients and requested that she meet them. Azhar's husband spoke to a few patients who would come to the hospital where he worked, and they agreed to meet with Azhar. Azhar says that she listened to their stories and what they had experienced and felt very strongly that she wanted to get involved and help people with HIV as much as she could. Azhar has worked with hospice and other faith-based NGOs.

4.1.2.2.3 Tima: Female Caregiver

Tima was fifty-two at the time of my interview with her, but she has since passed away. Tima was married to a biomedical doctor, a General Practitioner (GP), and it was from her husband that she first heard about HIV in the late 1980s. Tima and her husband lived in Gauteng from the late 1980s until 2003 when they moved back to Durban. Tima said that her husband had his practice in a mining town, and they saw the devastation that HIV and AIDS caused first-hand. Her husband was involved in HIV education and awareness and Tima became involved in these programmes at a community level. Tima was very active in the community and when she and her husband returned to Durban, she reconnected with a friend (this happened to be Mya) and they talked about the social working projects they had been involved in. Mya told her of her work with hospices and providing palliative care to PLWHIV and Tima decided to join Mya in her work.

4.1.2.2.4 Nani: Female Caregiver

Nani is a forty-five-year-old small business owner. Nani's domestic worker was diagnosed with HIV in the year 2000 and whilst Nani had heard about HIV and AIDS, she said that she did not take too much notice because she had never met anyone with HIV. Nani said that she had a good relationship with her domestic worker, Ntombi, and she took it upon herself to learn as much as she could about the disease so that she could help Ntombi. Ntombi lives on Nani's property because her home is in a rural area in KwaZulu-Natal and the time and distance to travel on a daily basis is too great. Nani takes Ntombi to the clinic when she needs to go, she drops her off in the morning and picks her up when Ntombi messages to say that she is finished. When Nani's business began to bring in a comfortable profit, she decided that she wanted to donate some of her profits to an NGO, specifically one based on Islamic faith principles. There are numerous Islamic faith-based organisations in Durban, KwaZulu-Natal and Nani researched them extensively and, in addition to donating money, Nani decided that she wanted to volunteer her services. Nani has attended lay counselling courses and basic care courses, and she has been providing care to PLWHIV for over ten years.

4.1.2.2.5 Sana: Female Caregiver

Sana is a thirty-five-year-old stay at home mother of three children. Sana said that she got married when she was very young and had her children young. She said that she did not have any personal connection to a PLWHIV when she began her care work, but rather that she felt compelled to help. Sana volunteers with two Islamic faith-based organisations in Durban and has worked with many MLWHIV. Sana has been working with PLWHIV for eight years and she says that whilst it is hard work and there is a lot of secrecy involved (only her immediate family are aware of the details of her care work), Sana finds that what she does is psychologically and spiritually rewarding.

4.1.2.2.6 Tasneem: Female Caregiver

Tasneem is a forty-three-year-old former nurse. Tasneem and Azhar are friends who met through their husbands. Tasneem's husband is also a surgeon. Tasneem first heard about HIV and AIDS when she was studying to become a nurse. She has worked in a public hospital in Durban and said that she has met "*countless HIV+ people*". Tasneem said that she decided to stop working full-time about ten years ago and has since focused her time and energy on HIV and AIDS awareness and education programmes at a community level through an NGO she volunteers at. She said that the NGO in question is not faith-based and the PLWHIV whom they serve include MLWHIV, some of whom she said are "*too scared to go to Muslim organisations because they are worried that they will be judged and treated poorly*". Tasneem also stated that the work she does is spiritually rewarding.

4.1.2.2.7 Jamia: Male Caregiver

Jamia is a forty-five-year-old male who has been working with PLWHIV through his local hospice and a faith-based NGO for almost twenty years. Jamia noted that male caregivers are not common and sometimes he gets teased by family and friends for what he does. Jamia works in Information Technology (IT) and said that he works remotely and that his hours are very flexible. Jamia's father is a biomedical doctor, a GP, and Jamia said that when he was younger he would spend some of his time at

his father's practice which was, at the time, based in an industrial area. Jamia would also accompany his father when he did home-visits and he said that in the early days of HIV and AIDS his father would have quite a few home visits to PLWHIV, and he watched his father sit with them and talk to them whilst he administered treatment. Jamia said that once he had completed his tertiary education and had gotten settled in his job, he decided that he wanted to be involved in community engagement. He says that he saw first-hand how PLWHIV are stigmatised and discriminated against, and seeing his father treat PLWHIV in a humane manner and the difference that it made to them, motivated Jamia to become involved in HIV and AIDS. Jamia noted that he remembers extended family members, at functions, whispering about his father's work, "*they would talk about how he went into the townships to treat people and then they would try to guess if my father also had HIV*". Jamia said that his father did not care about what people said about him behind his back, and that his father believed that it was his duty not only as a doctor but as a Muslim to ensure that he provided treatment and care to everyone he was able to. Jamia has adopted his father's philosophy and says that he tries to live his life according to Islamic principles which speak to treating other people with care and compassion and he feels that PLWHIV need this more than others.

4.1.2.2.8 Huzaifah: Female Caregiver

Huzaifah was fifty-eight-years-old at the time of her interview and has since passed away. Huzaifah was a stay-at-home wife (to a lawyer) for the entirety of her marriage. Huzaifah and her husband had four children and she said that once her children were all at school, she had a lot of time on her hands. Huzaifah said that when she got married her husband hired a domestic worker to help her out around the house, and with their children no longer taking up her time during the day, she was left to think about what she was going to do to pass the time. Her husband is friends with Mya's husband. Huzaifah's husband told her that if she wanted to get a part-time morning job she should, or alternatively that she should speak to Mya who is involved in social projects and volunteers at hospice. This was how Huzaifah was introduced to caregiving and working with HIV+ people. Huzaifah said that her husband was apprehensive at first when she told him that she would be providing care to PLWHIV,

but she reassured him that there were safety protocols in place. Huzaifah's husband said she was very proud of the work she did and that he was very proud of her and the strength she showed through the years. I found out that Huzaifah had passed away when I called for a follow-up interview in 2020 and Huzaifah's husband commented that he has had to deal with instances where extended family members or acquaintances would pass comments about Huzaifah having had HIV and that being the reason for her passing. Huzaifah noted, in a previous interview, that some people in their inner circle would pass comments about the possibility of her contracting HIV because she was in contact with HIV+ people but she was not concerned about this. Her husband said that she enjoyed what she did, and she knew that she was making a positive difference in people's lives and that was the most important thing for her.

4.1.2.2.9 Sabra: Female Caregiver

Sabra is a fifty-year-old part-time bookkeeper who has been working at a medical practice in Durban for twenty years. Sabra has worked with faith-based NGOs for twenty years in various capacities and began caregiving roughly ten years ago. Sabra's brother is a doctor who works at a provincial hospital, and she would often listen to his stories about his work and was especially saddened when he would talk about HIV and the effect that it had on people's health and well-being. Sabra said that she would sometimes go on home-visits with the NGO she volunteered at and would talk to PLWHIV that the organisation assisted. She said that she felt that just having someone listen to them without judgement seemed to make a difference and was comforting.

4.1.2.2.10 Nazia: Female Caregiver

Nazia is a fifty-eight-year-old mother of two children and has been married for forty years to a businessman. Nazia said that she started learning about HIV and AIDS after she read Nkosi Johnson's[75] story and she said that she was heartbroken at hearing about how HIV+ children were treated. Nazia has volunteered with AIDS orphans and

[75] Nkosi Johnson, who was born with HIV, was a young HIV and AIDS activist who passed away in 2001.

with adults living with HIV. Nazia was involved in setting up support groups for MLWHIV because she felt that if the community has cast them out, they would be able to form their own community and provide the emotional support that they needed.

TABLE FOUR: CAREGIVERS TO HIV+ MUSLIMS IN DURBAN

Caregiver	Gender	Reason for becoming a caregiver
Mya	Female	A clinic visit with her child made her aware of the stigma people with HIV and AIDS face and she decided to get involved in caregiving as a result.
Azhar	Female	Azhar's interest was sparked by her husband who is a surgeon.
Tima	Female	Through her husband who is a general practitioner.
Nani	Female	Though her domestic worker who tested HIV+
Sana	Female	Felt compelled. A type of 'calling' to do HIV and AIDS caregiving.
Tasneem	Female	Through her work as a nurse.
Jamia	Male	Though his father who is a general practitioner.
Huzaifah	Female	Through Mya.
Sabra	Female	Through her brother who is a general practitioner.
Nazia	Female	Became involved after reading Nkosi Johnston's book about his experiences as a child with HIV and AIDS.

4.1.2.3 Imams: Islamic Scholars and Community Leaders in Durban, Kwazulu-Natal, South Africa

The translation of the word *Imam* is leader, or one who leads (Huda, 2019; Goettel, 2022). In the most common sense, an *imam* is someone who leads other Muslims in congregational prayers. The term may be applied in two ways; (1) as a position of

authority and leadership in which case the word is capitalised (*Imam*), or simply; (2) as one who leads prayer and in this case the word is not capitalised (*imam*) (Huda, 2019). An *Imam* may be likened to a Christian minister or a priest. An *Imam* holds an important place in the community in which the *Imam* resides and works. An *Imam* both leads prayer at the *masjid* and provides leadership for the community. *Imams* are, in a sense, employed by their communities and live at or very near to the *masjid* where they work in either a house or flat/apartment. *Imams*, who are always men, are expected to have deep knowledge and understanding of the *Qur'an.* They should be able to recite it from memory and are required to know the English translation of verses (Huda, 2019). In addition to leading prayer, an *Imam* provides counselling to the congregation (Huda, 2019). Counselling may be of a personal, religious or spiritual nature and may occur individually or in groups (for example families or married couples). *Imams* are often contacted for religious advice; they officiate weddings and plan and execute activities for Muslim youth in the community. *Imams* are expected to build and maintain relationships with people in their community and visit the sick (Huda, 2019). As such *Imams* serve as guides and leaders for their communities.

4.1.2.3.1 Imam Hamzah

Imam Hamzah had been in his role for twenty years at the time of his interview. He is a younger *Imam* and is in his late forties. Imam Hamzah has been involved in HIV and AIDS activism from around the time he began his work as an *Imam*. He recognised it as a problem in the Muslim community that was going unaddressed, and he believed that HIV and AIDS needed to be spoken about. He has a very strong connection to his community and plays a very active role in it. I have been to the *masjid* he works at on numerous occasions and have heard comments from his congregation about how well he relates to them, especially the younger people, teenagers and children. He is a very approachable person, often makes pop culture references when he gives his speeches, and this has made him popular with the youth. Imam Hamzah has given numerous talks on HIV and AIDS at religious gatherings and as part of his sermons on a Friday afternoon. He believes in educating people on the disease rather than "*pretending that it doesn't exist*".

4.1.2.3.2 Imam Rafiek

At the time of his interview, Imam Rafiek had been active in his role as an *Imam* for more than forty years. He is well known in the Muslim community in Durban and has given talks at many religious events, "*I have lectured so many kathams that I can't count them anymore*". I have personally heard Imam Rafiek lecture on a number of occasions. Imam Rafiek holds a more conservative worldview and warns people against the "*evils of this world, and not to fall into temptation or give in to their nafs or hellfire awaits them*". Imam Rafiek is a very respected member of the wider Muslim community in Durban and, as such, has a strong influence. He has lectured on the topic of HIV and AIDS; however, his approach has been one of condemnation by focusing on the 'immoral' acts which he links to transmission of the disease. He views HIV and AIDS as a punishment that has been sent by Allah as a result of, what he terms, "*the waywardness of humanity*".

TABLE FIVE: THE ROLE OF IMAMS IN HIV AND AIDS IN DURBAN

Name of Imam	**Involvement**	**Stance**
Imam Hamzah	When he became an Imam and recognized HIV and AIDS as a problem in the Muslim community of Durban.	Important to educate rather than pretend HIV and AIDS does not exist in the Muslim community in Durban**.**
Imam Rafiek	Through his role as a Imam.	Conservative viewpoint and a stance of condemnation. Lectures on immorality.

Having introduced the key players in this chapter so as to set the stage for the ethnography, the following chapter engages with the concept of explanatory models and, as such, with how MLWHIV in Durban, South Africa, understand the disease they are afflicted with. The way in which a group of people understand a particular disease has an impact on how they seek diagnosis, treatment, and care as will be portrayed in the following chapter with respect to Muslims in Durban who have HIV and AIDS.

CHAPTER FIVE: EXPLANATORY MODELS OF HIV AND AIDS: THE MUSLIM PERSPECTIVE

"*There is no disease that Allah has created, except that He also has created it's treatment"* – Sahih Bukhari (71: 582)

The chapter explores how HIV and AIDS is explained and subsequently engaged with and then addresses how treatment is navigated in a pluralistic manner by Muslims living with HIV in Durban, South Africa. The information gleaned and analysed includes denialism, notions of sickness specifically with respect to HIV and AIDS, HIV and AIDS as a punishment from Allah as well as the concept of 'evil eye'.

Brown et al (2005) assert that any given society has its own medical system which provides a society with a way in which to understand and make sense of the cause/s of disease, with systematic ways in which to diagnose a sickness and with practices and medication[76] to combat or cure sickness. Religion also forms part of a society's medical system and has an impact on how people understand sickness. This chapter, therefore, is an ethnomedical enquiry, which Fabrega (1975: 969) defined as "the study of how members of different cultures think about disease and organise themselves toward medical treatment and the social organisation of treatment itself". Wellin (1978) explains that there is a rather complex relationship between health and sickness. This relationship includes the cultural and/or religious beliefs about health and healing. The manner in which sickness is understood within a community is important if intervention and prevention of disease transmission is to be successful. The sickness must also be believed to affect the members of the community in order for them to think about it and formulate ways of understanding treatment. The following sub-sections explore the manner in which HIV and AIDS is framed in Islamic discourse on the subject.

5.1 Sex and HIV as a Disease of the 'Other': "IT WON'T HAPPEN TO US"

According to Brown et al (2005: 10), "the purpose of basic research is to expand knowledge; the purpose of applied research is to help solve specific human problems".

[76] Medication, in this sense, is not merely biomedical and pharmaceutical. Medicine can be spiritual in nature.

At the beginning of this study the main aim was simply to understand the existence and experience of HIV and AIDS amongst Muslims in Durban, South Africa. At the very least the study aimed to shed light on an area of HIV and AIDS that has been neglected and expand upon knowledge in this area. Through the research process and the interviews conducted with various stakeholders, it became evident that HIV and AIDS is a human problem for Muslims. The response of denialism, as noted in Chapter Three, is evidently strong in this community. This can be seen in the difficulty that I had when trying to gain access to the field and find research participants. Sister Aisha has also noted that in all her years in the field, she finds that denialism about HIV and AIDS and Muslims is strong, "*if you mention HIV testing to a Muslim, they will ask you why you are telling them about it because Muslims don't get AIDS*". Sister Aisha further noted the denial about Muslims having pre- and extra-marital sex and ingesting recreational drugs, especially in relation to Muslim youth.

Participants asserted that there is little, if any, open discussion about sex and HIV and AIDS in homes and in religious spaces, for example, *Moulanas*[77] speaking openly about HIV and AIDS and the threat that it poses to Muslims. When HIV and AIDS is discussed in religious spaces, such as sermons[78] given by *Moulanas*, it tends to centre around HIV and AIDS being a disease that affects the 'other' and not Muslims, and that any infected Muslim is one who engages in risky behaviours and subscribes to Western cultural ideologies that encourage sexual liberation. Imam Rafiek was very clear in his opinion on the matter. He believes that Muslims have become too immersed in Western culture, first through television and now through social media. He stated that "*teenagers are hooked on their cell phones and eating up all these Western TV shows and things. Then they want to have boyfriends and girlfriends and copy what they see on TV, asthagfirullah*[79]*. Such acts of jahiliyyah*[80] *must not be tolerated*". Imam Rafiek firmly believes that Muslims must strictly follow the teachings of Islam in order to be safe from harm, stating, "*if you read your salah on time, stay away from the opposite sex, dress properly, and spend your free time reading Qur'an, then you will not get this thing. This* [HIV] *is not a problem for true believers*". He warns

[77] A Moulana is someone who is leader and scholar in the religious community and also serves as a preacher.
[78] This includes the sermon that is part of the Friday, Jumu'ah, prayer and at other religious gatherings.
[79] Asthagfirullah directly translates to "I seek forgiveness from Allah" and is often said when a person does something wrong or says something wrong (Shaikh, 2022).
[80] Jahiliyyah is the Arabic word for ignorance and is also used colloquially to describe someone who breaks rules and is disruptive.

parents about the dangers of social media and how it can influence their children and easily lead them astray into, *haram*.

Imam Hamzah, however, had a different approach. He believes that telling young people, or anyone for that matter, what to do and "*preaching fire and brimstone*" does not help to alleviate the problem. Imam Hamzah has worked on many HIV related projects and has counselled HIV+ Muslims as well. He believes that it is important to "*give people reasons other than that they are going to hell for eternity to burn. Allah is Ghafoor ur Rahim*[81]*, he forgives, and he is merciful. He knows we are flawed, He created us. He knows we will make mistakes. But we can be forgiven if we seek His forgiveness*". Imam Hamzah explained that he focuses on forgiveness because he believes that scaring people into submission does not work. He stated that when he runs workshops with the youth, he talks to them about safe sex and stresses the importance of young people taking care of themselves and not giving in to peer pressure.

Shamil and Habib both indicated that they had not thought that they would be susceptible to HIV infection. In the words of Habib, "*It just never crossed my mind. Now I know it sounds stupid, but I didn't think it would happen to me*". Shamil said that HIV was not discussed until very recently in religious spaces, such as during Friday sermons, however, now that it is, the sermon is usually very negative and tends to focus on the moral decline of society and how Muslims must not succumb to temptation in their everyday lives.

Badri (2000: 30) writes that HIV and AIDS is a "disease that affects homosexuals and the promiscuous" and as such anyone who is diagnosed with the disease must be deviant. Badri's (2000) work is very anti-Western in nature and calls for Islamic solutions to what he construes as deviant behaviours. Such solutions, Badri (2000) asserts, include getting married young so that one avoids having pre-marital sex, staying away from or reducing interactions with the opposite sex and women having sex with their husbands at their husband's will. Sex is not openly discussed in Muslim households and is considered a taboo topic. Sex education is not considered of any importance, and it is argued that it leads to promiscuity (Badri, 2000). All of my key informants noted that sex was not a topic for discussion in their homes when they were

[81] All or ever-forgiving (Morgan, 2010).

growing up. My female research participants said that sex was only mentioned in terms of childbearing and that sex for pleasure was not discussed. Narda and Sadira both said that they had no clue what to expect when they got married and their mothers were too shy to talk to them about sex, saying that their husbands would tell what to do. Narda said that her mother told her that her husband would know what to do and that would be good enough. Sadira said "*my mother told me that it was my job to please my husband and do what he asks. She was too embarrassed to talk to me about sex, I knew nothing when I got married and my husband didn't really seem that interested in sex, and I thought that this was normal. Now I know why he wasn't interested in sex with me, he wanted to have sex with other men*". She further stated that "*maybe if he was just allowed to be himself, we would not have gotten married, and he could have lived how he wanted to. He kept saying that marriage was to save him from haram, but it didn't really, it just helped him hide it. It messed up my life while he acted like nothing was wrong with him and that I was the problem*".

Sami echoed similar sentiments to those of Narda and Sadira. Sami stated that before he got married, his father sat down with him and spoke to him a little about the act of sexual intercourse so as to try and prepare him for it, but Sami says that the conversation was not very informative and was rather awkward as his father seemed embarrassed. Sami and his wife were very young when they married, and they were both inexperienced. He said that his wife was not comfortable when it came to sexual intercourse and was adamant that sex was only to be engaged in in the missionary position, and anything else was *haram*. He said that on the night of their wedding they were not sexually active, and it was perhaps two months after their wedding when they had sex for the first time. Sami said that he assumed that his wife was shy and perhaps scared as they did not know each other well because they had an arranged marriage. He said that "*sex with her was very boring. She would just lie there, and it was like she was waiting for it to be over… I don't know what her expectations were or even what she knew about sex, but she always seemed uncomfortable and, honestly, this was very off-putting*". I asked Sami if he had ever spoken to her about this and he responded that he had, stating, "*I tried to talk to her about it, but she would just change the subject or pretend that she didn't hear me and walk away*. Sami said he had asked her "*to try new things in the bedroom but she refused; she wouldn't even give me a blowjob*". He says it was this lack of having his sexual needs met that led him to seek

sex elsewhere, specifically with sex workers. Sami noted that he and his wife did go to therapy at some point after their diagnosis and he stated that it was in that space that she told him that sex was not something that was brought up in her parents' home, and that the night before her wedding her mother just said to her that her husband "*will take care of everything, you just have to lie there and he will do what he needs to*". Sami said that when they talked about sex in therapy his wife came across as being embarrassed to speak about it and it seemed that she did not think that sex could be fun and pleasurable but that it was simply a duty of the wife and a way to have children.

Women, research participants noted, are not engaged with concerning the topic of sexual intercourse and, when they are, the focus is on the man's pleasure. This is not a purely South African Muslim issue as Dr Heba Kotb, who is based in Egypt and describes herself as a 'sexpert to the Arab world', noted to Clark-Flory (2007). When asked about the female role of exploring and learning about their own bodies through masturbation, she responded that a woman does not need to masturbate and that she is not sympathetic to females who choose to masturbate because she believes that it ruins their sexual futures. Dr Heba Kotb continued to say that "They're ruining their sexual futures… a woman has to remain blank until she gets married and by masturbating, she is forming her sexual identity" (Clark-Flory, 2007). Dr Heba Kotb believes that men have natural urges that cannot be controlled and likened masturbation to a "call of nature" for men (Clark-Flory, 2007). Dr Heba Kotb further stated that if a woman is married then the only reason for her to masturbate is if her husband is not able to have sex. Dr Heba Kotb also noted, "There is no need. If her husband is operative and they are having sex, there is no need" (Clark-Flory, 2007). This perspective is common in Muslim cultures across the world which are patriarchal and hold that women must control their sexual desires while men are susceptible to their *nafs* or natural urges and are judged less stringently than their female counterparts.

There is a strong sense of denialism in the broader Muslim community as evident in the words of Hasnain (2005) who pointed out that HIV and AIDS is not a disease that Muslims feel the need to worry about because of strong religious morals. It is a disease for 'others' and for those who do not follow the teachings of Islam and are 'deviant'. If the disease is not thought about as affecting Muslims, then the community is not able to mobilise towards prevention and intervention. Sister Aisha talked about her work

experiences in a former Indian township[82] in Durban during the 1990s where she would come across Muslim men soliciting sex workers. She noted that she would approach these men and ask them if they needed condoms. Sister Aisha further stated that she would try to talk to them about HIV and AIDS, but she says that they would simply brush off her comments. Sister Aisha noted that she was told many times that "*HIV is a black disease, it's not a Muslim problem*". Sister Aisha also said that when she tried speaking to Muslims in the community about the importance of getting tested for HIV, they would laugh at her and tell her that she is wasting her time by coming and speaking to them about HIV and AIDS.

Imam Hamzah speaks about the dangers of HIV and AIDS often, and he says that he receives questions from his congregation about why he does this because they believe that Muslims don't need to be concerned with the disease. The Muslim community in Durban, through various NGOs[83], have organised to assist HIV+ non-Muslims, and where they have given assistance to HIV+ Muslims this is kept very quiet and, in some cases, denied. Denialism, thus, does not only exist in relation to believing that HIV and AIDS does not affect Muslims. Denialism also exists to silence the existence of the disease within the Muslim community. I discovered this when I was searching for an NGO to conduct my research at. A close friend of mine had mentioned organisations that I could contact as she knew that they provided support for Muslims living with HIV because she had either volunteered with them directly or knew someone who did. I approached all of the organisations and was informed that they did provide support and care for people living with HIV, moreover, that they did not know any Muslims living with HIV. One of the organisations, in particular, probed me quite strongly on how I arrived at the conclusion that they worked with HIV+ Muslims. The female working at the organisation whom I spoke to was very uncomfortable when I asked if they had Muslims living with HIV in the care of the organisation. She demanded to know who I was working for and did not readily accept that I was a student wanting to conduct research for my degree and that I was not affiliated with any other

[82] Townships are designated residential areas that were created during Apartheid specifically for black, Indian, and coloured populations. Townships have high population densities, in some instances higher than actual Towns and Cities (Donaldson, 2014).

[83] For example, the Muslim AIDS Programme, Islamic Relief and Bayt-ul-Nur.

organisation. I was met with equal suspicion at other organisations which I approached.

This secrecy and silence surrounding the existence of HIV and AIDS in the Muslim community can be detrimental if not addressed as my research reveals that the secrecy that veils the disease and the associated stigma places many people at risk.

The following sub-section will explore the medical system within the Muslim community.

5.2 Understanding Disease and HIV and AIDS: 'WHY ME?'

Lynch and Medin (2006) state that explanatory models (EMs) can be described as domain specific, namely, physical or psychosocial. EMs are useful in understanding the plurality that exists in relation to health and well-being, and a holistic understanding of a sickness is important for effective diagnosis, treatment, and care. EMs that fall under the physical domain relate to the natural physical world and biomedicine whereby illness is understood to be as a result of a disruption to the body's physiological processes (Lynch and Medin, 2006). EMs that are psycho-social in nature are linked to the social environment, to a person's thoughts and emotions, to the realm of complementary and to alternative medicine (CAM) (Lynch and Medin, 2006). The domain specific model sees these cognitive domains as separate. Anthropologists, however, have put forward an alternative hypothesis which combines the physical (body) and psychosocial (mind), i.e., the cross-domain hypothesis. The cross-domain hypothesis proposes that "psychosocial and physical causes can play distinct roles in a single explanation of illness" (Lynch and Medin, 2006: 287). The cross-domain hypothesis while only formally recognised recently, has been present in anthropological works for decades. Evans-Pritchard's (1937) work among the Zande is a prime example of the cross-domain hypothesis. The understandings that the Zande have about sickness and illness lie in both the physical and psychosocial domains. The Zande know what causes sickness, i.e., the biology and science behind it, but they also want to understand *why* a particular person is inflicted and *by whom* the feeling of sickness was caused. The explanations, for the Zande, lie outside the realm of biology and science, and move into the supernatural, which speaks to the

psychosocial domain. This is due to the fact that illness is often explained as having come from the negative thoughts and ill-will of another (e.g., jealousy), which leads to witchcraft being performed against a person. HIV and AIDS among Muslims can also be explained using the cross-domain hypothesis. Muslims understand the physical cause (the *how*) of HIV as being biological, but this is not enough to complete the understanding of the disease. It is important to understand the *"why"* (why me?) which can only be answered through a psychosocial framework which, in this case, leans against religious understandings of disease.

From unstructured interviews with my interlocutors the manner in which sickness is understood is two-fold, from a religious perspective and from a biomedical perspective. From a biomedical perspective my participants understand that disease is something that infects one's body. They understand that disease gets transmitted in various ways, for example, through the air and exchange of bodily fluids. My participants therefore stated that they understood how a person can get infected with HIV and how it is transmitted. Haleh, Hana, and Dalileh, as the youngest of my key informants, all said that they had been educated about HIV and AIDS when they were in high school. According to Haleh, "*the guidance counsellor spoke to our class about it. She told us what HIV was and how it was transmitted. She told us the best way to make sure that we don't get HIV is to not have sex*". Hana, who is the youngest of my key informants, said "*we had a class about STDs and HIV was mentioned. But it was very uncomfortable, and the teacher looked like she was very embarrassed. She told us the best way to keep safe from STDs was to just not have sex, but she also reminded us that condoms were freely available in the toilets, and we should use them if we couldn't control ourselves*". Six of my participants said that prior to them being diagnosed, they did not know much about HIV and AIDS and did not think that it would concern them. Sadira and Narda both mentioned that they had read about HIV in the newspapers and heard about it on the television news. Both said that they were not concerned about it because they were practicing Muslims and believed their husbands to be the same. Sadira said "*I wasn't worried about it at all. Why should I have been? I was doing all the things that I was told to do growing up. I was praying, I was a virgin when I got married and I only slept with my husband. There was nothing to worry about*". After their diagnoses they received pamphlets and researched what they could to find out more about the virus. Rahele said that a social worker at the hospital helped

her understand the disease well, "*She explained it to me so nicely. She was so patient, and she spoke to me in a way I could understand"*. All my participants are on anti-retroviral therapy (ART) and believe very strongly in taking their medication. Rahele and Narda's physical states have deteriorated over the years but they both feel that they would be in worse health if they had not stuck rigorously to their ART protocol, as Rahele stated, "*I could be dead*".

The psychosocial domain in relation to explanatory models, therefore, provides a different set of answers to questions that the biomedicine (which speaks to the physical domain only) cannot provide. The religio-cultural environment links to the psychosocial domain, and the following sub-section explains specifically how HIV and AIDS is explained through the lens of the psychosocial domain.

5.2.1 HIV and AIDS: 'Evil Eye' and Curses

EMs that relate to 'black magic' have been mentioned in the literature (Lynch and Medin, 2006) as well as by my participants. During an interview with Shiera, I was told of a woman she had seen who stated that she had been told by a spiritual advisor that someone was jealous of her marriage and had therefore caused the change in the behaviour of her husband which then led to them both contracting HIV. 'Evil eye', or *nazr*, is a common explanation for how 'black magic' is carried out in Islam (Rassool, 2018). 'Evil eye' may be accidental, where one may be jealous of another but not actively meant to harm the other person or it may be purposeful where the person responsible is fully aware of his/her thoughts and actions toward another (Rassool, 2018). Sister Rifat, Sister Aisha, Shiera, and Tasneem all said that they have worked with people who have used 'evil eye' as an explanation for how they contracted HIV. Shiera mentioned that 'evil eye' is a common notion used by Muslims to explain misfortune in general and has also been applied to HIV and AIDS in therapy settings. Shiera said, "*sometimes people don't want to be held responsible for their actions, so they blame it on jealousy. These faith healers are very quick to say that someone in your family is jealous of you and wants you to fail, and so they put nazr or curse you*". Dalileh said that one of her *'aunts'*, (her grandmother's sister), told her that "*someone must have 'put eyes' for my mother when she was young because my mother was very pretty and popular. That's why she got HIV and then she told me that whatever*

they did must have been so strong that it passed on to me". Dalileh said that she did not particularly believe this explanation, but that she understands that there are people who do.

5.2.2 Sickness as a Blessing, Sickness as a Curse: HIV and AIDS as a Punishment from Allah

Religion, as an institution in society, helps people to make sense of the world they are in, and helps people to navigate the world around them. In this sense, sickness is a symbol of something greater on a spiritual level. From a symbolic interactionist perspective, Strauss and Corbin (1990) argue that an individual's subjective perspective must be considered because this is how the individual makes sense of their world. From a religious (Islamic) perspective, sickness is believed to come from Allah, and is understood as either a test or punishment from Allah. This does not negate any biomedical understanding or experience of disease. There is, rather, a religious layer that is added to the understanding of disease in order to make sense of a person getting sick, the severity of the sickness and the pain experienced in relation to it. These understandings also speak to whether a person is seen as a 'good' person or a 'bad' person and as strong willed or weak willed in their spirituality.

When it is viewed as a test, sickness is understood by Muslims in a positive light. This tends to absolve the person from blame in relation to their sickness. For example, an interview that I had with a previous research participant (see Shaik 2009), reflects the sympathy and patience that she received upon her breast cancer diagnosis. She and her family and friends viewed her cancer diagnosis as a test from Allah and that she should, and would, persevere. Her family and friends rallied around her during her treatment and remission and there was no blame placed on her getting sick. A *hadith* found in Sahih Bukhari (550: 6235) proclaims that "if a person becomes sick, Allah rewards him for his sickness". In this sense, symbolically, sickness is seen to be a good thing in that it is understood to wash away one's sins and brings spiritual blessings to the afflicted person. Some further maintain that seriously sick people's prayers are answered and will often ask the sick person to pray for them (TheIslamicInformation, 2020). A *hadith*, narrated by Umar bin Al-Khattab, states "The Prophet (SAW) said to me: 'When you enter upon one who is sick, tell him to pray for you, for his supplication is like the supplication of angels'" (ahadith.co.uk, ND). When

my own mother was sick, a few years ago, she received numerous requests from family member for her to pray for them. Sickness, in this sense, is considered as a mechanism to purify one's spirit and relieve a person of their sins. This juxtaposes the experiences of my current research participants who expressed that they understand and experience their sickness (being diagnosed as HIV+) as being a punishment, and for most, so do their families. In the case of HIV and AIDS my participants were blamed because of assumed 'deviant' behaviour and there was a distinct lack of sympathy at the outset of discovering their positive status.

There is a hadith that states:

> *"The Messenger of Allah (PBUH) turned to us and said: "O Muhajirun[84], there are five things with which you will be tested, and I seek refuge with Allah lest you live to see them: Immorality never appears among a people to such an extent that they commit it openly, but plagues and diseases that were never known among the predecessors will spread among them."* (Sunnah.com)

This hadith is often used to explain the HIV and AIDS pandemic by Muslim scholars. Badri (2000: 30) has been especially vocal on this topic and has claimed that "AIDS is, in fact, the wrath of God over the promiscuous sexual revolution sustained by the loose and liberal mores of Western civilisation". Badri (2000) has referred to another hadith which states, "*If fāhishah[85] or fornication and other types of illegitimate sexual sins become rampant and openly practiced without inhibition in any group or nation, Allah will punish them with new epidemics (ta'un[86]) and new diseases which were not known to their forefathers and earlier generations*". The HIV and AIDS pandemic Badri (2000) regards as well suited to this viewpoint in that Badri asserts that the behaviours that are most at risk for contraction are what Badri (2000: 30) notes to be part of the "*Western sexual revolution"*. This hadith has been used as a warning and a response to the pandemic by Muslim scholars who argue that Muslims, and particularly the youth, are being exposed to Western cultural norms which are responsible for the

[84] This term refers to the first Muslims.
[85] Lewdness, perversion, or indecency.
[86] Plague

sexually deviant behaviour. Sadira stated that "*the Ulama*[87] *let us believe that it (HIV) was a curse from Allah, that one was being punished for one's sins*".

Rahele informed me that her mother had become sick a few years ago and when she said to her mother that she would pray for her, her mother responded by saying "*I don't need your dirty prayers. Why would Allah listen to you?*" This has happened to Rahele a few times since with other family members. Haleh has also experienced something similar with a family member. Her former father-in-law, with whom she has a contentious relationship, told her that she was not clean enough to pray, "*this was while I was still married to my husband, but it was after we found out we had HIV. I went to visit my in-laws and when it was time to pray, I got up to go and make wudhu*[88] *and he stopped me. He asked me what I was doing, so I said I'm going to read salah and then he told me I couldn't pray in his house because I was napak*[89] *and I would make the prayer space dirty*". In this it becomes clear the notion of the 'untouchable'. Family and other community members refrain from contact with an HIV+ Muslim, and this extends to the spaces that HIV+ Muslims are able to occupy should their status be known.

Caregivers similarly spoke to this in their interviews. They noted that some of the people they provided care for did not feel accepted in prayer spaces and were isolated in their homes. Imam Hamzah said that he was once questioned about whether he would let an HIV+ Muslim come to the masjid to pray and when he said that he would he was met with derision. He said that it was the same type of thought that an HIV+ Muslim is unclean and would "*soil*" the prayer area with their presence. Imam Hamzah said that he has made his point very clear and that he welcomes everyone to his masjid, and he reiterates often to his congregation that HIV is not a contagious disease that one can get from sharing space with an infected person. He maintains that "*we are all sinners, and only Allah can judge and forgive. There is no reason for me to stop an HIV+ Muslim from coming to pray, in fact it is a sin for me to do so. If I know that someone is HIV+ I don't mention it to anyone because it's not my business*".

[87] The word Ulama translates into "the learned ones". These are (usually) males who are considered to be "the guardians, transmitters, and interpreters of religious knowledge in Islam, including Islamic doctrine and law" (Gilliot et al, 2012).
[88] Ritualized ablution that a Muslim must perform before prayer.
[89] Unclean.

These kinds of situations contradict the earlier anecdote, where sickness was viewed as a test and not a punishment, and reflect a different side to how sickness is viewed. When sickness is perceived as punishment it is because a person committed a sin for Allah to send such a severe punishment to them. This notion led to my participants stating that they believed that they must have done something wrong earlier in their life to deserve this punishment. Dalileh expressed that she had an existential crisis because, "*I was born with this disease, why did I deserve that? What did I do, even before I was born, to get this thing?*". One response that Dalileh said she got to this question, was from an aunt (father's sister) of hers who said that *"the sins of the parent fall on the child"* and that her getting this disease was punishment for her mother. Dalileh stated that she has positive memories of her mother and does not believe that her mother was a bad person and so she refuses to believe that this is the reason for her being HIV+. Dalileh said that she moved away from trying to understand her diagnosis from a religious perspective because she could not find an answer that made sense to her, or that did not make her feel badly about herself. She believes that she needs to be positive about her situation so that she can be present for her family, rather than dwell on the negative and "*get lost in trying to understand why*". She said that "*if HIV is a test from Allah, then I will pass it!*".

Dalileh's outlook on her HIV status is more positive than most of my participants. There is a stark contrast with Rahele's experience and her feelings towards the disease, her diagnosis, and herself. Rahele feels like HIV has been used as a tool against her by her family. She believes that her diagnosis was a way for her mother and brother to "*get rid of me. They never loved me and would hurt me, and then used my HIV to say that I am a bad person and they don't want me around*". Rahele also questioned her diagnosis and contraction of HIV. She says she asked Allah "*why me? What did I do to deserve this?*" These questions have resonated with Rahele throughout her life, beginning with the abuse which she experienced as a child[90] by her brother, but became more pronounced upon her diagnosis. She says that she suffered from low self-esteem and negative thoughts as a result of her childhood and always tried to stay out of people's way, hoping that she would be left alone. Rahele's mother told her that she (Rahele) was being punished and when Rahele questioned her about what she was being punished for, she says that her mother told her that she was a bad child for

[90] Rahele inferred that the abuse began when she was 8 and continued until she was 13 years old.

accusing her brother of sexually and physically abusing her. Her mother maintains this attitude today. Rahele left school when she was thirteen years old as she felt that she had to fend for herself because her family was so poor and her mother constantly told her what a burden she was. Rahele noted that she ran away from home and lived with a family in the same general area as her own. Rahele stated that this was one of the few times in her life where she was happy and was treated well. When probed as to how she ended up back in her parent's home she said that her mother had forcefully taken her home. Rahele only told her father about the abuse when he was on his deathbed. The abuse she suffered at the hands of her brother was extensive. Some of the instances she described as "*you know the orange fine point pens? He used to poke me on my back with that and he used to hit me with iron on my head, up to today I've still got those chop marks*". The iron Rahele describes was a sad iron, a solid piece of cast iron that would be placed on hot coals to heat so as to be used to iron clothing.

Rahele married her first husband when she was in her late teenage years and divorced him about five or six years later. A few years later she was forced into a second marriage. Rahele was living in her parents' home, with her children from her first marriage, and when her father passed away her mother kicked her out of the house. Rahele says that her mother's reasoning was because her oldest brother (the man responsible for her childhood abuse), wanted to move back into the home. Rahele was then forced to live in a shelter and then her mother brought the man, Rahim, who was to be her second husband to her and insisted that she marry him. Rahele stated at many points during our interviews, that she "*is not a fighter*" and so she did not put up much of a fuss when her mother brought the man to her. She noted that she discovered later in the marriage that Rahim was HIV+ and that he had known his status for seven years before they got married. Rahim died a few years later from tuberculosis (TB). Rahele describes both her husbands as "*alcoholics, drug addicts… they used to hit me, even to be intimate with me, I used to get hiding for that and they used to send me out to go and beg and if I don't go and beg and bring things for them, drugs and everything, I used to go through a lot*". She goes on to explain that her brother as well as both of her husband's sold her for sex. Rahele stated that she has constantly questioned her life experiences and asks herself why she had to go through these experiences and what she is being punished for. Rahele recalls her angst when

she was first diagnosed. She told the doctors that her results must have been mixed up with someone else's and she asked for the test to be redone. She stated that she was tested five times, at different clinics and hospitals, and eventually she had to accept her fate. Rahele said that she was in a state of shock and wanted to die, "*I went and stood with my whole self in the centre of the road. I actually forgot that I had four kids, I just wanted to end it all*".

Each one of my participants said that they went through this stage of shock and questioning. My female participants expressed that they were, in the words of Sadira, '*good Muslim girls*' and questioned why they deserved such a punishment and what the punishment was for? Sadira, in particular, said "*I never went out and I was a virgin when I got married. Why? What did I do to deserve this and to deserve the husband that I got?*" Sadira, Haleh, Narda, Hana and Rahele all said that they had listened to their parents and elders growing up and followed whatever rules were put in place. This usually meant that they were not allowed to interact with boys or go anywhere with boys. Narda said that she wasn't even allowed to be alone with her male cousins. Rahele, Sadira, and Narda specifically mentioned that they did not have boyfriends before getting married because it was such a taboo topic and something that they were taught Muslims should not do. All my female participants stated that there were restrictions on their social activities and who they were friends with while growing up. Narda said that her grandmother told her that she should only be friends with Muslims and got upset with her when Narda mentioned a non-Muslim friend. Her grandmother's reasoning was that non-Muslims would lead her astray and she would engage in un-Islamic behaviours. Haleh and Hana said that they had had a boyfriend or two when they were in high school but that nothing physical had happened beyond "*holding hands and kissing*". They both expressed that they did not want to have sex before marriage and so would limit the physical contact that they had with their boyfriends. Haleh and Hana said that their boyfriends were in the same high school as they were in and they would spend time together during lunch breaks and before school started. Hana said that when her father discovered that she had a boyfriend he beat her for it. Hana further stated that her father told her that she "*deserved it*" when she told him about her HIV diagnosis because, according to him, she was "*running around with all the boys*". The theme of punishment filtered strongly through the reasoning and understanding of being an HIV+ Muslim.

Habib, Shamil and Sami all expressed similar sentiments about HIV and AIDS being a punishment, but they said that it was a punishment for their own actions, or as Shamil put it, the "*wayward life that I led*". They each believed themselves to be responsible for their contraction of the disease.

Thus, it becomes clear in this situation that illness originates from a change in one's physiological state in relation to a change in one's relationship to one's social world (Singer and Baer, 2012). By this I mean that the way in which an individual is treated by others in the social world (e.g., evil eye, or being looked down upon by elders in the community) as well as the thoughts that an individual has about himself/herself (e.g., low self-esteem, general negative thoughts) in turn affects the individual's body. It is important to understand EMs that include the psycho-social model, in this case religion as an EM for Muslims, as this can then be used to foster and implement positive change in a community. It is important to understand 'why' a disease is believed to exist because this attribute's blame, sometimes from the self to another, which is then important for understanding and healing.

The psychological effect of HIV and AIDS on a diagnosed individual is clear. There is an internal struggle with coming to terms with the disease and one's diagnosis. It leads to low self-esteem and possibly thoughts about suicide, which stem from how one see's one's worth as a person. This links with the notion of 'untouchability' as family and former friends keep their distance or treat the HIV+ Muslim negatively which impacts the social life of the HIV+ Muslim. The idea or notion that sickness is a punishment from Allah can be detrimental to a person's mental and physical well-being. Muslims try to force reasons beyond the biomedical to explain sickness and misfortune (Kahissay et al, 2017; Atum et al, 2021). This may be, as some note, a result of '*wayward*' or '*deviant*' behaviours, or a lack of regular salah (see Badri, 2000; Desai, 2004; Siddiquee, 2009; Bocci, 2013). It gives off the impression that the person suffering from affliction deserves what has happened and this may be regarded as victim blaming. Using such a reasoning translates into a lack of support being provided to those who need it. This also goes against the notion of non-judgmentalism that is proposed in Islam, the belief that only Allah has the right to judge a person.

Islamic teachings on sickness express the importance of visiting, caring, and praying for the sick and the spiritual reward that one receives for this is immense. Islam

preaches compassion, mercy, brotherly and sisterly love, sympathy and non-judgmentalism, however, in the case of HIV and AIDS this is not the reality, as my participants have pointed out (Esack, 2004; Positive Muslims, 2007; Esack and Chiddy, 2009). All my participants stated that the family members whom they told about their diagnosis shunned them and berated them about their diagnosis. Rahele was encouraged by a nurse to tell her mother and when she did, her mother laughed at her and immediately told Rahele's older sister-in-law (her eldest brother's wife), who then told all the neighbours. Sadira's husband became angry and violent and initially blamed her for his HIV diagnosis and told family members that she was an "*adulteress*". In Sadira's own words, "*I regarded myself as a God-conscious and God-fearing woman. I pray 5 times a day, I wear Niqab, and I keep my distance from men other than my husband. I was a virgin when I got married and have only had sex with my husband. But when I told him about it, he called me a slut, a whore and other names I will not mention. He blamed me for his infection, and I lived with this until he accepted and finally came out with the truth years later*". Even after the truth about her husband emerged, their families did not have much sympathy for her. Sadira said that her mother-in-law had said to her that if she had kept her husband satisfied then he would not have had sex outside of marriage. Bijan is the only exception in this study in that his stepmother, with whom he has a close relationship, was very supportive of him and has stood by him since he first opened up to her about his diagnosis.

It thus became clear through the research process that the response to HIV and AIDS by Muslims is contradictory to what Islam teaches. This ties in with what Esack (2004) noted about Muslim responses to HIV and AIDS; denial, silence, and rejection have clearly been exhibited, and my HIV+ participants expressed confusion over how to interpret their diagnosis and rationalise it. This is not to say that all Muslims respond in this way. It is important to note that there is a distinction between the general community (i.e., family and friends) and Muslim health care professionals and caregivers who work with Muslims living with HIV. The latter have shown to hold back their judgement and try to help where they can. Sister Aisha, a former nurse, specifically said that having worked in healthcare for over forty years and having been at the forefront of the response to HIV and AIDS, she feels that it is her duty to care for the sick. Sister Aisha has worked with NGOs that assist sex workers and, through her work, has come into contact with many Muslim men (she specifies) who have used

the services of sex workers. Sister Aisha has directly counselled Muslim men in testing and in the aftermath of a positive diagnosis. Sister Aisha further noted that there are more Muslims living with HIV than is commonly acknowledged and that most are too scared to tell anyone about their status. Caregivers expressed that they felt it was their responsibility to give Muslims living with HIV the support that they needed.

5.3 Practices and Medication to Combat and/or Cure Disease

Treatment for sickness tends to follow more than one avenue and is pluralistic in nature. Explanatory models directly impact treatment seeking behaviours. If the cause of an illness is psychological, then physical treatment is unlikely to work, or have much success. If a stomach ache, for example, is caused by anxiety, then taking medication will, at the most, alleviate the symptoms for a short while. If the anxiety is attributed to being the cause and this is worked on through psychological therapy, then the stomach ache will cease to be. My research pointed to a similar outcome in treatment seeking behaviours for HIV and AIDS. Medication in the form of ART is taken and adhered to but prayer (as a psychosocial treatment) is also regarded as a central factor of healing. In those whose viral load has become undetected this has been attributed to the power of prayer and to God's mercy.

The manner in which the relationship between health and sickness plays out exists alongside opportunities and restrictions afforded by existing broader social forces (Brown et al, 2005). This then determines if and how people seek medical help and the nature of that help i.e., purely biomedical, spiritual or a combination of healing systems. The culture of Muslim communities, which in this sense are the broader social forces in existence, have a strong social presence in an individual Muslim's life. The conservative nature of Muslim communities leads to judgement and stigmatisation of HIV+ individuals and, as I have learnt, those who are associated with them (Esack and Chiddy, 2009). This social force of silence and shame impacts the ability of a person to seek help, whether biomedical or any other form, because they are afraid of their sickness becoming public and of being ostracised by their community. A number of caregivers and professionals spoke to this, explaining that almost all of the Muslims living with HIV with whom they have worked have tried their best to keep their status to themselves. Tima noted that those who told family about their status were

stigmatised, treated badly and shunned, and she further stated that the only reason the person's HIV status was not spoken about was because the families were ashamed to be associated with an HIV+ family member. Sabra and Mya explained that they know many HIV+ Muslims who are so afraid of their status being made public that they forego medication for fear of someone finding out. Sabra said, "*I have known people whose health got so bad, I pleaded with them to go to the clinic, but they refused. They got so sick, and they would tell their families that they had cancer to explain why they were so sick*".

An HIV+ Muslim finds it difficult to get the support that they need and some resort to resourceful measures in order to do so. Some participants expressed, for example, that they did not attend the HIV clinic in their own residential areas but found a way to go to a clinic that was away from their home and where they were likely to not know anyone. They found ways to alter documents to provide proof of residence for the clinic they chose to attend. Tima says that some of her patients would go to the clinic before it opened, queue quietly to get their medication as soon as the doors opened and then leave so that they could avoid being seen. Sadira said that wearing a *niqab* is helpful because no one can see her face, "*people stare at me, obviously, but at least they don't know what I look like*". Rahele confessed to sometimes wearing a *niqab* to prevent people from recognising her. Jamia had a patient who forged his address so that he could go to a clinic in a different area and Nani said she once wrote an affidavit for a patient stating that the patient was living with her, so that the patient could go to the hospital in the area in which Nani lived which was quite far away from where her patient lived. Nani said, "*I just wanted to help, you know. They're so lonely a lot of the times, and suicidal too. Their families have already written them off, what happens when the community finds out? The families stay quiet to save themselves shame and embarrassment, not for any other reason, so I feel like if I can help in one small way and make life a little easier for a patient then I will do what I can*". Most of my participants expressed fear of being stigmatised by the wider community should they be seen collecting ARTs and so they did whatever they could to minimise that risk. Bijan and Dalileh were the only two who did not share the same fear. Bijan explained that he uses his medical aid to get his medication so he does not have to worry about it and additionally he said that his status is widely known anyway so it would be pointless him hiding when collecting his medication. Dalileh said that she felt that she

has nothing to feel bad about or to fear since she was born with HIV, and she therefore feels that she is not *"responsible"* for her HIV+ status in any way.

All my participants said that adherence to medication schedules is important but interviews with my participants elicited that treatment sought has been both biomedical and spiritual in nature. A few of my participants said that they also visit *Hakims*[91] as alternative spiritual healing so that they are able to have a holistic experience. Treatment that falls outside of the biomedical realm becomes a little less straightforward and is dependent on the person and their particular beliefs. All of my participants said that they prayed *salah* regularly. Salah is one of the five pillars of Islam, and a Muslim is required to complete five daily prayers, at various times of the day. Participants noted that they prayed at least twice a day. The reasons varied, with some saying that it is difficult to pray during working hours while others noted that they are sometimes too tired to do the longer prayers, especially when it is hot. Six of my participants went further to state that they used the service of *Hakims* to enhance their biomedical treatment. A common featured treatment offered by the *Hakim* is that they pray for the person coming to see them, they make a special *dua*[92] that is said just for that individual and the individual is then given a piece of paper with the scripture written on it that must be placed in drinking water. This is usually meant to be a one litre bottle of water that the person must drink every day. This 'holy water', or '*palita pani*', should be topped up every day and the paper must remain inside the bottle until a new one is given. Narda said, "*I take my meds regularly, I try my best not to forget, I put my alarm on my cell phone to remind me. I also go to this hakim once a month and he makes dua for me, and he writes a dua on a piece of paper that I put in my water jug and drink from every day. When I go back, he gives me a new paper, like a new script*". The frequency of visiting the *Hakim* is different from participant to participant with some saying that they go every month and others saying that they go as and when they feel the need to. *ZamZam*[93] water was also mentioned as a treatment. This is not easy to obtain but is prized when one is able to get it.

[91] Plural of *hakim*. A Hakim refers to a Muslim person who holds knowledge about religion and medicine and combines the two.
[92] Prayer.
[93] ZamZam water comes from Makkah and is believed to have special properties.

From my ten key HIV+ participants, six stated that they frequented Hadrath Badshah Peer's mazaar (shrine). Commonly known or referred to simply as Badshah Peer by local Muslims, the *mazaar*[94] is situated in one of the oldest cemeteries in Durban, Brooke Street Cemetery. The cemetery is separated according to four religious' denominations, namely, Christians, Muslims, Hindus and Jews. Badshah Peer's is situated at the heart of the Muslim cemetery and is built around the physical grave of Hadrath[95] Sheik Ahmed Badshah Peer, who was a great and well-known Sufi saint. Hadrath Badshah Peer is considered to be one of the most celebrated Muslim mystics in South Africa and it is believed that his lineage traces back to the Prophet Muhammad (PBUH). The shrine is very popular with local Muslims and is also visited by Muslims from around the world. Non-Muslims have been known to visit the shrine as well.

Hadrath Badshah Peer arrived in South Africa as an indentured slave labourer from India in 1860. He was indentured to the sugar cane farms North of Natal and it is believed that he performed mystical acts in his time as an indentured labourer. He was given an honourable release from his contract by the British government who recognised his abilities. Hadrath Badshah Peer was only recognised as a saint after his demise, and this was done by Hadrath Shah Goolam Muhammad Soofie, who, in his own right, was a great Muslim missionary and was responsible for the conversion of Hindu Indians to Islam in South Africa. He was also believed to be a saint. Soofie Sahib, as he is commonly referred to, has his own *mazaar* in Durban North and a number of *masjids* that have been built in Durban house his name and are occupied and led by his descendants.

Badshah Peer's is a place that is frequented by many Muslims for numerous reasons. These may be for spiritual upliftment, and/or to ask for assistance with problems, such as, health, monetary advice, safety and security. Six of my participants explained that they visited the *mazaar* as often as they could, at the very least once a month. Of the six participants who frequented the *mazaar*, four would take offerings with them. These offerings would be sweetmeats, usually *jalebi* and *sew*[96], and sometimes small amounts of money. The money is deposited into a box that is built into one of the inner

[94] Mausoleum
[95] See Hazrat
[96] Jalebi is a spiral shaped, syrup filled, deep fried batter and sew is a thin stripped deep-fried confection.

walls that houses the grave. The sweetmeats are taken by one of the priests who work at the mazaar and placed by the graveside and they are then prayed over and blessed. Some of the sweetmeats are returned to the person and are mixed with other sweetmeat offerings brought in by others. Each person had a different experience in how they used the *mazaar*. Some would either offer two *rakaats nafl salah*[97], when they entered the *mazaar*, after handing over the offerings, and some would read from the Qur'ans provided and then make dua and make their requests, which usually include good health and well-being. Once done with either of these forms of prayer, a group of people would then go to the entrance to the grave and a priest would say a prayer over the group of people, blessing them. The priest would have a wand of large and long feathers (usually ostrich) that is used to lightly brush over people as the prayer is said. After, a sip of ZamZam water would be offered and the visitor would leave the *mazaar* by walking backwards out of the building, because it is considered disrespectful to show one's back to the grave. The *mazaar* has symbolic meaning and provides spiritual upliftment. All the interactions within the *mazaar* are symbolic and ritualised and serve to help those who attend the *mazaar* with meaning and purpose in their lives and to know that they are not alone, and have help with the problems they are faced with. My participants expressed that the experience gave them spiritual strength each time they visited. This translated into psychological well-being. Rahele, for example, likes the privacy of the *mazaar* because she says that no one needs to know why you are there and she feels spiritually and psychologically uplifted after a visit. There is not much interaction between people inside the *mazaar*. Rahele tries to go as often as she can, which is usually about once a month.

The spiritual treatments have a more personal quality to them. Even though the interactions that my participants described at Badshah Peers are not always one-on-one, they feel a sense of community and spiritual upliftment from being there. The environment is very different from the hospital setting which my participants described as loud, congested, and uncomfortable, with rude staff. Sadira said, "*I hate going to the HIV clinic because it is always so busy and noisy, and the nurses can be so rude too. There are too many people too and it just makes me uncomfortable. I like going to Badshah Peer because even though it is busy, it is calming too and has such a strong effect on me. Everybody is nice because we are all there to ask for help. I*

[97] A short prayer.

always feel better after I've been there". My participants expressed that the spaces are very different from each other but that each provided them with what they needed, i.e., the hospital for their medication and the *mazaar* for their spiritual upliftment. The cross-domain hypothesis, as mentioned earlier, thus results in a cross-domain treatment plan.

My participants stressed, during their interviews, that the spiritual treatments that they undergo have a positive effect on their overall health and well-being. Hana had an undetectable viral load at the time of her interview, and she believes that it is because she is using alternative spiritual treatment together with her biomedical treatment. Rahele strongly believes that she is only alive today because she visits the *mazaar* often and prays regularly. None of my participants, however, believed that they could be completely cured by spiritual treatment alone. They did, however, have hope that a vaccine or a medication would be created to cure HIV and AIDS. Haleh said that "*Medicine is so advanced now, and technology is advanced too so maybe there will be a cure to what I have. I can pray and hope for the best!*". Hana said that she believes that the virus has not progressed in her body because she is combining spiritual treatment with her biomedical treatment. She said that ART is keeping her healthy and her efforts with the *hakim* she regards as keeping the virus at bay. The spiritual aspect of healing is tied to the psychosocial domain and is perceived, by HIV+ Muslims living in Durban, as an important therapy to adhere to.

Understanding how Muslims interpret and explain sickness is important in the fight against HIV and AIDS amongst Muslims. It is not simply more detailed research that needs to be done but awareness and discussion around the stigma-producing ideals, assigning and ascribing blame, and the intersection of religion and biomedicine in seeking treatment protocols that is important in gaining a better understanding of Muslims and HIV/AIDS in diverse socio-cultural contexts. Understanding the drivers of HIV and AIDS can lead to proactive measures being taken and intervention strategies being more successful, thereby reducing the spread of HIV and AIDS. Furthermore, understanding the different ways in which disease is perceived by Muslims can affect how treatment is approached and also how the stigma experienced by HIV+ Muslims may be engaged with and reduced.

This chapter has highlighted, through the voices of my research participants, how HIV and AIDS is understood in the Muslim community in Durban. It has drawn attention to the experiences of HIV+ Muslims, how they experience their disease socially and culturally and how they make sense of it in their lives. The chapter has also explored the various ways in which Muslims living with HIV seek alternative treatments to biomedical care in their quest for physical and spiritual well-being. The next chapter builds on experiences of Muslims living with HIV being ostracised and shunned by their families and significant others by drawing on Mary Douglas's work on purity and danger as an explanatory framework.

CHAPTER SIX: PURITY AND DANGER AS A FRAMEWORK FOR UNDERSTANDING HIV AND AIDS IN THE MUSLIM COMMUNITY IN DURBAN

This chapter draws primarily on the work of Mary Douglas's (1966) *Purity and Danger*. In her work, Douglas (1966) probes cultural ideas of purity and dirt and the attached symbolic meanings. *Purity and Danger* is grounded in symbolic anthropology and Douglas (1966) frames the application of symbols as having the ability to police or defile boundaries that are socially constructed (Leathem, 2020). Douglas (1966) frames the concept of dirt as 'matter out of place', something that does not belong or is not accepted by the socio-cultural standards of a community. Douglas (1966) likens pure and impure (dirt) to clean and unclean, and subsequently to sacred and profane. These concepts are further linked with notions of order and disorder in society (Datta, 2005; Leathem, 2020). These concepts have a symbolic nature and meaning is derived from how these words are applied in a socio-cultural context. Language is a significant part of symbolic interaction, and language has a socio-cultural impact through its application and interpretation by the people using it (Strauss and Corbin, 1990; Zaloom, 2020; Powell, 2022). The words referred to by Douglas (1966) have strong subjective meaning ascribed to them and affect the social relationships that people are able to forge and maintain.

The concepts put forward by Douglas (1966) are classificatory in nature, which determines how phenomena are understood and thus engaged with in a society. Dirt, classified as impurity, brings disorder and if left for too long dirt gathers, spreads, and contaminates what is close to it, leading to disorder (Douglas, 1966; Leathem, 2020; Powell, 2022). To restore order, the dirt must be removed from the environment and cleanliness must be restored (Datta, 2005, Zaloom, 2020). Classifications of purity and dirt speak to what is considered acceptable and what is not acceptable, which affects the social order of a community (Leathem, 2020). Douglas (1970, 2004) was critical of her work as she became a more seasoned academic and she noted that the framework of purity and danger was not perfect. Human beings classify phenomena in our social worlds in conjunction with a set of socio-culturally determined criteria (Fardon, 2016). Douglas (1970, 2004) noted that classifications are not neat or fixed entities, and that the broader social world (e.g., secular South African society) in which a local social world (e.g., Durban Muslim community) resides is dynamic and therefore there is a possibility that classifications may become 'unruly'. While this may be true

in some instances, I argue that it is not true in the context of my research. Whilst broader South African society has become more inclusive and accepting of phenomenon outside of what used to be the norm, for example becoming more accepting of diverse sexualities and accepting changes in sexual morality, the Muslim community in Durban has not been accepting of these broader changes. The classifications of pure and impure, acceptable and not acceptable, remain the same as they are tied strongly to religious cosmology, which has not changed. An absence of what the Muslim community deems to be sexual morality is perceived as dangerous and it is believed that if it is allowed to perpetuate and becomes acceptable to Muslims, it will corrupt Muslim society.

'Dirt', as it is linked to moral contamination, surpasses its physical boundaries due to the emergence of HIV and the affected individual's 'dirty' body is viewed as a significant threat to the established social structure (Henderson, 2011). This perception justifies the extreme forms of social exclusion that occurs in many instances. Henderson (2011) elucidates that disintegration of bodily integrity due to HIV is reflected by the disintegration of social relations. The physical body stands against the social body, it tenses and relaxes in relation to social pressures (Fardon, 2016). The physical body here, infected with HIV, is also 'infected' with perceived immorality by the local social world it finds itself in. The MLWHIV is physically and socially tainted and when members of the Muslim community paint MLWHIV in a negative light, 'other' them and ostracise them based on perceived assumptions about their moral character, the physical and psychological body is in a tense relationship with the social body (Muslim community) as they face social pressures alone. What is pure is placed high in the social hierarchy and what is dirt is placed low in the social hierarchy. Phenomena being classified as dirt leads to abjection and exclusion. This ties in with the notion of 'untouchability' as will be discussed in the forthcoming chapter.

6.1 MLWHIV as Matter Out of Place

Lawless et al (1996) state that HIV and AIDS is referred to as a dirty disease which contaminates the HIV+ individual, who is then also classified as dirty, resulting in their exclusion from society. The argument that I make is that HIV+ Muslims are perceived as 'matter out of place' in the Muslim community, in Durban, and that HIV, as a

disease, is dirt which is linked to impurity, in a physical and non-physical manner. Behaviours that are deemed to be 'risky' behaviours and correspondingly as putting one at risk of contracting HIV, are believed, in the Islamic community, to be morally impure and the body is regarded as becoming dirty through contamination with the disease. This notion stems from perceived or implied immoral behaviour that some Muslims believe will influence others. They are considered 'matter out of place' socially, spiritually, and physically in the eyes of other Muslims.

Mary Douglas's (1966) *Purity and Danger* has become a key part of the narrative experiences of my interlocutors. Douglas (1966) focuses her discussion on purity and danger around concepts of pollution and taboo in relation to religion. Her main argument centres around primitive religion, however, I argue that the concepts she proposed can be applied to beliefs in Islam (as a monotheistic and recent religion) and to relations of being between people. Concepts of purity, danger, pollution, and taboo are present in Islamic cosmology. Purity is a concept that is central to Islamic practice, for example one needs to be pure (clean) to be able to pray, and prayer must be done in a clean, pollution free environment. Purity and pollution can be physical concepts, but in terms of this study they are used as metaphors in relation to what is deemed to be the 'dirty' disease, HIV (Lawless et al, 1996, Zaloom, 2020). Douglas (1966: 1) tells us that "fear, terror, and dread" play a significant role in defilement and hygiene, which then links to spirituality. "Fear inhibits reason" and affects ideas around purity and defilement (Douglas, 1966: 1). Fardon (2016) built on this and noted that defilement needs to be viewed in terms of the complete structure of thought, or cosmology. Fear is a tool that has been used by *Moulanas* to maintain order in Muslim society. Traditionally, *Moulanas* have been rigid in their teachings, being firm in telling Muslims to stay away from *haram* or 'bad' people so that one does not become corrupted. I remember, as a young child and teenager, attending prayer gathering and the *Moulana* would be loud, strong, and forceful about what they were preaching, and their tone of voice would strike fear into the young people attending. They would preach that 'wrongdoing'[98] or association with 'wrongdoing' would lead to the 'hellfire' of *Jahannam*[99]. Cultural and religious cosmologies, as they have been preached in Islam, are rigid and a Muslim would not want to openly go against them for fear of

[98] Going against the tenets of Islam.
[99] Hell.

being ostracised and labelled as a ‘wrongdoer’. Order and disorder are two sides of the same coin, which also speak to notions of cleanliness and pollution, respectively. These will be addressed in relation to the ethnographic findings.

Cleanliness and purity are part of an ordered system in Islam which tells Muslims what is acceptable and what is not. Dirt and impurity are therefore all those elements that have been rejected by the ordered system and are thus considered disorderly (Powell, 2022). In this way Muslims living with HIV are not part of the ordered system, they are deemed ‘bad’ Muslims and are matter out of place, untouchable. Muslim society perceives that their disorderly actions and behaviours have led them to exist outside of the normal classification scheme. Douglas (1966: 40) states that “culture, in the sense of the public, standardised values of a community, mediates the experiences of individuals”. Words have literal meanings, and they have established and enforced social meanings. In the socio-cultural world of Muslims living in Durban, South Africa, the use of the term ‘dirty person’ is known to have a meaning beyond the literal sense of dirt, it means that socially the person is categorised as someone to avoid because they are deemed to be unworthy of society in some way (this may be due to lack of morals and non-normative behaviours). A MLWHIV becomes ‘untouchable’ in this sense as they are avoided and abandoned by other Muslims in their community.

Culture and religion provide basic patterns and categories of experience and understanding and neatly order values and ideals (Zaloom, 2020). The formalisation of behaviour is related to the force of the collective organisation which constrains individual choice (Fardon, 2016). Religion is in the realm of the public and categories that are recognised publicly cannot be easily changed and/ or adapted, especially if there are very few people who are against an acceptable norm. We construct our worlds through ordered sets of patterns and symbols that are built from what is acceptable to society (Douglas, 1966; Zaloom, 2020; Powell, 2022). Douglas (1970, 2004) later wrote that doctrine is wielded as a weapon which separates and expels those who do not conform or fit into its category of ‘good’. Fardon (2016) states, building on Douglas’ original work, that it can be said that the notions of purity and danger hold members of a local social world accountable to one another and this results in matter out of place. We accept (matter in place) and reject (matter out of place) cues based on our perceptions of phenomena and whether they fit with the patterns that exist in society (Zaloom, 2020; Powell, 2022). These patterns are the

‘good’ Muslim trope; one who prays five times a day, is obedient to their elders, fasts in the month of Ramadan and on other auspicious days, who is chaste before marriage and faithful during marriage. Discordant or different cues which are anomalies that do not fit the patterns laid out as acceptable by Muslim society will either lead to a modification of existing patterns of what a ‘good’ Muslim is or outright rejection of the discordant cue (Douglas, 1966; Fardon, 2016; Zaloom, 2020). The existing patterns of what a ‘good’ Muslim is and how we fit into these patterns gives one confidence in one’s understanding of it. Anything that deviates and does not fit into these patterns makes Muslims uncomfortable and is generally rejected, as matter out of place, in the quest to maintain the status quo and not disturb established and entrenched patterns. Fardon (2016), in his reflection on Douglas’ works, explains that those phenomena that do not fit neatly into classifications, which cross boundaries, become anomalies. Anomalies exist and it is only natural that they exist, and, as such, Muslims must react to and confront them. Anomalies can be dealt with in a number of ways including finding a way to reduce the anomaly, physically controlling the anomaly, avoiding the existence of the anomaly, and labelling an anomaly as dangerous in order to reduce its occurrence (Douglas, 1966; Fardon, 2016; Powell, 2022). My data reflects that those MLWHIV who have clearly acted in ways which go against the norms of sexual morality in Islam fall neatly into the classification of ‘impure’, as matter out of place and untouchable, for example, Shamil, Habib, and Sami. Those who have not necessarily acted in an unIslamic manner but are nonetheless afflicted with a disease that is perceived to be linked with sexual morality, for example, Haleh and Dalileh, are anomalies, yet they are still avoided and labelled as dangerous. This is because to accept those who are anomalies would be to accept the existence of what is still believed, by Muslims in Durban, to be an ‘immoral’ disease. Anomalies cannot be fully accepted, and it is reasoned that they are likely being punished for some transgression. The classification of ‘good’ and ‘bad’ is rigid.

One word that stood out in all my interviews with Muslims living with HIV is the word ‘dirty’. This word was also consistently mentioned in discussions with healthcare professionals and caregivers. It was either referred to by the Muslims living with HIV as a way that they described themselves after diagnosis or as how they themselves were described by family or friends. Healthcare professionals and caregivers similarly expressed that Muslims living with HIV used this term themselves in one of the two

ways mentioned. Sister Nadia said, "*so many of my patients get told that they are dirty and that their family members don't want to touch them or come near them. It's really sad to hear their stories and even sadder when they believe that they are also dirty*". Figurative applications of 'dirt' as well as literal render a MLWHIV untouchable. In my interview with Rahele, she mentioned how she felt 'dirty' because she was living with HIV and that her body was actually 'dirty' because of the sores that she had. She refused the offer of a hug from me when she was upset about a particular incident in her life and said that I shouldn't touch her because her body was 'dirty' – both literally and figuratively. My other participants also held similar notions of being 'dirty' through living with HIV and had mentioned that they had family members who refused to touch them because they were afraid. Notions of 'dirt' and 'untouchability' are therefore linked.

Through unstructured interviews that I had, the notion of a person living with HIV being 'dirty' was spoken of repeatedly, with many asserting that Muslims living with HIV are morally corrupt making them impure on a spiritual level. As such, they are 'out of place' in Muslim society. I was at a function held by one of the caregivers I interviewed and started talking to one of her children who was studying to be a doctor at the time. We were talking about my research because one of her daughter's modules was on HIV and AIDS. Another attendee overheard part of our conversation and stated, "*those people deserve what they get. How can you behave so immorally and loose and then think you can get away with it? These people have dirty hearts, and they do dirty things*". Other people around us agreed with her and said that they believe that only immoral Muslims will contract HIV.

From his extensive field research conducted in the Bushbuck Ridge municipality in South Africa, Niehaus (2007 and 2018) argues that sexual morality and 'promiscuity' have not been major factors in the existence and experience of stigma related to HIV and AIDS. In fact, Niehaus (2007 and 2018) argues that the stigma, fear, denialism, and silence comes from "the construction of person's living with AIDS as being 'dead before dying', and from the anomalous domain between life and death" (Niehaus, 2018: 845). This liminal state that Niehaus (2018) described resulted in PLWHIV in Bushbuck Ridge being perceived as matter out of place. HIV was likened to leprosy, however, Niehaus (2018) states that HIV and AIDS was perceived as worse because leprosy could be cured, and HIV cannot. In addition to this, the invisibility of HIV and

AIDS symptoms was discomforting. Niehaus (2007 and 2018) makes the argument that the people in Bushbuckridge were not concerned with sexual morality – sex before and outside of marriage, teenage sexual encounters, multiple concurrent sexual partners, or the bearing of children outside of wedlock – and that this did not influence the stigma that PLWHIV in the area faced. Sexual morality in Muslim communities, in contrast, plays a significant role in the stigma experienced by Muslim Living with HIV, as this chapter explains. Sexual morality is a social and cultural construct and each community defines the boundaries of what they believe to be sexually moral. Salazar (2006: 4) defines sexual morality as the "social and cultural institutions and regulations that surround human sexuality". Sexual morality in Islam means that Muslims must abide by a distinct behavioural code, as outlined in Chapter 2, which means that sexual intercourse outside of marriage (pre- and extra- marital) and acts of homosexuality are deemed morally 'deviant' and those engaging in such behaviours are scorned in Muslim society (Hasnain, 2005; Clarke, 2008; Esack and Chiddy, 2009; Rasmussen, 2015; Smith-Hefner, 2019). Sexual morality in Islam can be juxtaposed against Muslim perception of Western immorality (Clarke, 2008). Therefore, whilst Nieuhaus's (2007 and 2018) findings have provided important insight into the experiences of PLWHIV in Bushbuckridge, it serves as a point of divergence, indicating the need for in-depth qualitative research at the local level that uncovers detailed, insider community-based understandings. Social death, which is explored in detail in Chapter 8, describes the experience of social death as stemming from the stigma which emanates directly from perceived sexual immorally by family and friends of Muslim Living with HIV.

Amongst Muslims in Durban, HIV and AIDS was perceived as making the body dirty and impure and consequently a Muslim living with HIV was regarded as spiritually and physically impure. Several of the informal interviews steered toward the notion that the mind must also be impure because to have impure actions one must have impure thoughts, bringing psychological impurity to the fore. A Muslim man[100] who overheard me, during one of my interviews with Imam Hamzah stated that "*for a Muslim to get HIV they are obviously doing wrong things. Intention is important in action, so if they are doing wrong things then they are thinking wrong things too. Ideas come first; a dirty mind will do dirty things*". Few instances saw people talking about how a so-called

[100] I had my interview with Imam Hamzah at his masjid. We were in an open space and the man in question was nearby and overheard some of the interview and came over to speak to us.

‘good’ Muslim, who followed social and religious expectations, could also be infected and not be at fault.

6.2 HIV and AIDS: a ‘Dirty’ Disease

Before delving into the social and personal experiences of my interlocutors in relation to purity and danger, the notion of dirty disease will be explored. As mentioned in the previous chapter, disease can be understood as clean or dirty. In most cases a person has little control over their contraction of a disease. A disease like cancer is not perceived as dirty, it is understood that one’s body is attacking itself, and cancer is generally received with sympathy. Lung cancer may be one instance where a person may be blamed for their condition if they are a smoker (Chapple et al, 2004). The flu, as a viral infection connected to germs, would be considered to be a ‘dirty’ disease as it is a disease of contamination and people try to avoid contact with someone who has the flu to avoid transmission and getting sick themselves. The same may be said of chicken pox, measles, and similar diseases (Oaten et al, 2011). Sexually transmitted diseases (STDs) are deemed to be ‘dirty’ diseases and have the added presence of moral decay attached to them, which diseases like the flu and chicken pox do not. We sympathise with flu and chicken pox sufferers, but not with people who have STDs (Oaten et al, 2011).

HIV is an STD that has garnered worldwide attention through its rapid spread globally. People living with HIV, in the past, have been tainted as morally corrupt and dirty, as having ‘dirty blood’ and as being unclean. In the early years of the pandemic, people were reluctant to touch HIV+ people, even health care professionals were wary (Gerbert et al, 1992; Labra and Thomas, 2017; Yuvaraj et al, 2020). Breaking the stigma around this even after research showed that it was only through exchange of bodily fluids that transmission can occur, was difficult. Growing up, at the height of the pandemic, I distinctly remember iconic pictures of Lady Diana hugging AIDS orphans and shaking hands with people living with HIV. This did quite a lot to reduce the stigma around HIV and AIDS in certain social contexts and in the last three decades there has been a significant shift in public perceptions around people living with HIV (Yuvaraj et al, 2020). Yet the Muslim community (in Durban) still maintain notions that Muslims living with HIV are ‘dirty’ and therefore must be avoided.

Through interviews with caregivers, I found that most avoided openly discussing their responsibilities and details of their work with people living with HIV with family and friends. In most cases it was because they feared the response they would receive. Mya, a caregiver for 20 years, stated that her immediate family is aware of what her work entails but that outside of them no one else knows the details of her work. She explicitly stated that she wants to ensure that her mother-in-law does not find out because "*she would throw a fit and say I am going to bring that dirty disease into the house and infect everybody*". Such notions were likewise raised by other caregivers. Tasneem said "*my husband knows the kind of work that I do and the people I work with. He is very sympathetic, alhamdulillah*[101]*, but we both agreed not to tell our parents or anyone else because they are very fearful of HIV and also a little ignorant. They don't listen when we talk to them about HIV. They always worry about Hasan* [her husband] *getting a patient's blood in him when he is operating and don't listen when we explain the precautions. So, it's just easier to keep quiet about it"*. Nani, Tima, and Azhar spoke along the same lines, saying that the only people who are aware of the details of what they do are people they can trust, who are not judgemental or irrationally fearful.

Mya mentioned that a group of caregivers meet once a month to talk about their experiences and stressors and help each other navigate the problems they have encountered. Mya said that caregivers express that patients think of themselves as being 'dirty' and impure, which is often (but not always) compounded by unsupportive and judgemental family and friends, who have said these words to them. One of the most significant gestures one can make, said Nani, is to hold a patient's hand or hug them. In many cases, patients lack physical touch and interaction with people because people are either scared to come into contact with them or regard them as contaminated and thus 'dirty', refusing physical interaction. This entrenches the notion of 'untouchability' of MLWHIV. Rahele spoke about how it has been years since her mother touched her and even though her mother put her through a lot of pain (physically and emotionally) she still craves a hug or even her hand to be held by her mother because it is "*motherly love*". Rahele recalled the first time that she met Sister Rifat, the social worker who introduced her to me, and when Sister Rifat hugged her, Rahele said that she broke down crying because a stranger was willing to touch her

[101] Thank Allah, or praise be to Allah.

and hold her but her own mother would not. Sister Rifat said that much of her work with people living with HIV has involved, what she refers to as "*small acts of kindness, a simple touch on the hand or shoulder, a hug*" which she says makes a world of difference to the people she works with. She says that this is especially so with Muslims living with HIV. Many of the Muslims living with HIV whom Sister Rifat and Sister Aisha have worked with have been shunned by their families when their status is revealed. Sister Rifat says that because of this, many Muslims living with HIV choose to keep their status a secret for as long as they can because they fear being ostracised by their families and communities.

This sentiment was echoed by my ten key informants who attempt to keep their HIV+ status known to as few people as possible. Hana said that only her parents are aware of her and her husband's HIV+ status. Hana's mother has since passed away and Hana said that her mother was disappointed in what happened and that she felt helpless and responsible because Hana's father had arranged her marriage, and her mother did not resist his decision in any way. Hana's father, on the other hand, has been "*terrible! He's just horrible about it and threatens that he will tell my in-laws about us. He passes remarks here and there when we go to visit him. I see him at least once a month because I take him groceries and things. He always has something to say. He'll say we're filthy or napak and comment that he has to clean the house when we leave. I just leave him, but I hope that he won't tell anyone else. My husband's parents were very strict with him when he was growing up, he used to get beaten a lot. I understand that he made a mistake and I've made my peace with it. But we don't tell anyone unless they need to know, like Sister Rifat and Sister Aisha because we come here*".

My interlocutors spoke about how they felt "*unclean*" and "*contaminated*" when they were first diagnosed, and some of them still feel that way. Rahele feels this way in particular, and this is exacerbated by the state of her body which is heavily bandaged due to the sores that she has. Rahele refused to sit close to me during the interview process because she feels unclean and believes that her body smells badly due to the discharge from her sores. I tried to reassure her that this is not the case, that she does not look unsightly or smell badly, but she would not believe me. In the end I respected her desire to maintain distance. These sentiments were echoed by all my participants, in various ways. Habib and Shamil also expressed that for a time they did not attend

prayers in person at the *masjid* because they felt unclean/dirty and did not want to "*befoul*" a scared place of worship.

Muslims living with HIV are, as indicated above, perceived as spiritually tainted, physically unclean, and 'untouchable' because of what people call their "*dirty blood*". Dirt is something that must be removed and placed out of sight because it does not belong in ordinary spaces, let alone sacred ones (Douglas, 1966). Dirt is swept away, thrown into the dustbin, hidden, dirt is not something to be openly displayed, it is not something to be proud of (Douglas, 1966; Leathem, 2020; Simpson and Hughes, 2020). Muslims are especially pre-occupied with cleanliness and getting rid of dirt. In order to pray or even read the Qur'an, one must perform a ritualised ablution (*wudhu*) to cleanse oneself, both physically and spiritually. If one's *wudhu* breaks or is nullified then the individual needs to perform it again, to pray or read Qur'an. Some *Imams* even stress that Muslims should go to sleep in this state of purity. If a person relieves themselves (goes to the toilet), flatulates, or comes into contact with something *napak*, for example, a dog's saliva, urine or faeces, then their *wudhu* is broken and must be performed again after cleaning themselves. These concepts are impurities which cause disorder through uncleanliness (Douglas, 1966; Zaloom, 2020). When something or someone becomes impure, it, or they, must do something to rectify the situation in order to cleanse and restore order (Douglas, 1966; Zaloom, 2020; Powell, 2022). In such cases of coming into contact with something *napak*, the person should, according to religious rules, have a shower and change their clothes. The everyday acts of going to the toilet are also governed by specific rules of cleanliness. One must use their left hand when washing and wiping themselves and water must be used to wash oneself every time one goes to the toilet. Men are encouraged to sit down on the toilet when they urinate so that there is no chance of urine splashing onto their clothes and contaminating them and making them *napak*. When women menstruate, they are considered ritually unclean and are relieved from performing *salah*, fasting and other forms of worship until their menses has passed, after which they must perform a specific ritual of ablution to cleanse themselves. Not following these rules, which are upheld by Muslim society, is a deviation from the norm of purity. Notions of cleanliness and purity are thus central to Islamic belief and the phrase "Cleanliness is next to Godliness" comes to mind. This can then be seen to extend to some family

members ostracising the HIV+ family member because they view the person as impure and do not want to share space with them or have contact with the person.

As mentioned, Islam is centred heavily on notions of cleanliness and it is integral to religious acts and behaviours. Muslims are also told to cleanse our hearts and minds through prayer, meditation and repentance. Douglas (1966: 2) tells us that what is considered dirt "exists in the eye of the beholder". Each person and society perceive dirt differently and the scale of dirtiness is relevant to the person, the culture and religion of which they are a part. As indicated, however, Muslims have a strong religious and moral conception of dirt and cleanliness which then feeds into perceptions surrounding HIV and AIDS and those infected by the virus.

The nature of dirt in Islamic cosmology is that it is meant to be hidden. A rotten apple core, mouldy bread or used tissues do not belong in one's line of sight and are relegated to the bin, which is generally sealed and in a corner of the room out of sight. If dirt is kept anywhere else, it is 'matter out of place' (Douglas, 1966; Datta, 2005; Leathem, 2020; Powell, 2022). When a person becomes sick, depending on the nature of the sickness, that person becomes 'matter out of place'. Contagious diseases result in some form of isolation for the sick individual so as not to spread germs and the disease to others. This can clearly be seen with the COVID-19 pandemic that spread worldwide. A sick person was required to isolate for a number of days and the areas they occupied had to be sanitised to prevent the spread of germs. If one has the flu, the sick individual would be expected to remain at home to recuperate so that others may not get sick. As stated previously, diseases of contagion by their nature may be perceived as 'dirty' diseases, but diseases such as the flu, measles, chicken pox, and even COVID-19 have an end date and do not last forever. Isolation is thus temporary. In the absence of a cure, HIV remains in the body, and the stigma that has surrounded the disease since its discovery has relegated it to being a 'dirty' disease[102] that does not leave the body. The body with HIV is believed to be defiled and having crossed "some forbidden line" or developed an "impure condition" (Douglas, 1966: 1). Fardon (2016) notes that Douglas' later works acknowledges that defilement is rooted in the

[102] I would like to reiterate that there has been much movement in reducing stigma around HIV and AIDS, however, within the community under study there is still a long way to go in reducing stigma against Muslims living with HIV. This is due to the perception of HIV contraction generally being a result of risky behaviours which Muslims associate with morally corrupt and sinful behaviour.

structure of thought of a local social world and is strengthened by the collective, as it the case with HIV and Muslims in Durban.

6.3 Order vs Disorder; Fear vs Shame

In likening dirt to disorder, its existence is an affront to the ideal social order and if allowed to exist then it brings with it the danger of disorder and disorganisation of the social order, creating disharmony in society (Curti, 2017; Powell, 2022). Muslims see HIV and AIDS as a disease of the 'other', a disease that affects the promiscuous or westerners and they regard Muslims who engage in so-called 'risky behaviour' as being influenced by Western ideologies or whispers of devils (*waswas*[103]) as HIV and AIDS, it is believed, has no place in Muslim society. Throughout the research process with Muslims in Durban it became increasingly clear that the ideal of a 'good' Muslim, as Hasnain (2005) alluded to, is what every Muslim, male and female, should not just aspire to, but should be. In terms of such understandings, a 'good' Muslim has a place in society because the individual does not partake in behaviours that are construed as negative such as taking drugs, imbibing alcohol, having pre- or extra-marital sex and they are not homosexual. Being involved in any one of these activities makes one *'out of place'* in the Muslim community and, as per Muslim cosmology, pushes one toward the realm of being a 'bad' Muslim. 'Bad' Muslims are not acknowledged, they are hidden, hushed up, discarded and 'othered'. My interlocutors expressed that their families had cut them off because they believed that that they did not belong in their space and had reduced or cut contact with them, making them 'matter out of place'. Participants expressed feeling tainted by their disease.

Powell (2022) notes that fear is a factor in all of this as well - fear of being ostracised by the wider community if one accepts a family member who is HIV+. Bijan's stepmother, for example, is an anomaly as she continues to be incredibly supportive of him and has remained by his side throughout his experience. Bijan regards her as an important support system for him and he says that it is only through her bravery that some family members did not cut him off. Bijan stated, "*she has been incredibly*

[103] Waswas or waswasah are whisperings that believed to come from *shaytan*; devils among jinns or devils among mankind, and in some instances from one's *nafs* (self/ soul) (Islamqa, 2005).

supportive of me, she even fought with family who said horrible things to me and about me". In the grand scheme of things though, as Sister Rifat stated, many family members feel scared to be associated with an HIV+ person in the family because they "*fear being lumped in the same category*". Mya noted that "*they are afraid that they will be cast out if it comes out that their child or sibling has HIV. They feel like they will be seen badly by other people, like they were also doing wrong things*". Nani said that one her patient's parents said to her that "*people will say that they were bad parents and didn't teach their children the right way to live Islamically and that it is their fault too*". Sister Aisha stated that in all her time working with HIV patients and community organisations, "*the honest truth is that Muslims are out there having sex with prostitutes and taking drugs and being irresponsible. I have seen too many of them on the streets so we can't pretend that it is not happening or that any time a Muslim is diagnosed with HIV that they are innocent. People don't want to be associated with that, they don't want to be linked to someone who behaves in such a way because we all know our community judges and they are not kind to their own*". Even with the vast array of knowledge that is available on the transmission of HIV, there is still a fear that one could get infected. Caregivers and health care professionals who work with families of Muslims living with HIV explained that in most cases family members who are aware of the status of their HIV+ family member are afraid not just of infection for themselves or of their loved ones, but also of the social perception of being associated with an HIV+ person being in the family. Nani said that a common statement that she hears includes, "*how will I/ we hold out heads up in public with this shame? What will people think?*". Family members are afraid of being tainted by association and are afraid that youngsters in the family may fall into 'bad habits' that may lead to HIV contraction. In many instances it is overlooked that it is not always the individual's actions that lead to HIV infection. Context is often ignored when fear is present.

There is a fear amongst Muslims in Durban that not only will HIV+ Muslims spread the disease but also that they may influence those with "*weaker minds*" around them to engage in behaviours that are deemed to be unIslamic. Fear can lead to illogical and irrational thoughts. Removing dirt is related to re-organising and presenting the environment in a more acceptable manner and that it promotes conforming to social standards (Douglas, 1966; Zaloom, 2020; Powell, 2022). The moral values which a society upholds become entrenched in the very fabric of that society and, as a result,

affect how people relate to each other (Douglas, 1966; Powell, 2022). By removing or denouncing Muslims living with HIV, order, it is deemed, can be achieved as Muslims would not see themselves as being tainted by what they refer to as "*immoral actors*". Denying the existence of an HIV+ Muslim in the family creates the appearance of normalcy and wholesomeness that is coveted and provides a mechanism against the fear of being shunned by society.

Ideas of purity are also tied to virginity. The emphasis on virginity, and the related symbolism, is placed heavily upon females (Younus, 2008; Athar, 2018; El-Wardany, 2019). A woman who is not a virgin before marriage (i.e., who has engaged in sexual intercourse out of wedlock), is said to be impure, dirty and shameless (Younus, 2008; El-Wardany, 2019). Males do not face the same discrimination and are not thought of in the same manner. If a man engages in sexual intercourse prior to marriage, the onus is placed on his wife to change his behaviour and ensure that he is faithful. Haleh stated that this is what was expected of her by her husband's family when she found out about his addictions and sexual lifestyle and told them about it. His family, namely his parents, told her that it was her job to "*fix him... He is my responsibility and if I had done my job right and been a good wife then I wouldn't have gotten this sickness from him*". From the interviews with my interlocutors, it is evident that the burden of 'purity' is deemed as the responsibility of woman, and while men are not completely absolved of their role, they are often regarded as being weak willed and as easily swayed and tempted, thus reducing the accountability of their actions. Women, on the other hand, are touted to be stronger willed and are therefore expected to uphold the ideal moral standards.

Douglas (1966: 5) stated that "reflection on dirt involves reflection on the relationship of order to disorder". The fear of disorder, of a disorderly society, is strong in the Muslim community (Hammuda, 2016). Sister Aisha relates that people do not want it to be known that Islam can be disorderly. There is a constant and underlying strive for perfection and disorder deviates from this. There is also a fear that disorder can spread. Sister Aisha says that this is often a concern that is raised regarding children whom it is believed are too strongly influenced by Western ideologies through media. Sister Aisha, Imam Hamzah, Sister Rifat and Shiera all stated that parents frequently raise concern over their children's behaviours because of what is on television and due to contact with non-Muslims at school. Imam Hamzah argued that this is just

"*teenager-hood"*. He said that from his experience teenagers experiment regardless of where they are schooled, "*parents think that if they send their children to Islamic schools it will stop them from experimenting and deviating from Islamic teachings. That is not the case, it does not matter what school you send your child to, they are still watching TV and using Instagram and all these social media things. They will see kissing and sex whether we like it or not. And they will hide what they are doing from their parents. You know, the biggest joke is that some parents act like they were so innocent when they were teenagers. I know some of these guys, I grew up with them, and they weren't angels, and perhaps that is why they are so scared of what their children get up to*".

There is a belief by conservative communities, like Muslims in Durban, that sex education leads to promiscuity (Athar, 2018). This is evident in Sister Rifat's words, "*parents are scared that if they speak about all this openly, about sex and what not, that their children will want to experiment, that they will think HIV is normal and not a problem. This is especially so when we talk about how ARTs help HIV+ people to live full lives. They think that it lessens the fear of getting HIV if it looks like there are no consequences*". Imam Hamzah personally thinks that sex education for Muslim youth is important and would go a long way in addressing and reducing so-called 'risky behaviours', especially amongst young male Muslims. He argues that young males "*think that they are invincible and that nothing bad can happen to them. They get non-Muslim girlfriends, and they use them for sex until it is time to get married and then they want a virgin Muslim bride. And they think they are entitled to this! These attitudes are wrong and must be addressed*". Imam Hamzah further stated that 'disorder' has always been present in Muslim communities and in Islam, but it has been well hidden. A conservative community is a secretive community. The caregivers and healthcare professionals agreed with this sentiment when they were probed. My male participants also spoke to this attitude. They accepted that they felt like they could do anything and that being Muslim and male gave them some kind of immunity, because as Shamil said, "*it doesn't happen to us*". Three of my male interlocutors expressed that they did have girlfriends when they were in high school and university but that their families were not aware of this. They also alluded to the notion that non-Muslim girls are easier to persuade to enter into sexual relationships when they are in an established relationship. This, participants expressed, is partly because Muslim females' parents

tend to be very strict and often do not allow their daughters out of the house except for school or *madrassah*[104]. A striking point of observation, however, that came up in an interview was that Muslim males do not want to "*sully a Muslim girl*". There is a belief that Muslim females need to stay 'pure' for their husband and participants asserted that they did not want to be the reason that she would not be. Interestingly, participants did not associate males with the notion of purity, and this was something that was only reserved for their female counterparts.

Douglas (1966:7) expressed that monotheistic religions believe that "sacred things and places are to be protected from defilement". In Islam, the body is sacred in that it is believed to be a gift from Allah and must be treated with respect. One's body is an *amanah*[105] from Allah, and it is only a temporary vessel (Faruqui, 2021). As such, for Muslims, the body has a right over the individual and individuals thus have a duty to protect it and treat it well because it does not belong to the person, but rather, it belongs to Allah who created it, and it will be returned to Allah upon death (Faruqui, 2021). It is believed that each part of the body will bare testimony to one's life and to one's thoughts and actions on the Day of Judgement. Accordingly, both Imams Hamzah and Rafiek regard engaging in so-called 'risky behaviours' as being disrespectful to one's body. Substance abuse, they stated, harms the body greatly. Engaging in sexual behaviours prior to and outside of marriage is also regarded as disrespectful to one's body because, as they argued, the lack of control that these actions exhibit is harmful physically and psychologically. This can be exacerbated by not using condoms because a situation is created whereby the body is open to viruses and sicknesses which may harm it. Both Imams extended that substance abuse and sexual promiscuity are not just simply taboo in Islam, but haram, and thus major sins. These, it was stressed, create disorder and danger in a community if not addressed. Substance abusers, the Imams argued, do not harm only themselves, they harm those around them psychologically, physically or socio-economically. Imam Hamzah stated that he has counselled numerous substance abusers and done family therapy as well and spoke about the "*chaos*" that ensues in a home when a substance abuser is present. He stated that the same thing happens when an extra marital affair occurs. Imam Hamzah explained, "*When people engage in unIslamic behaviours it brings*

[104] Islamic school.
[105] A trust that one has been entrusted with

problems. When someone abuses drugs, they steal from their home, whether it's their parents or their spouse, and then they also can get violent too. Everything is in chaos then. When someone has an affair, they are bringing a third person into their marriage. The roles of husband and wife are disrupted. In these situations, with drugs and affairs, trust is broken, and it is hard to fix that". The home, Imam Rafiek stated, is thrown into chaos and disorder, which would not have happened if the incidents were avoided. Imam Rafiek thus argued that the "*rampant promiscuity*", as he called it, is why we have such problems in the world and that HIV was sent by Allah to curb these "*ungodly behaviours*". He believes that HIV was sent as a punishment from Allah for the disorder that exists in the world and that Muslims have been contaminated through the influence of Western media. He said that people deserved what they get for their behaviour. Of those who had become infected, although not engaging in perceived 'immoral acts' he said, "*we are fighting a war on immorality and there are casualties in every war*".

Sister Aisha, Imam Hamzah, and Sister Rifat disagreed with this sentiment and highlighted the problematic nature of such beliefs and how damaging they are to a sick person. It is important to note that while Imam Hamzah does not condone what are perceived to be *haram* actions mentioned earlier, he tries his best not to blame or judge the person. Imam Hamzah specifically stated that human beings should not lay judgement on others, to assume that to know the nature of another's heart, or to assume to know whether someone is being punished and why, "*judgement is reserved for Allah, not for imperfect mortal beings who are all sinners in one way or another*". Sister Aisha and Sister Rifat said that beliefs such as those held by Imam Rafiek are common and they are harmful to Muslims living with HIV as they reduce support and ostracise sick people further when they actually need help.

6.4 The Sacred and the Profane in Islam

Douglas (1966) denoted between the sacred and the profane. The sacred is clean and pure whilst the profane is impure and defiled. "The sacred is the object of community worship" (Douglas, 1966: 21). Imams Rafiek and Hamzah speak to this in that sacred rules and rituals of Islam are what bring people together, as they share in experiences. *Salah* for men is always in congregation and a man must pray with other men if there

is a group. They are expected to attend *masjid* for *salah*. Women, on the other hand, do not have the same requirement but it has become increasingly the norm for women to pray at the *masjid* and women's prayer spaces have grown as new *masjids* are built. Women's *salah* spaces are no longer relegated to hidden back entrances where only a few women may pray at a time. Imam Hamzah encourages women to come to the *masjid* for *salah* and his *masjid* has one of the largest prayer spaces for women in Durban. Duschinsky (2016) notes the importance of the relationship between the individual and the community. For Muslims, the community is an important aspect of daily life and maintaining that sense of community is crucial. The communal nature of *salah*, and other acts of worship, bring a sense of community, brotherhood and sisterhood, as well as togetherness to those who partake in it, which the *Imams* explain they hope will encourage others to join. This speaks to the contagious nature of the sacred which is seen as a positive phenomenon. Sacred spaces, therefore, must be kept clean and pure, both physically and ritually. Interviews with caregivers uncovered that many of their patients would not go the *masjid* for prayer because they felt that they contaminated the space because they are HIV+.

Sister Rifat, Haleema, and Shiera stated that when they counselled patients this was something that was brought up and they tried to explain to their patients that they had every right to attend the *masjid*. They said that they spent a lot of time with patients working through feelings of shame and uncleanliness and that it was sometimes a constant battle. Shiera said, "*there have been moments when I think that I have gotten through to my patient, but then when they come back the next time, we are back at square one because of something that someone said to them or that they overheard*". This is similar to what Shamil and Habib expressed, as noted earlier in the chapter, as to why they refrained from attending the *masjid* for *salah.*

The other side to this is that the sacred, then, also "continuously hedges in with prohibitions" which are meant to reduce the profane (Douglas, 1966: 22). Prohibition of dangerous thoughts and behaviours, which cross the boundaries of *haram* and are forbidden must be taken note of. In this context the prohibitions speak to the so-called 'risky behaviours' which may exacerbate HIV transmission. The sacred is contagious in that it brings people together through common beliefs and shared practices. The sacred controls and ensures order in a society. Imam Hamzah stated that sex within a marriage, virginity, keeping the body clean of impurities and following the basic

tenets of Islam are sacred practices and rules for Muslims. He explained that by following these rules and controlling thoughts and behaviour, order is maintained in Muslim society. The profane, on the other hand, includes behaviours that are 'risky' to contracting HIV. Imam Hamzah explained that engaging with the profane means that one is deviating from the sacred or the norms that have been imposed on society. The promise of danger through the profane, should one deviate from the sacred, helps to keep people in line and in order. Thoughts and behaviours are regulated, as Badri (2003) argued, in order to prevent deviant thoughts, which he stated leads to deviant behaviour. A Muslim can fast, make *isthigfar*[106] or be in a constant state of prayer so as to focus the mind on the *halal*. Imams Hamzah and Rafiek agreed with this. If a person deviates into the profane, they are cast out so that it may not spread within the community. This is what happens to Muslims living with HIV in many instances. They are cast out and labelled deviant and 'dirty', regardless of their specific personal experiences. Imam Rafiek said that it is only to be expected that those who covet the sacred would not want anything negative, or *haram*, to be close to them and be a temptation.

Cleanliness is central to the performance of the sacred Islamic rituals. A number of participants likened having HIV to having 'dirty blood' which was compounded by beliefs of family and friend who had shunned them, rendering them 'untouchable'. Rahele recounted her obsession with scrubbing her body almost raw after she was diagnosed as being HIV+ and the constant feeling she had of being dirty. Other participants expressed similar sentiments, with six of my key participants specifically referring to their "*dirty blood*". Whilst there are rituals of ablution to cleanse oneself physically and spiritually, there is not a specific ritual to cleanse the HIV+ body. The impurity, as it were, is inside the body and cannot be washed away. The mind (psyche) and spirit may be cleansed through meditation and prayer, and the external body through ritual ablution, but there is nothing to cleanse the internal body. Sadira mentioned an incident where she almost committed suicide. Sadira said that it was not her intention to kill herself, but rather she was convinced that she could "*clean my blood if I let it* out". She recalled that at the time, which was only a few days after her diagnosis, it made perfect sense to her, however, she now knows how illogical it actually was. Since cleanliness is equated to purity, uncleanliness is equated to

[106] Ask Allah for forgiveness.

impurity and subsequently to feelings of unworthiness. By placing Muslims living with HIV into the latter category, it leads to individuals feeling unwanted and unloved. Caregivers and healthcare professionals noted that in their work with MLHIV they see this all the time and they work hard to validate and uplift their patients. Refraining from judgement is important in their line of work because often they are lifelines for Muslims living with HIV who have been cut off by their families and close circles.

The reluctance of the Muslim community to acknowledge the existence of HIV within its boundaries means that what are deemed as anomalous behaviours, as discussed earlier in the chapter, are ignored and avoided and, as such, there is no way to reduce them. The pattern of consensus is that 'bad' Muslims who do 'bad' things get HIV. Accordingly, their actions are regarded as not fitting acceptable patterns (the sacred) and so their perceived deviance is rejected. Presumptions abound, such as, how can anyone get HIV in any other way than by being a 'bad' Muslim? Conversely, then, what then of the so-called 'good' Muslim who contracted HIV while not engaging in any form of behaviour deemed to be anomalous? One explanation offered is that of Imam Rafiek who regards HIV as a punishment for what he considers widespread sin and deviant behaviours that do not maintain the status quo and the established structures in society (the sacred). When confronted with the notion that an HIV+ status is not necessarily a result of one's direct choices and actions, he found it difficult to adjust and accept and rather chose to focus on it being punishment for some type of bad or sinful behaviour. He also alluded to the notion that people lie about their situations so that they can cover up their deviant behaviours and look innocent and play the victim. To modify thoughts around this seems to be a difficult thing to do, because without that who does one blame. Imam Rafiek may be one man but, as an older cleric, he is not alone in his thinking. These ideas exist amongst other clerics, and this is attested to by Imam Hamzah, (who himself comes from a long line of clerics), Sister Aisha, Sister Rifat and Sister Nadia. This ideology is something that they are constantly fighting against. Imam Hamzah and other healthcare professionals are working hard to change the conservative bias that exists in the Muslim community. Imam Hamzah openly talks about HIV in his sermons and other talks that he is asked to deliver. He speaks to youth in his congregation about sex and encourages them to talk to him when they have questions. He maintains that he tries to foster a healthy idea of sex and the body that he hopes will lead to better decision-making by young people, "*I*

don't condone sex out of marriage, in fact I think early marriage is a good thing when done right, but I know that our young people can't be controlled and will do the opposite of what you tell them to. That is the nature of being a teenager; rebellion and inquisitiveness is normal. Their bodies are changing and there is definitely a high chance of experimentation. But at the very least I hope that the talks I have with them will lead to them making better choices and even using protection should they choose to engage in sexual activities".

Muslims living with HIV are clearly thrust into the margins of Islamic society and their identity and place in society is in chaos. Douglas (1966: 107) explains that "it seems that if a person has no place in society in the social system and is therefore a marginal being, all precautions against danger must come from others", those who are within the margins of society who must stay away from the Muslims living with HIV and keep distance from them mentally and physically. In this way the attitude and perceptions of society impact heavily on the marginalised Muslims living with HIV. Muslims carry with them a "consciousness of social structure" and so they act accordingly, in a manner they see fit, and want to show conformity, i.e., the behaviours of a 'good' Muslim, and they want to distance themselves from anyone who threatens that social structure (Douglas, 1966: 101). A polluted person is always perceived to be in the wrong, regardless of their particular situation. They have crossed a line, whether purposefully or not, and this unleashes danger for the community (Douglas, 1966; Powell, 2022). This goes back to what Imam Rafiek stated, that Muslims living with HIV have no place in Muslim society and must be removed so as to maintain the correct social order and minimise and remove the danger to the community that a polluted person and anomaly brings.

Thus, polluted Muslims living with HIV are removed from the social order, pushed to the margins of society, and are placeless. They are regarded as dangerous to the social order and the status quo, and they are 'matter out of place' because 'bad' Muslims are unacceptable. This othering and forced removal from Muslim society stems from stigma and discrimination, which ultimately leads to social deaths. This stated, the next chapter will delve into stigma, through the application of Goffman's (1963) theory on stigma and the spoilt identity.

CHAPTER SEVEN: SOCIAL STIGMA AND THE SPOILED IDENTITIES OF MLWHIV IN DURBAN

Goffman (1963) begins *Stigma: Notes on the Management of Spoilt Identity* with a letter taken from Nathanael West's (1962) *Miss Lonelyhearts* purported to be written by a teenage girl with a facial deformity seeking advice. Her words are poignant:

> "*What did I do to deserve such a terribly bad fate? Even if I did do some bad things, I didn't do any before I was a year old and I was born this way. I asked Papa and he says he doesn't know, but that maybe I did something in the other world before I was born or that I was being punished for his sins. I don't believe that because he is a very nice man. Ought I commit suicide? Sincerely yours, Desperate*." (West 1962: 15 cited in Goffman 1963: 7).

The above entry may be fictional, but it is based on a reality that is lived by many who face stigma on a daily basis and who have no foreseeable way to change their circumstances. Goffman (1963: 9) described stigma as "the situation of the individual who is disqualified from full social acceptance". Goffman (1963) further stated that the term 'stigma' originated amongst the Greeks and was originally based purely upon visual characteristics or markings on the body. The use of 'stigma', as in the case of the teenage girl above, was thus in relation to visible signs on one's body that signified that there was something different from the norm. This could also include branding or cuts on the body that reflected the status of the person in society as a criminal, slave or traitor, for example (Goffman, 1963; Davis, 2017; Holleman, 2020; Hannem, 2022). The individual who was marked was perceived to be "blemished, ritually polluted, and was avoided by people within the society lest they become contaminated by association" (Goffman, 1963: 11). Goffman (1963: 12) further argued that a person deemed to be categorised as negative or as having negative traits would be "reduced in our minds from a whole and usual person to a tainted, discounted one".

In current times, the application of the term is focused on disgrace, the evidence of which is not always a bodily (physical) signifier (Goffman, 1963; Yang et al, 2009; Ros et al, 2013; Hannem, 2022). Stigma no longer has to be a visible signifier as is the case with HIV and AIDS and a more accurate notion would be to speak of perceptibility

(Goffman, 1963). With regards to HIV and AIDS, since the advancement of treatment, the body does not signify a blemish or any outward difference from others (until the final stages of the disease), and so the health status of the person is the blemish, from which the stigma follows. Goffman (1963: 14) distinguishes between three types of stigma, namely, “abominations of the body… blemishes of individual character… and tribal stigma”. For the purposes of this study, the second type of stigma is deemed to be most applicable, that of “blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty” (Goffman, 1963: 14).

7.1 Stigma and HIV and AIDS

Aggleton et al (2005) explain that from the outset of the HIV and AIDS pandemic, stigma and discrimination have been a significant part of the disease. Aggleton et al (2005) and Visser et al (2009) explain that the stigma that is related to HIV and AIDS is connected to numerous factors around misunderstandings and misconceptions of the disease and its transmission. Stigma in relation to HIV and AIDS impacts the social and clinical factors relevant to the disease. Stigma can fuel transmission of the disease and hamper prevention, intervention and treatment options creating and reinforcing barriers to care and support (Aggleton et al, 2005; Visser et al, 2009). Frankenburg (1994, cited in Leclerc-Madlala, 2001: 38) argued that HIV and AIDS is entrenched in contested terminology such as “social disease, contamination, discrimination, … religious doctrines, morality, sexuality, deviance, blame and death”. According to Deacon (2006), HIV-related stigma stems from complex social and individual dimensions, occurring through social processes in terms of how illness is perceived (either as controllable or preventable) and through associated perceptions of immoral behaviours. Deacon (2006) expanded upon this by stating that certain groups (which for the purpose of this study refers to Muslims) associate immoral behaviours as carrying the disease, thereby establishing the existence of the ‘other’ who is then, in turn, blamed for becoming infected and for infecting other people. Visser et al (2009) further noted that HIV and AIDS has been characterised as a deadly, transmissible disease which has negative social connotations attached to it, thus leading to the marginalisation and discrimination of people living with HIV. Social behaviours which

are assigned the label ‘risky’ and which have moral connotations attached to them result in blame being assigned to the HIV+ person who is often depicted as being deserving of the situation in which they find themselves (Aggleton et al, 2005; Visser et al, 2009; Rahmati-Najarkolaei et al, 2010). Hasbi et al (2021) likewise argue that HIV and AIDS is a disease that is rooted in behavioural issues with Yassin et al (2021: 131) expanding on such arguments by stating that the behaviours associated with the transmission of HIV are “deemed immoral and deviant within society”, further arguing that this has led to an epidemic of HIV-related stigma that is “both malicious and long-term”. In addition to this, HIV and AIDS is perceived in some societies as a form of punishment or a curse that has been sent by God for those who do not follow religious teachings, engage in so-called ‘immoral behaviour’, are evil, and, as such, HIV and AIDS has also been labelled the ‘sinners’ disease (Aggleton and Chase, 2001; Kopelman, 2002; Visser et al, 2009).

Stigma may be personal or perceived. Personal stigma is a “measure of the personal beliefs and attitudes of individuals towards persons with HIV/AIDS” (Visser et al, 2009: 198). This may stem from, or be prompted by, feelings of being better than the ‘other’, by seeing oneself in a more positive light, as a ‘good’ person who does not engage in behaviours that are deemed ‘bad’. Visser et al (2009) argue that blame and judgement are strong aspects of personal stigma. Perceived stigma, also referred to as attributed stigma, on the other hand, is the “extent to which …individuals attribute stigmatising attitudes to others in their community” (Visser et al, 2009: 198). Perceived stigma relates to the intrapersonal whereby acts of stigma are internalised in accordance with how much the prevalent stigmatising attitudes of people in the community are believed (Steward et al, 2008; Zhao et al, 2021; Chi et al, 2016; Yassin et al, 2021). Stigma may be enacted in various ways, for example, by gossiping about, shaming and humiliating a person living with HIV, through maintaining physical distance, by reducing or removing care and support and in some cases by physical harm (Aggleton et al, 2005; Visser et al, 2009; Rahmati-Najarkolaei et al, 2010).

According to Yassin et al (2021), other than personal and perceived stigma, stigma may be experienced as enacted stigma, vicarious stigma, and/or an internalised stigma. Campbell and Gibbs (2016), Yassin et al (2018) and Yassin et al (2021) state that people living with HIV are recipients of stigma and discrimination and that the person/people enacting stigma is an agent who is actively involved in “stigmatising the

'other'" (Yassin et al, 2021: 136). Yassin et al (2021: 136) explain enacted stigma as that "interpersonal aspect of HIV-related stigma, which involves acts of overt discrimination and humiliation directed at individuals infected or affected by HIV/AIDS" (see Chi et al, 2014; Wei et al, 2018). Internalised stigma, according to Yassin et al (2021) is the extent to which the stigmatised individual perceives stigma received as being valid (Stewart et al, 2008). Internalised stigma also stems from acceptance of received stigma as valid and from negative perceptions of the self-manifesting as a result of one's HIV+ status (Zhao et al, 2010; Herek et al, 2013; Yassin et al, 2021).

Writing about HIV-related stigma, Leclerc-Madlala (2001) described situations whereby HIV+ individuals have been physically chased out of their homes and communities and have even had their homes burnt down. She describes situations where no compassion was displayed and where even those who were physically in poor health faced no exception in their stigmatisation. Leclerc-Madlala (2001) recounted that staff at the Hillcrest AIDS Centre risked their lives to get resources to people living with HIV who were living in make-shift shelters, having been chased out of their homes and communities by angry mobs. Caregivers who were interviewed for this study expressed similar sentiments in that they faced discrimination and even rejection by their families if it became known that they work with and assist Muslims living with HIV. Leclerc-Madlala (2001) further argued that HIV-related stigma knows no bounds as children living with HIV are similarly stigmatised and it is difficult for HIV+ children to attend school in a scenario in which "teachers and pupils act together to chase the children away because they are 'unclean'" (Leclerc-Madlala, 2001: 44). Abandonment and prejudicial actions by family and community were common in the 1990s and early 2000s in South Africa and stigma continues unabated amongst HIV+ Muslims (Leclerc-Madlala, 2001; Yassin et al, 2021).

7.1.1 Stigma and Muslims Living with HIV in Durban

Stigma is also exacerbated by negative social perceptions that have been made prominent by the media and this has led to mass fear resulting in withdrawal of support for HIV+ Muslims (Ameli et al, 2021). The media has also added to the controversy

around HIV and AIDS in relation to issues that are socially and culturally sensitive[107] and this has created much prejudice and fear in relation to the disease (Visser et al, 2009). HIV-related stigma experienced by people living with HIV has, furthermore, resulted in emotions of rejection, despair and even depression (Ameli et al, 2021). Visser et al (2009) argue that notions of HIV-related stigma are powerful because they are based on existing stereotypes and prejudices held by society. HIV and AIDS is present in the Muslim community in Durban, but it is hidden, and people go to great lengths to ensure that it remains hidden. The stigma that causes it to be hidden silences any discussion about the disease. By creating and reinforcing silence around the existence of HIV and AIDS in the Muslim community in Durban, a response to the epidemic is potentially delayed or even prevented. There is a strong sense of denialism around HIV and AIDS amongst Muslims in Durban, a common sentiment among Muslims as purported by Esack (2004), and this denial and concealment of the disease further compounds the stigma experience of those living with HIV. The stigma that surrounds the disease leads to the perception of HIV and AIDS as being a 'problem' that needs to be hidden rather than as something perceived as a truth that requires action and solutions to contain and manage the spread of the disease. Concealment, stigma, and discrimination lead to the spread of HIV and AIDS as people do not want to get tested, or do not want to tell their partners about their status once diagnosed. Sadira and Haleh's husbands knew of their HIV+ status, did not tell their wives and did not use condoms when they had sex with their wives because it would have raised suspicion as to the use of condoms within a marriage.

Rahmati-Najarkolaei et al (2010) and Ameli et al (2021) further add to the discussions around HIV and AIDS amongst Muslims by noting that negative-value based assumptions about Muslims living with HIV are rooted in religion and lead to high levels of stigma and discrimination. This is in line with much of what my participants stated. The moral undertones of the disease, being linked to unprotected sex (pre- and extra-marital), men who have sex with men and drug use, all align with the concept of a 'bad' Muslim and 'bad' behaviours that are prohibited in Islam. The image of a perfect Muslim and perfect community is important to Muslims and the need to uphold this image results in concealment of the existence of HIV and AIDS in the community. Stigma is pragmatic and can be a tactical response to what is perceived to be a threat

[107] This is with regards to sex, sexuality, death, and recreational drug use.

to the community, that it may cause real danger, which is why it is also important to understand the stigmatiser (Yang et al, 2009). The fear that exists is so profound that some Muslims believe that their families may be tainted or influenced by the actions of the 'bad' Muslims and so they want to keep themselves and their families away from them, as will be shown in the chapter that follows.

Goffman's (1963) work is useful in studying HIV and AIDS amongst Muslims in Durban in that he stated that people come together as a community and establish the foundations of categories and attributes for what is deemed normal, appropriate and acceptable for a given community (Hannem, 2022). The attributes are then applied to people within the community and if one is construed as possessing the desired attributes befitting of the ascribed categories, the individual is then perceived to be a 'normal' and ordinary member of that society (Goffman, 1963; Ros et al, 2013; Hannem, 2022). Kleinman and Hall-Clifford (2009) state that it is important to understand the moral standing of an individual in a group and the context in which stigma arises through a social lens. Anthropological contributions to the study of stigma have highlighted moral experience as that which stigma is embedded in (Kleinman and Hall-Clifford, 2009; Yang et al, 2009). Visser et al (2009) added that attributes producing stigma are not necessarily deviant, but that they become stigmatised based on the meanings of deviance that are ascribed to the attributes by those who make up the local social world. These meanings are religio-culturally embedded in a society and are derived from specific historical or cultural contexts (Visser et al, 2009). Muslims have created categories of 'good' and 'bad' Muslims and the attributes that have been identified as key factors in determining which category 'good' Muslims fall into include (1) following the five pillars or Islam (2) abstaining from sexual intercourse before marriage and refraining from extra-marital affairs (3) abstaining from alcohol and drug consumption and (4) dressing modestly. Any deviance from this means that one is deemed to be a 'bad' Muslim. The risky behaviours, or attributes, that are noted in relation to HIV and AIDS include deviance from the attributes of a 'good' Muslim and result in Muslims living with HIV being perceived as morally and religiously apprehensible. These attributes are ingrained into Muslim children as they grow up by their parents and when they attend *Madrassah*.

Social cues establish what is deemed normal and acceptable against what is not. Muslim children are enculturated through their formative years and automatically, and

unconsciously, access cues and categorise for Muslim people whom they come across. Muslims learn the behaviours and characteristics of a 'good' Muslim and as such also know the behaviours and characteristics of a 'bad' Muslim. This means that by virtue of being Muslim an individual knows who belongs and is accepted in society and who does not. Attributes which a person holds are categorised and thus when one meets a stranger for the first time, one appraises and categorises the stranger and ascribe a social identity to them (Ros et al, 2013; Davis, 2017; Hannem, 2022). Therefore, when people come into contact with each other they watch for signs that the new individual may fall into the same category as they do (Goffman, 1963; Hannem, 2022). Some of the traits which help individuals categorise each other can be personal attributes such as honesty as well as structural attributes such as a person's occupation, and as such, their social status. Structural attributes allow us to create an image of the individual in our minds (Shaik, 2012).

Based on the perceived and understood personal and structural attributes a status is afforded to the individual and as such society has expectations based on what is presented by the person and the information about that person. The stigmatised and those who stigmatise are linked via local social obligations and anthropologists have explored the socio-cultural processes behind the formation of stigma in local social worlds (Kleinman and Hall-Clifford, 2009; Yang et al, 2009). When a Muslim meets another Muslim, they expect that the other is a 'good' Muslim based on the aforementioned criteria. This is an automatic assumption and is based on the perception that Muslims are good, moral, and upstanding citizens. There is a natural expectation that the Muslims one meets automatically embody what a 'good' Muslim should be by virtue of being Muslim. The social identity of a 'good' Muslim is thus ascribed in that initial meeting. As they spend more time together and/or hear things about each other from other people, the identity of a 'good' Muslim is either maintained or shifts. Rahele's case provides an example of this. On visiting her mother, Rahele met another Muslim woman who was new to the neighbourhood and Rahele noted that they had a *"good chat and talked about the upcoming fasting month of Ramadan".* They talked about how they both liked to go to the *masjid* for *tarawih*[108] and how spiritually uplifting it felt. Rahele's mother was not at home on that particular day. Goffman (1963: 65) explains that "know-about-ness" is an important factor in stigma,

[108] A special prayer, the last prayer of the day, during Ramadan.

and this speaks to what the person being interacted with by the stigmatised person knows about the stigmatised person at that point in time. Rahele does not live in the same neighbourhood as her mother, but lives nearby, and she later met the female in question at a shopping centre and tried to strike up a conversation with her having spoken to her previously. Rahele says that the woman brushed her off, noting, "*she was a little rude to me and acted like she didn't know me and left*". Rahele said that she was taken aback and a bit hurt because she thought that they had connected. A while later she met one of her mother's neighbours, (a non-Muslim woman who has maintained contact with Rahele[109]) and spoke to her about the incident. This particular individual then explained to Rahele that Rahele's mother had spoken to the woman and told her that Rahele was HIV+ because she 'slept around'[110]. This particular Muslim woman had an automatic preconceived perception of Rahele as a so-called 'good' Muslim upon their first meeting in which they spoke about fasting and prayer. However, upon hearing new information (about Rahele's HIV+ status) from Rahele's mother she changed her perception based on the attributes that her mother assigned to her. Rahele thus became categorised as a 'bad' Muslim by this particular woman and thereby deemed as necessary to avoid. As such, it is clear that when presented with new information a person can be re-categorised in accordance with the new information received. In this sense, Rahele was received with ease in her first encounter, however, upon hearing about what is perceived as an undesired differentness in the Muslim community in Durban (Rahele's HIV status and purported activities) Rahele's other attributes that had shaped their first encounter were totally overlooked in favour of viewing Rahele as a 'bad' Muslim and therefore as someone to be avoided. It did not matter that Rahele fasted and prayed regularly, her discrediting factor became the focus in the mind of the Muslim woman and determined their future interactions, or rather lack thereof. Ameli et al (2021) discuss similar experiences in their research whereby MLWHIV have been disowned by their families and their communities and in some instances have been forced out of their homes.

[109] Rahele mentioned that the non-Muslims in her mother's neighbourhood treated her well and did not discriminate against her.

[110] Rahele's mother had made it seem that had many sexual partners out of her own will, when in fact she was abused by her husband and forced into sex with other men.

7.1.2 Virtual and Real Social Identity: The Discredited and Discreditable Muslim Living with HIV

Goffman (1963) argues that the assumptions that one person makes about the other may, at times, be unconscious and, in this sense, Goffman (1963) distinguishes between a virtual social identity and a real social identity. Building on this, Yang et al (2009) note that the social dimensions of stigma are important to understand and interrogate. One's virtual social identity is related to the assumptions and demands that are placed on that person upon meeting another person. One's actual social identity comes from their real and actual categories and attributes that are exposed when one spends time with another and learns more about the other person (Goffman, 1963; Davis, 2017). A Muslim's virtual social identity is that of a 'good' Muslim in terms of broader Muslim cosmology and, as such, the initial attributes given to another Muslim upon meeting are categorised as such. A Muslim's actual social identity emerges through closer observation, further interaction, and new information emerging. The moral experience is important and what is at stake is the perception of a Muslim's character which can be threatened if one is stigmatised (Yang et al, 2009). Once evidence, or even simply an idea of a Muslim having an attribute or characteristic that removes them from the norm and makes them different emerges, (i.e., 'good' versus 'bad'), then that particular Muslim becomes less desirable and there is a distance that is created between the 'bad' Muslim and the rest of the Muslim community. A Muslims living with HIV does not have an outward appearance that distinguishes the individual from the so-called 'good' Muslim category, but when the individual's HIV status is made known to other Muslims, the person is removed from the norm category of 'good' and placed in the deviant category where 'bad' Muslims exist. Sister Aisha says that it is almost automatic, "*as soon as they know that someone is HIV+ they just jump to the conclusion that they must have been sleeping around. They don't even stop to think that there could be a different reason, they just judge without care. And even if someone slept around and got AIDS, so what. Isn't it that they can ask for maaf*[111] *from Allah, and it is Allah's will to forgive. Isn't He the most merciful?*" Despite this, those ascribed the status of 'bad' Muslims are marginalised, abandoned, and regarded as dangerous and weak willed, because the assumption is that they gave in to their *nafs*, and by virtue of this are not 'true' Muslims.

[111] Forgiveness

The ‘bad’ Muslim is reduced in the minds of other Muslims from “a whole and usual person to a tainted, discounted one” (Goffman, 1963: 12). This is due to the associated stigma of HIV and AIDS which, from the standpoint of being a ‘good’ or ‘bad’ Muslim, discredits and robs those deemed ‘tainted’ of being their whole self. Yang et al (2009) explain that stigma is a situational threat whereby the stigmatiser’s way of life (their norms and values) is threatened by the stigmatised because they have deviated from the norm. Anthropologists have noted that it is important to acknowledge the relationship between the stigmatiser and stigmatised because it enables the inspection of both parties in relation to what is considered most valued and most threatened (Yang et al, 2009). By virtue of being ‘othered’ as a ‘bad’ Muslim, an HIV+ Muslim experiences status loss as a result of the projection of blame by ‘good’ Muslims. Rahmati-Najarkolaei et al (2010) as well as Ameli et al (2021) state that in Muslim communities’ stigma is experienced more intensely. Stigma is the discrepancy between one’s virtual social identity and one’s actual social identity and when the discrepancy appears, and the attributes linked to ‘bad’ Muslims become apparent, the Muslim is reclassified and recategorized and their place and purpose in society is changed. In the case of a Muslim’s HIV+ status being publicised, the individual is no longer perceived to have a place in Muslim society and so is shifted to the margins where the individual is ignored or ill-treated.

As stated, an HIV+ body does not always show signs of sickness. With treatment being available and, if taken, people living with HIV live relatively normal lives. As such the stigma that a Muslims living with HIV faces may be that of the discredited or the discreditable. The discredited Muslims living with HIV, assume that people around them know their HIV status and so they react to this knowledge, whereas the discreditable Muslims living with HIV may assume that those around them do not know their HIV status, but may yet find out and, in turn, may be diminished (Goffman, 1963). It is not that Muslims expect each other to be immune to the “desires of the flesh”, rather a Muslim is expected to be in control over these desires that “plague humanity” and they are expected to control their *nafs* (Hasnain, 2005: 5). The concept of deviant behaviour is developed in the literature (see Badri, 2000; Ghaemparah et al, 2018; Yassin et al, 2018). So-called ‘risky’ behaviours are labelled deviant behaviours that are ‘dirty’ and ‘despicable’ in Islam (Ghaemparah et al, 2018; Jiloha, 2019; Ameli et al, 2021; Hasbi et al, 2021). According to Hasbi et al (2021) Muslims, through the

'invasion' of western media and culture have succumbed to alcohol, substance abuse and pornography and are engaging in sexual intercourse with sex workers or out of marriage which reflects a loss of self-control amongst Muslims. This means that Muslims living with HIV are perceived as being weak willed and easily led by their passions, and because they (mostly) hide their actions from others they are also perceived as being dishonest.

All of my interlocutors expressed that this was how they were perceived by their families, and in some instances by their friends as well. My male interlocutors stated that they were constantly told by their family members who were aware of their HIV status that they are weak willed and dishonest. Shamil stated that his wife always brings this up when they have an argument, "*she always tells me that I have no control and discipline. That I let my desires control me and that I am weak and that is why we are in this situation. If I just controlled myself then we would be okay. It hurts to hear her say that, but she is right. Maybe if my imaan was stronger I would not have succumbed to being so easily mislead*". Habib and Sami shared similar sentiments, and Sister Aisha and Sister Rifat expressed that their patients experienced these feelings too. My female interlocutors also had similar experiences, however, for females, accusations of dishonesty and metering out blame are even more extreme. Rahele's mother and sister-in-law did not believe that she was forced into sex with other men by her husband and said that she was lying. In the words of Rahele, "*they said that I was making excuses and that I liked to have sex and I was a loose woman making excuses because I got this thing* [HIV]*. My brother, who used to abuse me as a child, said that I was like that from small and I deserve what happened to me for misleading him. This is what they tell other people in the neighbourhood and people who know me. They want me to be alone*". Haleh, likewise, said that her husband's family tried to blame her for her and her husband's HIV+ status at first. As Haleh stated, "*they acted like he was the perfect man and he didn't do anything wrong. They made it seem like I was the one who went and got this thing and brought it into our marriage. But meanwhile they knew what he was getting up to, but they made me feel terrible*".

In Imam Rafiek's view, if Muslims follow the teachings of the Qur'an and the Prophet Mohammed (SAW) correctly then there would be no risk of HIV and AIDS in the community, as evident in his words, "*Islam gives us the tools that we need to live our*

lives without risk of HIV, drug abuse, alcoholism, and all that, it gives us protection from harm but our people have become swayed by western media and ideals and the easiness of leading a life without boundaries. We have to have boundaries and restrictions, look at what is happening when people ignore them!".

HIV+ Muslim women in Durban, according to my participants, are treated as less human than HIV+ Muslim men. Muslim women, my participants noted, are expected to be in control of themselves and their actions and, at the same time, in control of their husband's actions. Thus, if they contract HIV and AIDS, they are discriminated against as weak willed and dishonest individuals, who lie and trick people into feeling sorry for them. Sister Rifat mentioned that many of her female patients face this and are called liars and are said to be lacking in *imaan* by their families. The concept of being a 'bad' Muslim is however not only applied to HIV+ Muslims, but also to any Muslim who falls outside the categories of 'normal' and 'good'. An HIV+ Muslim is, however, perceived as being at the extreme end of the scale when categorising Muslims as 'bad'. Due to the fact that the concept of 'good' Muslim has been so ingrained into Muslims, the stigmatised Muslims living with HIV holds the same beliefs as others in relation to the social identity of a Muslim and the connotations thereof. Whilst they do believe that they should be given a chance, or a second chance, and not be shunned from society, they simultaneously feel that they are, as a result of the disease, deviant and are being punished for transgressing. This is something that they accept and have to adapt to. Muslims living with HIV understand that they will never be fully included in society again, even those who have had some support from their family, and some, like Bijan, have therefore opted to carve out a new social identity as an HIV activist. It must be noted, however, that this is often a long process, achieved only through self-acceptance and is an identity that only few manage to achieve.

7.1.3 Shame and the Spoilt Identity of the Muslim Living with HIV

For the most part, stigmatised Muslims living with HIV are reduced to what is viewed as their failings. They are reduced, in the eyes of the wider Muslim community, from what they could have been to what they are, and the stigmatized will inevitably remain that way. Muslims living with HIV are perceived to have fallen short of what they should have become, what they should have strived to be. Shame, therefore, is a central

component of stigma on the part of the stigmatised individual or group. Shame, as a response to stigma, leads to feelings of being undeserving of love and support by family and community, anger, vengefulness and lack of motivation to be healthy and follow treatment plans (Rahmati-Najarkolaei et al, 2010).

The attribute of HIV and AIDS is perceived as a defilement on one's character, and this is a shared perception by 'normal' Muslims and by Muslims living with HIV in Durban. Shame comes from the experience and attribute of defilement and may result in self-hate and self-derogation which stems from the hate and discrimination brought on by others (Goffman, 1963; Davis, 2017; Hannem, 2022).). Along with these detrimental characteristics, depression, as a result of social and self-stigma, is prevalent amongst HIV+ people (Mulqueeny et al, 2021). In holding a mirror to themselves, Muslims living with HIV focus on the defiling attribute and not on any positive aspects of their character. For example, most of my participants stated that they prayed regularly, which is regarded as a positive attribute in terms of Muslim culture, but that this is overshadowed, in their own eyes, by their HIV+ status. Narda said, "*I know that I have HIV because of my husband. His dishonesty and his weakness affected me in a very bad way. I know that I am a good person, I pray every day and I fast, but all I see is HIV when I look at myself. I mean, I know that I don't look like I have HIV but it's there, I know it is there and I can never not see it*". It does not matter that they may have asked for forgiveness from Allah, or that they do what are considered to be 'good' things, their personal shame and the shame forced on them by family and others outweighs any positives and Muslims living with HIV are, as a result, frequently overcome with shame.

Goffman (1963: 19) asserted that those who are in contact with the stigmatised individual do not give the individual respect in relation to the other "un-contaminated" parts of the individual's social identity and so the individual comes to expect to be treated with discrimination and without respect and thus internalises the treatment the individual is afforded (Hannem, 2022). The stigmatiser is concerned with the moral code being threatened (Yang et al, 2009). In some stigma instances, Goffman (1963) noted, shame may be reversed, but this is not likely with shame related to HIV. One cannot reverse one's HIV+ status, and it not the presence of the disease itself in the body that brings stigma and shame, but rather the stigma that surrounds behaviour perceived as leading to the contraction of the disease. The moral undertones are thus

tied to an individual's character and how others perceive their character. It does not matter how much a person may try to outwardly change the perception of their character; the negative perceptions prevail. My participants expressed that even though their families know that they pray regularly, that they fast, that they give to charity and follow the norms associated with being a 'good' Muslim, they are still, and feel that they always will be, tainted by their HIV+ status. No matter what they do, they are reduced to their HIV+ status.

The stigma which Muslims living with HIV experience is rationalised by 'normal' or 'good' Muslims through the othering of Muslims living with HIV, by categorising them as 'bad' and by placing importance on keeping distance from Muslims living with HIV so as to maintain their own perceived normality and 'goodness'. If the belief is that the HIV+ Muslim is being punished by God, then the 'normal/good' Muslim does not want to be associated with that punishment or taint themselves by association. Fear of contamination through contact still exists amongst Muslims in Durban, according to Sister Rifat, Sister Aisha and Sister Nadia, but it is mainly amongst the older generation. Sister Nadia explained that younger Muslims do not fear disease contamination in the literal sense, they are educated on issues around the transmission of HIV and understand the biology behind the disease. Rather, the contamination that is referred to is in line with previously discussed notions of dirt in Chapter Five. Younger people, Sister Nadia explained, refer to a more philosophical sense of contamination that is linked to spirituality and ritual contamination.

The stigmatised Muslims living with HIV thus comes to hold the same beliefs about their identity that 'good' Muslims do. There is an internalisation of the social identity of 'bad' Muslim. In trying to reason through their diagnosis, as noted in Chapter Four, the explanatory model that is used is one which sees HIV and AIDS as a punishment from Allah to humankind in general, but also as punishment for an individual's sins. Muslims living with HIV and AIDS thus believe that they have done something bad or sinful that they are being punished for and that, in some way, they deserve the disease. The Muslims living with HIV have thus had their social identity as a 'normal' and 'good' Muslim discredited and they have been ascribed a new social identity which they must navigate. As a 'normal' and 'good' Muslim they were just like any other Muslim in that

they had a place in society and depending on the nature of a transgression[112], would have been afforded the benefit of the doubt, would have been given a second chance, and would have been allowed to repent and redeem themselves in the eyes of Muslim society. They would be chastised but would not have be cast out of the Islamic community. What the Muslims living with HIV has assimilated from the wider Muslim community, in relation to their HIV+ status and self-identity, results in them seeing themselves as failing as a Muslim and, in turn, acknowledging that they fall short of their aspired social identity. This brings about feelings of shame in the stigmatised Muslims living with HIV, where they view their shortcomings as defiling their sense of self. Self-hate and self-derogation follow stigma and shame (Goffman, 1963; Davis, 2017). There is also the added internal conflict that Muslims living with HIV experience. If we look at Muslims living with HIV who have been infected by partners or, as is the case with Dalileh who was born with HIV, they are conflicted when reflecting upon their sense of self. On the one hand, there is the belief that sickness comes to a person for a reason, whether that be punishment or as a test from Allah. HIV and AIDS is clearly viewed by Muslims in Durban as a disease that is a punishment and a result of a perceived defilement of the body and spirit.

If the metaphor of looking in the mirror is used, as Goffman (1963) does, what they see in the mirror does not match how they feel inside. On the outside they appear well, and healthy[113], however, on the inside, as all my research participants noted, they know that they are sick, they feel impure and they feel shame because of their HIV+ status. The only way that another person will know that they are living with HIV is if they are told. Haleh explained that while she looks fine and healthy, she lives with fear, dread and shame. The internalised stigma and shame, my participants explained, makes them see themselves in a negative light but at the same time they all long to be the person they once saw in the mirror, blemish free and 'normal'. They struggle internally with the associated social identity that has been forced upon them, especially those participants who feel strongly that they did not do anything directly to contract HIV. However, with the explanatory model of punishment, there is also the belief that contracting HIV was somehow warranted. There is conflict around whether or not they really are 'bad' Muslims, but the manner in which they are treated by wider Muslim

[112] Being a minor transgression/ sin.
[113] With the exception of Rahele whose sickness is now physically visible.

society enforces that they must be ‘bad’ in some way to have gotten the disease. Goffman (1963) refers to this as ambivalence as the stigmatised individual oscillates between the identity they have and the identity they want. My participants who regard themselves as responsible for their past behaviours explained that when they reflect on their sense of self they feel extreme guilt and shame. This was especially true for Habib, Shamil and Sami who infected their wives. These participants noted that they do not feel conflicted because they view themselves as responsible for contracting HIV, but they do not see themselves as whole either because they feel that they have lost a significant aspect of their identity. In all instances, however, participants feel that nothing can be done in order to remove the blemish or correct it.

‘Good’ Muslims try to avoid contact with Muslims living with HIV and so social situations must be managed in such a way that they are easy to avoid. Social control and access to social spaces thus defines the lives of Muslims living with HIV. When Muslims living with HIV and AIDS are ‘othered’ and marginalised, they are cut off from Muslim society and are isolated both by others and by themselves. As they internalise the stigma placed on them, and the resultant shame which can be external as well as internally imposed, they take it upon themselves to stay away from ‘normal’ society. All the ‘good’ Muslims have to do is make it clear that Muslims living with HIV are not welcome in their social spaces and the Muslims living with HIV will do the rest for them. The stigmatised are left with rearranging their entire social lives to ensure that they avoid social spaces with the ‘good’ Muslims. Rahele mentioned that whilst she still wishes to have a relationship with her mother, she knows that it will never happen. She makes sure that she does not shop at the same places that her mother does and now also does not to go to the neighbourhood where her mother lives. Rahele avoids any form of social contact with her mother because she fears that her mother will lash out at her publicly and shame her, as she has done in the past. Rahele does not want to have to deal with public humiliation anymore and so she avoids her mother and her siblings as far as possible.

As a result of marginalisation and subsequent self-isolation, feelings of insecurity emerge and the person becomes unsure of themselves in social situations with ‘normal’ Muslims, whether they are aware of the person’s HIV status or not. This

feeling of being unsure, insecure, and nervous becomes a controlling factor in their everyday lives and interactions with people around them. There is also uncertainty in making new acquaintances because there is a fear of others finding out about one's HIV+ status, which would change the entire dynamic of the relationship and, in most cases, result in it ending prematurely. Muslims living with HIV therefore have to manage the information that exists about them and their social identity. They grapple with whether or not to tell others about their status or not, they fear the truth emerging and possibly being shunned by yet another person. My participants expressed that they ordinarily conceal their HIV status from new acquaintances because they are afraid of being judged, silenced and ignored, however, there is also fear around withholding the truth and being labelled dishonest and of having to live in fear of their secret coming out. There is a therefore a constant, overwhelming, feeling of trying to conform to the expectations of society but without any success because the cause of stigma and shame is not something that can be removed unless those culturally perceived as 'normal' and 'good' Muslims change their mindsets and accept Muslims living with HIV. In some cases, participants expressed that they tend to be very conscious of talking about the good things that they have done, or religious activities that they are involved in, feeling that this may minimise the negative view that the other person has of them. Goffman (1963) asserted that a stigmatised person therefore has reasons for feeling anxious in social situations.

7.1.4 The Sympathetic Other

There is another side to stigma, however, which speaks to the sympathetic other. As stated previously, the discrepancy between one's virtual social identity and one's actual social identity results in perceived stigma and the discreditation of the person (Goffman, 1963; Hannem, 2022). The discrepancy spoils the person's social identity, leading to a discredited identity, or spoilt identity. There are sympathetic others who sympathise with Muslims living with HIV and through the interactions that they have with each other, the sympathetic other aims to "share with him the feeling that he is human and 'essentially' normal … in spite of his self-doubts" (Goffman, 1963: 31). These sympathetic others come in the form of caregivers and professionals, and Goffman (1963) refers to them as the 'wise'. The 'wise' in terms of Goffman's

terminology is thus a cultural perceived ‘normal’ person, who is not stigmatised due to personal HIV and AIDS status, but who has a personal or professional connection with the stigmatised. The ‘wise’ sympathetic other chooses to be involved with the stigmatised group, and does not face the same discreditation, stigma and shame that the stigmatised group experiences. Rather, the ‘wise’ sympathetic other is accepted in society because they are perceived as doing noble work in helping the stigmatised Muslims living with HIV.

From the interviews I conducted with my participants it became apparent that those who hold professional qualifications and work with HIV+ people (regardless of religion) were not stigmatised by association. Sister Aisha and Sister Rifat noted that they have been told that they are doing a selfless job, and they are commended for their actions. Sister Rifat said “*I have been told by some family members that the work I am doing is important, that it's needed in society, and that I will be rewarded (spiritually) for it immensely. People have told me that it’s a very selfless act to put myself at risk to help HIV+ people*”. Shiera and Sister Nadia noted that people have acknowledged the stigma that is associated with HIV and AIDS, and specifically the stigma associated with HIV+ Muslims, and they have received positive feedback from people saying that what they do is important. My interviews with healthcare professionals and the *Imams* reflect that when there is a professional attachment involved the stigma is reduced, and may not exist, because it is ‘noble’ work. This has not been the case for caregivers, however, as three of the caregivers I interviewed were so concerned about their identities being revealed that they declined the interview to be audio recorded in fear of someone recognising their voice. Caregivers are afraid of the consequences of family and friends finding out that they work directly with people living with HIV. There seems to be a distinction between who is considered ‘noble’ and who is not.

Caregivers feel that their role in providing care to Muslims living with HIV goes beyond the physical and is, more importantly, social. Caregivers expressed that more than anything, it is simple acts of kindness that make a difference in the lives of the people they work with, for example, sitting down and having a conversation, giving a hug and simply giving time and making the person feel valued and human. Sister Rifat has counselled numerous Muslims living with HIV and she said that by just listening and thereby making the HIV+ individuals feel seen and heard as people is a crucial role. Caregivers and professionals are outsiders (as HIV- people) who, through their years

of experience and interaction with Muslims living with HIV, have become insiders as they are fully aware of the experiences of Muslims living with HIV even though they have not lived them. They are trusted by the stigmatised community and are embraced for the support and care that they provide.

Another form of 'wise' sympathetic other is the one who is stigmatised by association. Goffman (1963: 43) asserts that these sympathetic others "are all obliged to share some of the discredit of the stigmatised person to whom they are related". The family members, for example, who embrace this persona, like Bijan's stepmother and Rahele's children, live within the confines of the stigmatisation as the ascribed Muslims living with HIV's family member. The stigma by association is not as harshly received but gets ascribed by what Goffman (1963: 43) refers to as, "diminished intensity". One reason for this is that the 'wise' sympathetic others can break ties with the stigmatised Muslims living with HIV at any time and hence their status in society will revert to 'normal'. While many 'good' Muslims treat family members as tainted by association and minimise contact with them, some view the support they provide to their family members as an act of nobility. Rahele mentioned that one of her daughters received a marriage proposal from a family who had seen her at a function. Rahele's daughter is not HIV+, but her continued association and interaction with her mother has resulted in her being stigmatised by association. When Rahele's mother found out about the proposal she contacted the family and told them that Rahele is HIV+, among other things. The family immediately chose to retract their proposal, reinforcing the concept of stigma by association in the Muslim community of Durban. For HIV+ Muslims living in Durban, the support they receive from their family is not perceived as a noble act, rather it is perceived as the family member being accepting of so-called 'risky behaviours' because rather than stopping contact with their family they continue to have a relationship with them. Rahele said that her children often have to deal with comments that people make about her, and she said that once a Muslim woman told her daughter that "*she must have AIDS too if I am her mother. People also pass comments that my daughters must be loose like me, because of what my mother says*".

Sympathetic others come in two forms. The second that Goffman (1963) identified is the one who shares stigma with the stigmatised person, who he referred to as the 'own'. In this sense, Muslims living with HIV receive support and care from other

Muslims living with HIV because they have shared experiences. Sister Rifat and Sister Aisha strongly believe in support groups, where HIV+ Muslims can share their experiences with each other and help each other navigate the world they inhabit. Hasbi et al (2021) note that whilst they regard HIV and AIDS to be a result of deviant behaviours, they refer to Islamic teachings that are centred on compassion and care, thus arguing that HIV and AIDS is a test from Allah, and, accordingly, that HIV+ Muslims should not be forgotten or rejected but should be treated well and cared for.

Support groups allow Muslims living with HIV to be open about their experiences, get help with the problems they face and receive moral support from people who accept them. Ameli et al (2021) highlighted the importance of support groups for Muslims living with HIV, explaining that support groups help to build confidence, promote self-love and provide a sense of comfort and protection against stigma and discrimination. This is what Goffman (1963: 137) referred to as "in-group alignment", the real group to which the stigmatised belongs. In the support group, Muslims living with HIV are all equal, and there is no judgement. The support group provides a new community where one is accepted. In this situation HIV+ Muslims find a new place in a newly constructed society as well as a new purpose for those who are sympathetic others who are then, in turn, able to share their experiences with newer members. Muslims living with HIV share learning experiences as they navigate the outskirts of Muslim society. They share similar experiences in the changes in their social identity and personal sense of self as well as in the series of adjustments that they have had to make as a result of their stigmatised label. Rahele noted that the support group that she attends has helped her feel supported and human, "*I don't feel alone here. I can talk about everything with the ladies that come here, and they don't judge me. They understand, they know how it feels to be rejected by your family. And they help me, they encourage me, and it gives me strength*". Haleh also noted that she feels a strong sense of support from the people in her support group and she said that they "*feel like a family. It's nice because I can talk about my medication and how I am feeling about it, and I don't have to feel ashamed. I can get advice from people who are experiencing the same thing as me. We share our stories, and we help each other*".

The social information about a Muslims living with HIV plays an important role in the response that people have towards them. Social information is not just about words, but rather about how the message regarding the Muslims living with HIV is passed on,

the non-verbal cues such as body language and facial expressions that are expressed (Goffman, 1963; Holleman, 2020). The mere act of a 'normal' Muslim ignoring another seemingly 'normal' Muslim raises questions and as such holds social information. The sudden disappearance from social settings holds social information which simply needs to be verified. The stigma that Muslims living with HIV experience disqualifies them from social settings in the Muslim community where they are sanctioned. Rahele and Bijan spoke about how they are no longer welcome when their families host religious functions or prayer gatherings, either being told directly that they must not attend or not being told about the gathering at all. Rahele stated that on one occasion she heard that her sister-in-law, (her eldest brother's wife), was having a prayer at her house, and she decided to attend it thinking that her sister-in-law was unable to contact her (as Rahele noted that she did not have a telephone or cell phone at the time). Rahele explained, "*I just thought that she couldn't get hold of me to tell, or she forgot or something. I didn't think at all that she didn't invite me on purpose. But then when I got to the house, she asked me what I was doing there. I said, 'Bhabhi*[114] *I heard that you was having one function so I came to help and to be with my family'. She just laughed at me and then told me to get out because how can a dirty person like me come to a khatam*".

The differentness that is enforced between 'good' Muslim and 'bad' Muslim creates clear assumptions on social identity. These categories, of 'good' Muslim and 'bad' Muslim, determine one's place in the hierarchy of the social structure. 'Good' Muslims are at the top of the hierarchy and enjoy the benefits of being perceived as noble and just, whereas 'bad' Muslims are at the lower end of the hierarchy where they are differentiated by the severity of their perceived sins and deviations from the norm. The stigmatised are made visible by their place in society, which in effect, renders them invisible as they are then ignored and marginalised and as a social norm opt to alienate themselves from the community (Goffman, 1963; Holleman, 2020). In a small community, such as the Muslim community in Durban, when a member deviates from the prescribed set of norms for that community they come to play a specific role in the community and become a symbol. The deviant behaviour or attribute that the person embodies sees them being perceived by the community as a 'bad' Muslim and a symbol of the consequences of bad behaviour. Whilst the Muslims living with HIV may

[114] Bhabhi is the Urdu word for sister.

no longer be accepted in the community, they are used as an example for others of what will befall them should they too contract HIV/AIDS. Thus, they often actively withdraw from social life with those perceived as 'normal' so as to alleviate the emotional and psychological harm they experience.

The stigma that is experienced by Muslims living with HIV is significant. The irony is that one of the fundamental lessons that Muslims are taught growing up is to not lay judgement on others (regardless of religion, but especially for Muslims). A *hadith* states that a "Muslim is one from whose tongue and hand other Muslims are safe" and yet this sense of brotherhood and sisterhood falls apart in the face of stigmatisation, and rather than helping the sick and including the positive, they are ostracised and pushed to the margins of society to rely on strangers who are, in many instances, non-Muslim. Goffman's (1963) theory of the spoilt identity feeds into the notion of social abandonment and social death that are experienced by Muslims living with HIV.

Stigma and discrimination are thus very much a part of the experience of HIV+ Muslims. This is due to the connotations of morality and immorality in relation to transmission of the disease. As Campbell et al (2010) note, stigma undermines well-being, prevents access to treatment and support, increases exploitation of the vulnerable, increases victimisation and bullying and exacerbates psychological stress of people living with and affected by HIV and AIDS. Stigma plays a role in secrecy, which leads to barriers to testing, treatment, and care for Muslims living with HIV. Islamic cosmology forbids a Muslim from harming another person (regardless of religious affiliation), and the transmission of HIV from one Muslim to another is regarded as an act of harm. As such, it is important for testing to take place, and for stigma to be eradicated, so as to prevent the continued transmission of HIV. Lack of care and support for Muslims living with HIV is also recognised as causing harm, and in this way religious doctrine may be utilised to reduce stigma by reminding Muslims of their duty towards each other, i.e., to care for the sick and dying (Yassin et al, 2021). Strategies that appeal to religious ideals and work to reduce or eradicate HIV-related stigma and discrimination are important endeavours as these will have a ripple effect in Muslim communities.

Stigma and discrimination, however, set the groundwork for a person to experience a social death and serve to separate a person from the group and isolate them from their

previous social worlds. This then has an impact on social relationships and a person's continuation as a valuable and active part of their community. Social death, which is the subject of the following chapter, is then experienced.

CHAPTER EIGHT: HIV AND AIDS, SOCIAL DEATH, AND MUSLIMS IN DURBAN

"*A Muslim is one from whose tongue and hands other Muslims are safe*" – Sahih Bukhari.

This chapter builds upon the previous two chapters and introduces the concept of 'social death' as an analytical framework in interpreting the experiences of MLHIV in Durban. In Chapter Six Douglas's *Purity and Danger* was used as a theoretical toolkit to show Muslims living with HIV and AIDS as being 'matter out of place' in the Muslim community in Durban. Chapter Seven added to this by drawing on Goffman's (1963) theory of stigma and the notion of the spoilt identity. Being considered or perceived as 'matter out of place' in a community, or as an outcast due to imposed and internalised social stigma, reduces one's connections within the community and, as a result, pushes one to the margins of that community. Social connections are important to maintain order and to continue being an active part of a community and, when these social connections are removed, one becomes isolated and social death can result. This chapter deals with the conceptual framework of social death which, when applied to HIV+ Muslims, stems from symbolic notions of being 'impure' which then leads to the enactment of stigma and discrimination by HIV- Muslims targeting Muslims living with HIV.

8.1 Social Death

Kralova (2015) explains that the concept of social death has been used across diverse disciplines and that social death is a multifaceted phenomenon which may be applied to the most extreme forms of loss of connectedness (Rosa and Diaz, 2019; Ransom et al, 2021). Kralova (2015: 235) identifies three underlying notions of social death including, "a loss of social identity, a loss of social connectedness and losses associated with the disintegration of the body". Each of these notions will be explored in connection to Muslims living with HIV in Durban and their own specific experiences.

Social death has been widely theorised in studies related to health, sickness and well-being. Sudnow (1967) distinguished between three types of death, namely, clinical,

biological and social (Sudnow, 1967; Kralova, 2015). A clinical death is determined when vital organs stop working, for example the heart stops pumping blood and requires a machine to ensure its continued operation (Trueba, 2007). A clinical death is "an exercise of diagnostic judgement" which is made by a professional clinician (Trueba, 2007: 57). Anderson (2022) explains that biological death, which follows clinical death, occurs when all bodily functions stop (Sudnow, 1967; Trueba, 2007; Anderson, 2022). Social death, however, can occur when a person is alive as well as after clinical and biological death. Glaser and Strauss (1965) distinguished between the physical and the social and argued that the physical state of the person affects or determines the social interactions that follow once there is awareness that a person is dying. Glaser and Strauss's (1965) understanding of the term social death, is built on Goffman's (1961) concept of the "mortification of self – the series of humiliation undermining a person's social identity" (Kralova, 2015: 236). Sudnow (1967) examined the social processes that surround death and in so doing brought forth the concept of social death into social science discourse. This chapter is concerned with social death, as proposed by Sudnow (1967) and expanded on by Kralova (2015), which occurs when a person is still alive and is not necessarily related to their health status[115].

A social death is experienced by a person when others in their community or society "treat the person as already deceased, although clinically and biologically alive" (Kralova, 2015). The affected person is cut out from social activities and relationships and treated as though he or she no longer exists. A person's mind and body are still alive and functioning, but the individual in question is cut off from others socially and psychologically and their existence is ignored. Kalish (1968) expanded understandings of social death to include the physical, psychological, sociological and social. Kalish (1968) further explained that social death can be self-perceived, in the sense that a person believes that they are dead to society, or social death can be externally perceived where people in society treat the person as being dead (Rosa and Diaz, 2019).

[115] By health status I mean that the person is not physically about to die from a sickness. HIV is a detrimental disease, however, with the advancements in treatment once can live a very long life. In addition to this, none of my interlocutors were at a stage where they would succumb to the disease in a short period of time.

8.1.1 Social Value: 'Good' Muslims vs 'Bad' Muslims

Sudnow's (1967) original study was centred on observations carried out at two hospitals where he investigated whether the perceived social value of a patient who was near death affected how the patient was treated by medical personnel as well as the level of investment placed upon reviving the patient. A comparison can be drawn from this in relation to HIV+ Muslims in Durban and the perceived social value that they have. Discussions surrounding the subject of worth and personal value emerged during interviews with participants, including Muslims living with HIV, caregivers and professionals. What became pertinent is that one's self-worth and social value are embedded in whether or not one can be described as a 'good' Muslim in terms of understandings of the Muslim community in Durban. As noted, a Muslim who regularly prays, fasts, contributes to charity, assists other people, helps the sick and so on, is classified as a 'good' Muslim by virtue of carrying out such deeds, and accordingly, the social value of the individual is deemed to be extremely high. Such individuals are not only highly regarded by others in the Muslim community but are perceived as having the potential to influence how non-Muslims view Muslims and thereby as having the ability to promote non-Muslims viewing Muslims in a positive light. Imam Hamzah asserted that a significant and easy form of *dawah*[116] is simply attained by behaving according to the rules of Islam. Imam Hamzah noted, "*How we act, what people can see, is how they will think about us. If a Muslim helps another person then people will see this and think that this Muslim person is good. And if you tell them that this is what Islam teaches you to do then it has the potential to change their hearts and maybe the person will revert*".

A Muslim's sense of self-worth is often tied to being seen as a 'good' Muslim who has the ability to change perceptions of others and having strong social value can thus result in a positive sense of self-worth. Having strong social value would mean that other Muslims in the community would want to maintain connections with the person, ensuring their continued social vitality. If a Muslim with a high social value got sick (depending on the nature of the sickness) there would be a strong investment in treatment and working to reinstate health. An HIV+ Muslim, however, does not have

[116] Dawah is the act of inviting a non-Muslim to join Islam; this can be done through conversation or through one's behavior.

strong social value by virtue of the stigma that is attached to the the disease. Dalileh said that it does not matter to some of her family members that she was born with HIV, "*they don't care. They just keep telling me that it's a punishment. Some of them, I think, don't believe me. I overheard my cousin one time, they were busy whispering about me and thought I couldn't hear them, but I did. He was telling another cousin that he doesn't believe me, that he knows I had a boyfriend in high school and I must have slept with that boy and that's how I got it"*. There is a level of distrust that exists when a person explains their HIV status. This is because of the fear that is associated with the disease and the moral undertones that are linked to it. Sister Rifat noted that patients have said to her that family members frequently do not believe them about how they contracted HIV and accuse them of lying. Sister Rifat asserts that this is because there is such a strong emphasis on HIV transmission being a result of 'risky' behaviour among Muslims in Durban that they cannot see past that. Sister Rifat stated, "*I have spoken to family members of my patients, especially parents, and they seem to think that their HIV+ family member is lying about their contraction of HIV. They think that the person is embarrassed to speak the truth because they know what people will say about them, so they believe they must be lying*".

Therefore, it becomes clear that a Muslim's social worth and social value is strongly tied to how the individual is perceived, as either 'good' or 'bad'. Depending on the attached perception of the Muslim in question, membership to the Muslim community may remain intact, with social ties between the individual and other community members being maintained and strengthened or, as is the situation for Muslims living with HIV in Durban, membership to the Muslim community is broken and the social ties that once existed between the individual and the community cease to exist.

8.1.2 External Factors Which Contribute to the Social Death of Muslims Living with HIV

My data reflects that for all of my interlocutors the social death experience was external in that their family and community perceived them as 'dead', cut ties and stopped communicating with them. Interviews with my participants clearly show the notion of social death at play in their lives, albeit in varying degrees. They noted that since revealing their positive statuses to their families they immediately started being treated

as though they were ‘dead’ but, at the same time, the ‘death’, they noted, was simultaneously self-perceived in that they too felt dead to their family. Bijan said that many of his family members would ignore him when they saw each other in public, “*they pretend that I don’t exist, that they don’t see me. I know that I do not matter to them*”. Rahele explained that her family (mother and siblings) completely cut her out of their lives and refrained from communicating with her. Rahele has tried to reach out on numerous occasions but her mother ignores her or chases her away when Rahele tries to visit her mother’s home. Rahele explained that when she speaks to people who know her mother they inform her that her mother refuses to acknowledge Rahele’s existence and will either change the topic of conversation, belittle Rahele, or leave if probed further about Rahele. As a result, Rahele now acknowledges the loss of this relationship and sees little chance of ever salvaging it.

Gordon (2011: 13) describes social death as “not a singular biographical condition but a relational idiom of power”. In this instance, those who are ‘good’ Muslims wield the power and use it to push the ‘bad’ Muslims to the margins of society and so ensure their social death. Habib, for example, said that his sister has pushed him out of his family and continues to use his past actions and HIV+ status against him. Habib said, “*Tahira made it clear that she wanted nothing to do with me and pushed back against my parents accepting me. She said that she has always behaved appropriately, in line with the manner in which we were brought up, and that I brought shame to our family with my past actions. My father told me that she has a point, and so he goes along with what she says. Most times I am not invited to family functions, and on the occasions that I am, it is for my son to be present. So, a lot of the time I drop him off and pick him up when he is ready to come home*”. Sister Rifat and Sister Aisha have witnessed similar scenarios, where family members distance themselves from the HIV+ individual and actively keep them out of the social settings. Sister Aisha said, “*I see it happen a lot. The family wants nothing to do with the person and says that they can’t be associated with a wrong doer. They will say things like they pray five times a day, they fast and all that, so how can they associate with someone who does unIslamic things*”.

Power exists in all relationships, and Islamic society holds power over individuals who are members. Culture and religion dictate ways of knowing and ways of being to people who are members of the Muslim community. Muslims are not supposed to

judge another Muslim and yet they do so and feel justified in their judgement based on the moral undertones of HIV and AIDS (Jaffery, 2015). As such, it can be argued that social death is a means of social control which is applied in order to preserve and enforce the existing social order. The body becomes a site of morality that is linked to social relations and when the body is perceived as polluted, as it is believed to be in this situation, then the threat to the moral and social order must be dealt with, and this is achieved via alienation and social death of the person living with HIV (Henderson, 2011). Patterson (1982) explored authority and alienation in his work on social death. Alienation is of particular relevance to this study. Specifically, after diagnosis, Muslims living with HIV experience social alienation from their families and this can, in some cases, subsequently lead to alienation from themselves. Social suffering is a common experience of people living with HIV (Henderson, 2011). A person experiences alienation when they become disconnected from their social world, as in the case of Rahele who has been shunned by her mother. Alienation and social death have a strong connection. Both involve loss of feelings of connectedness in relation to a phenomenon. When a person is alienated from the family and community they lose the connection that exists between them and social death is experienced as a result of this alienation. Losing connection with one's family impacts one's identity and sense of self which, in turn, often results in a loss of sense of self, and thus alienation of the self occurs. Patterson (1982) expands upon this to include the notion of extrusive social death whereby a person who belongs to a community ceases to belong and is "expelled from normal participation in the community because of a failure to meet minimal legal … norms of behaviour" (Patterson, 1982: 41). Many Muslims living with HIV experience an extrusive social death. 'Minimal legal norms of behaviour' can be equated to minimal norms of moral behaviour in Islam. The immoral undertones that have become associated with HIV and AIDS, among Muslims in Durban, means that Muslims living with HIV are believed to have broken and deviated from the minimal norms of moral behaviour in Islam and so it is regarded as justifiable that they are expelled or removed from being a member of, and participating, in the community. Imam Rafiek believes that cutting off Muslims living with HIV from the Muslim community means that the community is safer and cleansed from any associated impurity. Accordingly, he stated, "*true believers, good Muslims, do not need to be mixing with people like this. They do haram things, these are major sins, and they are punished for it. I won't let an HIV+ person come to my mosque if I know about it*".

Habib, as mentioned earlier, is mainly cut off from his family, and he believes that if it were not for his son, then he would not communicate with them at all. Sister Rifat, Tasneem, Mya, Nani, and Azhar all related similar stories of patients who have been scorned by their families and communities.

When one group of people make another group of people the objects of pity and scorn, ignoring all other qualities of their personhood, the conditions for social death to be exacted is created. The socially dead are thus pushed into zones of social abandonment where they become isolated from others, and even their self (Wright, 2013). The biological death of a socially dead person is anticipated by their former social community, and there is an anticipatory relief that is experienced when their biological death is confirmed. Caregivers and health care professionals have attested to the fact that when they contact the families of recently deceased Muslims living with HIV, they are met more with relief than anguish over the death of the family member.

8.1.3 Internally Imposed Social Death by Muslims Living with HIV

A few research participants further stated that they felt that their social death was both internally and externally imposed. Self-perceived social death may result in self-chosen isolation from the community whereby a person willingly chooses to disengage from their natural social setting. When a person believes that they are dead to their community they may choose to stop participating in community activities and functions and actively opt to isolate themselves from their community. This is done because they feel as though they no longer belong to the community and/or because they do not want to taint the community by their presence. An HIV+ Muslim may do this to save themselves, and even their family, from shame or negative consequences and/ or experiences. Rahele no longer visits her mother or the neighbourhood that she grew up in, "*After my father died, and with how my mother treated me, I feel it is best to just stay away. It took a long time, I tried to keep the relationship but she was horrible to me and said bad things about me. My children said that I must look out for myself and forget about my mother and my family. So, I stay away now*". Bijan, also alluded to this, stating that he initially deliberately withdrew from social and religious functions and minimised contact with people as his HIV status slowly became public knowledge. He did so as he did not want his stepmother to be affected by his HIV+ status,

however, he says that she has remained a pillar of support for him throughout. "*My father passed away a long time ago, and it's been the two of us for a very long time. She has cared for me like I was her own child. When I was diagnosed I knew I could trust her with that information and I was right. When my status became known in my family, and I heard what people were saying I decided that it was best that I make it easy for them. My step mum and I had a talk, and I told her that I won't blame her if she decides to go her own way, but she said no, that I am her child, that she has a responsibility to me and that she promised my father she would take care of me. So, we don't go to many family gatherings or religious dos. People can't talk about you with satisfaction, if you're not there*".

Nani and Tasneem noted that they have patients who have fallen into depression and have isolated themselves from their families and friends, some of whom believe that it is better for them to take action first rather than face rejection. A sick person may choose to remain hidden from their community in order to preserve the memory their community has of them, to keep their sickness away from their community for fear that they pass it on, or for fear that they may become a burden to their community. In some instances, Muslims living with HIV have removed themselves from their family and/or community in order to maintain the secrecy around their HIV status for fear of being judged and outed to the broader community. Sami has not disclosed his HIV+ status because he fears rejection from his family and friends, and he also does not want to place his wife under any additional stress. He further added that he does not want his business to suffer because many of his clientele are Muslim.

Essentially, when a person or group experiences an extreme and/or profound negative change in their life, it may lead to loss of connections and subsequently to social death. Kralova (2015: 236) stresses that this may come as a result of "loss of role, of social identity, of social capital and social networks … displacement, social exclusion, loss of citizenship, of economic capital, of access to resources … interplay of power dynamics". The extent of a person or group's loss differs in relation to their experiences (contexts and circumstances) and Kralova (2015: 236 – 237) argues that with the loss of connectedness to things "their stigmatised status entails social exclusion, all of which impacts on their mental and physical health". Sister Rifat, Sister Aisha and Shiera, as health care professionals, attested to the fact that all their HIV+ Muslim patients have suffered from depression in various forms of severity. Shiera noted that

mental health affects physical health and she has had cases where she has had to counsel HIV+ Muslim patients to continue with medication when they seemed to have lost hope, "*I have seen depression get so bad that, while they don't want to take their lives, they don't want to help themselves either. You can live a long and healthy life if you follow your treatment plan, but it's not that simple. Mental health plays a big role in one's physical health, and depression makes it harder to get out of bed, to eat, and to take medication. When I worked in the public hospital, there were times when a patient would not come back. They would just disappear, and I knew that that was it for them*".

The three underlying notions of social death, "loss of social identity, a loss of social connectedness and losses associated with the disintegration of the body" (Kralova, 2015: 235) will be explored in the following sections.

8.1.4 Loss of Social Identity

Davies (2002: 4) defines identity as "the way people understand themselves in relation to other persons, to the world around them and to supernatural realms. Identity is a consequence of self-consciousness with particular social networks embedded within a particular language". People are born into communities that have cultures and identities, and every member of that community is enculturated into the norms and values of that society as they grow and forge strong connections with others within the community. People form relationships with those around them, their parents, siblings, extended family members, neighbours, religious community and so on, and these relationships, and in some cases lack thereof, foster a sense of who a person is and their purpose and place in the world (Davies, 2022). These relationships together therefore foster a sense of self and personhood (Rabinow, 2007; Kralova, 2015; Rosa and Diaz, 2019). Our identities and sense of self are forged in relation to people and phenomena around us. Breaking away from what we know leads to a break in the sense of self and a change in the self as one has to navigate new territory.

The loss of social identity may lead to one of three types of individuals, the non-person as proposed by Goffman (1961), the homo-sacer as proposed by Agamben (1998) or

the ex-human as proposed by Biehl (2004). Embedded in the concept of social death is the loss of one's social identity.

8.1.4.1 Becoming a 'Non-Person'

Goffman's (1961) notion of the non-person results from deculturation as an ongoing process. A person is removed from their natural social setting, which leads to them losing their social role/s in that community which, in turn, results in a loss of a sense of purpose and place. Goffman (1961) further argued that a degrading environment is created around the person which strips the person of important aspects of their identity and forces the individual to become a non-person (Ransom et al, 2021). Once a person is stripped of their support systems and sense of purpose and place in their community, it creates a feeling and position of uncertainty which is compounded by negative feelings and, as a result, leads to "a series of abasements, degradations, humiliations, and profanations of self" (Goffman, 1961: 34). This is compounded by stigma and feelings surrounding the loss of personal value. An HIV+ Muslim, through diagnosis, is removed from their natural social setting, their status, and role of a 'good' Muslim. Prior to diagnosis and disclosure of HIV+ status, the individual may not have been perceived as perfect, but not necessarily have been regarded as 'bad' or 'deviant' either. One's natural setting, is a comfortable position to be in. Upon diagnosis and sharing of HIV+ status with close family, however, the individual is pushed out, stripped of previous status and downgraded, meaning that purpose and place in society is lost. A Muslims living with HIV's social roles change and the individual is no longer welcome in the natural, social world. When removed from the natural social setting, this leads to experiences of social and psychological degradation, humiliation, scorn and a decline in social value (from both society and themselves) which is exacerbated by the imposed stigma. Muslims living with HIV are then cast out from natural society, deemed unacceptable for other Muslims to be in contact with, and becomes ostracised and socially dead to the community.

8.1.4.2 Intended Exclusion Facing Homo-Sacers in the Muslim Community in Durban

Agamben's (1998) notion of the homo-sacer is rooted in Ancient Rome. The label was initially given to people who committed a crime and who, as a result, no longer enjoyed legal, social and cultural protection. Muslims living with HIV are frequently regarded by other Muslims as having committed the crime of engaging in morally reprehensible activities and so they no longer enjoy the protection of the Muslim community who has cast them out. This stands in direct contrast to the Islamic principle that religion should protect the sero-positive individual because it is stressed in Islam that one Muslim should not judge another Muslim, and that it is important to take care of the sick and vulnerable (Jaffery, 2015). Religion and culture, however, while related are not the same. Religion may afford Muslims living with HIV protection regardless of the reasons for the individual's circumstances, but culture is not as accepting and easily casts out those who do not follow the norms and values set out, as Muslim culture does not have a divine entity deemed to be merciful and forgiving (Saidi, 2008; Mahmoor, 2017). The homo-sacer had no place in society in Ancient Rome, that homo-sacers could be killed without consequence to the person responsible and that homo-sacers were not even seen as fit to be used as human sacrifices and so were removed from religious contexts (Agamben, 1998; Dickinson, 2022). While not as extreme as being pursued to be killed, Muslims living with HIV however, because they do not enjoy any cultural protection, are seen as non-persons, and if they are ill-treated there are no consequences for it. In most cases there is no chastisement of those Muslims who treat Muslims living with HIV poorly and, in some instances, HIV+ Muslims may even be denied access to religious spaces when their HIV status is known. As mentioned earlier, Imam Rafiek does not allow an HIV+ Muslim into his mosque and he noted that he is not the only cleric to do so. Rahele noted that her mother has said many derogatory things about her and almost no one tells her to stop. Rahele's mother bullied her extensively and disclosed Rahele's HIV+ status to people in her neighbourhood. Rahele said, "*she told everyone about me. She called me all the names you can think off. My one neighbour, she is such a nice lady, she tried to stop my mother and she told her to stop talking about me but my mother went off at her. She swore her and said maybe my neighbour also has HIV otherwise why is she*

defending me. My neighbour kept quiet after that. I don't blame her, at least she tried, but you can't tell my mother anything".

Sister Aisha stated that in her experience people feel justified to ill-treat Muslims living with HIV because "*they think they have the high ground and moral superiority. I have heard people say horrible things about HIV+ Muslims and no one stops them or says anything different. I have been in many arguments over the years. It makes me so mad that our people lack compassion*". There have been numerous incidences where my interlocutors explained that they experienced bullying and ill-treatment from family members and neighbours, yet no one came to their aid and assistance to defend them. Habib spoke about his sister, "*She will take any chance she can get to pass a remark about me being HIV+. She will put me down any time she can because it makes her look superior. No one says anything to her. They are either too scared or they agree wholeheartedly with her*".

There is a constant sense of danger that emerges and this results in an uncertain existence due to the lack of protection and support. The homo-sacer's experience has inclusive and extrusion factors (Agamben, 1998; Dickinson, 2022). The inclusive factor means that the homo-sacer, because of the stigma, is an easy target for scorn. Those 'good' Muslims, residing in the natural social setting, are able to mock, ridicule, degrade, dehumanise and judge Muslims living with HIV as they are an easy target and Muslims living with HIV accept the scorn and punishment because, in many instances, they also believe that they deserve to be treated in such ill-mannered ways. Rahele, who has been diagnosed with depression, said that she felt that she must be in some way responsible for what happened to her, she said, "*I don't know but maybe I did something when I was small to make my brother hate me and do all the things he did to me. My mother told me many times that I was a rotten child so sometimes I think that maybe that's why I got this thing* [HIV]. *Why else did I get punished like this?* Habib said, "*I know that what I did in my past was wrong. I behaved very unIslamically and now I am paying the price. I understand my family's frustration*".

The 'crime' Muslims living with HIV have committed, in the view of Muslims residing in the natural social setting, is contracting HIV and, as such, they have lost the comfort and cultural protection that comes from being in the natural social setting of a 'good' Muslim. The exclusion factor is when the homo-sacer is segregated from the

community and the resources and protection that it offers. The scorned individual is turned into a non-person by being labelled homo-sacer. The absence of any form of safeguarding, coupled with societal rejection leads to a vulnerability of the homo-sacer, which results in their complete abandonment by their community (Agamben, 1998; Kralova, 2015; Dickinson, 2022). Muslims living with HIV lack the protection and support of their families, and sometimes friends, which creates a sense of vulnerability and uncertainty in their lives, which, in turn, leads to their social abandonment by the very structures in society that were meant to provide stability and safety. Muslims fear being associated with the stigmatised, in this case Muslims living with HIV. There is a fear of being labelled as 'bad' by association and there are repercussions thereof. Stigma is an integral aspect of the concepts related to social death as without the existence of stigma, social death may not occur. The social abandonment experienced by Muslims living with HIV is not only due to the shared perceived understanding of Muslims living with HIV being 'bad' Muslims, but is also reinforced by fear. The fear that is present in the community, ascribed to by family and friends, is the fear of being stigmatised by association. Muslims do not want to be associated with someone who is considered a 'bad' Muslim by societal standards.

Mya spoke about how, in her experience, some families are scared of being rejected and ridiculed because they are related to an HIV+ Muslim. She said that parents, especially, are afraid of what the community will say if they find out, "*they worry that people will say they are bad parents and didn't teach their children properly, you know, right from wrong, and how to be good Muslims and follow the teachings of Islam. Some of them think that other people will think that they have HIV too*". Becoming a non-person may be an unintended consequence of social experiences and interactions, however, becoming a homo-sacer is an intended punishment that is metered out by one's community (Agamben, 1998; Kralova, 2015; Dickinson, 2022).

8.1.4.3 The Final Stage of Transformation: Becoming an 'Ex-Human' in the Muslim Community in Durban

Biehl (2004) explored the notion of 'ex-human'. The concept of an ex-human is the aftermath of being cast out from one's community, of being labelled homo-sacer, of becoming a non-person. It is the last stage. Once a person is outside the normal,

natural social setting, existing on the margins of society having been forgotten as a result of being socially dead, a person is no longer human and is no longer afforded humane treatment (Biehl and Locke, 2017). Kralova (2015: 239) explains that "those who have fallen through the net of social protection … have been excluded from the wider community to experience an undignified death". Sister Aisha and Sister Rifat spoke to how, in their experiences over the last twenty years, they have known Muslims living with HIV who have been left to die on their own, having been abandoned by their families. Sister Aisha and Sister Rifat explained that familial relationships were almost non-existent, if they existed at all, and there were many cases where the only support their patients had in their final days was from the nurse, social worker or psychologist assigned to them in the hospital or hospice. People who are labelled ex-human are no longer perceived as human beings and are irrevocably excluded from the reality of their communities (Biehl, 2004; Biehl and Locke, 2017).

As a result of their HIV+ status, Muslims living with HIV's identity becomes embedded in shame and worthlessness to the extent that they do not believe that they deserve to be treated humanely. The Muslim community in Durban is a very close-knit one. In general, across the world, the events of 9/11 and the increase in Islamophobia have made the Muslim community even closer (Dubosh et al, 2015). Whilst there is a strong argument to be made that South African Muslims have not suffered much Islamophobia in relation to Muslims living in the West, it still exists on some level. The Muslim community in Durban is built on notions of brotherhood and sisterhood and Muslims living with HIV are expelled from this community because of the stigma associated with the disease and understandings of 'bad' Muslims being punished for their actions. There have been instances where religious protection, for example being denied access to prayer spaces and/ or spiritual guidance, has been removed because Muslims living with HIV have been deemed unworthy, or because they are considered 'dirty' in terms of Islamic values of purity and cleanliness. Thoughts of shame, worthlessness and degradation that accompany social death may also lead to biological death. Rahele almost killed herself after her HIV+ status was confirmed. Sister Aisha and Sister Rifat spoke about Muslims living with HIV who have committed suicide, knowing that the act of suicide is *haram*, but believing that there is no redemption for them and "*they would end up in Jahannam* [hell] *anyways*". An ex-human may be a non-person or homo-sacer, who has been stripped of self-worth,

sense of belonging to community, as well as social identity, generally, as a deliberate punishment by those who believe that they have gone against the natural rules of the social setting.

8.1.4.4 The Interconnectedness of 'Non-Person', 'Homo-Sacer', and 'Ex-Human'

These three forms of social death are interconnected. An 'ex-human' shares many characteristics with a 'non-person' and a 'homo-sacer'. Each of these social deaths entail "stripping a person of their social identity, self-worth, and belonging to a community" (Kralova, 2015: 239). The difference between them comes from how the social death is achieved i.e. was it an accidental phenomenon or was it purposeful and deliberate punishment for the person being cast aside? Muslims living with HIV have experienced deliberate punishment and removal from their community. Their social identity is tampered with and affected because of how they are perceived by other Muslims. Muslims living with HIV are perceived as less than Muslims, "*as Muslim in name only*" and this is something that affects their sense of self-worth and results in it diminishing over time. Support systems diminish, as support is withdrawn by family and (Muslim) friends who judge the person based on their HIV status, and their social value and worth are further diminished by claims made by other Muslims that Muslims living with HIV are not real/ true Muslims. Muslims living with HIV become 'othered' in their own community, and are pushed out. This results in their sense of belonging being broken and they are then pushed to the margins of Muslim society.

8.1.5 The Importance of Support Groups in the Avoidance of Becoming a 'Non-Person'

Caregivers and health care professionals who were interviewed expressed that, as a result of the above, support groups for Muslims living with HIV are incredibly important because this creates a space for Muslims who have similar experiences to come together and share their experiences and help each other grieve the loss of self, identity, and community. Support groups are also a place for a new community to form as Muslims living with HIV are able to connect with each other and support each other because they understand what they are each going through and experiencing. Support

groups provides Muslims living with HIV with a new community where they may find acceptance, support, and understanding through shared experiences and this may prevent them from becoming non-persons, homo-sacers or ex-humans. Sister Aisha and Sister Rifat argue that this is why support groups for Muslims living with HIV have become a very important part of their work. Rahele and Dalileh, who attend the same support group, expressed how important and helpful it has been for them. Dalileh said, "*you realise that you are not alone in the world. Don't get me wrong, Sister Rifat and Sister Aisha are great, but it's not the same as getting support from people who experience the same things that you do*". Sister Rifat said that "*the support group space is a space where HIV+ Muslims can come together and talk about their experiences and help each other. They can be themselves and they talk about anything and everything. Some of the people who are in the group have not disclosed their status to their families, so they spend most of their time hiding. But in the support group they can speak freely, talk about their health and their doctor's appointments and all that. If they are having any trouble then others in the group will give advice. It's a place where they are welcome*". Thus, while Muslims living with HIV may be viewed as inadequate, or 'not Muslim enough' in the eyes of the broader Muslim community in Durban, they are not completely lost and without community because, through their shared lived experiences, they are able to form a new community of sorts with other Muslims living with HIV.

Kralova (2015: 239) explains that the 'non-persons' removal from society is "underpinned by the idea of protecting others from the person themselves". This can be linked back to Mary Douglas' notions of fear driving ideas of purity and danger and removal of dirt from social settings where they are perceived not to belong. This fear stems from wanting or needing to portray the Muslim community as 'good' and 'wholesome' and fearing that HIV+ Muslims will taint such an image while simultaneously influencing the actions of others and leading people astray, especially the youth. 'Good' Muslims think that they are doing the community a favour, but as Imam Hamzah argues "*by doing so, they are behaving very un-Islamically. Our place is not to judge, we are all sinners, even me. It is our job to care and to help. We are brothers and sisters in Islam. We mustn't turn our backs on the sick, regardless of how or why they are sick with whatever disease they have*". Against being outcast by the wider community and simultaneously being relegated to the ranks of a 'non-person',

support groups provide MLHIV with renewed vigour and hope and with a semblance of their old social worlds in which they were a valued member of a community.

8.1.6 Loss of Social Connectedness

Social identities are inherently linked to social connectedness. The stronger a person's social connections to the people in their community, the stronger their social identity (Kralova, 2015; Biehl and Locke, 2017). Muslims have a strong social identity which is made visible through clothing, traditions and religious practices, as well as the presence of *masjids* in predominantly Muslim residential areas. One strong identifier is the way in which a Muslim greets another Muslim. In my experiences it is very rare, and also frowned upon, to greet a fellow Muslim[117] with anything other than the Arabic greeting of salaam, ***as'salaamualaikum***[118], regardless of where they are. By this I mean that the Arabic greeting is not reserved for religious gatherings or Holy spaces, it is expected that when one sees a Muslim, they greet the individual in what is deemed to be the appropriate manner. If one does not recognise another as a Muslim, and greets with a simple '*hello'* then the Muslim will reply with a *salaam* identifying him/herself as Muslim. This is not something that is common in many communities. My non-Muslim Hindi friends, for example, generally greet elders in their vernacular, but when they see their cousins, friends or other Hindi people they greet using an English colloquial greeting.

The Muslim community in Durban is very visible. *Masjids* are an important part of the eThekwini skyline. Religious symbols and sites, such as, Juma Masjid (also known as Grey Street Mosque) in central town and Soofie Saheb Riverside Mosque and Mazaar north of Durban are prominent and well-known sites. Formally so-called 'white areas' under the Apartheid regime that are now home to many Muslim families, for example, Westville and Musgrave, now also have *masjids* in the area. Every suburb in Durban that has a visible Muslim population, has a *masjid*. Halal eateries are plentiful and many have prayer spaces for Muslim patrons. Major shopping centres such as The Pavilion (Westville), Gateway (uMhlanga), and Galleria (Amanzimtoti) have prayer

[117] This is when the Muslim person is visibly Muslim, example wearing a headscarf or a long cloak, i.e. something that signifies that they are Muslim.
[118] Which translates to "peace be upon you" or "may Allah be pleased with you".

spaces in the buildings to accommodate Muslim patron's prayer needs when they are out shopping. There are numerous Islamic schools in Durban as well.

There is a strong social presence and, as such, there is a strong social identity for Muslims in Durban. Islam is a social religion. Men are expected to pray in congregation and family is very important. Building and maintaining ties with neighbours and the surrounding community is important. The loss of social connections is thus devastating to Muslims living with HIV. Furthermore, from birth Muslims are taught to love other Muslims as though they are family and to help Muslims wherever possible. The obligation of *zakat*[119] is stipulated to be given only to Muslims. If one holds a religious gathering, it is not only family and friends who are invited but any Muslim who hears about the event is allowed, and encouraged, to join in.

The degree to which one's social connectedness exists has an incredible impact on one's life. To be part of such a close-knit community and then cast out is traumatic. Rahele said that whilst she had a poor relationship with her mother and siblings, she had Muslim friends in the neighbourhood which she grew up in. Rahele said that while she was not popular, as she was a very shy person, she had made quite a few connections with other Muslims in the community. This changed, however, when her HIV+ status was disclosed and "*the people, they just stopped talking to me. They ignored me like they never knew me. I felt very hurt*". Shiera said that, in her opinion, one of the most common reasons for depression in HIV+ Muslims is either due to being rejected by their family and community or a result of the fear of that rejection and being cast out of society. Social connectedness is important in sickness as well as in death. It is expected that a Muslim will visit another Muslim who is sick. Groups of volunteers will go to hospitals to visit the sick. I remember when I was young when family would go to the hospital to visit a sick friend or family member, if there was another Muslim person in the ward, my grandparents and my mother would go and sit with that person and their family and vice versa. Many times, I would ask how my grandparents or my mother knew the other person because they would speak to each other as though they were friends but, in actual fact, they had just met in that moment. When a Muslim person dies, the funeral is open for attendance by any Muslim who

[119] Sadaqah (charity) can be given to anyone and is not dependent on religious affiliation. Sadaqah is encouraged, but not compulsory like zakat is.

has heard about it. Funeral messages are posted on *masjid* notice boards, through telephone chains[120], and WhatsApp messages in community groups or private messages. Men are expected to attend a funeral prayer and burial if they are made aware of the death, even if they are simply in the *masjid* for prayer when the news is announced. Losing connection in a community like this means that one loses the presence of the community during sickness and in death. One's social connectedness, or lack thereof, impacts on how one's death is received by the people from the society at large. Sister Aisha has been involved with HIV and AIDS for over thirty years and explains that she has been to many funerals of HIV+ Muslims and seen first-hand how the community shuns Muslims living with HIV even in death. She noted that the *Imam* is duty-bound to conduct the funeral, and does not have a choice to refuse, but there have been many cases where there have been just a handful of men at the funeral prayer, usually because they were present at the *masjid* during regular prayer time and would feel obligated to join the funeral prayer.

Social roles are important and help people make sense of their place in their community. Being Muslim is a huge part of one's personal and social identity, and having a place in society is just as important. Social roles are strong identifiers, and being Muslim is a strong identifier for Muslims. Clothes express one's affiliation to religion and the notions of 'good' and 'bad' Muslims are linked to this. A 'good' Muslim is identified through the way in which they dress, this is especially so for females who are expected to cover their hair, wear long pants and long sleeves, and whose clothing should generally be loose fitting so as to not show the shape of their body. Other identifiers include attending prayers at the *masjid*, which is compulsory for men, the manner in which a Muslim interacts with others and the way in which individuals portray and carry themselves. A 'good' Muslim will have a positive role in Muslim society, especially so as someone who is to be emulated by other Muslims and the youth. A 'bad' Muslim, conversely, espouses negative behaviours and engages in haram activities. If one is perceived to be a 'bad' Muslim, then that particular individual will experience a role reduction in society. For example, if a male who leads prayer sessions or gives the call to prayer is perceived to have transgressed in some way,

[120] Even with the advancements in technology, telephone chain calls are still one of the strongest ways of getting word out about the passing of a person. Landlines are still used where possible, and calls are preferred over text messages. One person from the family of the deceased will call a few choice people, who will then call others on their informal list and word will spread in this way.

and is labelled a ‘bad’ Muslim, these responsibilities are likely be removed from him, thus affecting his role in the Muslim community and effectively reducing it. If a female is prominent in women’s circles and host’s religious events at her home, she may have this removed from her responsibilities if she transgresses, thus effectively reducing her role in Muslim society. Social control is an important tool used to keep Muslims on the ‘right path’ (Thue, 1998). A decline or breakdown in community life affects one’s social connectedness to others in the community. There is, what Kralova (2015: 24) refers to as, a “disintegration of interpersonal relationships” and a negative impact on one’s social roles and identity. One’s social identity is strongly linked to one’s social connectedness, and when this breaks down, it may lead to social death. Steele et al (2015) have argued that when a person is ostracised by their close relations and community, this may increase thoughts of biological death. All my participants expressed that at some point or the other they had had suicidal thoughts. Rahele mentioned that after she became aware of her diagnosis she walked into the middle of the road and seriously considered placing herself in the path of an oncoming vehicle. Habib said that if it was not for his son, he is not sure if he would still be alive. Narda said that she has thought many times about killing herself, “*I am alone. My family don’t want me. I’m grateful for the help that they give me, but they want nothing to do with me. I have no friends, no family, so sometimes I think what’s the point, I might as well put myself out of my misery, but I can never go through with it*”. These sentiments reflect a mixture of factors including being cut-off by family, feelings of shame and disgust and fear of other people finding out about their HIV status.

The negative impact on social identity, of being labelled a ‘bad’ Muslim, after being perceived to be a ‘good’ Muslim, leads to a lack of ability to maintain social connections as they are cut, and as such one’s existential core is destabilised (Kralova, 2015; Biehl and Locke, 2017). In all cases family was the first to cut ties with the Muslims living with HIVs in this study. Family is the first port of socialisation, and the strongest social ties tend to be from one’s family. Having a connection break can leave a person feeling lost, alone and even isolated. Family is important to one’s social identity, as we carry the names of our ancestors, which, in turn, creates connections between families who share the same last names. Losing connectedness with one’s family is losing a significant part of one’s sense of self. For a Muslims living with HIV, social death begins with the loss of connection to their family and is then exacerbated and

entrenched through the loss or break down in social connections with wider society. The loss of social connections affects a person's existence, have a "profound impact on a person's quality of life" and reduce an individual's ability to "connect with their social universe" (Kralova, 2015: 241 – 242). Anxiety and depression being commonly noted experiences by my participants in dealing with the loss of social connectedness from family and community.

8.1.7 Losses Associated with the Disintegration of the Body

Kralova (2015) identified three notions of the body in relation to disintegration. Disintegration, for the purposes of this study, may be linked to a lack of or reduction of health and well-being of the body.

8.1.7.1 Powerless Bodies

The first notion is that of the powerless body. Kralova (2015: 242) argues that social identities are "connected to, and enacted through, our bodies". The body is the site of one's social identity. The breaking down or disintegration of one's body can be connected to the erosion of one's social identity, leading up to the individual's social death. HIV affects the body negatively, eventually leading to the breakdown of the body over time. HIV not only erodes social connectedness of HIV+ people to their natural social environment, but it also physically disintegrates the body, leading to biological death. Disintegration, however, also occurs on a psychological level due to the stigma that stems from the disease. Thus, it can be argued that HIV and AIDS disintegrates one's physical, social as well as one's psychological identity. A disease such as HIV and AIDS affects how a person sees him/herself and how those around the person perceive them, thus affecting one's social connectedness and identity. One's social identity is important to informing sense of, and place in, society. A cancer patient in remission, for example, is often referred to as a cancer survivor (Shaik, 2009). The application of the term 'survivor' as an identity marker creates and reinforces the perception of strength, survival and retention of life and personhood (Shaik, 2009). Being labelled as HIV+, however, on the flip side of the coin, has negative connotations as one may be labelled 'promiscuous' or as a person who

engages in ‘forbidden acts’ and therefore as a ‘bad’ Muslim. Furthermore, one does not ‘survive’ HIV, one lives with it for the rest of one’s life and it becomes part of one’s new social identity. The decay in the body (as well as in one’s social identity) brought on by HIV erodes the social connections that exist in one’s life and brings about social death. Social death is regarded as a shameful death where one’s social identity is undermined and social connections are broken (Biehl, 2004; Kralova, 2015; Biehl and Locke, 2017). Regardless of whether Muslims living with HIV have repented and asked Allah for forgiveness as is the customary norm of Islam, by virtue of being HIV+, the positive individual’s connections to other Muslims remain poor, if they exist at all. Identity remains undermined and damaged due to the associated stigma of the disease. Social bonds are broken, and only in exceptional cases do they remain or get recreated. For a social death to occur, the circumstances are extreme and there is no turning back from that point.

8.1.7.2 Powerful Bodies

The second notion put forward by Kralova (2015) on the losses associated with the body’s disintegration is that of the ‘powerful body’. Here, a disintegrating or deteriorating body does not necessarily equate to a path leading straight to social death. If one becomes a non-person, or homo-sacer, the individual still possesses the ability to change their situation. There may still be some agency present in the person’s psyche and the owner of the body may try to hold on to and maintain the role that they had in society, or, if that is not achievable, then they may create a new role to occupy in the natural social setting within which they existed (and were pushed out of). The individual may alternatively occupy a role in a new social setting and therefore create and maintain a new social identity. This speaks to activism within the HIV community.

8.2. Activism: A Mechanism for Avoiding Social Death and Achieving Social Vitality

People living with HIV experience biological and social suffering. Yet, it is important to highlight what Henderson (2011) notes as the body’s remarkable capacity to exercise agency in the face of challenging circumstances. Activism occurs when instead of

giving up and giving in to social pressure and social death, the HIV+ individual, after acceptance of one's situation, creates a new role that is meaningful and positive. Via the mechanism of creating a new social position hinged upon a meaningful social identity, social death is avoided as the HIV+ individual develops an identity based on 'being positive about being positive'. Whilst the broader community may not fully embrace this position and role they may accept it because it serves an important purpose. Muslims living with HIV who are activists own their HIV status and, it is perceived by other Muslims, are able to put the new status to use to 'warn' other Muslims to think carefully about the choices they make, especially Muslim youth. By creating a blueprint of 'what not to do', it creates a new place in the Muslim community for the Muslims living with HIV. Social ties may be reformed, albeit in limited ways, but the activist has a role and purpose in society and is able to build social connections, thus improving social identity somewhat.

The Muslim living with HIV as an activist is, however, important for more than just being a deterrent from 'bad' behaviour. Additionally, he or she is also able to help people who are new to the experience or who are in a worse position than that of the activist. The activist is able to speak to HIV+ Muslims and help them navigate their new status and place on the margins of Muslim society. Bijan is an example of such an activist. He stated that since his diagnosis, he has accepted his HIV+ status and has been actively speaking about HIV and AIDS. He further noted that although creating awareness about the disease is important, he does not want to be *'a victim'*. He stated instead that he mainly wishes to help other Muslim people who have experienced the same things that he has because, "*I am not shy to talk about my status. There must be a reason that I got this disease, and I decided that I will do something with it. I've given talks about being HIV+ and living with HIV as a Muslim. I have gotten good and bad reactions, but I know I have made some difference in a few people's lives, and that's important*". A powerful body, then, he maintains, *'asserts itself, it does not reduce in size or stature, but finds a way to be useful and meaningful'*. If an individual is equipped to exercise agency and autonomy in relation to their situation and experiences then the body can, "become an effective tool for sustaining personal identity" (Kralova, 2015: 243). An important factor that is required in such a situation, though, is for the HIV+ person who becomes an activist to have some form of support or a very strong sense of self-worth in the face of societal isolation. For

Bijan, the support of his stepmother gave him the strength that he needed to speak openly about his life as an HIV+ Muslim. He stated that without her he does not think that he would be as strong and resilient as he has become. He takes his role of educating the public and the Muslim community in particular about HIV and AIDS very seriously and feels that he has an important role to play in society.

In this sense one may argue that instead of experiencing social death, a person experiences social vitality. Card (2010: 237) defined social vitality as that which "exists through relationships, contemporary and intergenerational, that creates contexts and identities that give meaning and shape to our lives". These relationships can be with family, friends, and/ or co-workers. The common denominator is social connectedness through one or more relationships in order to maintain social connectedness and ensure that social death is avoided. Maintaining and creating/or forging new social connections strengthens one's social presence and purpose and subsequently strengthens social vitality. Henderson (2011) states the agency in the face of a disease such as HIV cannot be ignored and that with caring relationships comes the possibility for positive change. Interpersonal relationships are important for social vitality because one needs others and relationships/connectedness to others, to have social viability and vitality. White (2010: 164) states that "people become who and what they are in and through their relatedness to others".

AIDS activism is not a new concept. AIDS activism emerged soon after the epidemic became known in the USA in the 1980s. When HIV/AIDS was initially conceptualised as a disease infecting primarily homosexual males, homosexual males from San Francisco and New York became HIV and AIDS activists to raise awareness of the disease. Homosexuals were already a marginalised and stigmatised group at the time and HIV and AIDS compounded the existing stigma. Wright (2013) argues that social death posed a unique threat to PLWHIV and that AIDS activism, in the 1980s, began as a way in which to resist the occurrence of social death for PLWHIV. The Denver Principles document was a culmination of the most prominent AIDS activists in the 1980s and has since influenced later movements, one being the Treatment Action Campaign (TAC) in South Africa. AIDS activism has had powerful impacts at a political and socio-economic level and has effectively changed the way in which governments around the world have responded to the AIDS crisis.

Activism is a way to avoid social death, both for the activist and for the afflicted and scorned group. Support groups are important sites of social vitality and are important mechanisms to bring the socially dead back to life. Wright (2013: 1792) referred to the case of Larry Kramer who wanted to raise "community-wide alarm by emphasising the likely mortality of the new disease". The point that Kramer was making, argued Wright (2013), was that to keep the disease hidden is not helpful. Fear and ignorance festers as a result. Keeping the disease hidden in a community may lead to risk of spread continuing and prevalence within that community increasing. Bijan similarly stated that lying about one's HIV+ status is harmful. He further stated that he has met people who lie about their HIV+ status and get married and then infect their spouse. At the commencement of my interviews with Bijan he was single, however, he later began dating a Muslim woman. In follow-up interviews with Bijan he noted that he is open and honest about his HIV+ status with his (now) fiancé. Bijan stated, "*I had to tell her. I didn't tell her immediately when we started talking, but after a few months I realised that this was getting to be a serious relationship and if I was going to continue then I had to tell her and let her decide what she wants to do. I feel very lucky that she chose to stay with me, and we will take every precaution to ensure that she stays HIV-*".

MLWH activists have explained that raising awareness in the Muslim community is important so that others do not find themselves in the same situation. Some of my female participants expressed that they have encouraged young girls and women to become independent, especially financially, so that they do not have to depend on their husbands or do not need to find a husband in order to achieve financial stability in their lives. Sadira related that she felt 'stuck' in her marriage because she has no skills and has never worked outside of her home. She stated that she was completely blindsided by what happened to her and does not wish such a thing on anyone else. Being economically independent, Sadira maintains, grants an individual the opportunity to leave a situation as bad as hers. Rahele has told her children that before they get married, they should have HIV tests done to have peace of mind. Due to her past experiences of abuse Rahele is not trusting of people's words and has stressed to her children that one does not really know the person they are marrying and should safeguard themselves.

By bringing lived experiences to light, through activism, lives can be saved. Creating awareness about the existence of Muslims living with HIV is important because a

hidden population cannot help themselves or their wider community to protect themselves. Creating awareness removes the rose-tinted lens of "*it can't happen to us*" and addresses the reality that not only can Muslims contract HIV but that it does happen. HIV is spreading throughout the Muslim world and is a reality that must be accepted so that it can be addressed (Hasnain, 2005; Cochrane and Nawab, 2012; Kelly et al, 2012; Kamarulzaman, 2013). AIDS activism, however, is individualistic amongst Muslims. It is a personal choice to put one's HIV+ status in the public sphere, opening the individual's life up for scrutiny from the people around them. Muslims living with HIV can use their experiences to help assist with responding to the disease and its spread in the Muslim community. Furthermore, activism can create a platform for new social connections to be formed and can give new meaning to individual's lives, thereby bringing value to their existence once again. Bijan said that speaking out about HIV and AIDS has given him a new and different purpose in his life. Rahele said that since being a member of the support group she has felt that she has something to offer other people and this makes her feel important, "*I got this disease for a long time now, and I know a lot about it. So, I can tell new people coming to the support group about medication and things. I can advise people because I know, because this is my life and it's nice that I can help someone even in a small way*".

Activism changes the narrative of impending doom and reduces social isolation. It removes the victim label (often externally imposed) and paints the activist as a survivor who has something to offer society. Discrimination still exists, and so does stigma, but there is also purpose and value that comes through activism. Speaking out about the existence of HIV and AIDS in the Muslim community and how to live through it is important because, as Wright (2013) states, the reality of impending social death through diagnosis may result in the avoidance of diagnosis. Some people may prefer to remain ignorant as opposed to knowing their status, which potentially places others at risk. Sister Aisha recalled a man who frequented sex workers in the area where she was working, in Chatsworth, in the 1990s. He was a Muslim man, she said, and she eventually approached him and asked him if he would like to come to their testing facility to get tested for HIV or any other STDs. She said, "*he refused me and rudely said that he did not have to worry about such things and brushed me off*". Every time she saw him she would approach him and after numerous conversations with him he eventually told her that he did not want to know, that he had started to use condoms,

but that he if there was *"any damage done"* he preferred to live in ignorance. Most of my participants have not reached the activist stage, they are still reluctant to speak openly about their HIV status. Even Bijan, who has been open about his status and actively speaks out about his experiences, and who would be considered an activist still has qualms about revealing his status to people he knows more personally, hence, he waited to tell his fiancé about his HIV status.

The application of Douglas' (1966) purity and danger creates the setting for stigma and discrimination to occur as behaviours and actions are categorised according to what is acceptable (clean and pure) and what is not acceptable (unclean and impure and dangerous as a result). Stigma and discrimination then compound to lead to the social death of an individual. Muslims living with HIV, in Durban, experience a profound sense of loss and social death as they are cut off by and from their families and friends, and the wider Muslim community. Through social death, an HIV+ Muslim is pushed to the margins of the Muslim community and is ignored and/or forgotten. It becomes clear then that the application of Islamic beliefs needs to shift from those of condemnation to that of compassion. The experience of a social death puts one at risk for depression, anxiety, suicide and disruption of one's treatment regime. It goes against the very tenets of Islam; however, this is a reality for Muslims living with HIV in Durban.

This chapter on social deaths of Muslims living with HIV in Durban rounds off the analysis of the study and the next chapter aims to conclude the study and provide possible recommendations for further research on HIV and Muslims.

CHAPTER NINE: CONCLUSION AND RECOMMENDATIONS

HIV and AIDS, as a global pandemic without a cure, spread rampant across the globe in the early decades of the disease. With the widespread rollout and uptake of antiretrovirals, recent years have seen a decline in death rates globally, yet the disease has far from been eradicated and remains a major threat to global health. HIV and AIDS is not purely a biomedical disease but is intertwined with a host of socio-cultural, political, religious and economic problems and as such a biomedical lens is not sufficient in studying the disease and in implementing intervention strategies. Data reveals that HIV is spreading faster than ever before in countries with a predominantly Muslim population. A common reason cited for the spread includes increasing Westernisation which has brought with it a modern sexual revolution (Badri, 2000), coupled with a strong sense of denialism. By assigning HIV and AIDS to 'the west', it is therefore construed as a disease not fit for Muslims. HIV and AIDS in Muslim countries has historically been regarded as a disease of 'the other' and therefore as something that Muslims were largely exempt from due to the overriding moral codes upon which the religion is hinged. Individuals who contracted the disease have thus been regarded as having morally transgressed and, accordingly, as being punished by Allah through the disease. With the strong moral undertones ascribed to the disease in Islamic cosmology and so called 'risky' behaviours which run counter to Islamic religion being regarded as the drivers of the disease, HIV and AIDS has been overlooked as an issue of concern in Muslim communities.

HIV and AIDS has a history of being a highly stigmatised disease and while much has been done on a global level to reduce the stigma that surrounds the disease, in many social contexts it remains highly stigmatised. In predominantly Muslim countries and amongst Muslims in general, HIV and AIDS remains highly stigmatised and HIV+ Muslims are, as a result, stigmatised and discriminated against based on moralistic assumptions of how the HIV+ Muslim contracted the disease.

Islamic principles dictate that Muslims should care for each other in times of sickness and hardship and Muslims who have fallen upon difficult times are normally afforded the benefits of a broader, societal safety net. The response to HIV+ Muslims has not, however, been in accordance with such principles set out by Islam and Muslims who

are known to have contracted the disease are frequently shunned by family and by the broader Muslim community.

In order to reduce or prevent the spread of HIV and AIDS in Muslim communities, it is important to understand the disease from the perspective of those affected as has been the case in this particular study on HIV and AIDS in the Muslim community of Durban, South Africa. In this case, understanding how Muslims perceive HIV and AIDS is important because this allows for more relevant intervention programmes to be designed and implemented. Muslims are largely in denial about the presence of HIV and AIDS within their ranks, yet acknowledging its presence in the Muslim community is a fundamental starting point if the disease is to be adequately engaged with and tackled using culturally-appropriate strategies.

Muslims in South Africa comprise 2% of the population in the country, and HIV has become an increasing risk within this population group. The HIV-related stigma is amplified within this group and the continued focus on questioning the moral character of the infected Muslim does little to dispel myths, introduce intervention strategies and reduce stigma and much to increase social isolation of individuals relegated to the fringes of society by virtue of testing positive. This isolation, as a result of HIV status, has been conceptualised in the form of ritual impurity which has been addressed in Chapter Six of this dissertation. Mary Douglas's work is important in framing the experiences of Muslims living with HIV because it is a result of such beliefs surrounding purity and impurity that lead to the continued stigmatisation and discrimination of the HIV+ Muslim person. Notions of 'dirt' and of HIV and AIDS being a 'dirty' disease need to be challenged within the Muslim community as they are harmful to those affected by the disease. Purity being tied to morality, and impurity being tied to immorality has social and psychological repercussions for individuals. Chapter Seven focused on the subsequent enacted stigma and discrimination that Muslims living with HIV experience on a daily basis, leaving the HIV+ Muslim feeling isolated, alienated, alone and lonely. As a result of this, as is explored in Chapter Eight, social death is a common consequence in the experience of HIV+ Muslims. Chapter Eight explores the experience of social death as an individual is labelled an outcast, shunned by society and relegated to the hidden world of the forgotten. The chapter also however explores the possibility of social vitality which is achieved when

an individual, instead of being shunned due to HIV status, embraces the label that society has assigned and becomes a part of a support groups, or enters the role of an activist.

The chapters of this thesis have explored how HIV+ Muslims understand their disease, and experience it through the application of various frameworks. HIV and AIDS education is needed in Muslim communities in Durban for Muslims of all ages. From this it can be deduced that Muslims living with HIV, in Durban, face harsh psychological repercussions through the enacted stigma and discrimination that they experience. Support groups have been noted as an important tool to enhance social vitality and improve psychological health and well-being. HIV+ Muslims struggle to cope with the loss of social relationships, especially when this involves family members, and support groups therefore may serve as an alternative for these social relationships. This is one of many reasons why the silence and denialism of HIV and AIDS in the Muslim community needs to be addressed, as support groups may be able to offer assistance to more people.

While the Muslim response to HIV+ Muslims has largely been judgemental, exclusionary, deficient and negative (Ahmed, 2003), it is crucial that creating awareness be navigated carefully, without blame or judgement. Instead of focusing on moral overtones and discriminating on the basis thereof, other facets of Islam need to become the focus, such as showing care and compassion to the sick and those in need. This type of stance is evident in the work of my participants who provide both professional and voluntary care to Muslims living with HIV. The approach of Imam Hamzah to HIV and AIDS in the Muslim community in Durban is also a positive and caring one and instead of preaching ‘fire and brimstone’ and that HIV+ people are going to the hellfire, he preaches care and compassion. Instead of instilling fear and promoting stigma, it is important to have open and honest conversations that equip people with the social tools they need to navigate their sexuality and sexual activities. Should individuals then ‘transgress’ from the prescribed Muslim safety tool of abstention, they will have the knowledge and means to protect themselves from unwanted STIs. Spreading awareness about HIV and AIDS in Muslim communities and developing and implementing progressive Islamic-centered perspectives on HIV and AIDS through acknowledging the existing relationship between health and social

well-being is the way forward in the fight against HIV and AIDS in the Muslim community in Durban.

The response to HIV and AIDS by Muslim communities has not been homogenous, with differences of opinion in how to approach the pandemic being offered. While the dominant views are either hinged on denialism or the conception that HIV+ Muslims are weak in their faith and easily susceptible to HIV and AIDS as a result, other (newer) approaches move away from judgmentalism and promote a deeper understanding of stigma faced by HIV+ Muslims while simultaneously acknowledging vulnerability and not fixating on morals. Shifting the lens from focusing on sexual immorality to understanding HIV through a socio-economic and gendered lens is a good starting point. Further studies are needed in order to fully explore and understand the drivers of HIV and AIDS amongst Muslims in South Africa and in the broader context so that the similarities and differences in experience, belief and outlook may be ascertained. Once this has been established, the potential for contextualised and culturally relative intervention and prevention programmes which are more likely to result in a reduction in transmission of HIV and AIDS specifically amongst Muslims can be explored.

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