

# HIV/AIDS and Muslims in South Africa: The ‘Untouchable’ Disease

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## **Abstract**

UNAIDS (2015) reports that globally there are currently 36.9 million people living with HIV/AIDS. Despite the extensive biomedical, social and cultural research that has been conducted globally, Muslims have largely been absent in the discourse on HIV/AIDS. Worldwide, studies are few and statistical information about Muslims living with HIV/AIDS is lacking. The formulation of intervention programmes, amongst Muslims, is therefore challenging when information about the particular population group is scarce. This paper seeks to conceptualise HIV/AIDS amongst Muslims of Indian descent in Durban, South Africa, with an aim to uncover the social and cultural context of the disease. South African Indian Muslims are part of the worldwide Indian diasporic dialogue and as such certain cultural traditions are shared which influence the manner in which the disease is interpreted and experienced by this group. The study is exploratory in nature and seeks to understand the social and cultural challenges that HIV+ Muslims of Indian descent in Durban, face. Research findings are based on life histories that have been conducted with key participants in order to reveal the hidden nature of HIV/AIDS in the Indian Muslim community of Durban, South Africa.

**Keywords:** HIV/AIDS, Muslims, South Africa, Indian, Socio-cultural challenges

## **Introduction**

Illife (2006) states that in 1959 the earliest and most substantial evidence of the existence of the Human Immunodeficiency Virus (HIV,) that subsequently

causes the Acquired Immunodeficiency Virus (AIDS), was discovered in equatorial Africa. It was found, argues Abdoool Karim (2008) that the disease is spread from person to person through contact with, and exchange of bodily fluids. According to Parker (2001) initially HIV/AIDS was believed to be a disease that affects primarily homosexuals, however, the groups affected by the spread of the disease has expanded to include heterosexuals. This means that the number of people who could possibly become infected would continue to grow at a rapid pace. AVERT (2015) reports that there are around 2.5 million people, worldwide, becoming infected with HIV each year while 1.7 million people die of AIDS related diseases. Currently, the most rapid spread of HIV is in Eastern Europe and Central Asia and AVERT (2015) states that the number of PLWHIV<sup>1</sup> has, between the years 2001 and 2010, increased by 250%. UNAIDS (2015) reports that there are currently 36.9 million people living with HIV and from this sub-Saharan Africa has been the hardest hit region of the world. WHO (2014) points out that 1 in every 20 adults is living with HIV and from the worldwide total population of PLWHIV, sub-Saharan Africa accounts for roughly 71% of those infected.

Whilst biomedical research has been the focus of HIV research, social science research has become increasingly involved in the discourse on HIV/AIDS. Creating a social understanding of the disease has become necessary in order to implement effective preventative and treatment strategies in the absence<sup>2</sup> of a cure. On a global scale and indeed in South Africa, studies tend to be confined within specific populations, or within what epidemiologists have classified as 'risk groups'<sup>3</sup>. Research has been largely focused on the African indigenous population, with gender relations and power dynamics between men and women forming the focus of the research in Africa due to the largely heterosexual spread of the disease, (Abdoool Karim and Abdoool Karim, 2008). Reasons for the rapid spread of HIV/AIDS, as stated by Illife (2006), have been attributed to social inequalities, migration and poverty experienced by the sub-Saharan region as a result of colonisation as well as economic and

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<sup>1</sup> People living with HIV.

<sup>2</sup> Anti-retroviral therapy is the best form of treatment currently available and has recently been found to be successful in reducing infection when taken by HIV- risk populations.

<sup>3</sup> Men who have sex with men, sex workers, injecting drug users, children and orphans and women.

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political changes that have occurred in many countries. Parker (2001) asserts that anthropologists have carried out ground-breaking research that, since the 1980s, has raised concern around the significance of cultural systems in direct relation to shaping sexual practices which has related to the prevention and transmission of HIV. Despite such findings, however, research is heavily skewed in favour of biomedical, quantitative research.

In terms of studies concerning HIV and Muslims, Esack and Chiddy (2009) bring to our attention that the number of studies that have been conducted to ascertain HIV prevalence amongst Muslims as a religious group is relatively low. Even less has been done by the way of qualitative studies. Bocci (2013) substantiates this by pointing out that there are approximately 300 000 people living with HIV/AIDS across the Arab world yet detailed research in Islamic parts of the world is scant (Speakman 2012). In the past, as it has been noted by Bocci (2013), Muslim scholars often wrote about HIV/AIDS as though it was a disease that was experienced by European and American homosexuals only. In this way these scholars characterised HIV/AIDS as a non-Muslim disease which they regarded as being a result of the ‘modern sexual revolution’ (Bocci 2013). As such, the discourse on HIV/AIDS within the Muslim community has not been developed as extensively as possible.

This research, which is part of a larger Doctoral study on HIV and South African Muslims, has been conducted in Durban. A central aim of the study is to fill some of the gaps in the existing literature concerning Muslims and HIV/AIDS. The paper aims to provide an in-depth analysis and qualitative understanding about perceptions, attitudes and experiences of South African Muslims of Indian descent in Durban who are infected with HIV/AIDS.

## **Literature Review**

According to Cochrane and Nawab (2012) there is an estimated 1, 5 billion Muslims worldwide, however, literature on HIV/AIDS amongst Muslims, or in predominantly Muslim countries, as indicated, is scant. Ahmed (2013) points out that there is as yet no complete data set that can aid in the study of incidence, spread or mortality of HIV/AIDS amongst Muslims. This, however, is changing as the AIDS2016 Conference, held in Durban, had an entire panel presentation dedicated to HIV/AIDS and Muslims. Cochrane and Nawab

(2012) state that in most parts of the world the epidemic has stabilised with a decrease of incidence in some areas. Kamarulzaman (2013), on the other hand, brings our attention to countries that have seen an increase in incidence rates by 25% (since 2001), of which five countries have a predominantly Muslim population; namely Bangladesh, Indonesia, Guinea-Bissau, Kazakhstan and Kyrgyzstan. In addition to this, Kamarulzaman (2013) states that there has been a 35% increase in the number of newly infected people in the Middle East and the North African region.

The lack of statistics and literature in the past was often due to the stigma that surrounds HIV/AIDS and the beliefs that a 'good' Muslim should not engage in premarital sex, extramarital affairs, homosexuality nor imbibe intoxicants of any form (Hasnain 2005; and Essack & Chiddy 2009). Hasnain (2005) states that the social stigma that is often closely linked to HIV/AIDS is far more deeply entrenched in Muslim societies where individuals are rejected by their family and community. According to Kamarulzaman (2013) and Ahmed (2013) ideas about the contraction of HIV are viewed as being associated with notions of promiscuity and drug usage and thus leads to the heavily stigmatised nature of HIV/AIDS in a Muslim context. Hasnain (2005) further points out that the response of policy makers to HIV/AIDS in Muslim countries has focused primarily on individuals abstaining from sexual practices prior to and outside of marriage as well as drug usage. It is due to this stigma that those who are at risk are prevented from seeking assistance in the form of counselling, 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/AIDS epidemic. According to Hasnain (2005) it is important to take into consideration the social and cultural variables in Muslim societies that affect 'risky behaviour' as these variables are crucial to an in-depth understanding of the epidemic in Muslim societies. The AEI Newsletter (2005) and Hasnain (2005) state that while the World Health Organisation's Global Health Atlas does show the threat of an HIV/AIDS crisis in Muslim countries on the whole, data on incidence, prevalence and mortality for Muslims is still limited due to either under reporting or non-reporting of statistics which can have serious consequences for disease surveillance and may ultimately result in the continuous spread of the disease.

Research concerning Muslims and HIV has been almost exclusively limited to statistics and Hasnain (2005) reveals, there is noticeably no available numbers for people living with HIV/AIDS in predominantly Islamic countries such as Qatar, Saudi Arabia, Kuwait, the United Arab Emirates (UAE) and Yemen. Where statistics are available the numbers are low; for e.g. Oman and the Syrian Arab Republic have numbers less than 10 000. Africa has noticeably higher prevalence rates amongst Muslims than other regions of the world with numbers between 10 000 and 100 000 being presented for Egypt, Eritrea, Morocco and Somalia. Higher rates are found in Ethiopia and Nigeria where prevalence rates rise past 1 million Muslims living with HIV/AIDS. South Africa, however, does not feature on any of the broader statistical lists as South Africa has a Muslim population of only 2% of the country's total population (Muslims In Africa (2011) and Cochrane and Nawab (2012)). Speakman (2012) points out that studies have found that there is a negative correlation between HIV prevalence and being Muslim in Africa as a whole, as well as in sub-Saharan Africa as a region. Gray's (2004) study in sub-Saharan Africa, similarly showed the prevalence of HIV/AIDS to be lower amongst Muslims than non-Muslims. Gray's (2004) study has also been the most significant qualitative study on HIV and Muslims to date, however, the study does not focus on a particular ethnicity but rather religious affiliation.

The lack of statistics and qualitative literature on Muslims and HIV, as it has been argued, is due to the stigma that surrounds HIV/AIDS and the beliefs that a 'good' Muslim should not engage in premarital sex or extramarital affairs. According to Hasnain (2005) the social stigma that is often closely linked to HIV/AIDS is far more deeply entrenched in Muslim societies. As pointed out by Kamarulzaman (2013) ideas about the contraction of HIV are associated with ideas of promiscuity and drug usage and this leads to the heavily stigmatised nature of HIV/AIDS in a Muslim context. Discussions of sex and sexuality are also considered to be off-limits both within a family setting and outside of the family, for example, in education settings. Hasnain (2005) further points out that the response of policy makers to HIV/AIDS in Muslim countries has focused primarily on individuals abstaining from sexual practices prior to and outside of marriage as well as drug usage.

Speculation about the spread of HIV/AIDS in Muslim countries according to Hasnain (2005: 4), is in terms of religious doctrine, 'Islam places a high value on chaste behaviour and prohibits sexual intercourse outside of marriage' and prior to marriage. In addition, the use of intoxicants, adultery

and homosexuality are prohibited. Hasnain (2005) states that although it is clear what Islam's stance is on these issues, Muslims engage in so-called 'risky behaviours' that contribute to the spread of HIV/AIDS and this is then accompanied by a great sense of denial by Muslim governments and religious scholars alike regarding the increasing threat of HIV/AIDS. Hasnain (2005) 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 where they feel safe for disclosure. 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/AIDS prevention is discussed regularly in masjids and during the important Friday prayer sermon.

Efforts have been implemented in some Islamic States to curb the prevailing stigma associated with HIV/AIDS. The AEI Newsletter (2005) states that in Iran, as recently as 2001 and 2002 respectively, an HIV-positive employee could be dismissed and that patients with the virus could be refused treatment. There has, however, been 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/AIDS transmission.

In Bangladesh, the AEI Newsletter (2005) goes on to state that awareness programmes have been implemented in masjids drawing religious leaders into programmes. Ahmed (2013) refers to the first known case of HIV in Bangladesh in 1989 and points out that since then, the number has continued to steadily increase. Islam *et al.* (2010) point out that the Bangladeshi government responded by creating the National AIDS/STD Programme in the late 1980s which aimed to address a wide range of pressing concerns; namely testing, care, blood safety, sexually transmitted infections, prevention amongst women and migrant populations. Ahmed (2013) however, argues that there is still limited access to counselling and testing and this impacts on the ability to obtain accurate prevalence rates. This also makes it difficult to formulate prevention and intervention strategies.

Pakistan, similarly, had its first official diagnosis of HIV in 1986 and Maan *et al.* (2014) estimate the number of PLWHIV to be, at the lowest 46 000, and at its highest 210 000. Bhurgri (2006) and Maan *et al.* (2014) argue that although the prevalence rate in Pakistan is low, the risk of HIV is high and the spread of the disease, much like other parts of the world, is predominantly

heterosexual. Bhurgri (2006) considers that Pakistan's vulnerability in terms of increasing levels of poverty, low levels of literacy low levels of HIV awareness and information has led to the high risk of transmission. In addition to these, Maan *et al.* (2014) point out that Pakistan has a booming commercial sex industry which also has low levels of condom usage. The Pakistani government, however, has not been slow to react. In 1993 the National AIDS Control Programme was created. This programme, argues Maan *et al.* (2014), has led to a focus on HIV in the national strategic framework and in major health development projects. Maan *et al.* (2014) further points out that the strategic plan has unfortunately not transformed into meaningful action.

South African Muslims of Indian descent, much like Muslims in the global HIV/AIDS context, have largely fallen outside of both biomedical and social science research and as a result not much is known about prevalence within this group. Esack and Chiddy (2009) state that entwined with 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 Muslim South Africans of Indian descent. As a result there is a limited understanding of HIV prevention needs, opportunities, challenges and priorities faced by Muslims infected with HIV/AIDS and by those affected by the disease; such as family members, friends and care-givers. This does not, however, mean that the issue has been ignored in South African discourse as there are a number of groups which aim to provide support for Muslims living with HIV/AIDS; namely Positive Muslims, Islamic Careline (IC) and the Muslim AIDS Programme (MAP), yet research on Muslims in South Africa remains limited.

On the whole there remains a dearth of qualitative literature on Muslims infected with and affected by HIV/AIDS. Research that exists is predominantly quantitative and has sought, as a starting point, to establish incidence and prevalence rates through quantitative data gathering techniques. Rich qualitative analyses offering insights from the insider's perspective, however, remains limited, and there is thus a dire need for such research if we are to move beyond a surface level understanding of HIV/AIDS in the Muslim population.

**Indian Diaspora, the Caste System and South African Muslims**  
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. IndianDiaspora (n.d.) states 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, IndianDiaspora (n.d.). Of the more than 150 000 people, fewer than 12% were Muslim and most were illiterate. However, they brought with them traditions, customs, rituals and language that 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 Durban is the largest ‘Indian’ city outside of India. Indians in South Africa can be divided according to religion; the most prominent being Hindus, Tamils, Muslims and Christians. South Africans of Indian descent are considered to be a conservative group with a strong sense of community and the South African Muslim population is considered to be even more conservative than their fellow Indian South Africans (ISAs) and a strong reasoning for this, according to Amod (2004), is linked to religion.

Whilst numerous cultural and religious aspects of Indian origin remain amongst ISAs, the caste system, which operated in India for centuries, has not been strictly replicated. This was due mainly to the fact that, as Mukherji (2011) points out, those who made the decision to leave India were mainly from the poorest parts of Indian society and as a result of the indentured system were forced to interact with and co-exist with people of different castes and this resulted in new relationships being formed and a new identity that was not based on caste affiliation being established, IndianDiaspora (n.d.).

The findings of the study refer to the concepts of ‘untouchability’ and ‘ritual impurity’. 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<sup>4</sup>. The ‘Untouchables’, 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 were heavily excluded from the caste division and were 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’. Brazier (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, Brazier (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, ISAs 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 se, this paper argues that the concept of untouchability and ritual impurity is being applied to those living with HIV/AIDS as a result of the stigma that is attached to the disease. It is with this in mind that this paper seeks to explore the concept of ritual impurity and the application of the concept of

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<sup>4</sup> ‘Varnas’ are ‘Castes’.

‘untouchable’ to the physical and psychological segregation of HIV+ Muslims from society as a result of the stigma associated with the disease.

## **Principle Theories**

Grounded Theory has played a significant part in the analytical framework of this research due to the fact that qualitative research regarding the Muslim community is rare. Grounded Theory started out as the key theoretical framework for the study and has shaped the research, however, during the research process, other theoretical frameworks have emerged. Grounded theory, first proposed by Glaser and Strauss in the 1960s, was considered to be the best approach, at the outset, to this particular study as it provides a framework for understanding and analysing the data that is collected throughout the research process. Such a framework, which encourages the development of theory from research grounded in the information uncovered, is an excellent method of social analysis in the field of medical studies and it is indeed in the social studies of health that grounded theory was first conceptualised (Thomas & James 2006).

The use of Grounded Theory enabled the information uncovered during the research process to guide the choice of theoretical framework and as such Goffman’s theory of stigma has proven to be useful in analysing the data gleaned. The reason for this can be linked to what Cochrane and Nawab (2012) refer to as the ‘hidden’ statistics for HIV/AIDS and Muslims. Individuals who have been infected with HIV/AIDS have traditionally faced stigma from society although this has since changed somewhat due to awareness programmes and drives by governments and non-governmental organisations (NGOs) to educate the public about HIV/AIDS. However, literature indicates that stigma remains surrounding HIV/AIDS in the Muslim population and the fact that little is known further reveals the hidden nature of the condition amongst Muslims. The isolation of the infected (in this case the HIV+ 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 further rejection.

Society chooses how people are grouped according to personal and public attributes that are felt to be 'ordinary and natural for members of those categories' (Goffman 1969: 11). 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 his/ her experiences and through society's understanding of that particular condition. With respect to HIV/AIDS and how society has traditionally responded to the disease, it can be seen that the response has been 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/AIDS has moral undertones and the disease has been associated with people placed in stigmatised 'risk groups' such as sex workers, unfaithfulness, men having sex with men and intravenous drug users. Within the Muslim community stigma surrounding HIV/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.

## **Discussion of Findings**

The findings of this study have been drawn from the life histories that have been conducted with five key respondents as well as supplementary information provided from semi-structured interviews with ten volunteers and care-givers of Muslims living with HIV/AIDS. The reason for the choice of life histories with key participants is due to the difficulty of obtaining participants who fit the demographic of the research sample. HIV/AIDS is a highly stigmatised disease and even more so amongst South African Muslims of Indian descent, as this study has found. Whilst there are numerous non-governmental organisations that work with HIV+ Muslims (of varying ethnicities) it has been extremely difficult to find individuals who are willing to talk openly about their experiences as HIV+ South African Muslims of Indian descent. Non-governmental organisations were contacted by the

researcher and interviews were arranged with willing participants. Life histories were chosen as the researcher believed this to be the best option in order to obtain detailed descriptive data concerning the research participant's life and experiences as an HIV+ South African Muslim.

Due to the sensitive nature of the research study the approach to the research subject area has differed from the normative anthropological approach of participant observation. The aim of the study was to understand the lived experiences of research respondents and the best manner in which to do this, argues Bernard (1994) is with the use of qualitative research methodology. Qualitative methodology thus allows for a holistic investigation of the main issues such as experiences of individuals living with HIV/AIDS, effects on family, patterns of care-giving, coping strategies as well as community responses (Bernard 1994; and Akeroyd 1997).

According to Denscombe (2007) the qualitative method of the life history interview is a frequent tool of Anthropology and health sciences. Life histories provides insight into the research participants life and the interview schedule that was utilised covered a range of topics from the respondents early childhood years and experiences leading up to their current life situations. Denscombe (2007) argues that the use of life histories challenges the researcher to understand the current attitudes and behaviours of the respondent and how this has been influenced by decisions and experiences from the respondent's past. Life history interviews also allows the respondent to reflect on their own experiences and this may allow for deeper insight into their past and present experiences and behaviours. Each interview was approximately 1 – 2 hours long, and was conducted in places suitable to the respondent's privacy needs.

Research participants of this study have been living with HIV for long periods of time; ranging from 10 years to 23 years as HIV+. For this study, three women and two men were interviewed as key participants and ten female volunteers and care-givers. Pseudonyms were utilised in order to protect the identities of research respondents and each respondent was supplied with an informed consent document and their rights regarding the research, as respondents was clearly explained. In addition, respondents were allowed to end the interview if they wished or to not answer questions that made them feel uncomfortable. The ages of respondents at the time of the interviews were as follows: Maymoona (57), Rahman (43), Razak (35), Tasneem (31) and Shafieka (25). Maymoona and Shafieka are currently married, whilst Rahman and Razak are divorcees and Tasneem has never been married.

As stated above, the search for HIV+ Muslims has been slow as there are not many who are willing to speak openly about their disease and experience thereof and thus, at the outset of the research process, it has been clear the strong stigma that exists in this community. Therefore, the issues that will be highlighted in this section of the paper deal specifically with the stigma of HIV/AIDS and how this stigma leads to the 'untouchability' of South African Muslims of Indian descent living with HIV/AIDS. The study focused on HIV+ Muslims of Indian descent who were born and are living in Durban, KwaZulu-Natal.

Rizvi (1994) states that Islam recognises that human beings are sexual beings and as such have sexual urges and thus sex is viewed in a positive light. In fact, celibacy and monasticism are discouraged in Islam. Rizvi (1994) further states that Islamic guidance does not expect followers of the religion to suppress their sexual urges, however, the concept of 'free sex'<sup>5</sup> is not accepted in Islam. Rather, Rizvi (1994) points to marriage as being a solution to the fulfilment of sexual urges experienced by individuals. Marriage, he goes on to state, is considered to be a responsible solution whereby two, or more, people commit to each other and satisfy their sexual needs. It can thus be found that Muslims are encouraged to marry young lest they are tempted to engage in 'sinful acts of promiscuity'. Long term relationships between individuals of the opposite sex are discouraged and it can often be found that parents of such young people encourage the parties to marry, (Islamqa 2005). Thus, Rizvi (1994) explains that Islam makes provision for sex to occur in a safe environment which reduces the chances of the transmission of sexually transmitted infections between partners as they are in monogamous relationships. In addition to sexual intercourse, Islamic teachings specify that the consumption of drugs, alcohol and other intoxicants are forbidden. Islamqa (2005) states that the consumption of an intoxicant, renders the prayers of an individual to be invalid for forty days.

As a result of the above, those who engage in risky behaviours are stigmatised through their behaviour and are pushed to the margins of society. Behaviours that go against the teachings of Islam are considered to be immoral and HIV/AIDS is a disease that brands the individual with that immorality. These individuals are considered to be 'bad Muslims' and those who judge them so reduce their interactions with the individuals.

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<sup>5</sup> I.e. sex before marriage or out of marriage.

When referring to stigma, Goffman (1969) argues that originally, stigma referred to physical signs on the body that would bring to the fore that something was not 'right' regarding the moral status of the person. In this sense it meant a criminal or traitor who had been branded to reflect their status. If we look at HIV/AIDS, the disease is one that targets the immune system of the body and thus the body 'breaks down'. In the early days of the epidemic and prior to the mass rollout of anti-retroviral medication, Illife (2006) states that within five years of contracting HIV, the body would show physical signs of the disease and this, for example, would be in the form of sores all over the body. With treatment of the disease having advanced in recent years a person living with HIV/AIDS can live a long and healthy life and as such the physical signs of HIV/AIDS are not as prominent as they were in the past. Stigma moves from a position of fixating on the physical branding to non-physical branding as people who are diagnosed with HIV continue to be stigmatised. Often times this stigma is reflected in how people interact with HIV+ individuals. The stigma then becomes associated with the notion that the individual is 'blemished, ritually polluted, to be avoided, especially in public places' (Goffman 1969: 11).

Research participants expressed that they felt 'dirty' and Tasneem stated that when she disclosed her status to her family, they avoided physical contact with her telling her that they did not want to 'catch her disease and become dirty'. Maymoona said that 'no matter what I did, I washed and scrubbed but I could not get rid of this feeling that I was filthy and my family, instead of helping me, told me that I was soiled and would not even pray with me in the same room'. Responses such as this bring to the fore the notion of ritual impurity, acts that are linked to unclean activities with no prospect of being able to wash away the impurity. This then renders the individual as needing to be separated from society. Research respondents explained that they were cut off from those around them both in a physical and psychological sense. Goffman's (1969) *spoilt identity* then can be linked to this experience as individuals express that their sense of self is tainted by their own feelings of being 'dirty' and their families' rejection as a result of their status.

When discussing their diagnosis, all respondents had stated that they had not been to the hospital for an HIV test but rather were diagnosed as a result of other medical conditions. Two female participants had been diagnosed when they had gone to the hospital when they were pregnant with their third and first child respectively. The third female participant had become ill and

when the cause of her illness could not be determined an HIV test was carried out without her permission. The male participants had been in hospital for surgery and had routine tests performed, which included an HIV test. None of the participants had anticipated the need for an HIV test and were not prepared for the results that would, as Maymoona put it ‘change my life forever’. Maymoona and the other participants responded similarly to their diagnosis, asking the questions ‘why me, what did I do?’ and ‘what will my family think of me?’ From the outset, these individuals had expressed that they were afraid to disclose their status to their families as they feared that they would be judged as having been immoral and having engaged in ‘sinful’ acts. Female participants in particular stated that their families had accused them of ‘sleeping around’ and Maymoona points out that she was called a ‘whore and other cruel names’ when she revealed her status to her family. Male participants had also expressed that their revelation was met with disappointment and scorn, however, not with the same severity their female counterparts experienced.

As stated earlier, the spread of HIV/AIDS has been attributed to what may be referred to, in Islam, as immoral acts or behaviours; i.e. individuals engaging in risky behaviours and Islam has strong beliefs around these concepts. Maymoona and Shafieka expressed fear and concern as both had been diagnosed during routine testing when they were pregnant. Shafieka had been a virgin when she got married and her husband was the only man she had had sexual relations with and thus believes she contracted the disease from him. She was afraid of what people would say about her and her child if her status was revealed, ‘what would people think of me? I was scared that I had gotten this disease from my husband and that people would say that it was my fault that he had slept with other women. What would become of my child who did not ask for this disease?’ Neither Maymoona nor Shafieka’s children were born with HIV.

When questioned about how long it took for participants to reveal the status to their immediate family, the responses ranged from six months to two years. The reason for this, participants stated, was due to the fact that they were afraid of what their family’s response would be. HIV/AIDS was already, at the time, highly stigmatised in society in general and even more so within the Muslim community.

Maymoona did not disclose her status to her then husband. She describes him as ‘abusive’ and stated that he also forced her to have sex with

other men in exchange for money. She is not sure whether she contracted the disease from her ex-husband or from a man she was forced to have sex with. Maymoona eventually found out, after her daughter was born, that he had contracted HIV several years before they were married and soon after the birth of her last child she divorced him and moved back to her mother's house. It would be two years before she would disclose her status to anyone, (she had not told her ex-husband that she was HIV+ as she believed that he would blame her and tell everyone in her family and community and she was not ready for that). Maymoona disclosed her HIV+ status to her mother initially and she did so at the request of a nurse at the clinic that she attended who told her that it was important that her family know as they would be able to help and support her. The nurse encouraged Maymoona to at least tell her mother and Maymoona said that 'I took the advice and I told my mother and my mother told my big sister in law ... who made it like a joke and started telling each and every neighbour ... my mother was not sympathetic, knowing what I went through in my marriage ... she stood outside and told my neighbours that I am a whore, I am a bitch ... she pulled my hair and she threw me outside and hit me and wanted me out of her house'.

Similar situations have been experienced by the remaining research participants, except for Rahman. Shafieka, Razak and Tasneem expressed that when they each disclosed to their immediate families that the response was negative and they were called names which had a severely negative impact on their dignity and self-esteem. Rahman explained that when he told his (now late) father and father's wife (stepmother), whilst both expressed disappointment, they did not attack him in any way but rather, were extremely supportive, especially his stepmother (who he describes as being very over protective of him).

Thus, four of the five participants interviewed in this study experienced stigmatised responses by their immediate family upon revealing their HIV status. This, for the most part, translated into family, and even close friends, 'cutting them off' and stopping contact with the participant by actively avoiding any interaction with the individual. This was done in different ways; for example, Maymoona's mother forced her to leave the family home and to stop contact with her family, Tasneem (who lived on her own) had been told by her family not to contact them as they 'wanted nothing to do with me'. Even Rahman stated that although his parents accepted his diagnosis, his extended family and even colleagues at work had responded negatively and their inter-

actions towards him had changed.

From this it is evident that whilst not all participants experienced the same response from their immediate family, that the overwhelming response was negative. This correlated with responses from the interviews that were carried out with volunteers and professionals, (social workers and counsellors), as they recounted the experiences of other Muslim clients who had disclosed their HIV status to family members.

Participants expressed that their family, for the most part, have either cut them off completely or reduced their interaction with them. Shafieka explains that when she first told her family about her HIV+ status, they refused to touch her and she felt like a ‘pariah’. She was excluded from many family gatherings as her parents were afraid of what others would think of them still associating with her and were also concerned that they may contract the virus from her. As such, she, and other participants, stated that they felt cut off from others and unwanted by their own family and friends. They were viewed as being ‘dirty’ or polluted by those close to them and were avoided by their family. Research participants expressed that their families’ ignorance of the disease and wanting to distance themselves from a ‘morally’ questionable person by association lead to a highly stigmatised separation and ostracisation from the family.

From this it can be deduced that the HIV+ South African Muslims of Indian descent, in this study, experienced a form of ‘untouchability’. Whilst the notion of the ‘untouchable’ disappeared in South African Indian society, with the spread of HIV/AIDS and the growing spread of the disease amongst the population of Indian descent in South Africa, this concept can be applied in a different sense, one that is health related and ties into social stigma that is faced by South African Muslims living with HIV. HIV continues to be a stigmatised disease that is related to ‘morally questionable’ behaviour and this stigma leads to the HIV+ individual becoming a new type of ‘untouchable’ who is ritually polluted through their positive status and have become cut off from their families as a result. They are isolated from their families who, for the most part, want nothing to do with them for fear of being polluted through their association with the HIV+ individual who has ‘dishonoured them’ and is regarded as ‘impure’ or ‘dirty’; both ritually and physically.

## **Conclusion**

HIV/AIDS is an epidemic that has rampantly spread throughout the world. With the introduction of ARVs death rates of HIV+ individuals have declined in recent years, however, the disease is far from being eradicated. HIV is not simply a biomedical disease. It has socio-economic components that affect its continued spread and the most recent data reveals that HIV is spreading faster than ever before in predominantly Muslim countries. Hasnain (2005) states that changing the behaviour and lifestyles of individuals is necessary to break the chain of transmission and to contain the HIV/AIDS epidemic. However, due to the complex and in some cases poorly understood forces that shape and influence human behaviour breaking the chain of transmission is, as the AEI Newsletter (2005) states, more challenging. The social and cultural variables in Muslim societies that affect 'risky behaviour' must be considered and understanding these variables are crucial to an in-depth understanding of the epidemic in Muslim societies. Although the statistics can be improved, it has significantly shown a rise in HIV rates in Bangladesh, Indonesia, Libya and Turkey, to name a few. Understanding the spread of the disease in Muslim populations is important if interventions are to be addressed and so qualitative studies are needed to provide an in-depth view into the world of HIV amongst Muslims in their various locations around the world.

Although there is widespread stigma relating to HIV/AIDS within the Muslim community there are groups who aim to assist Muslim individuals living with HIV/AIDS by using a de-stigmatising approach. According to Cochrane and Nawab (2012), in South Africa, Islamic Careline (IC) and the Muslim AIDS Programme (MAP) approach HIV/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, for example, include life skills training, education and development and are aimed mainly at the 'high risk age group' of 14 – 29. Cochrane and Nawab (2012) further elaborate that the life skills training offered by MAP addresses issues of information on disease, assertiveness, sex, sexuality, death and dying and the belief is that these discussions will enable youth to take more informed decisions in the future. Further initiatives have

also been taken to assist in areas of violence against women and children and other social issues that plague South Africa. In addition to this IC and MAP assist non-Muslim individuals infected with HIV/AIDS as well as providing assistance to the wider community. In South Africa, Muslims make up 2% of the total population, however, HIV has become an increased risk within this population group. The stigma that is associated with HIV is amplified within this group as a result of religious beliefs surrounding the moral character of the individual who has contracted the disease and as such has often resulted in the HIV+ individual experiencing isolation from family and friends. This isolation, as a result of their HIV status, has been conceptualised in the form of ritual impurity and as such this paper has aimed to prove the notion of these individuals being regarded as ‘untouchables’ in their society, those who are on the outskirts of society, who are left to themselves and others like them.

The best way to overcome stigma is through education and ensuring that information is disseminated throughout society to ensure that all the myths surrounding HIV are debunked which may result in a change in the attitude towards HIV+ individuals.

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