Intergenerational Change in HIV/AIDS-Related Stigma in Cato Manor

MiJin Cho
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Intergenerational Change in HIV/AIDS-Related Stigma in Cato Manor

MiJin Cho
Advisor: John McGladdery, School for International Training
May 08, 2023
I. Acknowledgements

I would like to thank the School for International Training for providing me with the opportunity and resources to complete my study project. I would like to thank my advisors John McGladdery, Christine McGladdery, and Clive Bruzas for their immense guidance over my project and ensuring a high standard of ethics throughout the study. I would also like to thank NoThando Mhlongo for her role in recruiting participants and translating during my interviews. Finally, I would like to thank all the women from Cato Manor who opened up their homes and agreed to interview with me. Without them, this study would not have been possible.
II. Abstract

In South Africa, the world’s epicenter of the HIV/AIDS pandemic, HIV-related stigma and stigma-enforcing stereotypes continue to serve as major health barriers to receiving adequate HIV prevention and treatment. While there continues to be a rise in research and advocacy, there is a need to study HIV stigma through a multigenerational lens that addresses the changing HIV/AIDS stigma in the post-apartheid era. Using qualitative methodology, this study aims to explore the generational differences in perceived HIV stigma between females in their 20s and above 50 years of age (as denoted by “50s+”) living in Cato Manor, South Africa. The study did so through semi-structured interviews with two different-generation female persons living with HIV (PWLH), followed by interviews with 15 female participants in their 20s and 15 female participants in their 50s+ regarding their perception of changes in HIV stigma in the community (n = 32). Through thematic analysis, the data showed that participants, regardless of age, perceived decreased overall HIV-related stigma throughout their lifetime. When separated into different types of stigmas, data found that fear of non-sexual transmission and interpersonal distancing decreased greatly in both participants in their 50s+ and those in their 20s. Sexual and moral judgments also decreased among both groups but to a lesser extent than the fear of non-sexual transmission. Moral judgment persists as a central topic of gossip in conversations among participants in their 20s. A new judgment of negligence has emerged as a dominant manifestation of stigma within interviews with both age groups, which suggests that HIV stigma continues to evolve with time. Finally, the study discusses the potential benefits of a multigenerational approach to monitoring and addressing HIV/AIDS-related stigma.
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III. Frequently Used Terms:

AIDS: Acquired Immune Deficiency Syndrome
ARV drugs/ART: Antiretroviral Drugs/Therapy
HIV: Human Immunodeficiency Virus
KZN: KwaZulu-Natal
PLWH: Person(s) Living with HIV
PrEP: Pre-exposure prophylaxis
TB: Tuberculosis
IV. Introduction

According to the CDC, stigma and stigma-informing stereotypes are negative beliefs and disapproving attitudes toward a certain group of people (Centers for Disease Control and Prevention, 2021). Stigma is associated with labeling people of different characteristics as socially unacceptable or unvalued, oftentimes leading to actions that discriminate or marginalize the stigmatized group (Goffman, 1974; Nyblade et al., 2019, p.1). In the context of health, stigma has been named a major barrier to global health equity for conditions including HIV/AIDS, mental illnesses, and gender-affirming surgeries (Major, Dovidio, & Link, 2017, p.3). A fear of infection, lack of awareness or education, and institutionalized practices can strengthen the stigmatization of certain health conditions (Ogden & Nyblade, 2005, p.9). Stigma and stereotypes contribute to fatal health consequences including refusal to seek proper treatment, disengagement from preventative behavior, and compromise of a healthy quality of life (Major, Dovidio, Link, et al., 2017, p.4; Nyblade et al., 2019, p.2).

In South Africa, stigma related to HIV/AIDS impedes prevention, treatment, and intervention (Armstrong-Mensah et al., 2019, p.2). Infected individuals are often socially labeled as carriers of a fatal transmissible disease and judged to have engaged in culturally immoral behaviors (M. J. Visser et al., 2009, p.207). These individuals are left to carry blame and responsibility in a nature of deservedness that can dissuade them from seeking proper health services, testing for HIV, using condoms, preventing mother-to-child transmission, and adhering to antiretroviral therapy (ART) (Ncitakalo et al., 2021, p.1). Additionally, in traditional Zulu culture, beliefs about HIV/AIDS may place the blame on witchcraft, ancestral curses, and spirits (Pantelic et al., 2018, p.207). As stated by former President Nelson Mandela, “Many people suffering from AIDS and not killed by the disease itself are killed by the stigma surrounding everybody who has HIV and AIDS” (South African History Online, 2022).

The study site of Cato Manor is located in South Africa’s highest HIV-prevalent province, KwaZulu-Natal (KZN). In Cato Manor, the stigma against HIV/AIDS plays a pivotal role in the choice of residents who may choose to not disclose their HIV status or purposefully avoid being seen in the nearby Cato Manor clinics (Conversation with Andy Gray, 2023). Although one in six residents is estimated to be living with HIV, the topic of HIV/AIDS continues to be an uncomfortable or avoided subject matter (KZN Department of Health, 2015). Multiple factors, including a fear of being an outcast, lack of education, and loss of privacy in crowded clinic settings, have been noted to impact the local stigmatization of HIV/AIDS in Cato Manor (Cato Manor Development Association, 2022; McMahon, 2016,
However, despite community awareness of stigmas, the nuances of the evolving HIV-related stigma and its tangible impacts on community members and PLWH of different ages have never been studied in a formal research setting. Understanding changes in HIV stigma becomes essential in addressing the barrier of stigma unique to each age group and promoting the overall health of Cato Manor residents.

This study sought to answer the question, how have female perceptions of HIV/AIDS-associated stigma and stereotypes changed, if at all, between those born before the 1960s and those born in the 1990s (i.e., females in their 50s+ and their 20s) living in Cato Manor, South Africa? The author hypothesized that there has been a change in HIV stigma perception with the older generation perceiving greater levels of HIV stigma and stereotypes related to HIV as a death sentence and associated with prostitution, while the younger generation perceives greater normalization of HIV and is thus less associated with overall stigma. The aims were to: (1) compare differences/similarities in the perception of HIV stigma and stigma-inducing stereotypes between female participants in their 20s and their 50s+ living in Cato Manor; (2) propose HIV stigma interview guides with a generational focus and input from different-generation PLWH; and (3) explore the potential benefits of taking a multigenerational approach to monitoring and addressing HIV/AIDS-related stigma. By taking a multigenerational approach, the study sought to better understand and accommodate for age-dependent HIV-related stigmas within the Cato Manor community.
V. Context

The World Health Organization reports that 38.4 million people worldwide live with HIV, of which 19.7 million are women (World Health Organization, 2021). Occurring concurrently with the HIV/AIDS pandemic are the associated stigma and stigma-enforcing stereotypes, which former director of WHO Special Programme on AIDS, Jonathan Mann, called a second “epidemic” during the 1987 United Nations General Assembly (South African History Online, 2022). Negative attitudes and prejudice towards PLWH have limited HIV testing uptake and prevented treatment initiation and ART adherence (Hargreaves et al., 2022, p.1). Since being identified as a major issue in 1987, the stigmas underlying HIV have been recognized as one of the most formidable constraints to effective HIV prevention and ARV treatment.

South Africa has the fourth highest adult prevalence rate of HIV, carrying 21% of the global burden (Statistics South Africa, 2021). This equates to about one in every five adult PLWH living in South Africa. The impact of HIV-related stigma in South Africa continues to be evident and plays a role in the estimated annual incidence of 231,000 new infections (Statistics South Africa, 2021b; Zuma et al., 2022, p.8). Currently, HIV incidence is the highest among young adult women (aged 16-35) at four times the rate of incidence as their male counterparts (Palanee-Phillips et al., 2022, p.3). The 2015 United Nations Convention on the Rights of Child has commented upon the role of stigma in the high incidence rate in South Africa, attributing the stigma’s root cause to a lack of proper knowledge and guidance on the topic of sexual health and protection (Convention on the Rights of the Child, 2015). In contrast, however, the 2017 South African National HIV Prevalence, Incidence, Behaviour, and Communication Survey – one of five HIV prevalence surveys conducted in South Africa since 2002 – reports that while access to in-depth HIV/AIDS education has increased since 2002, there is still a lack of behavioral change of South Africans engaging in risky sexual behavior and delaying treatment in regards to HIV/AIDS (Zuma et al., 2022, p.7-9). Zuma et al. (2022) cite HIV stigma as a dominating barrier to decreasing HIV incidence and indicate that new interventions must address the various types of stigmas related to HIV/AIDS, including fear of disclosure and perception of social shaming.

One of the nine South African provinces, KZN, retains the highest HIV prevalence of 27% in 2018, as compared with 13.0% in Gauteng and 12.6% in Western Cape (Kharsany et al., 2019, p.2). Since 2009, KZN has been named a national epicenter of the HIV pandemic, with the most prevalence concentrated disproportionately in Black South African populations (Psaki et al., 2022, p.2). The study site of Cato Manor, located in KZN, consists of
predominantly Zulu- and English-speaking, low and middle-class Black South Africans and reports an adult HIV prevalence of around 17% in 2015 (KZN Department of Health, 2015; McMahon, 2016, p.8). Despite the high prevalence of HIV in Cato Manor, the impacts of HIV-associated stigmas on the thoughts and behaviors of Cato Manor residents, particularly PLWH, have not been thoroughly studied or qualified. There is currently a need to better understand the role of HIV-related stigmas in Cato Manor residents to more appropriately address how residents, of various age groups, perceive and react to stigma.

VI. Literature Review

Since 2013, there have been two major studies that examined and measured changes in HIV-related stigma in South Africa, and both studies have indicated that HIV-related stigma has decreased since 2004. In Mall et al.’s survey study of HIV-related stigma changes between 2004 and 2008, researchers found that HIV stigmatization decreased in randomly selected households in peri-urban Western Cape. The decreased HIV-related stigma in Mall et al.’s study was primarily attributed to increased HIV/AIDS knowledge and the availability of ART starting in 2004 (Mall et al., 2013, p.194). The pattern of decreasing stigma was further corroborated by Visser (2018). In the study, Visser compared 10 identical survey responses from 2004 and 2016 in multiple neighborhoods of Tshwane to assess personal and community stigma. The data demonstrated a significant decrease in personal stigma, including less moral judgment, but there was no significant decrease in the community fear of physical or social contact with PLWH (Maretha J. Visser, 2018, p.735). Visser’s findings of changing levels of personal stigma resonate with those from Mall et al. in that more South Africans report that they hold less HIV-related stigma than they did in the past. However, given a lack of decrease in interpersonal distancing stigma in Visser (2018), questions related to why certain types of HIV stigmas have remained stagnant or changed within the last few decades have remained unanswered.

When examining the role of HIV-related stigma in different age groups in South Africa, recent HIV studies have suggested that older rather than younger South African women tend to hold more HIV-related stigma and stereotypes. A 2021 study monitoring the HIV incidence rates in KZN over 16 years (2004 to 2019) found significant differences in the incidence rates between older and younger female populations (Akullian et al., 2021, p.1-2). Specifically, the incidence rate has decreased by 44% in women aged 15 to 19, 24% in women aged 20 to 24, and less than 20% in women aged 30 to 39 (Akullian et al., 2021, p.1-2). Akullian et al. suggested that the changes may be due to increased government efforts to
normalize and de-stigmatize HIV in young female populations whereas the incidence rate among older women continues to remain unaffected (Akullian et al., 2021, p.5-6). The rapidly decreasing versus stagnant incidence rate in differently aged women point to a possible change in HIV stigma perception between the female generations, leading to behavioral differences between the groups.

Similarly, another study by Lambert et al. (2018) found that females aged 18 to 35 show greater willingness to be tested and treated for HIV due to increased peer support for HIV/AIDS and greater exposure to conversations about accessible HIV services (Lambert et al., 2018, p.736). This finding supports Akullian et al.’s conjecture that increased HIV normalcy in young populations is associated with more positive health behaviors, such as getting tested and treated, among younger women. In contrast, Pantelic et al. (2020) stated that HIV normalization cannot be generalized to all youth, as young women in South Africa are still at a greater risk of exhibiting and experiencing stigma-based actions than their older counterparts (Pantelic et al., 2020, p.2). Pantelic et al. rationalized that increased peer discrimination and stigmatization amongst younger women is a part of adolescent maturation, during which self-concept and group formation between ages 12 to 24 drive actions of stigma. This increases the likelihood that stigmatization of diseases like HIV/AIDS is more prominent in younger populations, leading to young women exhibiting and experiencing greater overall stigma than older women. Taken together, there have been mixed findings on the impact and presence of HIV-related stigma in the different-aged groups, however, generally, research seems to indicate that young women hold and perceive less HIV-related stigma than older women.

One reason for the potential differences in perceived HIV stigma in older versus younger female generations may be due to the complex historical ties of HIV/AIDS and apartheid. Before the founding of South Africa’s democratic government in 1994, HIV/AIDS was dismissed by apartheid leaders to be the result of the “promiscuity” of blacks and gays (South African History Online, 2022). This was during the first wave of the HIV epidemic beginning in 1982 when most cases were limited to Black South African hemophiliacs and homosexuals (South African History Online, 2022). From 1990 to 2000, the years immediately before and after the end of the apartheid government, South Africa experienced an exponential increase in HIV/AIDS incidence, most of which occurred within the Black heterosexual population (Bell et al., 2022, p.2). Factors including high commercialization of sex, increased number of sexual partners during the migrant labor system, and limited government attention are attributed to the HIV explosion (Conversation with Andy Gray,
In particular, sex workers and prostitutes contributed largely to the exponential HIV incidence rate in the 1990s, which formulated a close association between HIV/AIDS and prostitution (Stone et al., 2021, p.1). The stigma of risky sexual behavior about HIV has remained a pertinent aspect of contemporary HIV stigma, particularly for older generations who have lived through apartheid (Bell et al., 2022, p.2).

Another early manifestation of stigma was interpersonal distancing. The lack of accessible in-depth knowledge about HIV in the late 1990s and early 2000s coupled with high mortality rates of HIV/AIDS introduced a public fear of casual transmission (South African History Online, 2022). Due to the lack of adequate treatment available for Black South Africans under the apartheid government, Black South Africans were disproportionately under-cared for by the state hospitals, and Black patients were estimated to have a significantly higher AIDS patient death rate than their white counterparts (Haal et al., 2018, p.2). Additionally, public healthcare and HIV treatment were not free to Black South Africans and required patient fees until 1997 and 2004, respectively, leading to high HIV/AIDS mortality rates (Wilkinson et al., 2019, p.8). This led to HIV stigmas associated with death and intense avoidance of physical contact with PLWH within the Black South African PLWH community (Conversation with Cheryl Baxter, 2023).

Furthermore, HIV’s associations with an already-stigmatized disease, tuberculosis (TB), served as another layer of complication when it came to the fear of casual transmission associated with HIV (DeSanto et al., 2023). At the time of the HIV pandemic, people with TB were often quarantined and avoided due to the contagious nature of TB. When HIV cases first began to rise in numbers, many South Africans treated PLWH similar to how TB patients were treated: with an intense fear of physical and social contact (DeSanto et al., 2023, p.5). Thus, the stigma surrounding TB further intensified the stigma development for HIV/AIDS. This fear of non-sexual transmission of HIV/AIDS fueled a culture of “othering” of PLWH living in South Africa, during which extreme acts of discrimination against PLWH became prominent (Simelela et al., 2015, p.257). In some cases of mob fear, like within the story of HIV activist Gugu Dlamini, people who openly spoke about their HIV status faced physical violence from their community (South African History Online, 2022).

Recent efforts made by the South African government to reduce HIV and HIV-related stigma include establishing an HIV/AIDS and STD office in the Department of Health, funding educational entertainment such as Soul City (1994-present) and Scrutinize (2012-2016), implementing HIV education programs, and increasing affordability of PreP and ARVs (Conversation with Eliza Govender, 2023; South African History Online, 2022).
However, older generations continue to feel the residual effects of apartheid and its influences on public HIV/AIDS perception (Bell et al., 2022, p.2). The last of the surviving generations with directly lived experiences during apartheid and the initial rise in HIV/AIDS cases in the 1980s are current South Africans in their 50s or older, making their input on the evolution of HIV-related stigma critical for a multigenerational HIV study.

Since the start of governmental actions, there have been several programs targeting adolescent girls and young women, the highest-risk population for HIV infections, including the She Conquers campaign (2016-2019) and USAID’s Determined Resilient, Empowered, AIDS-free, Mentored, and Safe (DREAMS) (CDC, 2022; Conversation with Eliza Govender, 2023). Anti-stigma counseling is another emerging intervention, during which contact with PLWH may be utilized as part of the de-stigmatization process for HIV/AIDS (Rao et al. p.399). Despite the increased education and prevention, the continued high HIV incidence rate among the youth in South Africa has created a new wave of blame towards youth because of a belief that the youth are being negligent about their health. In one commentary by UNAIDS Executive Director Anthony Lake, Lake stated that neglect plays a role in young adults who contract HIV during a time of heightened education and preventative measures (Convention on the Rights of the Child, 2015, p.3). However, no further formal studies have examined the influence of the public’s view of youth negligence on HIV-related stigmas.

HIV stigma negatively affects the psychological state, health behaviors, and intrapersonal relationships of PLWH (Earnshaw et al., 2018, p.1-2; Kalichman et al., 2019, p.362-363; MacLean & Wetherall, 2021, p.1-3). While there continues to be a rise in HIV research in South Africa, there remains a need to study HIV stigma through a multigenerational lens that both quantitatively and qualitatively addresses the changing concepts of the stigma associated with HIV/AIDS. Understanding the generational changes in stigma perception may help healthcare professionals and public health offices better address stigma-related health factors and cater prevention and treatments towards different-aged groups. For example, younger PLWH experiencing more intrapersonal HIV stigma may benefit more from group psychiatric counseling coupled with ART programs. On the other hand, older PLWH experiencing more internalized HIV stereotypes may benefit more from HIV/AIDS educational workshops focused on clarifying beliefs surrounding HIV as a death sentence or evidence of moral corruption. Using an exploratory mixed methodology, this study aims to explore the differences in generational HIV-associated stigma.
VII. Design and Methods

Sampling

Prior to the study, two females (Participants 1 and 2) aged 24 and 66 respectively from the same family living in Cato Manor disclosed their HIV+ status to me, the primary researcher, and offered to be a part of a study. Participants 1 and 2 said that they have openly shared their HIV experiences within the Cato Manor community for the past few years and are comfortable sharing more with me in the setting of formal research. Participants 1 and 2 served as interviewees in the primary qualitative portion of the study to explore how HIV stigma has impacted and changed throughout Participants 1 and 2’s lived experiences as PLWH. The researcher contacted and scheduled interviews with Participants 1 and 2 on two separate days, according to their availability. The interviews took place in the living room space of Participants 1 and 2’s homes to maximize comfort and familiarity with the interview setting, as both participants shared that they feel most comfortable telling their stories in their own homes. The interviews with Participants 1 and 2 helped guide and inform the remaining portion of the study, where Cato Manor community members in their 20s and 50s+, regardless of their HIV status, were interviewed regarding their perception of changes in HIV-related stigma.

In terms of community member participants, two age groups from Cato Manor were sampled for the study: females in their 20s and females older than 50 (as denoted by “50s+”). These age ranges were chosen to match the age range of Participants 1 and 2 and strengthen the homogeneity of the study’s participants. A larger range for age was included in 50s+ to allow for greater flexibility for participant recruitment as recruiter NoThando Mhlongo conveyed difficulty in recruiting older participants due to their smaller population in Cato Manor. Eligibility criteria for the study were: (1) female; (2) either in the 20s or 50s+ of age; (3) Black, English/Zulu-speaking working-class resident of Cato Manor; and (4) willing and able to provide written and verbal consent. Cato Manor, which includes Masxha and Chesterville, is a predominantly Black South African, Zulu-speaking, and working-class community, so a representative sample included these characteristics in the criteria. Cato Manor was selected for the study site because of the familiarity of the community with the researcher and recruiter and because preliminary data collected from conversations with community members suggested that there have been major changes in HIV-related stigma in recent years.
Except for Participants 1 and 2, study recruitment was carried out through convenience and purposive sampling by the SIT community liaison and gatekeeper, NoThando Mhlongo. Mhlongo was a fellow resident of Cato Manor and has built trust and connections within the community, which is particularly important as I, the primary researcher, am not a native local of South Africa. Mhlongo briefed all participants on the study’s aims and received their informed consent to participate before their one-on-one interviews. I received verbal and written informed consent a second time from the participants immediately before starting the interviews. The sampling was convenient because Mhlongo chose participants based on who is known to her and other factors such as her contacts, proximity, relationships, and familiarity with Cato Manor residents. The sampling was purposive because Mhlongo chose participants based on the specific eligibility criteria listed above. Mhlongo further aimed to recruit an equal number of participants in each age group. Following the specific eligibility criteria, Mhlongo recruited 15 female participants in each age group. Including Participants 1 and 2, 16 women in their 20s and 16 women in their 50s+ were recruited for the study, for a total of 32 participants (n = 32). Important and relevant details of the participants, including age and age, were recorded and specified in Table 1.

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Table 1. Demographic information of all study participants.

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Hennink and Kaiser (2022) stated that 9 to 17 interviews are often sufficient to reach data saturation for qualitative research, within a homogenous sample. While this study exceeded Hennink and Kaiser’s minimum interview number (9) for each age group, the standard for data saturation used in this study was not solely based on the number of interviews. The condition for data saturation in this study was that no new information was found, and the ratio of answers remained consistent even as the sample size increased. Following these conditions of saturation, the researcher determined that data saturation was reached within both age group interviews.

For each participant except Participants 1 and 2, the interviews took place on days that were the most convenient for the participants in a location close to their home or at their home. Mhlongo oversaw contacting the participants, scheduling their interviews based on their availability, and securing transportation for the participants. As the primary researcher, I facilitated the interviews, collected the data, and interviewed the participants in English. If any of the participants had limited English knowledge and/or fluency, Mhlongo served as a translator between myself and the participant.

HIV status was not solicited from any participant in the study. Any unsolicited disclosures, during which participants freely disclose their status to the researcher as did Participants 1 and 2, would have been recorded with care and protective measures to ensure that such information was not attributable to individual participants. No other participants besides Participants 1 and 2 disclosed HIV+ statuses to me, the researcher. All participants in the study were anonymous and confidential so that their identities were not recognizable by
descriptions of their lived experiences or opinions. This ensured that no harm would come to the participants, particularly for Participants 1 and 2, following the publication of the study.

**Design Overview**

*General qualitative research with semi-structured interviews*

The study employed a general qualitative research design that closely followed that of Zuma et al. (2018), who used a similar approach in a study to explore rural South Africans’ experiences of healing in the context of HIV/AIDS. Greater narrative emphasis and more interview time were placed on the semi-structured interviews with Participants 1 and 2, as the life stories of these participants directly spoke to the experience of PLWH perceiving and reacting to HIV stigma in the community. The researcher utilized semi-structured interviews with the remaining participants to allow triangulation between Participants 1 and 2’s stories and the stories of other Cato Manor community members (Creswell, 2014, p.104). This design was particularly well-suited for the study because the study aimed to analyze common themes surrounding changes in stigma perception within a township community in South Africa while also humanizing HIV/AIDS through a narrative focus on the lived experiences of PLWH (Participants 1 and 2).

The interviews with Participants 1 and 2 were conducted first. The information gathered from the interviews with Participants 1 and 2 was used to re-evaluate and refine the interview questions for the remaining participants. Any changes made were assessed and approved by the Academic Director prior to use. This was followed by one-on-one, semi-structured interviews with Cato Manor residents in their 20s and 50s+ to examine how HIV stigma has changed in Cato Manor over the generations. All participants except Participants 1 and 2 were recruited through convenience and purposive sampling by SIT community liaison, NoThando Mhlongo.

**Data Collection Instruments and Methods**

Data was collected through semi-structured interviews, and I, the author, directly interviewed the participants. Community liaison NoThando Mhlongo briefed each participant on the study’s purpose and served as the translator for participants who felt more comfortable and preferred to speak in Zulu. All participants provided written and verbal consent (translated into both English and Zulu) before being a part of the study. A three-way dialogue
took place for informed consent, and I and Mhlongo entered into conversation with the participants to ensure that the participants fully understood what will be done with their interviews. Participants were compensated R50 for their time spent in the interviews, and Participants 1 and 2 were compensated R250 for their two in-depth interviews. During the recruitment process, monetary compensation was not advertised to limit the purely financial motivation for the study. All participants were encouraged to not answer any questions that they do not want to answer and were told that they can leave the study at any time without any fear of losing compensation.

A total of 32 semi-structured interviews were conducted using two different interview guides: Guide 1 for Participants 1 and 2, and Guide 2 for the remaining participants in their 20s and 50s+. Guide 1 encompassed 13 questions further probing Participants 1 and 2’s reactions to their diagnosis and their lived experiences with HIV amidst HIV-related stigma over the years (Appendix A). Some interview questions were adapted from questions asked as part of Visser’s 2018 study, during which Visser quantified the most prominent HIV-related stereotypes and stigmas in South Africa, and borrowed language from Mall et al.’s study of changes in HIV stigma level (Mall et al., 2013; Maretha J. Visser, 2018). Guide 2 consisted of nine questions about community perceptions of HIV stigma in Cato Manor and changes in HIV stereotypes over the years (Appendix B). Guide 2 was developed at the same time as Guide 1, but focused more on community reactions and excluded any questions regarding the lived experiences of PLWH. Prior to use, Guide 1 and Guide 2 were piloted with 5 community residents, who were broadly asked if they experienced changes in HIV-related stigma and asked to recall specific changes in HIV stigma that have occurred within their lifetime. The preliminary findings from the pilot study were compiled into specific questions to improve clarity and contextualize them within South African culture and history. The most significant change made to the interview questions included simplifying the diction and rephrasing the wording of questions to ease understanding across potential language barriers.

Interviews were carried out at a time and location most convenient to the participants. For all cases, the location was within the home of the interviewee or a neighbor’s house within walking distance from the interviewee’s home. The interview setting included the interviewee’s living room, bedroom, kitchen, doorsteps, backyard, and front yard. The interview for Participants 1 and 2 took place in their living room, as they indicated that they felt most comfortable in their own homes. Before starting the interview, all participants were asked if they would be comfortable being recorded. They were told that their recording will
only be heard by the author, used for transcribing their interview, and will be destroyed following the conclusion of the research. Furthermore, participants were told that if they decide after the interview that they do not want to remain a part of the study or wish to retract a particular statement, they were welcome to contact the author to do so before the publication of the research. Once permission was granted, the interviews began.

During the interview, I used the appropriate printed, on-paper interview guide to facilitate the interview and took notes on both verbal and nonverbal communication throughout the interview. If at any point, the participant showed any sign of discomfort with the questions, I paused the interview to make sure that the participant was comfortable answering the question and encouraged the participant to skip the question if she was not feeling comfortable. For example, one participant, Participant 12, leaned away from the researcher and raised her eyebrows when asked a question about if her feelings towards someone would change if that person had HIV. I immediately paused my questioning to ask her if she felt comfortable answering this question. I soon realized that she misunderstood the question and thought that I was asking if she personally knew anyone with HIV/AIDS. I quickly addressed the misunderstanding and clarified my question, to which she answered comfortably and without hesitation. This and similar processes took place for any participant who showed verbal or nonverbal signs of potential discomfort. Following each interview, 5 minutes were allotted to summarize the interviews and write down key points and themes from the interview. Following the conclusion of the study, all data storage associated with the interviews was deleted from all devices by July 1st, 2023.

Data Analysis

Following the conclusion of data collection, recordings of all interviews were transcribed entirely or partly into Microsoft Word documents within one to three days of the interview, and some parts were double-checked for accuracy before further analysis. During the initial transcription process, the researcher simultaneously conducted a preliminary exploratory analysis during which the researcher manually made note of common keywords and themes used throughout interviews using the highlight feature on Microsoft Word (Creswell, 2012, n.p.). These served as major themes that were added to a code book. Due to a time constraint, the researcher did not fully transcribe some of the later interviews and instead listened to each interview for references to established codes and new codes. Some sections of the interviews were transcribed fully to be used as part of written sections. All
Interviews were analyzed thematically using transcriptions of the interviews and manual identification of patterns and keywords and concepts (Kiger & Varpio, 2020). Following the 6-step thematic analysis guideline of Kiger and Varpio (2020), all interviews were coded, sorted into overarching repeated themes, and reviewed. As the final step, the names of themes were carefully considered before producing the manuscript in the context of the greater research questions of the study (Kiger & Varpio, 2020).

Additionally, data analysis focused on providing the in-depth narratives of Participants 1 and 2. This emphasis on providing a large portion of Participants 1 and 2’s narratives was present because their experiences as PLWH amidst the HIV stigma were invaluable in gathering a greater understanding of how HIV stigma directly affects PLWH of different age groups.

Limitations and Biases

Within the sampling recruitment process, Mhlongo relayed several times to the researcher that there was difficulty in recruiting older women into the study. Mhlongo explained that this was mainly due to the lack of older-aged groups of women living in Cato Manor in addition to the possible hesitation of older South African “gogos” to engage in conversation or research with an outsider of the community. One participant, after her interview, stated that another reason for the fewer number of older women in Cato Manor may be that most of the older generations passed away amidst the HIV/AIDS pandemic before the ARVs were accessible. These factors all played into the age group range of the older participants being expanded from women in their 60s to women in their 50s+. The expansion of the age range allowed for a greater number of older participants but decreased the homogeneity of the sample. By grouping a larger age range, the study lost nuances between the views of women in their 50s, 60s, and 70s as each age group may have presented a different opinion of a particular stigma change within their lifetime. The researcher attempted to mitigate this by listening and transcribing interviews by the age range of the participants, however, ultimately compiled the findings and analysis based on only the two main age groups: participants in their 20s and their 50s+. This is a limitation that may have impacted the findings and analysis of the study.

Within the study design, it is important to note that convenience sampling via a community liaison may have added to the unrepresentativeness and biased homogeneity of the sampling population as there were likely familial and friend ties between the recruiter and
the participants. By having only one gatekeeper and recruiter, quite a few participants had a previous connection to the School for International Training as having been a participant in other students’ research projects in the past. Thus, the study acknowledges that the sample may not be representative of the entire Cato Manor community, however, this limitation cannot be adverted due to the constraints of time and safety concerns about approaching Cato Manor residents directly. Further, it is essential to acknowledge that Cato Manor may not serve as a direct representation of the entire Black South African population due to its high English proficiency, socioeconomic range, and geographical location.

Furthermore, within a one-on-one semi-structured interview design, the quality of the findings depended upon the rapport between the researcher and the participant. Thus, in cases where the participants felt even slightly uncomfortable talking to a non-local researcher, they may not have divulged their full opinion or view of the topic. I tried to limit this during the informed consent process, during which I explained my project and why I was conducting it with full sincerity and transparency. However, the underlying discomfort or unfamiliarity of the participants with a one-on-one interview setting with a foreign researcher may have limited the content and depth of information shared by the participants.

Bias within interpretation was also a factor that played a limitation within the study project. The primary researcher had built a relationship with Participants 1 and 2 before the start of the study project and has had several informal conversations with Participants 1 and 2 about the topic of HIV-related stigma. Due to the repeated exposure of the researcher to the thoughts and views of the two PLWH in the study, the researcher may have had unconscious bias when picking out major themes from the other interviews and analyzing the findings. I attempted to address this limitation by spacing out the timing of the initial interviews and follow-up interviews with Participants 1 and 2 amidst the interview with the other participants in the study project. However, the frequent and multiple exposures to the stories of Participants 1 and 2 may have contributed to a bias within myself, as the researcher, as I went about my findings and analysis.

Another limitation is that stigma does not have a direct translation in Zulu. The closest translation of the word is, ukucwasa, which means discrimination. Thus, when interviewing participants in their 50s+ who required translation, the researcher had to describe various manifestations of stigma in order to conjure a broader picture of what stigma can encapsulate, including physical or verbal assault of someone based on their HIV status, community judgment about PLWH, and peer-to-peer gossip around HIV/AIDS. Many participants equated stigma to acts of judgment and discrimination within the community.
While this prompted conversations about various manifestations of stigma, the lack of a direct translation of the word “stigma” may have impacted the quality and validity of the interview, particularly the answers to the questions that directly inquire about the amount of stigma in the Cato Manor community. This was an important limitation of the study.
VIII. Ethical Considerations

Careful consideration of ethics was given throughout the duration of the research to ensure the protection, privacy, confidentiality, anonymity, and informed consent of vulnerable populations. Given the research topic of HIV stigma, participants may have felt uncomfortable answering questions regarding a stigmatized topic in the community. To minimize the risks, all interview questions were reviewed by the Academic Director, John McGladdery, and Advisor Christine McGladdery before use. The interviews were conducted by me, the primary researcher, and Mhlongo served as a translator between myself and the participants if the participant felt more comfortable answering in Zulu than in English. All participants provided verbal and written informed consent before participating in the interviews. This was conducted in a conversational setting so that there was a three-way dialogue between the participants, Mhlongo, and myself to ensure that the participants fully understood the purpose of the study and what will be done with their interviews. Additionally, all participants were told verbally before the start of the interviews that they can stop at any time. On the consent form, the option to not answer questions or stop the interview at any time was written so all participants understand that they can stop participating at any point without any questions asked. Every participant was reminded that the completion of the interview and the quality of the interview did not have any financial consequences. Even if the participant chose to not answer questions or leave the study, the participant was told that she would receive a financial compensation for their time regardless. I also asked the participant to not share anything they do not want others to know about. At the end of the study, participants were invited and encouraged to ask the same questions of the researcher.

Before the start of the study, two participants (Participants 1 and 2) freely disclosed their HIV+ status to me, the researcher, and offered to be a part of my study. The two females (one in their 20s and one in their 50s+) were both from Cato Manor and were grandmother and granddaughter. Having had multiple casual conversations with them prior to the study, the researcher, myself, had formed friendly relationships with Participants 1 and 2. Participants 1 and 2 encouraged me to ask questions about their lived experiences with HIV and offered their living room as space to have further conversations and/or interviews. They told me that they have openly shared their HIV experiences within the Cato Manor community for the past few years and verbalized that they were comfortable with sharing their experiences living with HIV with people who ask questions.
HIV status was not solicited at any time before, during, or after the study, and PLWH were not actively recruited as part of the study. Any unsolicited disclosures, during which participants freely disclose and wish to share their status with the researcher like as did Participants 1 and 2, would have been recorded with the care and protective measures to ensure that such information is not attributable to individual participants. However, no other participants besides Participants 1 and 2 disclosed their HIV status to the researcher. The researcher’s topic of HIV stigma was not widely broadcasted to increase confidentiality throughout the study. Mhlongo, during her participant recruitment, made sure that the study was welcome to any females within the age groups of interest for my study, and HIV status was not by any means a factor in the recruitment process of the study.

All participants were asked if they would prefer the interview to be conducted in English or Zulu. If they were comfortable in English, the questions were asked in English by me directly. If any participant preferred to interview in Zulu, NoThando Mhlongo (SIT community liaison, participant recruiter, and translator) translated the interview between the participants and myself. For Participants 1 and 2, I interviewed Participant 1 in English as Participant 1 (in her 20s) was a fluent English speaker, and Participant 1 served as a translator between Participant 2 and me as they are family members and told me that they felt comfortable with one another.

All participants in the study were confidential and anonymous so that their identities are not recognizable by descriptions of their lived experiences or opinions. Names and other identifiable characteristics were not collected, documented, or published in any way. If I suspected that a detail in an interview may be used to identify an individual, I chose not to use the statement with the detail. For example, one participant provided a physical description of her neighborhood when speaking about her close relationships with PLWH. This statement was excluded from the findings to protect the participant’s anonymity as the neighborhood description may be attributable to the participant herself. Furthermore, for Participants 1 and 2, the interviews took place in the living room space of their home, where they stated that they felt the most familiar and comfortable, without any outside translators, and were not seen interviewed by anyone else besides their family. Moreover, there were two other student researchers doing research with Cato Manor residents on other topics including unemployment and abortion, which reduced the possibility of the data from informants being associated directly with my specific participants.

All participants except Participants 1 and 2 were interviewed once using the appropriate interview guides, and throughout the interview, I took time to clarify their
answers after each question to ensure the most accurate transcription and interpretation of their answers. Although I did not follow up with anyone besides Participants 1 and 2, I had asked for all participants for their phone numbers so that I could follow up with them over the phone, or ideally in person, one more time if needed to verify their quotes and ensure that what I have is accurate and consented upon. Participants 1 and 2’s interviews and follow-up interviews were split over two days to ensure that the interviews do not become longtime commitments to the participants.

Furthermore, in the course of a conversation or interview, if the participant divulged things that they didn’t intend to be used in the study, I clarified and asked if they want to say the statements in confidence. I did so by including the following question at the end of each interview: “Is there anything you told me that you want to keep between you and me, that I must not write down?” I, as the researcher, was always alert to this as a possibility and requested clarification if I even slightly suspected that the participant might not want what they said written down or documented. Immediate feedback was given to each participant to ensure that all information was correctly documented, and opinions were correctly interpreted. Phone numbers were exchanged to ensure that any significant inputs not included in immediate feedback can later be inserted into the final product and discussed with the participant. Each participant was given time to elaborate or change their opinion at any point before the conclusion of the study.

Interviews were recorded on an iPhone (researcher’s iPhone) using the application Otter.ai for automated transcription. The interviews were transcribed on Microsoft Word documents on the researcher’s laptop. Any device (phone or laptop) containing any element of participant data was password-protected and inaccessible to anyone but the researcher. All interview recordings remained in the iPhone during the duration of the study and were destroyed permanently after the conclusion and publication of the study. Any data collected, including the recorded interviews, was destroyed following the conclusion of the study and not accessible after the publication of the study on the SIT website.
IX. Findings and Analysis

In this section, I present my findings and analysis of the collected data. Findings are grouped topically and contain important themes that arose during the coding process. Findings are followed by analysis, which is labeled under a separate heading, and include a deeper examination of the changes in HIV-related stigma within the context of other recent HIV research in South Africa. The data is organized into seven sections, separated under larger topics. The first topic, General Findings, contains the first two sections, *Broad Overview of HIV Stigma Changes* and *Age Group Differences for Holding Stigma*. This section focuses on general information and patterns in overall HIV-related stigma in Cato Manor, which lays the foundation for the remaining five sections. The second topic, Interpersonal Distancing, contains two sections, *Fear of Non-Sexual Transmission* and *HIV as an Early Death Sentence*. This topic focuses on the earliest forms of stigma related to HIV/AIDS, during which people would avoid physical contact and socialization with PLWH. The third topic, Sexual and Moral Judgment, is a standalone section that focuses on a second wave of the stigma that arose after public knowledge of HIV/AIDS as a primarily sexually transmitted disease. The fourth and final topic, Judgment of Negligence, contains two sections: *Negligence within Newly Infected PLWH* and *Anti-Stigma Education*. Here, a persistent new judgment – judgment of PLWH as negligent – is presented and discussed as a potential newly-articulated form of stigma. Alongside this new stigma, findings regarding contemporary anti-stigma approaches and interventions are discussed.

General Findings

1. Broad Overview of HIV Stigma Changes

Findings

When asked if the stigma associated with HIV/AIDS has changed within her lifetime, Participant 1, a 24-year-old woman, answered that HIV-related stigma “is less than before” (Participant 1, 2023 April 3). Participant 1’s statement was rephrased into an interview question for the other participants, to which 30 out of 32 participants agreed that stigma has decreased within their lifetime. The two participants who did not agree were Participant 31 and Participant 32, who were aged 21 and 65, respectively. Participant 31, aged 21, stated
that “There has always been the same amount of judgment” (Participant 31, 2023 April 13). Participant 32, aged 65, elaborated that although she knew what stigma was like before, she does not know currently because “most of my time is spent going to church and coming back” and rarely in the Cato Manor community (Participant 32, 2023 April 18). Overall, most participants reported perceiving decreased HIV-related stigma within their lifetime.

In specifying which year(s) the participants perceived the most stigma in Cato Manor, there was a variety of answers, depending on the age of the participant. Among the participants in their 50s+, 13 participants said the most stigma occurred between 1990 to 2000, when “HIV first came out” (Participant 5, 2023 April 3). This was followed by “2000 to 2004” and “2004 to 2008” for three of the participants. One participant, a 54-year-old woman, who answered “2004 to 2008,” stated that “2008 was when a lot of people still died from HIV. They used to take more than one pill with many side effects, so people stopped taking them and died” (Participant 16, 2023 April 6). This suggested that the lack of optimal medication and treatment options contributed to heightened stigma in the early 2000s.

Among the participants in their 20s, most of the participants could not identify a specific year or range of years for when the stigma was the greatest. Seven of the 16 young participants indicated that they perceived the most stigma in their years just before entering secondary school because that was when they witnessed a lot of community judgment against PLWH, including gossip and rumors regarding who has HIV. One participant, a 28-year-old woman, stated: “Before I went to secondary school, I saw a lot of judgment. If they saw someone at the clinic getting their pills, they would gossip and say they have HIV. They would judge them” (Participant 4, 2023 April 4). Two other participants in their 20s stated that HIV/AIDS stigma was the greatest before their birth. One of the two participants, a 20-year-old woman, added to her answer, stating “Before I was born, they used to kill people with HIV” (Participant 18, 2023 April 6).

The 30 participants who indicated perceiving a decrease in HIV-related stigma during their lifetime were asked to identify the year(s) when they started noticing a decrease in stigma. To this question, the older and younger participants gave different ranges of dates. 14 of 15 participants in their 50s+ stated that stigma decreased when free ARVs became available in public clinics, which was nationally rolled out in 2004. One participant, Participant 8, aged 52, stated that stigma only started changing recently in the 2020s because of the “TV education and campaigns” (Participant 8, 2023 April 4). Participants in their 20s gave a year or a range of years between 2008 to 2016 in specifying a time when perceived stigma started to decrease. When asked if the year(s) correlated to a particular event, 13 of
the 15 younger participants mentioned exposure to a form of HIV education in the year(s), including workshops at the local Cato Manor clinic, involvement with the non-profit Love Life, and life orientation classes at school. One participant, Participant 1, age 24, who gave the year 2010 as the start of stigma change stated that by the 2010 FIFA world cup, “It was more commercialized by then. People were well-educated by then” (Participant 1, 2023 April 4). Another participant, a 28-year-old woman, recalled feeling “more comfortable talking about HIV” with friends and family around the time she entered her secondary school years (Participant 4, 2023 March 31).

When asked if HIV stigma still exists in Cato Manor, 26 of the 32 participants said yes. One participant, a 28-year-old woman, elaborated that HIV was still a strictly uncomfortable topic to talk about amongst her Cato Manor peers and family: “Let me say that HIV is a topic that most of us don't talk about. We don’t talk about HIV because maybe no one in our age or in my friends have it so we don’t talk about it” (Participant 13, 2023 April 6). For other participants, however, the ongoing presence of HIV-related stigma had more to do with the persistence of the community in judging PLWH, rather than the comfortability of HIV/AIDS as a topic in conversation. “There was and there is stigma, a lot of judgment against people with HIV,” said Participant 8, aged 52. Participant 8 further elaborated on her answer:

> But it's a different kind of stigma now. Before, HIV stigma was, well you have HIV or AIDS because you’re a loose cannon. You didn't take care of yourself. But now, the stigma is that how. How did you get HIV? Why didn’t you use protection? The stigma is, ‘You're so ignorant.’ (Participant 8, 2023 April 4)

The changing type of HIV-related stigma was echoed by other participants, particularly in their 20s who stated, “[The stigma is now] ‘You're getting what you deserve because you weren't being sexually safe or cautious’” (Participant 3, aged 23, 2023 March 31). According to Participant 2, previous manifestations of stigma took physical and verbal forms in community settings, ranging from name-calling to stoning a person with HIV. Currently, “gossip and side-eyes” and interrogation-like questioning make up the bulk of the stigma forms (Participant 1, 2023 April 11). These participants present a novel insight into the changing types and manifestations of stigmas in Cato Manor throughout the years, and I will investigate these more in-depth under the section, Judgment of Negligence.

Analysis
The general consensus of the participants (94%) in perceiving decreased HIV/AIDS-related stigma within their lifetime serves as an important background in understanding the contemporary context of HIV stigma. Two other studies have also examined similar changes in HIV-related stigma in South Africa since 2004: Visser (2018) and Mall et al. (2013). For these studies, direct comparisons between their findings and my study’s findings were not made due to major differences in location, interview questions, and participant demographics. However, major trends were picked out and noted to be similar or different between the studies and my study to create a bigger picture of how HIV-related stigma has changed in South Africa in recent years.

In Mall et al.’s 2013 study, researchers found that having greater in-depth knowledge about HIV/AIDS and access to HIV treatment correlated to a significant decrease in HIV stigma over time in a peri-urban area of Western Cape (Mall et al., 2013, p.194). The inverse correlation between knowledge and stigmatization found in Mall et al. was similarly noted in my study, where 86% of my participants in their 20s indicated that efforts towards education and awareness contributed to the start of the decrease of HIV stigma in Cato Manor beginning in the early 2000s. Cato Manor’s Life Orientation course at schools, health promotion campaigns at clinics, and youth education through Love Life served as examples of the “community-based HIV awareness and education” contributing to de-stigmatization, as mentioned in Mall et al. (Mall et al., 2013, p.195). Furthermore, the large influence of the national ART roll-out on stigma resonated with the views of 86% of my participants in their 50s+ who specified that the start of decreased HIV stigma began when ARVs became publicly accessible. Taken together, HIV/AIDS education and access to ARVs between 2000 and 2004 contributed significantly to the first dip in stigma perceived in peri-urban and urban areas of South Africa. This is further triangulated by the fact that the Mandela administration prioritized increasing HIV/AIDS awareness and ARV roll-out to urban areas with high HIV rates like Cato Manor (South African History Online, 2022). The effect, as evidenced in my study, is that South Africans in these regions have noticed a significant decrease in stigma and have reported a continuous decline since 2004.

Although most participants in my study perceived a significant decrease in HIV-related stigma, still more than half of the participants stated that stigma remains prevalent in Cato Manor. Similarly, a study by Visser (2018) found that while there was an overall significant decrease in HIV-related stigma in Tshwane over a 12-year duration, there were still high levels of discomfort with interacting with PLWH (Visser, 2018, p.734). In both studies, a general trend of decreasing overall HIV-related stigma with some persisting
stigmas was found. In the case of Tshwane in Visser (2018), respondents held the same level of fear regarding physical and social contact with PLWH in 2004 and 2016. On the other hand, in Cato Manor, the persistent stigma held by my participants were moral judgment and judgment of negligence, which are further investigated under the remaining themes. Both studies highlighted the pervasiveness of HIV-related stigma even in communities where stigma has been said to have decreased. The specific type of persisting stigma may differ, however, as it did between Tshwane and Cato Manor. The difference can mainly be attributed to the community’s access to HIV/AIDS education and ARV treatments, as both factors have been evidenced to contribute greatly to the level of stigma in a community. This points to the idea that de-stigmatization occurs at different rates in different communities, and thus, stigma must be addressed individually at the community level to target the most resistant stigmas. As such, my study will focus upon Cato Manor’s specific stigmas and how they have changed over time, which may not be representative of other parts of South Africa but serves as an example of how stigmas can be monitored and changing in other similar peri-urban townships.

Overall, the finding of my study that there has been a generally decreasing amount of HIV-related stigma in South Africa since 2004 was well-supported within the context of the ongoing literature regarding HIV-related stigma. The persistence of certain stigmas in my study and Visser’s study suggests that stigma may be occurring in waves, with the intensity of specific types of stigmas increasing and decreasing between certain years and within specific communities. The highly fluctuating and constantly changing direction of HIV-related stigma also evidenced in my study goes to show that a blanket statement of “there is decreased HIV stigma” is not sufficient to cover the nuances of the changes in stigma. Unless stigma is continuously monitored, an in-depth understanding of how pervasive and prevalent HIV-related stigma has changed within South Africa is difficult to ascertain. Using the two recent studies and my study, however, it can be generally stated that since 2004, the level of HIV-related stigma held by South Africans in peri-urban or urban areas has decreased due to increased education and accessibility to affordable HIV/AIDS treatment.

2. Age Group Differences for Holding Stigma

Findings
When asked which age group of women (aged 20s or 50s+) currently holds more stigma about HIV/AIDS, there was a mixed response from the participants, as shown in Figure 1.

**Figure 1:** Pie charts of responses for which age group of people, women in their 20s or women in their 50s, the participants perceived greater HIV-related stigma from.

Nine of 16 participants in their 50s+ said the younger generation had more stigma while five stated that the older generation did. The remaining two participants in their 50s+ stated that they did not know the answer and that stigma was probably “the same” in both groups (Participants 32 and 12, 2023 April 19). Of the participants in their 20s, nine stated that the younger generation had more stigma while seven stated the older generation did. Taken together, 56% of the participants perceived greater stigma amongst younger women in their 20s, and 37% perceived greater stigma in older women in their 50s+. Although statistical significance cannot be drawn from the percentages, a trend was found in people of all age groups perceiving greater stigma in women in their 20s than in women in their 50s+.

For participants who perceived greater stigma in the younger generation, when asked why the participants chose the age group, all participants indicated witnessing young people gossip more about PLWH than older people. One participant, a 28-year-old woman, stated that “They’re not going to tell you directly, but when they’re sitting together and you’re not there, they’re going to talk about it. How come she's just got HIV blah, blah, blah” (Participant 13, 2023 April 6). In addition to gossip about the HIV status of individuals, Participant 14, age 21, delved into other types of gossip about PLWH in current conversations among people in their 20s, including PLWH “sleeping around,” “having multiple partners,” and “drinking too much” (Participant 14, 2023 April 6). Participant 14 attributed the stigma often present in youth gossip to a particular mentality of people her age: “I just think that people [my age] have a mentality that if you have HIV, you don't love yourself... Stuff like if you get HIV, it means you’re basically sleeping around, you know, not protecting yourself” (Participant 14, 2023 April 6).
Of the 12 participants who perceived greater stigma in older generations, three participants in their 50s+ and four participants in their 20s stated that older generations tended to maintain harsh HIV-related stigma from apartheid times. These 7 participants attributed the apartheid government’s denialism and apathy towards HIV/AIDS as being the reason for the discomfort and “lack of openness” that older people feel towards the topic (Participant 1, 2023 April 3). When asked to elaborate, four participants – Participants 23, 30, 58, and 21 – blamed the apartheid government for dismissing HIV/AIDS as a “disease for Blacks,” which led to a heightened sense of shame towards HIV within older Black South African women (Participant 23, 2023 April 18). Others expressed heatedly that “they were waiting for Black people to die off,” which contributed to a heavy fear of death within Black South African communities (Participants 19 and 20, 2023 April 11). Due to the high prevalence of HIV stigma at the start of the pandemic, there seemed to be a common belief that those who grew up witnessing judgment and stereotypes related to HIV/AIDS tended to hold onto those beliefs. This was evidenced by one participant, a 28-year-old woman, who noted, “Most older people have same mentality as before. It is a matter that their education has to repeat itself several times and it has to be exposed in many, many, many places to change their mentality.” (Participant 23, 2023 April 18).

However, this contradicts the opinions of some older participants, nine of whom indicated that all older people are wiser and more accepting now. Participant 28, aged 63, noted the wisdom of the older generation after coming in direct contact with PLWH: “At our age, we know that the thing can kick and come anyhow. Because sometimes if you have a husband, he can go outside and come back in with it” (Participant 28, 2023 April 18). Another participant, a 53-year-old woman, agreed that older generations have become better educated over the years, stating “At 53, We are well aware of it. We are no longer like taking it as a bad thing” (Participant 5, 2023 April 3).

**Analysis**

The generational differences in stigma perception in my study showed a pattern of greater perceived stigma coming from women in their 20s rather than women in their 50s+, as most evidenced by heightened youth gossip of PLWH. The trend of younger generations holding greater HIV-related stigma contrasted drastically with the findings of two other recent literature. In Akullian et al. (2021), researchers suggested that greater societal acceptance and normalization of HIV in South Africa since 2004 have reduced the stigma
and thus the incidence rate in young female populations (aged 15 to 24), but not to a significant degree in older females aged 30 to 54 (Akullian et al., 2021, p.1). Although the incidence rate was not a focus of my study, Akullian et al.’s suggestion of decreased stigma in youth aligned with the view of 37% of the participants in my study, who attributed current HIV stigma to mainly the older generation. However, for a majority of my participants (57%), stigma held greater weight and presence within the young female population of Cato Manor, which was contrary to Akullian’s finding. This difference may be attributed to the differences in age groups utilized in the studies because Akullian et al.’s age range of 15 to 54 excluded women who were past 54 years old. The limited age range in Akullian et al. fails to consider the experiences and opinions of older generations who have long-lived experiences under apartheid and thus had greater exposure to PLWH during the exponential rise of HIV/AIDS in the early 1990s. As stated by Participant 5, participants older than 50 years old have greater familiarity with the devastating impacts of HIV stigma and thus potentially greater sympathy towards PLWH that may actually reduce stigma within the older age group. This may explain the difference between my study and Akullian’s study and the high number of my participants who stated that they perceived more HIV-related stigma among young women in their 20s.

In another study, Lambert et al. (2018) found that young women were more willing to utilize HIV testing and treatment than older generations due to greater peer support and conversation about HIV/AIDS (Lambert et al., 2018, p.733). While this finding supports Akullian et al.’s conjecture of greater HIV normalcy within South African youth, it cannot be directly correlated with a decreased HIV stigma because HIV-related stigma was not explicitly studied as part of Lambert et al.’s study. However, it is important to note that in recent literature like Akullian et al. and Lambert et al., there has been a trend of younger generations of women exhibiting less stigma than older generations. This is contrary to the generational differences in stigma found in my study. The contrast in findings may be due to the specific differences in age groups in the studies as mentioned above. It may also be due to the fact that my study was specific to one particular community, Cato Manor, whereas other studies sampled more broadly among different South African communities.

Stigma-driven gossip arose more among conversations between young women, rather than older women, and this created a perception of greater stigma within the women in their 20s than their 50s in my study. To further explain the heightened gossip noted in young women in Cato Manor, Pantelic et al.’s 2020 study of adolescent development and HIV stigma in South Africa contextualized peer acceptance and self-concept to be the main driver
of HIV-related discriminatory actions among youth. In townships like Cato Manor, adolescents living with HIV in South Africa often “stand out” from their peers and become more at risk of experiencing peer discrimination and isolation (Pantelic et al., 2020, p.2). This, in addition to the youths’ greater fear of being ostracized, generally increases the level and depth of stigma exhibited and experienced by young women. In Cato Manor, gossip served as one main method in which stigma can be manifested amongst adolescents. Peri-urban townships like Cato Manor that have the same gossip culture may experience a similar generational trend of younger women holding and perceiving more HIV-related stigma than older women, who do not engage as much in community gossip.

The 38% of participants in my study who perceived greater stigma in older women suggested a connection between the apartheid times and HIV-related stigma held by that age group. The contribution of the apartheid government to HIV-related stigma felt by older generations was also noted by Bell et al. (2022). Bell et al. specifically stated the denialistic attitude of the government towards HIV/AIDS, a disease disproportionately impacting Black South Africans, and the lack of affordable healthcare in Black communities created intense socioeconomic strain for Black South Africans. These events contributed to South Africans’ reported fear of coming into contact with PLWH and stereotypes associated with moral corruption and death concerning HIV/AIDS (Bell et al., 2022, p.2). The historical link made between apartheid conditions and HIV stigma in Bell et al. provided context that triangulated the perspectives of my participants who believe that stigma is still greater in older generations. This leads to the idea that with more years spent under the apartheid, HIV-related stigma may be more firmly cemented in the minds of older South Africans. Even given this logic, however, most participants in my study project perceived greater stigma within the younger population, which suggests that the number of years spent under apartheid is not a strong indicator of the amount of stigma an individual holds.

Taken together, the generational differences in the overall perceived HIV-related stigma did not show a clear pattern but indicated a trend of younger women engaging in more HIV-related gossip than older women. In Cato Manor specifically, the greater engagement of young women in gossip created a perception that there was greater HIV-related stigma among younger women. This contrasts with the suggestions of two other studies that younger women hold less stigma due to greater normalization of HIV/AIDS within their lifetime. Some of my participants in their 20s have echoed this through a logical appeal to how older women have been exposed longer to the greater intensities of HIV stigma and thus might continue to hold onto those negative stereotypes about PLWH. However, given that most
participants attribute greater stigma to younger women in my study, Cato Manor may be an exception to the ongoing national trends. This can be further attributed to differences in the culture of gossip that is present in various townships, with more younger women involved in HIV-related gossip than older women in Cato Manor.

**Interpersonal Distancing**

3. Fear of Non-Sexual Transmission

*Findings*

When HIV/AIDS cases first started appearing in the mid-1980s, all participants in their 50s+ stated that most Black South Africans in the Cato Manor community did not have access to adequate knowledge about HIV/AIDS. This includes a lack of information about “how you contract it,” “risks behaviors” associated with contracting HIV/AIDS, and “different precautions and treatment options” (Participant 11, 2023 April 6). Commenting further upon the lack of education, Participant 8, aged 52, described, “Back in the 90s, we didn’t have any awareness about HIV. We didn’t have any media awareness or awareness in clinics. We didn’t have any pamphlets. We didn’t have a lot of information” (Participant 8, 2023 April 4). One participant, a 67-year-old woman, stated that she was the exception. She learned about HIV/AIDS earlier than other people in Cato Manor because “I was working for a white lady, a doctor, and I asked her questions about it and how you get it” (Participant 27, 2023 April 18). However, she states that most of her peers remained uneducated about the disease until “years later.”

The lack of public knowledge regarding the nature of the disease instilled great fear of HIV/AIDS. Participant 2, aged 66, recalled the fear of an unknown disease heavily influencing how people interacted with PLWH. She described, “People were afraid of contracting it and confused on how you caught it. Don’t use that spoon. Don’t use the cup, plates. Don’t sit next to that lady. She’s HIV positive. They'll also add that we’re not clean.” Participant 2 also commented upon how this fear of transmission limited her willingness to disclose her status to friends and family: “So I chose to be private about my HIV status and tell my immediate family” (Participant 2, 2023 April 11). 14 of 16 participants in their 50s+ and 10 of 16 participants in their 20s described different ways that segregation and peer isolation may have taken place to limit contact with PLWH:
Participant 5, age 53: “Back in the 90s, yeah, when you find that maybe my sister is HIV [positive] now I don’t want her inside the house. I'll build the shack outside. Don't touch my plate. Don't touch my kids and all those kinds of things... You look at your neighbors and see the treatment they are giving their siblings and do the same” (Participant 5, 2023 April 3).

Participant 30, age 48: “A lot of people didn't want to touch or eat or share things with people with HIV, because there's no way of knowing where it was coming from and how you get it and how you treat it. Like they had no knowledge whatsoever” (Participant 30, 2023 April 18).

Participant 17, age 58: “They used wheel barrels to push people with HIV around. So usually at that point, it would be like well, the immune system is failing them. They probably can't walk and they have lack of energy. They only knew that if you touch somebody with HIV you will be also infected. So it was part of what was one of the stereotypes that they had. That if you touch somebody in the barrels like you'll also be infected as well” (Participant 17, 2023 April 6).

Participant 19, age 25: “Because all of us who are afraid because we didn't know what was HIV. All we knew was it was disease that you can’t sit next to a person but the time when you learned about it, found out about it, it’s when we started realizing this is the same thing as cough. It's just that you have to cure HIV like every day” (Participant 19, 2023 April 11).

The responses to HIV/AIDS stigma varied in intensity. One particular story was mentioned in nine separate interviews and used to describe the brutal treatment of PLWH in the early years of the pandemic. It was the story of Gugu Dlamini, a young woman who was beaten and stoned to death for disclosing her HIV+ status. Three participants in their 20s and six participants in their 50s+ referenced Dlamini when describing the previous stigma about PLWH. Participant 2, aged 66, stated: “The reason why she was stoned to death is because they literally associated HIV as being a shame and they didn't want to be involved with her, so they just killed her” (Participant 2, 2023 April 11).

In all cases Gugu Dlamini’s story was mentioned, it was used as a measure of comparison to the treatment of PLWH in 2023, which was much less violent than before. 30 of the 32 participants agreed that physical violence towards PLWH is not something that can
be commonly found today in Cato Manor. Participant 10, aged 26, stated that if there are still acts of violence still occurring, it would be in “rural areas where there is no education” and not Cato Manor. However, three participants in their 20s stated that older generations in their 50s+ may still treat PLWH with the same fear of non-sexual transmission. Participant 15, aged 29, elaborates upon this:

**Nowadays, still, the older people, like, isolate you. They wouldn't say like leave the house, but they wouldn't really let me do anything. Like don't touch the food. Or don't cook now – it's fine. We're going to cook. Maybe even if my mom were like, make bread for me. And then she thinks like, 'no, no, don't do it anymore. It's fine. I'm going to do myself,' because she's going to think that disease or whatever, I left it on the plate. That's how they are. They wouldn't really tell you but they would show me that they don’t want me around. Because I think they have stigma because they're still stuck in that lack of knowledge.** (Participant 15, 2023 April 6)

When participants in their 50s+ were directly asked how they would treat friends or family who are diagnosed with HIV, none of the older participants mentioned isolating, quarantining, or restricting the activities of the PWLH, as suggested by Participant 15. All participants in their 50s+ stated that their behavior or actions would not change towards the PLWH. On the contrary, when young participants were asked the same question, two individuals in their 20s, Participants 9 and 13, stated they would distance themselves from PLWH in fear of contracting the disease. Participant 13, aged 28, stated “I’m not sharing things. Toothbrush. I know we can’t share toothbrush.” Similarly, Participant 9, aged 24, stated, “I would try not to touch. You can get AIDS by helping someone while having a cut in your hand. Toothbrush, if you're sharing a toothbrush, you can get AIDS.” Such intentional distancing is reminiscent of a fear of non-sexual transmission, which suggests that the manifestation of early HIV/AIDS stigma continues today.

**Analysis**

The findings showed a unanimous consensus among participants in their 50s+ that a lack of access to HIV/AIDS education drove the initial fear of HIV/AIDS in Cato Manor in the late 20th century and early 21st century. This finding was a common theme that emerged in the context of other HIV stigma literature. South African History Online, a non-profit that partners with seven national universities to create a comprehensive history of South Africa, attributed the lack of early access to HIV/AIDS education to the government’s failure in
creating policies geared towards raising HIV/AIDS awareness. This was the same argument made by Participant 8 in my study, who stated that the government had not handed out pamphlets or other similar things to educate the public about HIV/AIDS. As a result, misconceptions about non-sexual transmission intensified in South Africa, including the idea that sharing objects and non-sexual physical contact with PLWH will automatically transmit the disease.

The story of Gugu Dlamini as an activist who fought against HIV stigmatization and denialism was also noted in South African History Online. After Dlamini publicly disclosed her HIV+ status on national television on December 1st, 1998, members of her town in KwaMashu threatened Dlamini as she “brought shame onto their community.” The threats eventually escalated into the stoning and stabbing of Dlamini the same year (South African History Online, 2022). Given the proximity of Cato Manor and KwaMashu (20.8km), it can be assumed that Cato Manor residents are more familiar with Dlamini’s story than those in other parts of South Africa. This matched up with the consistent mention of Dlamini in nine separate interviews with participants. The impact of one local activist upon the residents of Cato Manor suggests that the history of extreme treatment towards PLWH is well-retained within the memories of current Cato Manor residents. As such, this may serve as one of the reasons why some participants still feel that HIV stigma is an uncomfortable topic to bring up in conversation, which contributes to the perceived stigma associated with HIV/AIDS in Cato Manor. On the other hand, it may also explain why a majority of my participants perceived a drastic decrease in stigma since the times of Dlamini to 2023.

Interestingly, Cato Manor residents showed remarkably lower interpersonal distancing than studies in other parts of South Africa. Visser (2018) found that compared with the 2004 survey results on perceived HIV stigma, the 2016 survey results showed a significantly high tolerance for personal contact with PLWH. However, a quarter of the respondents still viewed befriending and dating PLWH as threatening. In comparison to Visser’s findings, a higher percentage of participants (94%) in my study stated that they would not change their behavior or purposefully distance themselves from PLWH than those who did (6%). Only two participants mentioned changing their actions, but this did not involve physical distancing from PLWH and was more related to the sharing of items. The difference between Visser (2018) and my study may be attributed to an increase in education on HIV/AIDS since Visser’s study in 2018, particularly in the form of non-profits that have arisen since 2018. Recent non-profits include Love Life, which was mentioned in interviews with multiple participants in their 20s who stated that their knowledge of HIV/AIDS
increased through their participation in the organization. Young women, who learn about HIV/AIDS from non-profits like Love Life, bring their newly acquired knowledge back to their homes where they relay the education to older family members. Thus, education becomes dispersed to both young and older people within families and communities through HIV/AIDS non-profits. The increase in education brought by non-profits since 2018 thus serves as one reason for the greater decrease in interpersonal distancing in my study versus Visser (2018). The difference between Visser and my study also speaks to the limitations of a sample of 30 from a peri-urban town, as this finding may not be generalized to be compared to statistics in other parts of South Africa. However, it is plausible that Cato Manor is generally more inviting to contact PLWH than more rural areas and that community opinions have shifted in the 5 years since the 2018 study by Visser.

Overall, the absence of in-depth HIV/AIDS knowledge in South Africa fueled the first major wave of stigma towards HIV/AIDS, the fear of non-sexual or casual transmission. In Cato Manor, the result was evidenced in most of my participants who were able to recall a wide array of ways people distanced themselves from PLWH. This ranged in intensity from the stoning of PLWH to preventing children from playing with children with HIV. Even today, Participants 13 and 9 both still expressed great reservations about sharing toothbrushes with PLWH due to a fear of transmission, which is reminiscent of the early stigma of interpersonal distancing. However, Cato Manor has shown a rapid decrease in stigmas related to interpersonal distancing from PLWH since 2004, which is surprising given the fact that a vast majority of participants still perceive HIV stigma to be present in Cato Manor. The decreased fear of non-sexual transmission indicates that other types of stigmas may be having a greater presence among South Africans in 2023. These stigmas are most likely sexual and moral judgement or judgment of negligence, which will be further addressed in the remaining sections.

4. HIV as an Early Death Sentence

Findings

Underlying the historical acts of segregation towards PLWH was a deeper fear rooted in the incurable nature of HIV/AIDS. It served as the basis of the intense stigma around interacting with PLWH. Both younger and older participants talked about the fatality
entwined with having HIV/AIDS and how it fueled a perpetual fear about being around PLWH and thus the stigma. Participant 16, aged 54, stated:

*It's a very life-threatening disease. We never think that one would get in contact with such a terminal disease, that we might get sick, because we think we're just going to be good and just die after a normal life without having to come across such things. What's shocking is that it's something that is not even curable. It's not like a flu when you get the flu. And then it's just, it's over. Because of this, people think of it as something that can just be passed on by just having the people next to you.*

(Participant 16, 2023 April 6).

Participant 19, aged 25, further echoed this sentiment when asked if she previously or currently considered HIV a death sentence. She answered that she currently still believes, stating “For me, yes, it is. It’s not a usual disease. It’s unlike the other ones, it’s scary. There are big consequences, so people are afraid of even thinking about having it.” However, for 29 of 32 participants, HIV/AIDS was no longer strongly associated with death in contemporary stigma. As one participant, a 58-year-old woman, noted: “It’s no longer a death sentence. We have education and pills now. People with HIV are living even longer than people who don’t [Laughs]” (Participant 30, 2023 April 18). Similar comments were made by participants in both age groups, who agreed that with proper medication treatment, PLWH live just as long if not longer than people who do not have HIV.

For three participants in their 50s+, the idea of assured death associated with HIV/AIDS created a stigma similar to that already present with TB, another highly prevalent and often fatal illness in South Africa. Participant 6, aged 67, correlated the initial treatment of PLWH to people living with TB: “When we were growing, it was TB. I mean, when we were very young, like TB patients used to have their own things like their own spoon, spoon everything, and you can't share. That’s how HIV was treated when we first knew about it” (Participant 6, 2023 April 3). The acts of isolation often witnessed with TB resonated with other participants’ descriptions of previous treatment toward PWLH in the late 1990s and early 2000s. In explaining the impact of TB on HIV, Participant 2 connected the fatality of the two diseases: “They’re judged more or less the same way because the diseases are fatal without treatment. People with TB will be treated with segregation, meaning that they will be isolated in one area and not stay with other people due to it being contracted. It was similar with HIV.”

However, some participants didn’t agree with the sentiment that TB was treated as similar to HIV/AIDS because of the clear differences in symptomology. Participant 30, aged
commented: “Most of the people who had TB within the community were seen with like frail bones and skinny and huge cough. He or she would have shivers when it's sunny. So it was a more of a physical thing, the symptoms that TB people have rather than HIV people.” Similar statements regarding differences in appearance included swollen glands, leather-like skin, and rapid change in weight for those with HIV, rather than TB. Regardless of the physical appearances of infected individuals, Participant 30 commented that TB was curable after taking treatment while “HIV is for life,” which she indicated made HIV have a greater stigma than TB (Participant 30, 2023 April 18).

Even in the context of having accessible HIV treatment options, however, Participants 1 and 2 stated that the notion of HIV and early death continued to play into the stigmas surrounding contracting HIV/AIDS. When they were each diagnosed with HIV at the Cato Manor clinic in 2021 and 1998 respectively, they each automatically correlated HIV to their early death. Participant 2, aged 66, stated “I knew it as a death sentence. When I went to the clinic and went to talk to the doctor, he reassured me that you’re not going to die and you're going to live long. I believed the doctor, but I saw the people dying. I was in-between.” For Participant 1, aged 24, her diagnosis of a potentially fatal disease brought upon denial: “I thought ‘Oh, I’m dying now.’ I mean obviously with the nurses, they did counseling and they counsel you as best as they can. But I'm so confused at the moment, it doesn't ring. I felt guilt and was in denial. It was just a lot of anxiety.”

Analysis

When it comes to HIV as an early death sentence, Gilbert (2016) stated clearly in her review of HIV stigma in South Africa that “one of the main reasons for the high levels of HIV-related stigma in SA was its association with death” (Gilbert, 2016, p.4). The lack of affordable public health services for PLWH, alongside the disproportionate number of Black South Africans affected by HIV/AIDS, cemented the perception of the disease as a terminal illness (Haal et al., 2018, p.2; Wilkinson et al., 2019, p.8). This resonated with Participant 16’s statement on how the incurability of AIDS drove intense fear within the community, as it was nothing like the common flu that people can get better from with time. Instead, AIDS festered in the body until “it’s over” (Participant 16, 2023 April 6). The notion of AIDS as a death sentence carried a symbolic weight that fed into acts of harsh discrimination against PLWH in the community, from chasing away family members with HIV to quarantining individuals with HIV. Multiple participants described the harsh distancing from and shunning
of PLWH upon contraction of the disease in fear that others can catch it by simply being near PLWH. The mere presence of HIV/AIDS was a deadly threat to South Africans in the 1980s and 90s.

A history of quarantining and social isolation for people with TB in South Africa has been recorded in previous literature since TB’s first major outbreak in South Africa in the 1870s. In a 2023 study by De Santo et al., South African TB patients explained the stigmatization associated with their disease, which contained similarities to the statements made by participants in this study regarding the treatment of PLWH. One commonality was an intense fear of transmission, which often led to peer and self-isolating behavior for TB patients (DeSanto et al., 2023, p.5). Those with TB mentioned not being able to eat with others, being prevented from joining community events or activities, and avoiding physical touch with friends and family members, which aligned with Participant 6’s description of everyday interpersonal distancing from PLWH such as refusing to share spoons during mealtime. Given the timeline of the TB/HIV co-epidemic, during which TB was established in South Africa about a century before HIV’s introduction, it is highly reasonable that similar treatment was given to those with HIV, grounded in the same fear of non-sexual transmission. The common prevention technique of distancing from those with TB further explains the immediate response of South Africans to distance themselves from PLWH within a time of inadequate knowledge and awareness of HIV/AIDS.

DeSanto et al. (2023) stated that in contemporary times, the stigmas related to TB and HIV cannot be separated, but instead must be studied as a double stigma. In the context of the TB/HIV co-epidemic, the dominant stigmatizing disease is HIV and the less stigmatized is TB (DeSanto et al., 2023, p.5), which was directly corroborated by Participant 30’s statement comparing the two stigmas. When analyzing the influences of the diseases on one another, TB stigma may have had an impact on the initial development of HIV stigma at the start of the HIV pandemic, but the intensity and depth of the stigma associated with HIV have had a larger influence on TB stigma over time. In particular, TB patients in DeSanto et al. greatly feared being associated with HIV due to anticipated HIV judgment based on sexual and risky behavior (DeSanto et al., 2023, p.4). This co-influencing of the stigmas, or double stigma, was not explicitly mentioned in the interviews with participants in this study. However, the comparisons made between the two diseases support the idea that HIV-related stigma may be currently controlling the stigma associated with TB, a disease that is often comorbid with HIV/AIDS.
In the contemporary context of HIV as an early death sentence, there was a consensus among my participants that HIV is no longer regarded with indiscriminate fear due to its association with death. In fact, 97% of my participants believed that HIV is not associated with early death. Participants like Participant 30 and other literature like Mall et al. attributed this decrease in death-associated fear to the more accessible educational sources and the national ARV roll-out for HIV/AIDS over the years (Mall et al., 2013, p.194). The prevalence of ARV accessibility and education during the lifetime of currently living South Africans have for the most part dispelled the misinformation that HIV is an automatic death, especially as HIV/AIDS treatment became an integral part of South African public clinics. It is reasonable to generalize that the fear of non-sexual transmission is no longer guided by the notion of fatality in current times, but rather by remnants of the fear as passed down from or held onto by older South Africans who have lived in times when there was intense interpersonal distancing from PLWH. This explains why older women, like Participant 16, still firmly believe in the fatality of the disease when talking about HIV/AIDS. The fear of HIV as an early death sentence is the one form of stigma that can be confidently described to have decreased drastically in South Africa as of 2023 due to the introduction of HIV/AIDS treatment and education in public clinics.

5. Sexual and Moral Judgment

Findings

23 of the 32 participants stated that previous and current stigma around HIV/AIDS was and is associated with promiscuous or risky sexual behavior. Especially in the 1990s and early 2000s, older participants recalled the moral implications of the disease to be particularly strong. Although the participants in their 50s+ could not recall a specific year or time when they learned that HIV was primarily transmitted through sexual contact, participants stated that people learning about HIV’s sexual mode of transmission made the disease “shocking,” “shameful,” or “embarrassing” (Participant 2, 2023 April 11). One participant, a 73-year-old woman, stated: “It was a shocking thing. Because the way how you get AIDS or HIV, it's sex. You know, it's not something that you just pick it from, you know, you have to sleep with someone and then you get HIV. So, it was an embarrassing thing” (Participant 12, 2023 April 6).
The most frequently used terms to describe the moral underpinnings of HIV-related stigma in association with sexual behaviors were: “sleeping around” (22 times), “naughty” (14 times), “prostitution” (8 times), “ill-behaved” (6 times), “irresponsible” (6 times), “bitch” (4 times) and “risky” (3 times). The term, “bitch,” as defined by Participant 1, aged 24, in the context of HIV/AIDS, has the meaning of “prostitutes, or people who slept around” (Participant 1, 2023 April 4).

The close association between prostitution and HIV/AIDS was particularly noted during the interviews with the participants in their 50s+, during which 8 of the 16 participants made an association with the topic of prostitution. Participant 2, a 66-year-old woman, commented upon the mining labor system under the apartheid government, during which men would leave their families for the mines and “they would want a quick fix so they would go to these prostitutes and buy, and then take those diseases back to the homesteads” (Participant 2, 2023 April 11). Participant 2 alluded to the rise of prostitution under apartheid as one reason why HIV/AIDS became so prevalent in South Africa. When asked to elaborate upon HIV/AIDS’s link to prostitution, most older participants utilized logic as the basis of most explanations. Participant 20, aged 52, referred to the absence of accessible condoms to justify the prostitution belief: “…when you're prostituting, nobody, wears these condoms things. I don't think they were introduced by the time HIV started. People didn't know if they got infected by the prostitute when they are doing their business” (Participant 20, 2023 April 11). On the other hand, Participant 2 used the high number of sexual partners of prostitutes to justify the claim: “…prostitutes would sleep with five or four men a day, in a week in a month. Those numbers increase. So obviously the chances of you contracting those types of diseases are much higher than other people with like a husband and one partner” (Participant 2, 2023 April 11).

As someone who was diagnosed with HIV in 1998, Participant 2 stated that she “always kept it to myself” to avoid being labeled as a prostitute by others. Participant 2, aged 66, stated, “I didn't want to be called names like those. It wasn’t until I went to a doctor and clarified everything for me, that it’s not that. Because I wasn’t a prostitute. I was married and had recently lost my husband.” When she decided to tell her mother about her diagnosis a week later, Participant 2 was met with confusion as to how she could have HIV because “I was married and wasn't sleeping around with any men.” She noted that she kept her HIV status to herself and only her family for the next few years due to the stereotype tightly associated between HIV/AIDS and prostitution.
For 14 out of 16 participants in their 20s, however, prostitution was and is not commonly associated with PLWH. Participant 25, aged 29, reacted with surprise when asked about the stereotype of prostitutes getting HIV/AIDS. She stated, “Aybo, I’ve never heard of that. Anybody who has sex can get HIV. It’s for everyone.” (Participant 25, 2023 April 18).

In 2023, for 25 of 32 participants regardless of age, moral judgment is “still there but less so” (Participant 1, 2023 April 3). Of those who explicitly denied “naughty behavior” as playing a large role in current stigmas, more young participants (5 participants) than older participants (2 participants) denied the moral implications underlying HIV/AIDS stigmas. Participant 3, aged 23, stated: “It's more than just one’s sexual choices. Some people believe that you get HIV because of how you've been carrying yourself. So being overly sexually active, whatever the case may be. But really, one can be born with the disease, one can attain the disease from being raped.” 15 of 32 participants mentioned alternative ways of receiving HIV/AIDS besides sexual contact. This included being born with HIV (10 times), rape (8 times), contacting the blood of PLWH while helping them (6 times), and vehicle accidents (2 times). Although many indicated that knowledge regarding HIV/AIDS transmission beyond sexual transmission has increased significantly since the 2000s, both participants in their 20s and their 50s+ stated that moral judgment is still the main driver of most current gossip surrounding HIV/AIDS.

Analysis

The second wave of HIV-related stigma that appeared in South Africa shortly following interpersonal distancing was the symbolic stigma based on negative moral judgment. 72% of the participants in my study, of both age groups, agreed that morality played or currently plays a large role in HIV-related stigma. The sexual and moral judgment associated with HIV/AIDS has been well-documented in South Africa and has been readily established in the literature. Based on Gilbert (2016), in the context of a traditional South African culture, the knowledge of HIV/AIDS as a primarily sexually transmitted disease created great dissonance in the public view of HIV/AIDS (Gilbert, 2016, p.3). Multiple participants in my study attested to this as they recalled feeling shocked or embarrassed after learning of HIV’s sexual transmission. Particularly within the setting of Cato Manor, values of virginity and female chastity embedded within the traditional Zulu culture added another layer to the previous stigma associated with the fatality of HIV/AIDS (Conversation with Eliza Govender, 2023). There then arose a culture of blame: a broad assumption that
contracting HIV was the result of moral decisions or choices. Although no studies have directly compared HIV/AIDS stigmas to stigmas surrounding other sexually transmitted diseases in South Africa, researchers like Gilbert have found a consistent link between the idea of sexual transmission and the shaming of the infected. This suggests that diseases that are associated with sex in South African culture may inherently invite stigma, most likely due to a cultural Zulu value of delayed sexual debut for young women. Changing the South African culture itself, however, is a long and gradual process, and this sheds light on why there continues to be persistent sexual and moral judgment associated with HIV/AIDS.

When analyzing the change in sexual and moral judgment over the years, my study found that moral judgment has significantly decreased for 78% of my participants, with seven participants explicitly denying the role of morality in current HIV-related stigma. These findings were not isolated to Cato Manor because similar results arose in other studies on HIV stigma, including Visser (2018). In Visser (2018), a significantly lower number of respondents in 2016 than in 2004 agreed with survey statements that morally or sexually shamed PLWH including statements such as, “Getting HIV is a punishment for bad behavior” (Maretha J. Visser, 2018, p.736). The findings from Visser alongside my study point toward a pattern of decreasing sexual and moral judgment regarding HIV/AIDS in South Africa. The decrease can mainly be attributed to a growing public consensus that HIV/AIDS is not a straightforward case of moral decisions. Instead, many South Africans have become aware of alternative situations, such as rape and being born of HIV/AIDS, where a person would not actively have a choice in contracting their disease. My participants, for example, repeatedly named four different alternatives for contracting HIV/AIDS besides risky sexual behavior as reasons why blame should not casted upon the PLWH for their disease. The increased knowledge of other alternatives links back to the rise of in-depth HIV/AIDS education in schools and clinics since 2000 – education that includes teaching about the different methods of HIV transmission. Taken together, there appears to be a significant decrease in South Africans who make an automatic association between an individual’s sexual or moral choices and their status of HIV/AIDS.

However, I cannot go as far as to state that moral and sexual judgment does not have any stake in the contemporary HIV stigma in South Africa. Even in Visser (2018), no respondent completely denied the association between morality and HIV/AIDS. There is still stigma that corresponds to blaming PLWH for their sexual and moral behavior. As further seen in my study, the seven words used by my participants to describe the moral judgment of HIV-related stigma – sleeping around, naughty, prostitution, ill-behaved, irresponsible, bitch,
and risky – were all correlated with casting blame and/or shame upon the infected individuals for acting or behaving in a certain sexual or moral manner to contract HIV/AIDS. The active use of these seven words in describing the contemporary HIV-related stigma suggests that moral blaming continues to impact PLWH in 2023, although to a lesser extent than previously.

In looking at the association between prostitution and HIV/AIDS, a higher percentage of participants in their 50s+ (50%) referred to the association than their younger counterparts (19%). This difference was attributed to the direct experiences of the older participants who lived much longer under the apartheid government. Bell et al. (2022) described how apartheid’s racist policies restricting economic and occupational opportunities for Black women created gendered poverty in Black and Colored communities (Bell et al., 2022, p.1-2). The economic exclusion of Black women created a rise in transactional relationships and sex work that disproportionately affected the HIV incidence rate in Black women. This triangulated the fact that older women in their 50s+ who lived under apartheid recalled the strong ties between prostitution and HIV/AIDS. In particular, Participant 2’s fear of being called a prostitute confirmed that the ties between prostitution and HIV deepened the moral stigma attached to the disease. The contemporary correlation between prostitution and HIV/AIDS has weakened since the apartheid. According to Stone et al. (2021), prostitution and sex work contributed to only 6.9% of the HIV incidence rate in 2019, with the majority of new incidence cases coming from non-transactional sex scenarios (Stone et al., 2021, p.1). Combined with the 69% of my participants who did not associate HIV/AIDS with prostitution, it can be assumed that prostitution no longer plays a significant role in the moral stigmas underlying HIV/AIDS. The significant decrease in HIV/AIDS amongst sex workers is likely due to the increased public education about HIV/AIDS and free access to PreP and ARVs at public clinics.

**Judgment of Negligence**

6. **Negligence within Newly Infected PLWH**

*Findings*

With greater education and prevention methods, the stigma associated with HIV/AIDS has now changed towards one of blame for negligence for those who are currently
being infected with HIV. This was a view that was held by participants of both age groups, but a greater number of participants in their 20s (11 participants) made a reference to it than participants in their 50s+ (6 participants). Participant 28, aged 28, stated: “It's basically negligence. Negligence. It might be something that you need to blame yourself for it because… You are educated about it, but you chose to ignore it” (Participant 28, 2023 April 18). The sentiment of negligence was echoed in other interviews with participants, including the following:

Participant 31, age 21: “We will judge him or her. We will say he or she got it on purposefully. Because there are condom distributed everywhere. There is PreP at the clinic so he or she must prevent himself or herself” (Participant 31, 2023 April 18).

Participant 19, age 25: “You get it by choice now. You get it by choice. You have to think something for yourself whenever you're having unprotected sex. If you take your partner for the test, then you can sleep without using condom. But then it's also not safe at the same time because you wouldn't know if you can trust that person” (Participant 19, 2023 April 11).

Participant 3, age 23: “It goes beyond age. They have this thing of saying that if you have HIV, it related to your sexual choices. You're getting what you deserve because you weren't being sexually safe or cautious” (Participant 28, 2023 March 31).

Participant 8, age 52, noted: “In this day and age, in the 21st century, there’s a lot of information in social media and clinic. The government is trying their best to give us protection and give awareness, campaigns and all that stuff. That’s why it’s so questionable in this day and age, like how you even got HIV.” “They get HIV out of ignorance because they know that there is protection. But still, they decide to have unsafe sex. But before, we didn't have any information about condoms and stuff and other options like PreP...” (Participant 8, 2023 April 4).

Within the older generation, there was less of a consensus that negligence plays a role in HIV/AIDS stigma. As several participants in their 50s+ have pointed out other factors that play a role in people who are infected with HIV today. One participant, a 73-year-old woman, lamented the high youth unemployment rate in Cato Manor and connected its effects on young women selling their bodies and contracting HIV. She stated, “They need money.
They will mess around with their lives and at the end of the day they will get this AIDS because they are desperate” (Participant 12, 2023 April 6). Another participant, a 58-year-old woman, pointed out a belief in Zulu culture that “sex is more enjoyable without protection,” thereby exponentially increasing the chances of HIV infection (Participant 30, 2023 April 18). This belief was more firmly held by men, as stated by Participant 2. Participant 2 commented that men will often make excuses for not using condoms including that it's “… it’s too small or too tight. Things like that. I wouldn’t know because I [don’t] use it. I guess it's just the way of their mentality.”

For Participant 1, aged 23, the question, “How did you get it?” was a question often asked to shame her. When she was first diagnosed with HIV, Participant 1 recalled healthcare workers and other patients at the Cato Manor clinic repeatedly asking her this question. She stated, “It’s more especially the tones. How did you get it? [Said calmly]. How did you get it? [Said in a lower tone with squinted eyes]. The tones are different. One comes with stigma and the other one comes with sympathy.” Participant 1 elaborated that from the perspective of PWLH, the question felt “Like you are questioning me. Also judging me. Like you probably deserved it, you know?” In the 6 months following her initial diagnosis, Participant 1 faced a period of intense denial and self-shaming due to this pervasive judgment of negligence. “Like how did I put myself in a situation?” Even after deciding to start ARV treatment, Participant 1 chose not to disclose her status to anyone beyond her mother and grandmother for 3 years because she had witnessed the detrimental impacts of the current HIV/AIDS stigma on other PLWH her age. She commented, “Young people have died in Cato Manor by suicide. Because of a friend who told another person, now the whole area knows. A girl decided to commit suicide. There was cyberbullying. Like postings of who has HIV and how they got it. I’ve seen it happening to people.” Participant 1 indicated that her reasons for initially not disclosing her status to the community were most likely similar to others her age who test positive for HIV but choose not to share their status.

When dealing with the judgment of negligence from others, Participant 1 conveyed her desire to clarify that for some people, negligence plays only a small role in why a person may get HIV/AIDS. She stated, “But that wasn’t the case for me. I met somebody, we fell in love, he didn’t tell me and then I got it. I was sleeping with one person, and he was not open enough or he did not know at that time.” Participant 1 stated that overcoming this and other judgments related to HIV/AIDS has more to do with the PLWH’s “toughness” than it does with trying to stop the judgment from happening. She commented, “I mean, you can’t rely on people. Let’s start there. You already got it, you need to learn to adapt… You’re positive, but
you're not going to die.” Furthermore, Participant 1 noted that by being surrounded by “people who are always willing to learn and understand,” By surrounding oneself with people who are open to learning, PLWH can correct any misconceptions about HIV/AIDS and thereby not allow negative stigma and false stereotypes among their peers and family to impact the quality of life for PLWH.

Analysis

The third wave of stigma I found in my study was the judgment of negligence. The judgment of negligence, as defined in my study, is the blame people cast upon PLWH for contracting the disease despite the prevention, education, and intervention available to them. It is the generalization that PLWH, particularly of young age, contract HIV/AIDS because of their active choice to not listen or use the resources assumed to be readily available to them. This judgment disregards any alternative scenarios of contracting the disease due to non-consensual sex, peer pressure, a lack of accessible condoms, malfunctioning of preventative measures, or sexual partners who are dishonest about their HIV status. This judgment was distinct from other previous types of stigmas, including fear of casual transmission or moral judgment, due to its unique contextualization within the 2010s and 2020s, during which there are abundant HIV/AIDS educational campaigns and affordable preventative measures.

It is important to note that in the interviews, the word “ignorant” and “negligent” were often used interchangeably. While the two words hold different meanings – of which “ignorant” refers to not having access to relevant knowledge and “negligent” refers to having access to facts but choosing not to utilize them – the word “negligent” was determined to be the more appropriate word, as all interviews using either of the words referred to people who intentionally made certain choices despite their knowledge or education.

In my study, the judgment of negligence came much more from the participants in their 20s than in their 50s. In fact, 68% of the participants in their 20s either agreed with the judgment of negligence or stated that they had either witnessed or heard about the judgment. On the other hand, only 37% of the participant in their 50s+ agreed with or perceived this form of stigma in the Cato Manor community. The greater percentage of participants in their 20s who have engaged or witnessed this judgment indicates that the judgment of negligence may be exacerbated by younger rather than older generations within the community. Furthermore, the judgment was specifically targeting young women who have recently been
diagnosed with HIV/AIDS, which enhanced the idea that this judgment is peer-led and used to exclude young PLWH from people within their age group.

I performed a public health literature search for the judgment of negligence, using a combination of keywords including negligence, ignorance, judgment, refusal to listen, PLWH, HIV stigma, and South Africa, and I produced only one result that spoke directly to a new judgment of negligence in South Africa. This result was the commentary by UNAIDS Executive Director Anthony Lake in a feature story in 2011, during which he stated: “For many young people HIV infection is the result of neglect, exclusion, and violations that occur with the knowledge of families, communities, and social and political leaders” (Convention on the Rights of the Child, 2015). Neglect, as used in the commentary, is a word that is often used interchangeably with negligence. According to Oxford Dictionary, the main difference is that neglect refers to “an instance” while negligence refers to “a habit or trait.” Lake’s attribution of neglect as one of the reasons behind the high HIV incidence rate in young female populations confirmed a public view that negligence was attributed to young PLWH. Comments such as Lake’s contribute to the third wave of stigma, the judgment of negligence, that falsely generalize newly infected PLWH as being negligent for becoming infected within a time of highly accessible education and prevention strategies. However, without further studies on the emergence of this judgment of negligence in South Africa, more cannot be concluded on this topic. Most likely, very few health workers or researchers would publicly call the behavior of someone who has acquired HIV “negligent” because this judgment will add to the stigma. It seemed that negligence is something that was frequently spoken about rather than written about.

7. Anti-Stigma Education

Findings

When asked about what makes the difference between a person who currently judges PLWH and a person who doesn’t judge, 31 of the 32 participants stated that it depended on how “educated” or “learned” the person was. Participants described that education could come from many different places in Cato Manor, including schools, clinics, the internet, community programs, and at home. Participant 2, aged 66, recalled the way education regarding HIV/AIDS slowly improved within the three generations of females in her family in Cato Manor. In describing her age group, Participant 2 stated:
It was difficult for me when growing up to even speak about HIV. Then it became a little bit better when it was my daughter's generation because that's when they started gradually talking to students about HIV and unplanned pregnancy and things like that. Now in granddaughter’s generation, people are being educated on TVs and media. We get it on our phones and our TVs and things like that. (Participant 2, 2023 April 11).

For participants in their 20s, life orientation and clinic were mentioned most frequently as the primary mode of youth education for HIV/AIDS by the people in their 20s. One participant, a 25-year-old woman, elaborated, “At school, we had a course, life orientation, where we started learning about HIV, TB, all those kinds of things” (Participant 19, 2023 April 6). Three participants in their 20s mentioned attending workshops with a non-profit called Love Life, which focuses on “educating young girls about HIV and AIDS” (Participant 3, 2023 March 31). However, some young participants stated that school and clinic education was simply “not enough” to fully understand and decrease the stigma around HIV/AIDS. For example, Participant 13, aged 28, stated that at school, “Most of the time, me, I was busy doing sports, so I didn’t have time or interest for it.” Thus, she stated that she never fully understood HIV/AIDS. Social media was the third most frequent answer for sources of education for the youth. For Participant 19, aged 25, social media sites like YouTube, Instagram, and TikTok were places where “I've learned for myself… Symptoms of getting HIV, how we should treat people, when you have it what you should do, the things that you shouldn't do. That it’s not a bad thing.” She recalled changing her mind drastically after watching Instagram influencers living normal lives after being diagnosed with HIV because “they look and act like us” (Participant 19, 2023 April 6).

For participants in their 50s+, HIV information dispersed in the clinic and direct experiences with PLWH were the most frequent answers to where they got their knowledge of HIV/AIDS. One participant, a 63-year-old woman, elaborated that older individuals coming into the clinics for other chronic illnesses like diabetes and high blood pressure were often “taught about HIV/AIDS while waiting to see a doctor” (Participant 29, 2023 April 18). Furthermore, most participants in their 50s+ recalled having a neighbor, friend, or family living with HIV/AIDS and learning about their condition through watching or talking to them.

Participant 1, aged 23, stated that having direct exposure to someone living with HIV/AIDS in their family or friends makes “a huge difference” in how they perceive PWLH. She noted that when talking about HIV/AIDS with people who have had direct exposure,
they are often “more understanding, compassionate about it” rather than those who do not. This is because “family members often influence a lot of conversation and a lot of stereotypes. And school sometimes isn't enough to change that because they are not family.”

Participant 1 went on to highlight the importance of being able to humanize HIV/AIDS through direct exposure to PLWH as a way to combat HIV-related stigma as it fosters “more openness and willingness to learn or be corrected.” Another participant, Participant 23, aged 28, agreed with Participant 1 in that having personal and direct relationships with PLWH creates a long-lasting impact on how those individuals contribute to the HIV/AIDS stigma. Participant 23 stated, “If you expose yourself to people living with HIV, especially family, you get education that can change you” (Participant 23, 2023 April 18).

**Analysis**

Eliza Govender from the University of KwaZulu-Natal (2023) stated that the major sources of HIV/AIDS education for South Africans were clinics, schools, and online platforms. These were the three most frequent sources of education mentioned by participants in their 20s in my study. In the clinical setting, participants in both age groups stated that they engage in conversation with healthcare workers who relayed in-depth knowledge about HIV/AIDS. This was triangulated by Govender, who explained that one of the first actions taken by the government was the dispersal of HIV/AIDS information in community clinics through programs like She Conquers and DREAMS (Conversation with Eliza Govender, 2023). Although none of the participants specifically mentioned engaging with She Conquers or DREAMS at the Cato Manor clinic, participants in both age groups were able to recall witnessing or participating in other clinic-led programs on HIV/AIDS. A national rise of clinic-based HIV/AIDS education was evident in my study’s findings and triangulated by Govender. While it cannot be generalized that all local clinics in South Africa engage in HIV/AIDS education, it is very likely that most clinics in peri-urban and urban townships engage in some form of health promotion regarding HIV/AIDS due to the sheer number of programs and campaigns that have been in place since 2004. The multiple ways of being exposed to in-depth HIV/AIDS knowledge further explain the overall decline in HIV-related stigma seen in South Africa.

At school, the official South African curriculum of the class, Life Orientation, contains a section during which teachers inform students of HIV/AIDS and sexual health education (Conversation with Eliza Govender, 2023). Although the exact content of the
HIV/AIDS information taught was not publicly available, the sexual health education implemented as part of the curriculum triangulated my participants’ mentions of school as a main source of obtaining HIV/AIDS education. Most of my participants in their 20s stated that the Life Orientation course on HIV/AIDS was one of their first formal introductions to HIV/AIDS education. This was not true of participants in their 50s+ because all the participants in their 50s stated that their schooling under apartheid did not contain any information about HIV/AIDS. Under apartheid, Life Orientation did not exist and thus, the vast majority of participants in their 50s learned about HIV/AIDS not through schooling but through the clinic or by talking within the community. Furthermore, for participants in their 20s, after-school programming with non-profits like Love Life fostered a second interaction with HIV/AIDS education. Three participants in their 20s directly connected their knowledge of HIV/AIDS to their active participation in Love Life afterschool sessions. Overall, school and after-school programming have emerged as a major source of HIV/AIDS knowledge for South African youth following apartheid. The increased exposure to the topic of HIV/AIDS may be helping to normalize the topic among South African youth, contributing to the steady decline in HIV-related stigma among young women in South Africa. However, as mentioned by participants in my study, school-based learning about HIV/AIDS is “not enough” to completely combat stigma amongst the youth. Hence, my participants still perceived greater stigma coming from the younger generation than older generations despite the youth’s greater exposure to HIV/AIDS education in school settings.

The increasing presence of digitalized media has created new ways of informing the public. As mentioned by Participant 19, the government has utilized media to promote television programs like Soul City that depict strategies for prevention and treatment and short-clips animations like Scrutinize that use seven recognizable community figures to encourage sexual caution. These programs, which inform the public through a combination of education and entertainment, are part of the growing field of edutainment HIV intervention within the past few years (Conversation with Eliza Govender, 2023). Participants in my study have reported the direct impacts of edutainment on their education as one participant, Participant 16, aged 54, even mentioned that Soul City is a fan favorite. Programs like Soul City become broadcasted on television screens across South African homes in an effort to depict real-life scenarios of HIV/AIDS prevention and treatment in relatable fictional South African characters. The positive impacts of digitalized media and online platforms in increasing awareness of HIV/AIDS have allowed edutainment to become an integral part of a
national effort to combat HIV-related stigma in South Africa and stop new HIV infections from occurring.

The most frequent source of education reported by my participants in their 50s+ was direct experiences with PLWH. Direct exposure and/or personal relationships with PLWH have had a positive impact on an individual’s formation of HIV stigmas. As one of the oldest residents of Cato Manor, participants in their 50s+ were firsthand witnesses to the exponential rise in PLWH in the late 1900s and early 2000s and recalled meeting at least one PLWH during their lifetime. Particularly in a smaller township like Cato Manor, many participants in their 50s+ noted how the small size and multiple family lineages within the community allowed community members to regularly interact with PLWH, primarily since many PLWH were close family or family friends. Older Black South African women in their 50s+ beyond Cato Manor are similarly likely to have family members in their immediate or extended family or be closely linked to someone in their community who are or were PLWH. The frequent mentions of direct contact and association with PLWH among older women may further explain why most participants perceived less stigma in older women than younger women in Cato Manor. Given another close-knit township within South Africa, similar findings of frequent contact with PLWH and decreased stigma can be anticipated.

The positive influences of having direct exposure to PLWH is the basis of contact-based de-stigmatization counseling, which has “…emerged as one of the more promising strategies” for HIV/AIDS intervention (Shiyanbola et al., 2021, p.797). In contact-based counseling, consenting PLWH are brought into the scene to engage in dialogue with the counselee about their experiences living with HIV. Rao et al. (2018) stated there are three clear benefits of social contact between community members and PLWH (1) providing an opportunity to dispel misinformation, (2) generating empathy for affected individuals, and (3) humanizing the disease. In Participant 1’s interview, she commented upon each of the three benefits. The contact creates a “willingness to…be corrected” (dispel false information about HIV/AIDS) and the person to be “more understanding, compassionate” (humanization of disease and empathy towards PLWH). The benefits of contact-counseling as evidenced by Participant 1’s statement in my study and Rao et al. (2018) suggest that a movement towards the use of social contact with PLWH may be extremely effective in de-stigmatize HIV/AIDS within communities of South Africa. This may be a push that can serve as the next potential national health intervention for combatting the barriers to HIV/AIDS treatment and prevention.
X. Conclusion

This study sought to explore changes, if any, in the perceptions of HIV/AIDS-associated stereotypes and stigma between two age groups of females, in their 20s and 50s+, in Cato Manor, South Africa. In general, across all stigma types, participants reported perceiving a decrease in HIV-related stigma in Cato Manor since the start of the HIV pandemic. This was consistent across both age groups, with older participants in their 50s+ portraying a more drastic change in stigma than the younger participants in their 20s. The trend of decreased HIV-related stigma was not isolated to this study, as multiple studies of recent stigma change have also confirmed a general decline in the intensity and pervasiveness of HIV/AIDS stigmas in peri-urban and urban locations of South Africa. Upon closer examination, however, the data indicated that there are multiple threads of changes occurring simultaneously, and the blanket statement of “decreased HIV stigma” does not sufficiently cover the nuances of the changes occurring within the three waves of stigma. The waves of stigma in chronological order of their emergence in South Africa are the fear of non-sexual transmission, sexual and moral judgment, and judgment of negligence. Specifically, my study’s data suggested that the first two waves of stigma, fear of non-sexual transmission and sexual and moral judgments, have decreased drastically over the years, particularly among the older age group of women. However, a third new wave of stigma, the judgment of negligence, has emerged as a dominant manifestation of HIV-related stigma that comes mostly from younger women and impacts newly infected PLWH in 2023.

Fear of casual or non-sexual transmission has decreased significantly within both age groups. This fear was one of the earliest forms of stigma related to HIV/AIDS and served as the root cause of contact fear and interpersonal distancing against PLWH. Since the 2000s, however, most participants regardless of age have reported decreased interpersonal distancing and increased physical contact with PLWH within the Cato Manor community. Education served as the most frequent reason for this change in stigma, and this is further triangulated in other studies relating access to in-depth HIV/AIDS education and HIV stigma. Educational access to HIV/AIDS information and sexual health seemingly had a significant impact on dispelling the public fear of non-sexual transmission of HIV/AIDS in South Africa. Given that some participants in their 20s shared concern about older generations not having similar access to education, this finding suggests that a greater focus on educating and dispelling misinformation about HIV/AIDS for South Africans in their 50s+ may help decrease any residual fears of causal transmission in that age group. The conversations with the two
PLWH in the study further supported this suggestion, as both indicated the importance of all generations having access to HIV/AIDS knowledge in combating ongoing stigmas.

Compared to the fear of non-sexual transmission, sexual and moral judgment has also decreased in the Cato Manor community but to a much lesser extent. Well over half of the participants perceived that stigma around HIV and sexually promiscuous behavior has decreased in their lifetime, and there was a much weaker association—if any—made between prostitution and HIV/AIDS in the younger participants than in the older participants. However, this form of judgment continues to control much of the gossip mill and rumors in Cato Manor, particularly amongst other young women.

Lastly, a new type of stigma – the judgment of negligence – emerged within a majority of the interviews conducted during this study project. As Participant 28 eloquently put it, this new stigma is based on the idea that “You are educated about it, but you chose to ignore it.” This judgment contained a similar culture of shaming as found with sexual and moral judgment, but the source of blame was not the sexual immorality of a person but the inaction of the person to take protective measures against HIV/AIDS despite their education on HIV prevention. Negligence as the reason for contracting HIV/AIDS came up more frequently amongst participants in their 20s than their 50s+, which further indicates that this form of stigma is relatively new and potentially more prevalent among the young adults of South Africa. Given the lack of direct research on the concept of negligence in HIV-related stigma, however, no generalizations can be made beyond a strong suggestion for further research on this phenomenon.

The changes in the types and forms of stigmas found in this study – whether it is the decreasing moral judgment or the emergence of a new type of judgment – indicate that HIV-related stigma is a topic that must continue to be studied and examined. The topics cannot be simply ignored and or labeled as resolved because novel insights into stigma changes continue to be discovered. As evidenced by the interviews with Participants 1 and 2, HIV-related stigmas have the capacity to impact the lived experiences of PLWH in both age groups. This can include the PLWH’s choice to disclose HIV+ status and their feeling of acceptance or “othering” among their peers. The benefits of a multigenerational approach to monitoring and addressing HIV/AIDS-related stigma include a greater understanding of the smaller and nuanced changes in stigma and the development of potentially new stigmas that have evolved in recent years. Close monitoring of stigma changes through generational or longitudinal models will further help demonstrate the effectiveness of anti-stigma interventions and therapeutics that address age-appropriate and age-dependent stigmas within
the different generations of South Africans. Having a firm understanding of how certain stigmas play a role in different age groups will aid healthcare workers and practitioners in better accommodating the lived experiences of HIV/AIDS stigma that different-aged patients face in their everyday. The HIV stigma interview guides curated as part of this study project can be further utilized in other studies of HIV stigma to include a generational focus as a vital design element.
XI. Recommendations for Further Study

A recommendation for a topic of further study would be on the new form of stigma that was commonly identified in the study project: the judgment of negligence. In this study project, this stigma appeared to be a common phenomenon as more than half of the participants (53%) mentioned negligence as part of their conversations about contemporary HIV-related stigma. This judgment, as described by the participants, focuses on casting blame upon young adults who contract HIV despite the vast public access to HIV/AIDS preventative techniques and knowledge. The reasons why communities judge people, especially young women, as negligent and if the same judgment is cast upon young males need to be further studied. In addition, the impact of this stigma on the lived experiences of PLWH will greatly benefit from more in-depth analysis, as the extent of the actual impact of this stigma on PLWH is unknown.

Another recommendation is to perform a similar exploratory, multigenerational study in a purely PLWH population. This study project was restricted in its inclusion of PLWH because the researcher did not have access nor clearance to work with a large PLWH population, such as an HIV clinic, to perform this study. Given the opportunity to collaborate in such a setting, this study will benefit from having the full opinions and experiences of multiple PLWH who directly feel the impact of the stigmas surrounding their disease. A new study focused on understanding the different ways HIV-related stigmas and changes in the stigma can hold real-life consequences for PLWH will serve as an important milestone in research, as the results of the study can potentially point to a new direction in intervention and care for PLWH. Particularly with the continued focus on multigenerational exploration, further studies on the topic of HIV stigma may result in better catering of health services for the different-aged groups of PLWH.
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Participant 5, 53-year-old female, (2022, April 3), Personal Interview. (M. Cho, Interviewer)
Participant 6, 67-year-old female, (2022, April 3), Personal Interview. (M. Cho, Interviewer)
Participant 7, 54-year-old female, (2022, April 4), Personal Interview. (M. Cho, Interviewer)
Participant 8, 52-year-old female, (2022, April 4), Personal Interview. (M. Cho, Interviewer)
Participant 9, 24-year-old female, (2022, April 4), Personal Interview. (M. Cho, Interviewer)
Participant 10, 26-year-old female, (2022, April 4), Personal Interview. (M. Cho, Interviewer)
Participant 11, 60-year-old female, (2022, April 4), Personal Interview. (M. Cho, Interviewer)
Participant 12, 73-year-old female, (2022, April 6), Personal Interview. (M. Cho, Interviewer)
Participant 13, 28-year-old female, (2022, April 6), Personal Interview. (M. Cho, Interviewer)
Participant 14, 21-year-old female, (2022, April 6), Personal Interview. (M. Cho, Interviewer)
Participant 15, 29-year-old female, (2022, April 6), Personal Interview. (M. Cho, Interviewer)
Participant 16, 54-year-old female, (2022, April 6), Personal Interview. (M. Cho, Interviewer)
Participant 17, 58-year-old female, (2022, April 6), Personal Interview. (M. Cho, Interviewer)
Participant 18, 20-year-old female, (2022, April 6), Personal Interview. (M. Cho, Interviewer)
Participant 19, 25-year-old female, (2022, April 11), Personal Interview. (M. Cho, Interviewer)
Participant 20, 52-year-old female, (2022, April 11), Personal Interview. (M. Cho, Interviewer)
Participant 21, 22-year-old female, (2022, April 11), Personal Interview. (M. Cho, Interviewer)
Participant 22, 25-year-old female, (2022, April 11), Personal Interview. (M. Cho, Interviewer)
Participant 23, 28-year-old female, (2022, April 18), Personal Interview. (M. Cho, Interviewer)
Participant 24, 70-year-old female, (2022, April 18), Personal Interview. (M. Cho, Interviewer)
Participant 25, 29-year-old female, (2022, April 18), Personal Interview. (M. Cho, Interviewer)
Participant 26, 59-year-old female, (2022, April 18), Personal Interview. (M. Cho, Interviewer)
Participant 27, 67-year-old female, (2022, April 18), Personal Interview. (M. Cho, Interviewer)
Participant 28, 28-year-old female, (2022, April 18), Personal Interview. (M. Cho, Interviewer)
Participant 29, 63-year-old female, (2022, April 18), Personal Interview. (M. Cho, Interviewer)
Participant 30, 58-year-old female, (2022, April 18), Personal Interview. (M. Cho, Interviewer)
Participant 31, 21-year-old female, (2022, April 18), Personal Interview. (M. Cho, Interviewer)
Participant 32, 65-year-old female, (2022, April 18), Personal Interview. (M. Cho, Interviewer)
Participant 21, 22-year-old female, (2022, April 19), Personal Interview. (M. Cho, Interviewer)
Appendix A

Interview Guide 1: for Participant 1 and Participant 2

To be written and verbally said to participants prior to interview: All answers will be treated as confidential and anonymous, so any identifiable details or characteristics will not be recorded or written to protect your identity. Please feel free to not answer any questions that you are uncomfortable answering. You may stop the interview at any time. You are also welcomed and encouraged to ask the same questions of the researcher.

1. Tell me about your journey with HIV … start at the beginning.
2. Can you tell me about the counseling and testing when you first got told you had HIV?
   a. Was the nurse or counselor nice or judgmental to you? How did you feel?
3. Can you tell me about the first few days after you heard you must live with HIV?
   b. How did you feel?
4. How long did you keep it to yourself? What made you think you must keep it secret?
5. Who did you choose to tell first? Can you talk about how you felt deciding who to talk to and when to tell them?
6. What made you decide to be careful who you told your status to?
   a. Another way to phrase this: What things were you afraid of when thinking about telling others about your status?
7. Did you hear any stories about bad things happening to people who told others about their HIV status?
   a. Can you tell me these stories you heard?
8. Have you thought about disclosing to a group of people about your HIV status… maybe your church, neighbor, stokvel or a local HIV support group?
   a. Tell me if you’re worried about disclosing to a group and why, perhaps, you’re worried?
9. Did you ever wear a HIV+ T-Shirt and join other women walking in the neighborhood telling people they have HIV?
   a. If so, when?
   b. What changed to make this possible or what is it that makes this too difficult to do?
10. Do you think stigma is the same now as it was when you first knew you have HIV?
    a. What things have happened to perhaps make people have less stigma to HIV?
    b. Can you think of things that helped change stigma?
    c. If so, when did these things happen or has there been just a slow change?
11. How is it now talking with me about HIV?
12. What must I understand about stigma?
13. Is there anything else you’d like to add? Thank you!
Appendix B
Interview Guide 2: for participants in their 20s and 50s+, excluding Participant 1 and 2

To be written and verbally said to participants prior to interview: All answers will be treated as confidential and anonymous, so any identifiable details or characteristics will not be recorded or written to protect your identity. Please feel free to not answer any questions that you are uncomfortable answering. You may stop the interview at any time. You are also welcomed and encouraged to ask the same questions of the researcher.

Prior to start: Are you okay with me asking about how you feel about stigma? If it makes you uncomfortable, we can talk about other things.

1. If you find out a person has HIV, does that change how you feel about that person?
   a. If so, what are you feeling?
   b. If not, why not?
2. Do you think that there was or is HIV stigma in Cato Manor?
   a. If yes, when was that stigma most strong. What made people feel that way?
   b. If no, ask why not?
3. Has the amount of stigma changed?
   a. If answered with decreased stigma, follow up: Would you agree that HIV stigma has decreased within your lifetime?
   b. Were there things that made people change their minds about stigma?
   c. Was there a year that you noticed a change … if so when was it and what made that happen?
4. Where do these feelings about HIV stigma come from?
   a. Another way to phrase the questions: What things make people judge people with HIV?
5. Are you comfortable with me talking about people dying of HIV? Remember I’d like you to skip a question if it makes you feel uncomfortable.
   a. I was told that having HIV was having a death sentence. Do you or did you believe this?
   b. If your belief has changed, was there a time you realized PLWHIV can live a long life? When was that? What changed your belief?
6. I was told that HIV is punishment for bad/naughty behavior. Do people in Cato Manor think this?
   a. If yes, ask how so?
   b. If no, ask why not?
7. How do you think people in your age group (either 20s or 50s+) would react now if a close friend or family tested positive for HIV?
8. What do you think is the biggest challenge facing people living with HIV in Cato Manor today?
9. Is there anything else you’d like to add? Thank you.
**Human Subjects Review  SARB/IRB ACTION FORM**

**Ethical Clearance Form**

<table>
<thead>
<tr>
<th>Name of Applicant: MiJin Cho</th>
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| ISP/Internship Title: Intergenerational Change in HIV/AIDS-Related Stigma in Cato Manor |

| Date Submitted: 9 May 2023 |

| Program: SFH Durban Community Health & Social Policy |

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| IRB organization number: IORG0004408 |

| IRB registration number: IRB00005219 |

| Expires: 27 September 2024 |

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<th>SAR members (print names):</th>
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<tr>
<td>John McGladdery</td>
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<td>Clive Bruzas</td>
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<th>SARB REVIEW BOARD ACTION:</th>
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<tr>
<td>X Approved as submitted</td>
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<tr>
<td>□ Revise and resubmit</td>
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<th>SARB Chair Signature:</th>
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<td>Date: 10 April 2023</td>
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SARB Committee Feedback: Repeatedly remind that partners may stop if uncomfortable without penalty. Stop if body language suggests discomfort.

Form below for IRB Vermont use only:
Research requiring full IRB review.

**ACTION TAKEN:**

__ approved as submitted __ approved pending submission or revisions __ disapproved

________________________________________________________________________

IRB Chairperson’s Signature                        Date
Consent to Use of Independent Study Project (ISP)

Access, Use, and Publication of ISP/FSP

Student Name: MiJin Cho

Email Address: chom6@vcu.edu

Title of ISP/FSP: Intergenerational Change in HIV/AIDS Stigma in Cato Manor

Program and Term/Year: Spring 2023

Student research (Independent Study Project, Field Study Project) is a product of field work and as such students have an obligation to assess both the positive and negative consequences of their field study. Ethical field work, as stipulated in the SIT Policy on Ethics, results in products that are shared with local and academic communities; therefore copies of ISP/FSPs are returned to the sponsoring institutions and the host communities, at the discretion of the institution(s) and/or community involved.

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