THE STIGMATIZATION OF CHILDREN WITH HIV/AIDS IN NAIROBI, KENYA

by

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ABSTRACT

The study investigated stigmatization of HIV/AIDS children in Nairobi, Kenya. It involved eight HIV/AIDS infected children aged 7-15 years from Joseph Kangethe Primary school, with an equal mix between boys and girls from diverse ethnic groups. A qualitative approach using interview questions and a phenomenological inquiry strategy was adopted. Data from in-depth personal interviews was transcribed, coded and categorized into themes and analyzed through the post-colonial lens. Stigma was detected through what the children felt about their status and their experiences. Key themes identified were: the children experienced different psychosocial impacts, including fear, denial, shame, fear of isolation and loneliness, and trauma. They confirmed the efficacy of anti-retroviral therapy (ART). From these findings and supporting literature, the study recommends counseling facilities, provision of anti-retroviral therapy, re-conceptualized education using modern and traditional approaches, forums to discuss sexuality and HIV, home based care, community mobilization and empowerment to reduce HIV stigmatization.

Keywords: Children and HIV/AIDS, stigma, denial, shame, fear, home-based care, postcolonial theory, Kenya.

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Dedication

I dedicate this thesis to my husband Charles and to my loving children Innocent, Hope and Evence and to all Kenyans on the proclamation of a new Constitutional dispensation.

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CHAPTER ONE

Introduction

No other region has been as negatively impacted by HIV/AIDS as Sub-Saharan Africa, where HIV prevalence is higher than 15% in some countries like South Africa, Botswana, Lesotho, Namibia, Swaziland and Zimbabwe just to mention a few (UNAIDS, 2009b). Others have prevalence of above 5% (including Kenya with a prevalence of 7.8% in 2008 according to UNAIDS). UNAIDS estimated that by end of 2008, the global population of persons living with HIV/AIDS was 33.4 million, of which 22 million or 67% live in Sub-Saharan Africa, with 70% of the new infections occurring in this region (UNAIDS, 2009b). AIDS was first reported in Kenya between 1983 and 1985 amongst sex workers (AIDS Newsletter, 1986) who are still the group with the highest prevalence. Estimates of HIV prevalence among sex workers varies from 23 to 50% (Ferguson, 2004 as cited in Morris, 2007). Other groups identified to be most at risk include homosexuals, intravenous drug users (IDUs), transport workers and truck drivers (Carswell, Lloyd, & Howells, 1989).

Kenya is located in the East Coast of Africa and borders Uganda, Tanzania, Ethiopia, Sudan and Somalia. Kenya lies along the Equator and borders the Indian Ocean to the East and is named after Mt. Kenya its highest mountain and the world's eighth highest mountain. Kenya covers 580,367 square kilometers and has a population of approximately 39 million people, 42.3% (16.5million) of whom are in the 0-14years age bracket, and 22% of the population lives in the urban areas (Central Intelligence Agency [CIA] World Fact book, 2010). Kenya was colonized by the British and attained independence in 1963. Kenya has a rich diversity with 41 different ethnic groups mostly professing the Christian faith (78%) with 10% estimated to be

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following the Muslim and indigenous faiths (Central Intelligence Agency [CIA] World Fact book, 2010).

Recent GDP growth increased rapidly from 0.6% in 2002 to 6.1% in 2006. However, economic growth was negatively affected by political instability that followed the disputed presidential election in 2007 (Government of the Republic of Kenya [GOK], 2007). Agriculture is the main economic activity and the country is an important source of tea, coffee and pyrethrum. It is blessed with well known tourist destinations such as the world famous Maasai Mara game park, one of the Seven Wonders of the World, the Great Rift Valley, picturesque scenery and wildlife and receives over a million tourists a year (GOK, 2007). Her sportsmen have carved a niche in the area of middle and long distance running. The capital city of Nairobi has a population of 3 million a large percentage of whom live in informal settlements the largest of which is Kibera where most of the participants hail from.

National AIDS/STI Control Programme (NASCOP) (2009a) reported wide variations in prevalence within the country (see Figure 1, which shows HIV prevalence by province). Nyanza province has a prevalence of 15.3% whilst another North-Eastern province has a prevalence of 0.8% (NASCOP, 2009a). Prevalence is higher in urban areas at 9% compared to 7% in the rural areas and among women at 8.7%, compared to men at 5.6% (NASCOP, 2009a). There is a clear correlation between poverty and HIV prevalence levels, with the poorest province having the highest prevalence (Kenya National Human Development Report, 2006).

Sobering as these statistics are, the numbers for the children are even more so. The same report estimated that a staggering 90% of the 2 million children (under 15 years of age), living with the virus reside in Sub-Saharan Africa (UNAIDS, 2009b). Most children are infected from mother to child i.e. through vertical transmission (Rehm & Franck, 2000) and face victimization

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and marginalization (UN Committee on Rights of the Child, 2003) and severe physical, emotional and economic challenges in their day to day living (UNICEF, 2006). The Committee confirmed that AIDS affected children in diverse ways, impacting on their "civil, political, economic, social and cultural" rights and specifically on their right to non-discrimination (Article 2), survival, life and development (Article 6), the right not to be separated from parents (Article 9), to appropriate standard of living (Article 27), right to education and leisure (Article 28 & 31) and to protection against economic and sexual exploitation (Article 32 & 33). These children who face severe challenges in getting education were the participants in this research project.

Antiretroviral therapy is estimated to reach only 15% of children in need (UNAIDS, 2009b) even though treatment has proven so effective that it resulted in a 29% drop in mortality (NASCOP, 2009b), and 93% reduction in orphan hood in Uganda, a neighboring country (Mermin et al., 2008). An estimated 15 million children worldwide have lost one or both parents to HIV/AIDS and are likely to experience poverty, hopelessness and discrimination (UNAIDS/UNICEF/USAID, 2004). According to the Kenya National HIV and AIDS Estimates (2010), 184,052 children under 14 years were living with HIV/AIDS in 2009 and an estimated 22,259 children got newly infected in the same year. High as these figures appear, they are likely to be only the tip of the iceberg given the reported 1 million women over 15 years living with the virus and the low penetration of HIV testing. Kenyan Ministry of Health estimated that 83% of Kenyans living with HIV remained undiagnosed in 2007.

Stigma has been identified as a major constraint in the fight against HIV/AIDS, (Political Declaration of HIV/AIDS, 2006) in discouraging people from going for testing, accessing antiretroviral therapy (ART), discouraging adherence to treatment, promoting abandonment, and is seriously disadvantaging those affected and infected by HIV/AIDS, through increasing their

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helplessness and causing them unnecessary pain and suffering. UN Secretary General Ban Ki Moon (2008) targeted stigma as an affront to our common humanity that had the effect of driving the infection underground, where it spreads unchecked. UNAIDS Director Peter Piot (2008) concurred, and reaffirmed that stigma and discrimination surrounding HIV/AIDS remained strong. UNICEF, in recognition of the impact of HIV on children, declared 1997 "the year of children living in a world of AIDS". Various studies (Odindo & Mwanthi, 2008; Rehm & Franck, 2000) have established the prevalence of stigma; however, studies involving children are scarce (Deacon, 2008; Rehm & Franck, 2000).

The AIDS pandemic is a truly global, and persons with HIV (PWHIVs), are "stigmatized throughout the world to varying degrees" (Herek, 1999, p. 1106). They are stigmatized "through social ostracism and personal rejection of PWHIVs, discrimination against them, and laws that deprive them of basic human rights" (Mann, Tarantola, & Netter, 1992; Panos, 1990 as cited in Herek, 1999, p. 1106). Many authors including Goldin (1994), Mann et al. (1992), Panos Institute (1990) and Sabatier (1988) (all cited in Herek, 1999) concur that HIV/AIDS stigma "is effectively universal, it takes different forms" (Herek 1999, p. 1107), its specific targets "varying considerably" (Herek, 1999, p. 1107) from one country to another . Odindo and Mwanthi (2008), in a cross-sectional survey of 1331 households based in the informal settlements of Kibera, in the capital city of Nairobi concluded that 43% of the study population experienced stigma and discrimination. Anecdotal evidence such as the landmark court case in 2004 to force public schools to accept such children, suggests stigma is widespread (Lacey, 2004). There have been media reports of infected infants being abandoned or infected children killed (Dolan, 2006; Nyumbani Children's Home, n.d.), however, no systematic research has to my knowledge been conducted in this specific area.

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Stigma creates a vicious cycle, whereby the infected children fail to get education, and denies them a chance to break out of poverty (Mishra et al., 2005). Rehm and Franck (2000) noted that stigma has potential to impact on opportunities for children to get education, by hindering the child's full participation and making it difficult to achieve universal primary education. Thus stigma acts as a major barrier to elimination of poverty. This study is an important first step in documenting stigma, which has potential to impact on the achievement of several millennium development goals namely: 1) eradication of extreme poverty and hunger, 2) achievement of universal primary education, 3) reduction of child mortality, 4) improvement of maternal health, and 5) combating of HIV/AIDS, malaria and other diseases. The study's findings will inform organizations working with children, people living with HIV/AIDS, advocacy groups and policy makers on ways to mitigate stigma and its influence upon this vulnerable group, helping to ensure their continued and effective education. Given the grave statistics, the important role of stigma in the fight against HIV/AIDS, and the lack of research on stigma from a child's perspective, the author felt this was an important issue to research.

Theoretical and contextual frameworks

The theoretical framework chosen to analyze the stigmatization of children in urban areas in Kenya is postcolonial theory. It was felt that this framework was the most appropriate for illuminating the underlying issues, and the decision was partly inspired by Roseval (2007) who identified historical power structures as significant contributors to stigmatization. Treichler (1999) argued that individual and communal responses to diseases are shaped by culture and that HIV through its far-reaching individual, social and political impact is a cultural and linguistic phenomenon, in effect "an epidemic of meanings" (Treichler, 1999, p.11). Far from being a geographical perspective, post-colonialism concerns itself with how power structures influence

relations between dominant and subordinate groups in the economic, political, ideological and cultural arena (Elenius, 2008). Decolonization, Elenius argues, cannot be achieved without deconstruction of this system and the establishment of a new order. Although termed difficult to define by Young (2003) and Viruru (2005) several concepts are central to postcolonial thinking. First is the idea that institutions that help sustain colonial domination were handed over at independence to the indigenous elite groups (Young, 2003). These institutions and systems continue to perpetuate themselves and to exert immense power and influence. Secondly, it is inexorably linked to poverty, class, ethnicity, gender and to some extent racism (Loomba, 2005 as cited in Josefsson, 2006). Thirdly, it is linked to globalization, profit, Western interests, control of resources and sustenance of neocolonial status (Young, 2003), or hegemony. Fourthly, it is linked to power over resources in all its forms financial, material, and productive. Fifthly, it involves the creation of the 'other' category (Mudimbe, 1994 as cited in Chilisa, 2005, p. 660) that is defined by what it is not, for example, anything non-western is deemed uncivilized etc (Chilisa, 2005). The oppressed are systematically stripped of their identity and encouraged to become appendages of Western culture (Chilisa, 2005). The ultimate aim was to "colonize the mind" and undermine their self belief (Mudimbe, 1994 as cited in Chilisa, 2005, p. 660; Teffo 2000). Chilisa (2005) avers that colonialism accentuated the traditionally flexible gender system into an entrenched patriarchal system. Sixthly, it is related to the rejection of Western, Eurocentric perspectives and the universal, positivist approach that derives from this perspective. Seventhly, the theory calls for a considerable amount of introspection on the part of the researcher to avoid the trap of adopting the very perspectives and languages they seek to oppose. Lastly, the post-colonial thinking is an activist position seeking to bring about social transformation (Young, 2003).

Nowhere is such a system more evident than in the home environment of the children in this study. Kibera is an informal settlement area covering 250 hectares located 3 miles to the southwest of the city of Nairobi. Home to over a million inhabitants, Kibera has the dubious distinction of being the largest such settlement in Nairobi and possibly the largest informal settlement in sub-Saharan Africa. Kibera is divided into 12 villages with heavy ethnic overtones in their naming and make up. The subdivisions are a legacy of the divide and rule tactics employed by the British to control the indigenous peoples and they were so ingrained that they continue to perpetuate suspicion and even hatred between the various ethnic groups. These villages have played a prominent role in the flare-ups of ethnic clashes. Its origins have been traced to the resettlement of Nubian (Sudanese) King's African Rifles soldiers from the first World War by the British in the then forested areas, as a token of appreciation for their service to the crown because as 'de-tribalised natives' they did not qualify for land in the 'Native reserves'. Its name derives from the Nubian word 'kibira' which means 'forest' or 'jungle' and it has indeed become a veritable human jungle with a population density of over 1250 inhabitants per acre, plagued with high unemployment, crime and frequent disease outbreaks. Most inhabitants walk to the city to get casual, low paying jobs unable to afford the $0.14 fare. Through the postcolonial lens one can clearly see the creation of the 'other' category i.e. those who do not belong to the city in the dichotomy between 'jungle' and 'city'. Chilisa (2005) terms this "definitions and names relational to the colonized" (p.660). In this case, the colonizers maintained the name for a 'jungle' in an effort to make the indigenous people feel inferior and also an effort to make them aspire to sameness in the image of the colonizer.

The colonial British government ignored the haphazard developments and subsequent governments have largely followed suit. Services are virtually non-existent and residents are

forced to pay high rents to landlords, and to purchase water and other services from individuals re-selling such services. It is clear example of the perpetuation of the subjugation under colonial rule being carried forward. From the perspective of the HIV/AIDS pandemic, the residents are too poor to afford proper nutrition for the infected, and living in close quarters exposes many to risk of infection. Violence against women and the girls leads to increased risk of infection to a segment of the population that is already disproportionately affected by HIV/AIDS. Many cannot afford anti-retroviral therapy (ART) both because of high prices, and the cost of travelling to a clinic, thereby posing a greater risk to their partners (Vienna, 2010). Lack of employment forces many young girls into sex work as the only means of survival further fuelling the spread of HIV/AIDS and the stigma that arises from the association of the disease with the sex industry which the community views as an unacceptable occupation (Olenja, 1999).

Many of the children experience a double jeopardy in that superimposed on the subjugation from postcolonial influences that relegate them and their families to poverty and the periphery, they have to contend with cultural practices that oppressed children's right to express themselves. For example, poverty makes close relatives not to be able to take care of orphans as would be the case in the traditional society. This leads to loss of identity and culture for the children. In many Kenyan communities, children are traditionally not recognized or allowed to be party to any decision-making until they are initiated into adulthood through circumcision or other initiation rites. Children thus lack a forum to obtain information on or discuss sexuality (Roseval, 2007).

CHAPTER TWO

Literature Review

In examining stigma, the words of a South African High school student quoted in the Campbell, Nair, Maimane and Sibiya (2005) have a potent ring: "If you have AIDS you die twice because the first thing that kills you is being lonely, when everyone discriminates against you, even family members. The second one is the actual death" (p.8). This statement encapsulates the isolation, loneliness and discrimination that results from stigma.

Definition of Stigma

Stigma is defined as the "negative thoughts and feelings" that other people have towards an individual or a section of the society (Goffman 1963). In his seminal work, Goffman (1963) noted that stigma was caused by "an undesirable or discrediting attribute that an individual possesses" (Goffman, 1963 as cited in Brown, Trujillo & Macintyre, 2001, p.4), a characteristic or group membership which diminishes that "individual's status in the eyes of society" (Goffman, 1963 as cited in Brown et al. 2001, p.4). Such a characteristic can be a "physical deformity" (Goffman, 1963 as cited in Brown et al. 2001, p.4) such as visible symptoms of a disease, or "it can stem from negative attitudes towards the behaviour of a group, such as homosexuals or sex workers" (Goffman, 1963 as cited in Brown et al. 2001, p.4). Brown et al. stated that in the case of HIV/AIDS, it is the negative feelings towards the individual who is infected or affected by HIV/AIDS and their families. Stigma exists in the thoughts of people and their communities (Campbell et al., 2005; Treichler, 1999). Campbell et al. (2005) determined that the behavior of the people in the community such as the belief that certain behaviors which are associated with HIV/AIDS brings shame to them, makes them feel guilty about the disease,

and puts their families and the community in a disgraceful situation of being despised, and this hinders them from successfully managing HIV/AIDS.

Prevalence of Stigma

Estimated number of persons infected by HIV in Kenya is between 1.3 million and 1.6 million (KAIS, 2007; National AIDS Control Council [NACC] 2010). HIV prevalence amongst the general population in Kenya is estimated by UNAIDS to be 7.8% in 2008, having increased from 6.7% in 2003. It has been suggested that this could be due to the impact of use of anti-retroviral therapy resulting in lower mortality. The highest prevalence is to be found amongst sex workers at Majengo in Nairobi, Kenya. Studies seem to suggest that stigma is quite prevalent (Odindo and Mwanthi, 2008). KAIS (2007) found that 61% of participants either did not wish to know their results or feared others would know their status, and that 81% of those who tested positive had either not taken a test, (57%) or misreported their status, (26%) leading to strong suspicion of unwillingness to share information about their status due to stigma. Odindo and Mwanthi (2008) found that 43% of the study population experienced stigma and discrimination with 75% of the HIV-positive respondents reporting experiences with enacted stigma. A study in the Dominican Republic (Urena, 2009 as cited in MacQuarrie, Eckhaus & Nyblade, 2009) assessed verbal stigma of being gossiped about at 60%, with 25-30% reporting verbal abuse. A recent study by Action Aid International (2009) in three districts in Kenya found that 60% of people interviewed traveled long distances to access care so as to conceal their status.

Causes of Stigma

The major causes of HIV related stigma are fear of infection and death, lack of accurate and appropriate HIV/AIDS information, and the fact that HIV/AIDS is linked to sexual intercourse (Hunter, 1990; Olenja, 1999). The lack of open discussion and appropriate forums to discuss HIV/AIDS can also fuel stigma (Roseval, 2007). Rehm and Franck (2000) noted that affliction with HIV/AIDS results in a stigmatization and isolation of the individual and families due to its association with drug use, poverty and lower ethnic status. Stigmatization is a dynamic process that arises from the perception that there has been a violation of a set of shared morals, values, attitudes or beliefs (EngenderHealth, 2004). This can lead to prejudicial thoughts, behaviours, and/or actions on the part of governments, communities, employers, health care providers, coworkers, friends, and families (Cameron, 1993; Jayaraman, 1998; Zierler et al., 2000).

Fear arises from the concerns about contracting the disease, and the fact that it is incurable. EngenderHealth (2004) blamed lack of knowledge about HIV transmission, judgmental attitudes, fear of infection and perceived sexual promiscuity for stigmatizing attitudes amongst health care workers. People transfer their fears, anger and hatred of the disease towards individuals affected or infected with HIV/AIDS. The end result is stigmatization of these individuals. This transfer of hatred, fear and anger gives those who stigmatize a false sense of security that through such isolation, they may separate themselves and remain safe. From a postcolonial perspective this is a creation of an 'other' category deemed to be more susceptible to HIV/AIDS. On the other hand, stigmatization causes those infected with HIV/AIDS to deny their status and to shun treatment. Individuals may deny their "risk of HIV, refuse to use condoms, or refuse to disclose HIV status, in fear of the possible negative reactions of family,

friends, and community" (Brown et al. 2001, p.4). Quoting Martin Luther King Jr., Roseval (2007) states that as humans we "fear that which we do not know" (Roseval, 2007, p.67) and that stigmatization derives from our inborn instinct to protect our lives and minimise danger.

Lack of accurate information about HIV/AIDS can cause people to believe that they can contract HIV/AIDS though casual contact with infected persons, leading them to shun contact with and to isolate such infected persons. EngenderHealth (2004) identified lack of knowledge on casual transmission and the association with an incurable and degenerative terminal illness as major contributors to stigma. They further identified the fears of health care workers that they may get infected as a key factor that generates stigmatization in health care settings. Interestingly, research has shown that provision of accurate information alone through AIDS awareness campaigns, is not sufficient to counteract stigma (Roseval, 2007). This may be partly due to people not trusting the information. It could also be due to entrenched attitudes such as belief in customs and witchcraft. Roseval (2007) found out that even well informed nurses still held on to their stigmatizing attitudes. ActionAid (2009) found that even after 25 years of sustained information and communication campaigns in Kenya 48% of respondents in a study expressed still fear of contacting AIDS through casual contact and 55% were not willing to share a meal with a person known to have HIV/AIDS. 95% of respondents thought stigma could push those who tested positive to commit suicide and indeed there have been media reports of suicides after persons received HIV positive test results (ActionAid, 2009).

Lack of open discussion and appropriate forums to discuss HIV/AIDS can result from parents failing to discuss sex with their children (Roseval, 2007). It can also result from social institutions such as the Church, family and traditional leadership's hard line and judgmental attitudes towards AIDS sufferers (Odindo and Mwanthi 2008). In many African communities,

discussions about sex, sexuality in a family setting are regarded as a taboo. Roseval (2007) found that similar taboos in Suriname fuelled stigma. Children in such communities lack opportunities to discuss their fears and concerns about HIV/AIDS. Contracting AIDS is generally held to be synonymous with being promiscuous, which itself is looked down upon, with the disease being seen as punishment for engaging in prohibited sexual behavior (Olenja 1999). In this regard, the Church has also been complicit through its stance in proclaiming sex outside of marriage as sinful.

Culture has also been identified as an important factor that can fuel stigma. Some researchers such as Parker and Aggleton (2003) contend that the reason stigma has proved to be such a huge challenge, is due to the fact that it is varies so much between cultures and contexts, such that it cannot be easily generalized. It would appear that culture plays an important role in institutionalizing and perpetrating stigma and this leads to diversity in the types and levels of stigma. This makes both the measurement of stigma and the devising of solutions that can work across cultures and contexts difficult (Parker & Aggleton, 2003). The wide variations in prevalence between Kenyan provinces shown in Figure 1 come to mind. UNAIDS (2009b) recommends decentralizing of responses and the tailoring of responses to local needs and conditions. Hamra et al. (2005) found beliefs and knowledge were closely related to the quality of care offered by family members and caregivers to persons living with HIV in general, and children in particular. They established that amongst clients of the Lea Toto Kangemi Outreach Program, in Nairobi, Kenya who included children, less stigmatizing attitudes were associated with greater care, support, knowledge and insights into the needs of children under care. The findings point to the importance of tackling stigma in order to ensure proper care for infected

children. Unfortunately, data for the study was drawn from one ethnic group and perspectives of children were not sought.

Waterman et al. (2007) in their study on home based care, established that women suffer more stigmatization and that community leaders had a key part to play in minimizing stigma. ActionAid (2009) found 35% of women in three Kenyan districts suffered greater stigma than men and identified other factors that play important roles in fuelling stigma as social power structures, culture, historical discourses and patriarchal systems. It found that women were held to a higher standard and were expected to uphold prescribed societal (i.e. patriarchal) values. Kaai et al. (2007) also found that women exhibited higher internalized stigma than men, in agreement with earlier studies that had similar findings. Children whose parents are living with HIV/AIDS are often subjected to stigma by association since it is assumed they are infected (UN Committee on Rights of the Child, 2003). The committee noted that such children were likely to be discriminated against, and denied information, education, health care, social and community life and even in extreme cases could end up being abandoned by their family or community and become even more exposed to the risk of exploitation and infection living in the streets. Yamuna (2007) postulated that the impact of HIV/AIDS occurs in waves with the final wave deeply impacting the children through the loss of parental affection, support and protection all key factors in a child's development. He identified psychological trauma on the children, social dislocation and poverty as issues that further exacerbate stigma and discrimination. UNAIDS (2009b) found that young women between 15 and 19 years of age in Kenya were three times more likely to get infected than their male counterparts. In the absence of appropriate intervention measures this translates into more infected children through vertical transmission.

Drawing from earlier work by Parker and Aggleton (2003), Waterman et al. (2007), concurred that stigmatization is maintained by the prevailing hegemony and cultural understanding and cannot be separated from issues of culture, power and difference and that the political economy affects how stigma reduction interventions are conceptualized. The ruling class in Kenya for example, has shown limited interest in improving the living conditions for residents of Kibera. These residents provide a cheap source of labor and also significant voting block that is easily manipulated because of their poverty and desperation. This serves the interests of the ruling class. Parker and Aggleton (2003) and Waterman et al. (2007) proposed that in order to tackle stigma, home based care personnel needed to challenge social constructions of stigma within the community. One reason communities feel justified to stigmatize is because the infection is seen as having been self inflicted due to its early association with commercial sex workers and drug users (Hunter, 1990; Olenja, 1999).

Olenja (1999) found that the community displayed negative attitudes towards infected persons due to fear, and a belief that infected persons had been promiscuous, to justify ostracizing and rejecting them. She documented leaders making inflammatory statements against infected persons describing them as "hated", "seen as outcasts – nobody wants to be near them" Olenja (1999, p.193). Gathirua, et al. (2005) found that irresponsible media reporting, cultural and social obstacles such as traditional beliefs and self-stigmatization were major contributors to stigma. Genberg et al. (2008) confirmed the link between lack of previous testing, lack of knowledge of antiretroviral therapy (ART), low ART coverage and lack of communication about HIV with negative attitudes towards persons with HIV/AIDS.

Parker and Aggleton (2003) argued that differences that lead to stigmatization may be arbitrarily defined in the context of the social competition or through culturally constituted

stigmatization and related this to symbolic violence due to the struggle between classes as postulated by Pierre Bourdieu. Thus stigmatization can be viewed in the context of social actors seeking to legitimize their dominant positions within existing structures that support social inequality (Castro & Farmer, 2005). Parker and Aggleton (2003) also examined the issue in the context of globalization and the resulting exclusion as well as within the historically pre-existing inequalities such as racism, ethnic discrimination and religious conflict. This raises the notion that maybe HIV/AIDS only acts as a trigger for underlying and layered stigma already present in the society (Roseval, 2007). Parker and Aggleton (2003) called for a re-conception of the stigmatization in terms of power, inequality and exclusion and for the use of project and resistance identities to drive community mobilization initiatives to respond to and fight back against stigmatization. In addition, the researchers called for advocacy for social change, legal and policy interventions and the eventual enshrinement of legal frameworks that would criminalize discrimination as a breach of human rights through the enactment of appropriate civil rights legislation.

Types of Stigma

Stigma encompasses not just the stigmatizing attitudes but also perceived stigma, enacted stigma and expressed stigma. It also includes self-stigmatization where the individual is afflicted by low self worth. Perceived stigma is defined as fear of stigma and captures the respondents "beliefs or perceptions about the magnitude of stigma" (UNAIDS, 2009a, p.4) whereas enacted stigma "refers to stigma experienced and reported by a person living with HIV" (UNAIDS, 2009a, p.4). Expressed stigma encompasses stigmatizing behaviors and attitudes (Hamra et al., 2005). Brown et al. (2001) noted that many researchers divided stigma into *felt* or *perceived* stigma and *enacted* stigma (Jacoby, 1994; Malcolm et al., 1998; Scrambler, 1998; Scrambler &

Hopkins, 1986 as cited in Brown et al. 2001). They define felt stigma as the "real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute or disease (such as HIV), or association with a particular group" (Brown et al. 2001, p.4). They noted that this could cause an individual to deny their "risk of HIV, refuse to use condoms, or refuse to disclose HIV status for fear of the possible negative reactions of family, friends, and community" (Brown et al. 2001, p.4). Brown et al. (2001) concluded that felt stigma was "a survival strategy to limit the occurrence of enacted stigma, such as when someone denies their risk of infection or fails to disclose HIV status in order to avoid being ostracized" (Brown et al. 2001, p.4).

Enacted or experienced stigma, on the other hand, refers to a real experience of discrimination (Brown et al. 2001). For example, the disclosure of a HIV-positive status could lead to loss of a job, health benefits, or to social ostracization. Odindo and Mwanthi (2008) found the most prevalent form of stigma experienced by HIV/AIDS sufferers was segregation and separation, followed by rejection and loneliness, with the worst violators being friends, followed by family members and then the community. A particularly disturbing example of stigmatization noted by the study was that of a church allocating separate seating for HIV/AIDS sufferers. Kaai et al. (2007) reported that respondents experienced stigma in a variety of ways including isolation, rejection, withholding of emotional and financial support, denial of health services and loss of employment.

Olenja (1999) documented stigmatization of infected persons by health workers, as did Roseval (2007). Roseval (2007) noted one such case in Suriname where the patient was sent away and referred to a clinic run by an NGO for street based commercial sex workers. He found that nurses at the health facilities shared information on patients test results but curiously enough

they were not likely to share such information in the case of a family member. This is a clear example of health workers defining non-relatives as 'others' in a post-colonial context. EngenderHealth (2004) found stigma resulted in poor quality of care for infected persons and discouraged then from seeking care and services such as voluntary counseling, testing and that access to services were determined by the respect shown by health care workers. EngenderHealth (2004) identified stigmatizing language used by healthcare workers as a deterrent to visiting treatment centers. Rehm and Franck (2000) noted that stigma is manifested in its various forms such as fear of rejection, social isolation, fear of disclosure and lack of usual social support networks. Families felt stigmatized by the Church through being judged and through the perceived fear of those infected with AIDS. That some parents were not free to tell their children of their status due to the "shame and embarrassment" (p.79) is again a clear indicator of stigmatization by the community.

One particular form of stigmatization that might be injurious to the children would be gossiping and back-biting (verbal stigma). Since these children are in a formative state where they are trying to explore and forge their identities this form of stigmatization would present a huge barrier to their declaring their status.

The personal impact of HIV/AIDS stigma

In a telephone survey carried out in the United States more than three quarters of the respondents "expressed the belief that people with AIDS are unfairly persecuted" within society (Herek & Capitanio, 1998 as cited in Herek, 1999, p.1110). The study further revealed that People with HIV/AIDS (PWHIVs) and their loved ones were greatly affected by stigma, and documented actual experiences of prejudice and discrimination. Furthermore, researchers have found that stigma "affects many of the choices that PWHIVs make about being tested and

seeking assistance for their physical, psychological, and social needs" (Alonzo & Reynolds, 1995; Chesney & Smith, 1999 Hays et al., 1993; Klitzman, 1997; Lester et al., 1995; Lyter et al., 1987; Siegel & Krauss, 1991 as cited in Herek 1999, p.4; ActionAid, 2009). For example, "fears of AIDS stigma and its attendant discrimination may deter people at risk for HIV from being tested" or "seeking information and assistance for risk reduction" (Chesney & Smith, 1999 as cited in Herek, 1999, p.1110).

In addition, AIDS stigma has a huge impact on PWHIV's decisions about disclosing their health status to others (Herek, 1999). Herek noted that fearing rejection and mistreatment, many PWHIVs keep their seropositive status a secret. Crandall and Coleman, 1992 further argued that, "hiding one's HIV-positive status can lead to isolation at a time when social support is badly needed" (Crandall & Coleman, 1992; Johnston, Stall, & Smith, 1995 as cited in Shapiro, 2005 p.630) leading to increased stress. When HIV patients fail to disclose their status, even to their families and friends, it is likely to lead to a stigma that is widely internalized in the society, the result of which is "self-loathing, self-blame, and self-destructive behavior" (Herek, 1990; Klitzman, 1997 as cited in Herek, 1999, p.1110). The loved ones of PWHIV are also at risk of AIDS stigma and its negative effects (ostracism and discrimination) through association with a PWHIV.

Social consequences of stigma

Stigma can cause severe psychological trauma, depression and despair, increase People Living With HIV/AIDS (PLWHIA's) helplessness (Political Declaration of HIV/AIDS, 2006) and causes them pain and suffering. Many women do not know their status until they are expectant and are tested at anti-natal clinics, when it may be too late to protect the unborn child. Thus, more children end up being born with the virus. The fact that denial makes it difficult to

fight the disease was recognized by all civic, administrative and religious leaders in Kiambu District, in Kenya (Olenja, 1999).

Realizing the impact of stigma, many governments made commitments during the Declaration of Commitment on HIV/AIDS (2006) to reduce stigma and discrimination for persons living with HIV and groups vulnerable to HIV infection. However, there is widespread consensus that much still needs to be done as outlined in Joint Action for Results, UNAIDS Outcome Framework, 2009-2011(2010) which set out nine priority areas. The three that relate to child stigmatization are efforts to "remove punitive laws, policies, practices, stigma and discrimination that block effective responses to AIDS"(p.8), "to empower young people to protect themselves against HIV/AIDS" (p.8) and to "enhance social protection for people affected by HIV/AIDS" (p.8).

Gifford (2000) drawing from Treichler (1999) notes how mainstream media and television in the US managed to focus "the narrative away from the gay characters with AIDS" through "emphasizing the illness of their heterosexual relatives" (Gifford, 2000, p.1343). The disease was attributed to 'outsiders' or 'others' – socially marginalized groups such as sex workers, IDUs and homosexuals. Stigma acts to create a vicious cycle whereby the very people who need help cannot be helped. Families with sick members deny they are sick, and in so doing deny them access to help. Denial and secrecy become a form of protection from the isolation that stigma invariably brings. The disease is often labeled using different names such as 'the thing', 'the disease', 'sickness' or mislabeled by using a traditional name such as 'chira' (suffering ill effects of breaking a cultural taboo believed to cause wasting syndrome) in Kenya, even amongst health workers (Odindo and Mwanthi 2008). Data by Odindo and Mwanthi (2008) indicated that 34.1% of the community perceived the sick persons to have malaria and 32.9% cited

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tuberculosis, with only 29.2% citing HIV/AIDS. This indicates the possible impact of stigma, denial and an unwillingness to face up to the epidemic. When persons infected with HIV/AIDS deny the infection, they are unlikely to pursue antiretroviral treatment and may succumb earlier to the infection leaving more orphans and vulnerable children. Stigma, once entrenched, results in active discrimination against infected persons or those thought to be infected (EngenderHealth, 2004). Stigma and discrimination are interdependent, mutually reinforcing and self-perpetuating (EngenderHealth, 2004; UNAIDS fact sheet, 2003).

Stigma breeds social isolation. Hunter (1990) in a study on orphans in Uganda gave a detailed and illustrative account of what orphans face and how HIV/AIDS placed a huge burden on the elder generation after orphaned children were shunned by the community when their parents died. She found that cultural practices in Uganda that encouraged remarriage of mothers after the death of their husbands made them abandon their children as they sought partners elsewhere. HIV/AIDS, Hunter (1990) noted, led to poverty and hopelessness that deeply affected the orphaned children who become cynical, bitter and difficult to manage. They suffered lack of guidance as the grandparents who are forced to care for them were too old to meet their psychological needs, or discipline them. Constant lack of food drove these children to market centers, to look for casual jobs or to towns where they were victimized and/or abused. They failed to get education and became juvenile delinquents and rebels and degenerated into social rejects due to ignorance, deprivation, poor socialization and joblessness. Their poor self-esteem made them more likely to drift into criminal activities. Hunter (1990) blamed the very rapid spread of HIV/AIDS itself on the racist and genocidal policies of redlining (denying access to credit, mortgage financing etc.), quarantining and isolation used in New York in the early days of

the epidemic, and related these to the stigma and dehumanizing practices that forced sufferers to move from their communities to where they are strangers further fuelling the spread the disease.

Literature on care-giving shows that fear of contagion, and fear of death have clear negative effects on health care workers' attitudes towards persons living with HIV/AIDS (PLWHA) (Gerbert et al., 1991; Weinberger et al., 1992). Roseval (2007) initially relates this fear to lack of knowledge but later confirms that knowledge alone cannot overcome stigma. Pattullo et al. (1994) found troubling lack of knowledge among Kenyan secondary school students about:

> *the inability of mosquitoes to transmit the virus, the protective effect of condoms, the lack of protection from medications, the fatal and incurable nature of AIDS, and the fact that those infected with HIV may appear healthy* (p. 173).

Even when people know they are seropositive, they may elect not to pursue antiretroviral therapy in order not to be known to be sick.

Stigma was also identified by Rehm and Franck (2000) as a stressor in families with HIV infected children, and that caring for infected children causes stress and depression in the parents. Children also get stressed and traumatized after the death of sibling(s) and/or parent(s). Equally stressful is the individual's constant awareness of the disease and its consequences in order to manage stigma and the need to focus on stigma management which was so important to all affected families. One of the social consequences of stigma is that persons do not feel free to declare their status even to family members and this makes it difficult to plan for the future of their children (Ehiri et al., 2005). The children and the parents perceived that silence about their HIV status preserved enabled them to be treated normally and to blend in (Rehm & Franck, 2000), a clear manifestation of stigma within the community. Schools and social contacts were

informed on a 'need to know basis' and parents advised their children to be cautious about informing others about their status for fear of being isolated. EngenderHealth (2004) suggested that such social isolation could conceivably extend to exclusion from the processes that develop intervention measures against HIV/AIDS.

Although laws are now in place in many countries to prohibit stigmatization and hence discrimination of infected persons in the workplace, stigma still exists and can result in financial consequences for infected persons whereby they lose their jobs. Unfortunately, amongst some patriarchal societies, women and children are not just stigmatized but are often physically abused and deprived of their rights. Olenja (1999) reports how married women were chased away and deprived of property and land after being blamed for infecting their husbands. The children are most often chased away with the mother and suffer extreme deprivation as a result.

Impact on affected Children

It is instructive to look at the impact of stigma on the children. Chief amongst its impact on children is the fact that stigma discourages parents from taking children to be tested for HIV/AIDS, such that by the time the disease is identified ART is not as effective and that parents feared and do not know how to disclose their status to their children (India HIV/AIDS Alliance, 2009). Naturally, a positive HIV test result for a child would, of necessity, disclose the mother's status and thereby subject her to stigma, a major disincentive against testing children (India HIV/AIDS Alliance, 2009). Stigmatization, insensitivity and lack of confidentiality amongst healthcare staff can also discourage parent/caregivers from taking children to be tested. Stigma affects children in several ways, the main ones being the creation of a barrier for social protection schemes for children (WHO, Children and AIDS Fourth Stocktaking Report, 2009). Hunter (1990) documents how stigma has reversed decades of gains from immunization. Stigma,

she posits, encourages shunning of immunizations by children and parents in the erroneous and paranoid belief there is a plan to exterminate them, rolling back recent advances in lowering child mortality.

Education

Children who are infected face a difficult time in school. Those undertaking antiretroviral therapy need to take a cocktail of drugs and this raises questions from amongst their peers who invariably want to know why they are taking so many medicines. One child with the pseudonym Robert was reported by a Ugandan NGO official at a consultative meeting on East Africa HIV law to have discovered that he was HIV positive when he was 15 years old (Kiapi, 2009). He stopped taking his medication and stopped going to school because of stigmatization. He grew tired of being asked about his medication by peers and the nurse and about why he was always sick (Kiapi, 2009). HIV/AIDS may also affect children's nervous systems causing them to be more challenged academically. This would expose them to ridicule for being "slow" or "stupid". Such children may end up being shunned by their peers once they are found out to be seropositive.

Income and Basic needs

The onset of the HIV/AIDS drains the family's resources both through the inability of the breadwinner to work and the expensive medication and nutritional needs. Consequently, the children may lack shelter, nutrition and medical attention (Mishra et al., 2005). When parents fall ill, the children's education invariably suffers, as they often have to drop out of school to take on extra family responsibilities. Children find themselves in dire need of finances for school fees, uniforms, books and even stationery (Mishra et al., 2005). At the onset of full blown AIDS in

their parents, such children are likely to be withdrawn from school due to reduced family income and to provide care to ailing parents (Mishra et al., 2005).

Psychological impact

The children experience anxiety and fear while their parents are sick, and have feelings of grief and loss when they pass away. This is a particularly traumatizing time for the children and many never fully recover (India HIV/AIDS Alliance, 2009). The transitional period is not easy for many children, who are suddenly thrust into the role of taking care of younger siblings. Disclosure of HIV status can lead to negative emotions in children (India HIV/AIDS Alliance, 2009). The study noted that children faced problems of comprehending and coping with the disease in addition to stigma, uncertainty about their future, and end of life issues. Infection with HIV is linked to mental health issues (Ciesla & Roberts, 2001; Gallego, Gordillo & Catalan, 2000), and is a major cause of stress in People Living with HIV/AIDS.

Vulnerability, exploitation and differential treatment

Due to poverty and lack of adequate planning/preparation by their parents, many children are left vulnerable to exploitation and often have their basic rights violated (Mishra et al., 2005). Many are dispossessed and end up on the streets and extremely vulnerable to exploitation in an effort to supply their basic needs (Catalan, 2000; Hunter, 1990; Mishra et al., 2005).

UNAIDS estimated there were 650,000 AIDS orphans in Kenya meaning that one child in every nine is orphaned. Amongst children aged 15 years and younger, 9% have lost their father, 4% their mothers and 2% have lost both parents (UNAIDS, 2009b). Fostering of such children is largely shouldered by their extended families with some support from faith based NGOs and community initiatives. Mishra et al. (2005) found that such children were

disadvantaged in schooling compared to other children; they were more likely to be undernourished and to suffer abuse, neglect and be less likely to receive medical treatment.

How to tackle stigma

Waterman et al. (2007) noted that reduction of stigma is a lengthy, complex and iterative process that should be part of an overall strategy against HIV/AIDS. Genberg et al. (2008) confirmed the difficulty of developing tools across multiple cultures and contexts. Hunter (1990) identified the close relationship with sexuality as one of the main reasons stigma is proving so difficult to master. Parker and Aggleton (2003) decried the lack of a conceptual framework on the nature of the processes and deep analysis of the workings of stigma in relation to HIV/AIDS and cited this as the main reason for the lack of success in mitigating stigma. They argued that stigma is not static or merely culturally construed but that it is a social process in the wider context of power and domination and closely linked to the production and reproduction of social inequality. EngenderHealth (2004) concurred that stigma is dynamic and linked to issues of power and social control and that it frequently fortified existing societal attitudes and perceptions.

Gelmon et al. (2009) reported that sex workers were estimated to account for 14.1% of infections. This led to the interlinked notions of HIV/AIDS as a "gay plague" or a "woman's disease" (UNAIDS, 2009a, p.7) or even as just punishment for 'immoral' (UNAIDS, 2009a, p.8) or deviant behavior. EngenderHealth found that with many PLWHAs being members of already marginalized groups such as the poor, sex workers and homosexuals they were likely to experience compounded stigma on multiple fronts. Certainly, the work of Roseval (2007) in Suriname validates this view and anecdotal evidence indicates that many HIV/AIDS victims live in conditions of economic deprivation.

Olenja (1999) clearly linked the spread of HIV in a rural township to poverty which drove the villagers into sexual relationships with truck drivers, as did Carswell, Lloyd and Howells (1989), and it also ruled out care in hospitals due to expense. Poverty also forces families to live in confined spaces raising the risk of infection and denies infected persons the means to afford appropriate care and treatment. In order to make headway in the fight against stigma therefore, there is an urgent need to address the economic and social processes that marginalize the victims and keep them in the informal settlements and at the margins of economic activities.

Key players in the structures that sustain stigmatization need to be identified and recruited in the fight against stigma. Institutions such as the Media (The Internet, radio, television and newspapers) are key opinion shapers and can make a difference in the way society perceives and treats infected persons (Olenja, 1999). The most important role for the media is to dispel erroneous information regarding casual transmission of HIV and to remove the fear that derives from this lack of knowledge. Media can instead be used to inform the society of infected persons' need for nutrition, love, hope and spiritual support. Other key players identified by Olenja (1999) were village health committee members, politicians, leaders and men in patriarchal societies. However, there is hope in that Roseval (2007) found that in Suriname the society had changed to such an extent that many now believed that infected persons had a right to sexual relations. In all, it is important to create and foster an environment where sex, sexuality, sexual relations and infections can be freely discussed especially with children.

Making antiretroviral therapy (ART) available is an effective way to tackle stigma. Kaai et al., (2007) found that internalized stigma reduced measurably after the 12 months of ART. Although women exhibited higher internalized stigma than men they benefitted from a greater

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decline in stigma during the study. Respondents disclosed their status to more members of their families especially children. The study's findings are in broad agreement with Abadia-Barrero and Castro (2006) who in their ethnographic study in Sao Paulo found that children experienced a shift their stigmatizing experience over their life trajectory as a result of greater provision of ART services. Recent scientific evidence also suggests that ART can lower the risk of infection to partners of PLWHA (Vienna, 2010).

Establishment of home based care facilities was found to be a good way to combat stigma and is in line with Roseval, (2007)'s findings that there was less stigmatizing attitudes amongst relatives. Such facilities also have the potential to alleviate the huge costs associated with hospital stays and the burden on developing countries' economies and deprivation of surviving family members including children.

Perceived gaps in research

Although a lot of work has been undertaken on stigma and discrimination there are relatively few studies focusing on children. One of the few studies that touched on stigmatization of HIV infected children was by Norman et al. (2009) that found considerably more sympathy (and less stigmatization) towards children and heterosexual women. The study was conducted in Puerto Rico and analyzed the attitudes of 1138 women living in public housing towards persons living with HIV/AIDS (PLWHA). The study used a 218-item, self-administered survey, and documented high levels of discriminatory attitudes towards persons living with HIV/AIDS at both the individual and societal level. Two important findings were that a lack of knowledge about HIV transmission correlated with a less tolerant attitude and that those who knew a PLWHA were more tolerant towards other PLWHAs. Certainly no data were found on any

study conducted on stigmatization with a focus on HIV infected children in Kenyan urban centers.

The International Center for Research on Women (ICRW) in its review of literature (Nyblade & MacQuarrie, 2006) identified that although progress had been made in measuring stigma (Nyblade & MacQuarrie, 2006; Genberg et al., 2008, Stein and Li, 2008; Visser, Kershaw, Makin & Forsyth, 2008), comparative studies of the prevalence of stigma across settings or populations were rare.

Most of the help offered to children affected by AIDS focuses on food, shelter, health and education but many institutions and organizations fail to meet the social and emotional needs of these children. Those that are not cared for by institutions end up with the heavy responsibility of caring for themselves and for younger siblings. Another area identified as under-researched is the evaluation and efficacy of stigma reduction initiatives and programs (Brown, et al., 2001). During the course of the study, the author sought to find out if there were any stigma reduction programs relevant to the children under study, and the impact of such stigma reduction measures/programs.

For the researcher, critical knowledge from the literature review were the ways in which persons with HIV/AIDS are stigmatized to help in framing the questions for the proposed research. Analysis of the various methodologies used by past studies was also useful in informing the researcher's choice of approach and methodology.

Research question

The central research question for this study was to identify ways in which HIV infected children in Nairobi, an urban centre in Kenya experience stigmatization as a result of their being infected

with HIV/AIDS and to explore the social constructions that may contribute to such

stigmatization.

CHAPTER THREE

Methodology

Scope of the Study

It was important to delineate the limits of the research in order to ensure it is achievable. The study focused on the children's perspective of stigmatization. Yebei, Fortenberry, and Ayuku (2008) found that levels of stigma depended on the social setting, and differed between urban and rural areas. In order to obtain clarity, it was decided to choose one of the two settings. The study is to be carried out in an urban area, specifically in the informal settlements in the capital City of Nairobi, Kenya. The structures are spread over a considerable area but have neither official land demarcations nor basic services like running water, electricity or a sewerage system. Private individuals have set up companies to fill this vacuum. The sample to be studied was small and restricted to this particular area and the study cannot be generalized to the whole country or even to the all urban centers in Kenya. The participants were restricted to 7-15 years of age and these findings may not necessarily apply to older children. The time limit for my thesis was the end of the academic year, so the time set for the research study was four months. Ideally, a phenomenological study should be conducted over an extended period of time. However, the researcher felt that over this period of time, a sufficiently close relationship was formed with the participants leading to valuable findings.

Purpose of the Study

This study aimed to add to the body of knowledge on stigma especially against children viewed from a child's perspective as advocated by UN Convention on the Rights of the Child which encourages the participation of children in all matters that affect them with due regard for their evolving capacities. The study gave voice to the affected children to express how

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HIV/AIDS had impacted their lives so that these perspectives could be considered in designing measures to mitigate stigma.

Approach

The nature of the study was to explore and understand a particular phenomenon – stigma with regard to children living with HIV/AIDS. The results were expressed in terms of findings that were contextual and that described the participants' lived experiences. From the above considerations, the study and the approach naturally needed to be qualitative in nature. The numbers involved were small and the time frame was limited both of which favored a qualitative study. It is believed that qualitative research respects "the complexity, subtlety and detail of human transactions" (Basit, 2003, p. 146).

Phenomenologists take an experiential view towards understanding phenomena, and highlight the human experience as valid, and of great importance to understanding human existence and the meanings these events have to them (Morrissey & Higgs, 2006). They emphasize "experience in the lived world" and hold that meaning is "co-created by researchers and those who experience the events or lived phenomena being investigated" (Baker, 1992, as cited in Morrissey & Higgs, 2006, p.163).

Through the use of the phenomenological strategy, the researcher hoped to illuminate the phenomenon of stigmatization from a child's perspective. This strategy valued their everyday experiences and events as a productive source of knowledge that cannot be obtained in any other way (Baker, 1992, as cited in Morrissey & Higgs, 2006) and sought to understand the essence of human experience about the phenomenon as described by participants (Creswell, 2009). Guided, semi-structured interview questions and audio recordings were used to gather the data. This ensured the researcher could carry out deeper analysis on the data. Data collection and analysis

was carried out in three stages. Firstly, the researcher examined the literature for studies on stigmatization and the ways in which persons with HIV/AIDS are stigmatized. This provided valuable input and informed the questions to be asked of the children as well as the initial coding. Secondly, the researcher asked the participants questions using the interview guide attached in the Appendix D, to ensure that similar topics were covered with each participant. Further questions arose naturally from the participants' answers. The questions asked included cross-referencing questions to confirm the researcher had correctly understood the meaning of the participant's answers and to achieve a deeper understanding of the participants' perceptions (Baker, 1992 as cited in Morrissey & Higgs, 2006). Finally, data analysis was carried out through deep and repeated reading of all data (transcripts) and use of analysis procedures as described below.

The researcher chose children to be the participants in order to document their perspective of their condition and experience of stigmatization. Advancing the concept of children being seen and heard in events and experiences that relate to them, the need for their perspectives to be honored as competent witnesses of their own lives (Danby & Farrell, 2004) and the need to ensure their involvement in decision making (Clark, McQuail & Moss, 2003), the study sought to understand and document children's perspective of stigmatization. Some researchers such as Smith and Tarr (cited in Lewis and Lindsay, 2000), have argued that children's experiences are often significantly different from adults' experiences, that the reality and experiences of children "cannot be fully comprehended by inference and assumption" (Smith and Tarr as cited in Lewis and Lindsay, 2000, p.61) and that their meanings are "not necessarily the meanings that their teachers or parents would ascribe" (Smith and Tarr as cited in Lewis and Lindsay, 2000, p.61). Indeed children are "competent interpreters" of their everyday world and

"active participants" within their social environment (Danby & Farrell, 2004, p. 38) and this requires that researchers undertake a deeper analysis of their talk, actions and interactions. This is also in the spirit of Article 12 of the UN Convention on the Rights of the Child (1989) that asserts the rights of a child to express their views on all matters that affect them.

Sampling

The researcher purposively sampled children recruited from Joseph Kangethe primary school in Nairobi, Kenya as the targeted population. No school records were used, and participants self identified themselves. Purposive sampling starts with the purpose in mind and consciously excludes those who do not fit the desired profile (Creswell, 2009 and Patton, 1990). Purposive sampling as espoused by Patton (1990) and Punch (2006) was used to identify the participant children who hailed from Kibera, an urban informal settlement area, on their experiences living with HIV/AIDS, and how they are stigmatized because of their status. Creswell (2009) stated that purposefully selected participants help the researcher to understand the problem and answer the research questions. Dean (1990, as cited in Creswell, 1990) asserts that it allows the researcher to focus on respondents she had good grounds to believe held information critical to the research and that would illuminate the issue being investigated. Lincoln and Guba (1985) stated that this method is particularly suited to studies which seek to discover such as this one. Mutonyi (2007) justified the use of purposive sampling for widely distributed and diverse populations such as the one in this study.

A well known downside of this method which is popular in qualitative research studies is that it can be subject to bias and error. Punch (2006) noted that qualitative sample sizes tend to be small and often have no statistical grounds for guidance. The researcher believed that stratified purposeful sampling was particularly useful as the potential participants could be

stratified using certain criteria such as gender and ethnic background. The number of participants chosen was reflective of the ratio of the stratum in the general population to enhance the accuracy of the findings (Selltiz, Wrightsman & Cook, 1976 as cited in Mugenda & Mugenda, 2003).

The sample selected consisted of four girls and four boys aged between 8 and 15 years. One boy and two girls were from the Luhya ethnic group, one girl and a boy from the Kamba ethnic group, one boy from the Kikuyu ethnic group, one girl from Luo ethnic group and one boy from mixed parentage (Kisii and Kikuyu). All preferred to speak in Kiswahili which is the national language except for one girl who was fluent in English. Thus the sample was fairly representative of the major ethnic groups.

Study Setting

The study upheld concerns regarding privacy and confidentiality in the conduct of research. The school the children attended was ruled out as an interview venue due to the risk of children being exposed to the breaches of confidentiality and possible stigma. After some thought, their homes which are based in the informal settlements were found to raise similar concerns. The researcher therefore made arrangements and secured a private house in the residential area close to the school where the children were interviewed ensuring both visual and aural privacy. The parents were also given a chance to give their input on where the interview was to be conducted. A convenient time was agreed with the children and the parents entirely at their convenience. Adequate time was allocated for the researcher to build a rapport with the children prior to the interview.

Participants

Parents, caregivers, guardians and children who had HIV/AIDS were informed about the study through the use of flyers which the researcher used to recruit the participants. A copy of the flyer is attached in Appendix A. Parents, caregivers, guardians and children self identified and were invited to a meeting held at the private venue, wherein they were given further information about the study and given an opportunity to ask questions. The researcher went through the consent form attached in Appendix B verbally with parents, caregivers, guardians and children and translated it into the Kiswahili language which most of them were more familiar with. They were informed that they were free to withdraw their children from taking part in the study, in case they changed their mind. The researcher also informed them that some of the questions which would be asked might be uncomfortable for their children to answer because of their status. Twelve parents/caregivers/guardians volunteered for their children to participate in the study. From the twelve, eight participants from diverse communities and with an equal mix of boys and girls were selected and given the consent forms to sign. Children were given the assent form attached in Appendix C to sign before they took part in the interview, and they were told they could withdraw from the study anytime they wished even if the parents, caregivers or guardians had already signed the consent form. They were informed and assured that the confidentiality of any information the children gave during the interview would be upheld.

Data collection and tools

An in-depth interview was used to collect the data. The venue of the interviews was in a private room approximately one mile away from the school where the participants were recruited. The researcher used phenomenological inquiry methods to conduct the interviews. Interview guide questions, a copy of which is attached in Appendix D were used to guide the

interviews. The interviewer used Kiswahili as the language which was more familiar to the children to ask them questions. Before the interview, the interviewer explained to the children the use of the audio-tape and why it was necessary for interviews to be audio-recorded. The interviewer encouraged the participants to talk freely about their lived experiences. Probing questions words like "how", "when" and "what" were used to stimulate conversations during the interview. The interviewer re-framed the questions asked when it was clear the questions were putting participants in an awkward situation or they felt shy answering the question. At the start of the interview, demographic information was collected about their age, ethnic background, religious affiliation, grade in class and who they lived with. The interviewer used additional probe questions, to prompt the participants to narrate their story. The interviews lasted between 30 and 45 minutes except for two challenging participants whom the researcher gave frequent breaks and whose interviews lasted 60 minutes. The audio-tape was replayed for the children to listen to their voices and to confirm and clarify the answers they gave to the interviewer. Table 1 shows the demographic data for the eight participants.

Ethics

Approval for the research to be conducted was granted by Ryerson University Ethics Board and the study was carried out in strict accordance with guidelines for research involving human participants. The rights of the children, academic integrity, honesty and respect for other persons were upheld at all times (Punch, 2006). Consent of the parents and the children's assent was obtained after the process was explained to them and prior to the commencement of the research interview. Ethical issues relating to confidentiality and anonymity were explained to both the parents/caregivers/guardians, pseudonyms were used to ensure strict confidentiality. They were informed that they had the right to withdraw from the study at any time without

adverse consequences and that the research would not lead to any quick or tangible results. Interviews were carried out in an environment that was familiar, comfortable and conducive to the children's welfare with the likelihood of stress and discomfort was minimized by taking time to build rapport and trust and through having the parent/caregiver/guardian on standby during the interviews.

Data organization

Data from the interviews was audio recorded. All of the data were appropriately labeled (date, time, location, participant [using pseudonyms] and comments) and locked in a secure location accessible only to the researcher during data collection. Sensitive data were labeled using codes known only to the researcher and the encoding key together with a master list (spreadsheet) of all data collected was kept at a separate secured location. Access to laptops and computers used was restricted physically and also through the use strong passwords.

Data Analysis

This is seen as the central and most crucial aspect of a qualitative research project (Basit, 2003; Robert-Holmes, 2005). Basit (2003) conceptualised it as "an intense and prolonged period of deliberation" (p.152) and Ely et al. (1991) (as cited in Basit, 2003, p.144) termed it "a very close, intense conversation between a researcher and the data". The first activity was the transcription of the interviews which involved a fair amount of translation from Kiswahili which was the language most familiar to the participants and language used for nearly all interviews. The researcher was confident of the translation, being fluent in the language and having taught it in various schools. Transcripts were re-read and checked to confirm their correctness. The use of electronic software for coding was considered but not used due to the small number of interviews. The data analysis processes begun with familiarization with the data after data were

transcribed. The data were then organised and listed and any names of participants substituted with pseudonyms. The next process involved reading, organizing and making sense of the textual raw data and presenting it in a meaningful form (Basit, 2003). The main objective of the analysis was find relationships, patterns and groupings as well as similarities and differences between the perspectives of the participants (Basit, 2003). The data were first read to obtain a general idea about the data as suggested by Creswell (2009). The most interesting interview transcript was selected and used to start the process of identifying the themes. The transcripts were re-read several times and interesting text to be coded was highlighted using different coloured markers and links between the data and literature established. Some pieces of the data fell into more than one thematic category and this was allowed. Extensive comments were noted on the transcripts at the margins. After this the data were subdivided into categories as proposed by Dey (1993) and grouped into thematic categories. Codes were attached to bits of data associated with each thematic category on the transcripts. Categories were derived from the data in concert with inductive and grounded approach (Glaser & Strauss, 1967). This process was iterative and as the codes were attached new categories would emerge or sometimes changed. Data were coded and re-coded several times. The twin analytical procedures of making comparisons and asking questions were extensively used in creating the categories and later in re-defining and modifying the themes. Topics that were related or close to one another were merged to reduce the number of categories. The researcher decided what data and thematic categories to use and what to leave out of the findings.

Once the data were analyzed the themes and categories were explored for relationships, patterns and inferences and these were further refined. As Basit (2003) notes the process of data analysis continues throughout the life of the research project and the researcher often went back

to refine the categories and themes. There was a constant and conscious effort to choose and modify the codes, categories and themes to illuminate and explain the phenomenon of stigma (Basit, 2003). These techniques helped the researcher set aside her own experiences and to understand and describe the lived experiences of the participants (Moustakas, 1994, Nieswiadomy, 1993). Experiential analysis (Moustakas, 1994), and narrative analysis (Reisman, 1993) was explored in addition.

The interaction and integration between the data and the literature was used to arrive at the findings and this led naturally to the recommended policies and changes (Holliday, 2002 as cited in Robert-Holmes, 2005). The findings were presented in the thematic categories and supported by quotations from the participants. Post-colonial theory was used as a lens to explore ways in which the research could empower those who were stigmatized because of living with HIV/AIDS, and to explore and reveal how and why stigmatization occurred (Creswell, 2009). It is believed the use of Kiswahili as a language of expression by the participants facilitated their expression of indigenous epistemologies. In analyzing the data, the researcher kept in mind that the sample selected was small and was not necessarily representative and that the findings were not generalizable. Furthermore the researcher was acutely aware that this was only one interpretation or perspective of the data.

Limitations of the study

Benefits of interviews included the capture of historical information and the ability on the part of the interviewer to direct the interview process (Creswell, 2009). Limitations included the information being filtered by the interviewee, unnatural settings, possibility of bias being induced by the researcher and not taking into account the fact that not all participants are articulate (Creswell, 2009). In the translation from Kiswahili to English, some things may have

been lost or misunderstood. Validity was enhanced through replay of the audio-tapes to the participants (Robert-Holmes, 2005). The study's trustworthiness was be enhanced by use of direct quotations of the participants' accounts, and self-reflection (Johnson, 1997).

Because of the small sample size and the study was unable to capture the breadth of the diversity of ethnic groups, and only five or six of the 41 ethnic groups were represented. The study presents valuable insight on the lived experiences of children at this school but the data is not sufficient to give any insight about stigmatization in other schools, in urban or rural settings. There exists substantial cultural diversity between the ethnic groups hence the results cannot be generalized. Comparison with similar studies in other schools and different settings would enhance the validity of the results. The children's answers could have been influenced by the fact that the researcher was a former teacher at the school, and represented an authority figure. The inherent power relations may have led the children to say what they felt the researcher/teacher wanted to hear. The male children could have been uncomfortable discussing the issue due to its linkage with sex and the researcher's gender and thus held back some information. Cultural inhibitions on discussion about sex and sexuality could also have had a bearing.

The study was conducted within a fairly tight timescale and this limited the time the researcher had to develop relationships with and to create a rapport with the children. The self-stigmatization was very clear to the researcher from the interview with the participants and the recommendations would certainly mitigate stigma for these children, however, some caution must be exercised due to the small sample size and inability to generalize the findings.

CHAPTER FOUR

Study Findings and Discussion

The study adopted a qualitative research design while embracing the post–colonial theory as a lens to analyze the stigmatization of children living with HIV/AIDS in the city of Nairobi, Kenya. According to Lofland (1974), data collection and analysis strategies are similar across qualitative methods, but the way findings that are reported are diverse. Consequently, the researcher presented the findings on the topic under study in a descriptive and narrative format. The names of the participants here are replaced with pseudonyms to mask their identity in order to meet the requirements of the research ethics approval. A summary of the demographic data of the participants (4 boys and 4 girls) can be found in Table 1.

Several key themes emerged during the study on stigmatization arising from the way in which the children who are infected with HIV/AIDS felt that they were treated by virtue of their status and position in the society. The researcher found that children manifested various kinds of stigma. They exhibited denial, shame, and fear, and felt disempowered (diminished). They showed felt and perceived stigma, as defined in the literature review, and there was one reported incident of enacted stigma.

Researcher self-disclosure

The postcolonial lens calls for introspection and in line with that, the researcher feels it appropriate to disclose that she is a Kenyan and nominally belongs to the Luo ethnic group to which her parents belong. This study led her to research Luo customs and traditions related to this issue, leading to some self discovery. She grew up in a middle class home in the western part of the country in the urban centre of Kisumu, and lived most of her adult life in Nairobi, the

capital city. Thus she did not experience first hand living at the economic margins, raising the question of whether she can truly speak for the subaltern, to paraphrase Spivak (1988).

A teacher by profession, she taught at the school where the flyers were distributed for the participants to self identify. Due to this, she represents an authority figure, and this may have influenced the power relations and therefore the answers given by the children. On the positive side, she had only been away for slightly over a year and was fluent in the Kiswahili which was the language the interviews were conducted in, for all but one participant. Breaking this language barrier was important for the children to freely discuss their feelings and perspectives and also allowed the participants to use their indigenous language to express themselves as opposed to the English language that is less familiar. However, there might have been things that could have been said that were not mentioned due to the perception that the researcher already knows about them, being Kenyan. The researcher's prior personal experiences with significant numbers of these children had a significant impact on the selection of this research topic. The postcolonial stance and lens, as discussed above, is necessarily an activist position and the researcher in this case was advancing an argument seeking to change the situation of these affected children.

Every research is to some extend colored by the researcher's "subjectively identified social position" (Lindermann, 2007, p.54). With this in mind I felt a need to clarify my social position. As an Early childhood educator I have a deep concern for issues affecting young children in general. This is also informed by my experiences as a teacher dealing with children in their formative years of schooling. I am also a mother, and parent and this makes me empathetic towards the plight of children in need. My parents lived through the colonial era and espouse many of the traditional beliefs of the Luo ethnic group and this would influence my perspective. Born during the transitional period at the eve of Kenya's independence, I never experienced

colonialism directly but have experienced and been impacted by its enduring influence in my education and upbringing. In terms of the social stratification, I would consider my upbringing privileged and middle class in a nation where many live in conditions of extreme poverty. My research perspective is influenced by the social constructivist notion that meaning is co-constructed by the researcher and participant (Freeman & Mathison, 2009). It is from this position that I approach my analysis of research themes.

Fear

When asked if he feared anything in life, Paul an 11 year old Kikuyu boy answered: "I am just afraid of having the disease". Joshua, a 10 year old boy from the Kamba ethnic group told the researcher that he feared contracting the disease because he feared dying. The reason he gave was "Because others don't have HIV\AIDS.... and I may die". These children obviously faced weighty end of life issues at a very young age.

There was a strong fear of being isolated if their playmates knew that they were infected. Joshua expressed this during his interview:

Q: Why should they hate you?

A: They will not play with me.

Q: You mean if they know you have HIV/AIDS they will not play with you?

A: Yes.

Ruth a 10 year old girl from the Luhya ethnic group when interviewed surmised:

Q: Would you tell people that you have HIV/AIDS?

A: No!

Q: Why?

A: Because if they know they might not want to play with me and they will not come near me.

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Q: You mean to say that if you have HIV/AIDS it is better for you to keep quiet?

A: Yes.

There is evidence that the children were forced to keep their status secret, placing a very heavy burden on them at such a tender age. Not even the church could offer them any comfort. Even in church, there was the ever present danger of verbal stigma. Clare, a 14 year old girl from the Luo ethnic group gave the reason why she would not confide in anyone in church:

Q: You told me that you were Christian, so would you like anybody to know about your status in church?

A: No!

Q: Why?

A: They would start gossiping about me.

Brenda an 11 year old girl from the Luhya ethnic group also narrated her fear of verbal stigma:

Q: Brenda, now you are HIV/AIDS positive do feel free talking about it?

A: I don't want people to know about my status.

B: What will happen if they know about your status?

A: They will start talking bad about me.

And later in the interview:

Q: What about your neighbors?

A: They don't know I am HIV/AIDS positive.

Q: And would you like them to know?

A: I would not like them to know because they will start talking bad about me.

Q: How would they talk bad about you?

A: They will start to abuse me and to say bad things about me.

The children also feared they would be the target of hatred as articulated by Paul, an 11 year old boy from the Kikuyu ethnic group:

Q: Have been you told that they will hate you because you are HIV/AIDS positive?

A: Yes.

Q: Do mean to say that if you have this sickness people will hate you?

A: Yes.

HIV/AIDS stigma impacts greatly on the social and personal domains of those affected and infected with HIV/AIDS. For instance, according to a report by the UN committee on the Rights of the child (2003), children facing stigma are more likely to be discriminated against, denied information, education, healthcare, social and community life and even in the extreme cases could end up being abandoned by their family or community and become even more exposed to the risk of exploitation and infection.

When the researcher probed Brenda, she stated her fear (above) that if people know about her status they would gossip about her. Brenda's example indicates the social and personal consequences of felt stigma, that is, "real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute, disease" (Brown et al. 2001, p.4). The findings reveal that stigma forces individuals "to deny their status or refuse to disclose their status" (Brown et al. 2001, p.4). If they confide they do so only to select people; in the case of Brenda it was her teacher, due to fear of possible negative reactions from friends, family and the community. Duncan confided in his uncle, but only in the security of the bedroom. Clare, a 14 year old girl from Luo ethnic group showed she possibly lacked companionship by leaning and

holding the researcher as she talked. She stated that she did not want anybody to know her status, not even her friends, as gleaned from the interview:

A: Do they know you are HIV\AIDS Positive?

B: They are not aware.

Q: If they are aware that you have HIV/AIDS what do you think their reaction will be?

A: They will hate me, and not play with me, so it better for me to keep it secret.

Q: Do you mean to say it is better for you to keep quiet?

A: I would rather be quiet to maintain our relationship.

Clare's responses indicate that she feared rejection from her friends and family members. Keeping this secret caused psychological stress on these children. These findings concur with Olenja (1999) who found that the worst violators were friends of HIV/AIDS patients, who through a variety of ways including rejection and isolation, aggravated the HIV/AIDS stigma levels. Clare's response further supports a study by Engender Health (2004) who noted gossiping and backbiting as a prevalent form of stigmatization. This could be particularly injurious to the children as they try to explore and forge their identities, and a huge barrier to their declaring their HIV status.

The children did not feel free to discuss their status even with family members or close friends. The findings reveal that the parents perceived that silence about their HIV/AIDS status preserved "their ability to be treated normally and to blend in with others", a clear manifestation of stigma within the community. This is in line with Ehiri et al. (2005) who found out that schools and social contacts were informed on a "need to know basis" and parents advised their children to be cautious about informing others about their status for fear of being isolated.

According to Paul, an 11-year-old boy from Kikuyu ethnic group, his friends loved him and treated him well, because they didn't know his status. As noted before, felt stigma and secrecy about status are both seen by the children as survival strategies to avoid being ostracized (Rehm and Franck, 2000; Herek 1999).

Such secrecy would lead to increased stress, for the children (Herek, 1990; Klitzman, 1997; Ciesla & Roberts, 2001 and Gallego, Gordillo, & Catalan, 2000). Children also clearly recognized that secrecy was linked to being treated normally. Herek (1990) and Klitzman (1997) found self-loathing, self-blame resulted from stigma and Rehm and Franck (2000) found that constant stigma management was stressful. These children were constantly engaged in stigma management as they could not afford to divulge their secret and must consequently have been under stress. Odindo and Mwanthi found respondents in their survey blamed other diseases for their ill health. These children similarly denied they had AIDS and didn't even want to mention the name of HIV/AIDS. Most of the children stated they always wanted to go to school even if they were sick. They did not want to remain at home as this would make others to ask them why they stayed at home.

Denial

Joshua, a 10 year old boy from the Kamba ethnic group when asked if he had knowledge of HIV/AIDS, denied any knowledge and stated that he had only read about it in books.

Q: Have ever heard of anyone talking about HIV/AIDS?

A: Yes, I have heard.

Q: Where did you hear this?

A: From books.

The researcher noticed that when answering the questions, he had a sad expression and the tone of his voice was low, possibly suggesting that he was trying to hide something from the researcher.

Often in the interviews the participants would both accept and deny they were infected. Joshua a 10 year old boy from the Kamba ethnic group was a good example:

Q: When did you find out that you have HIV/AIDS?

A: Quite for sometime.....I was not told.

Q: And do you know if you have HIV/AIDS?

A: I don't know.

Paul, an 11 year old boy from the Kikuyu ethnic group first admitted, then denied, and later admitted to having HIV/AIDS.

Q: When did you find out that you have HIV/AIDS?

A: I was told by Aunty.

Later during the interview, this took place:

Q: Earlier you told me that your Aunty is the one who told you that you had HIV/AIDS?

A: I don't have any HIV/AIDS

Subsequently,

Q: You told me earlier that you went to the hospital?

A: Yes.

Q: And you were given medication?

A: Yes.

Q: The medication was because of that disease?

A: Yes.

Q: Is it because you're HIV positive?

A: (Silent for some time). Yes.

Ruth a 10 year old girl from the Luhya ethnic group first stated she did not know why she routinely took medication, then later admitted the medication was for HIV/AIDS:

Q: So you are just taking medicine and you don't know why you take the medicine?

A: Yes.

Q: This medicine for HIV/AIDS?

A: Yes.

Her mother admitted to the researcher to not having disclosed her status to the child nor told her she was infected.

Shame

Ruth a 10 year old girl from the Luhya ethnic group was questioned about how she would feel if she had AIDS:

Q: Ruth you have told me that you don't whether you have HIV/AIDS and what if you did, how would you feel?

A: I would feel bad.

Joshua a 10 year old Kamba boy similarly stated:

Q: How would you feel when someone tells that you have HIV/AIDS?

A: I would feel bad.

And further:

Q: When you were coming to school did you feel ashamed or not?

A: I was ashamed.

A: I was ashamed.

Q: Was it because you are HIV/AIDS positive?

A: Yes.

When Paul an 11 year old boy from the Kikuyu ethnic group was interviewed he stated:

A: Yes, it was my uncle and also the Doctor sat down with me and told me I was HIV

positive.

Q: When you were told, how did you feel?

A: (After a long pause). *I felt ashamed*

Grace an eight year old girl from the Kamba ethnic group was very emotional and clearly

ashamed of having HIV/AIDS when interviewed:

Q: When did you find out that you have HIV/AIDS?

A: I was told by Mum.

Q: When you were told what was your reaction?

A: I felt bad.

Q: Why?

A: I felt like crying

Q: Why?

A: Because I don't like to hear that I have HIV/AIDS.

And later in the interview Grace stated:

A: Because I have the virus, I don't like to hear about the virus it makes me cry.

When Brenda an 11 year old Luhya girl was interviewed, this was said:

Q: Who told you that you were HIV/AIDS positive?

A: My mother.

Q: What was your reaction?

A: I felt sad.

Q: What did you do?

A: I just felt sad, sad.

And later in the interview:

Q: When you are in school do your friends knows that you are HIV/AIDS positive?

A: I don't want them to know.

Q: Do you take the medicine openly when your friends are watching you?

A: No!

Q: Why?

A: Because I don't want them to know that I am HIV/AIDS positive.

Q: You told me when you found you had HIV/AIDS you felt bad, you were ashamed and

didn't want disclose it to anybody?

A: Yes.

There was clearly a high degree of self-stigmatization amongst the participants since almost all of them stated that they felt bad and ashamed about being infected. Paul, an 11 year old boy from the Kikuyu ethnic group mistakenly felt he would infect his playmates and this made him not to want to go to school.

Q: When you were told that you had HIV/AIDS were you able to play with other children?

A: No.

Q: What of coming to school?

A: No.

A: Because I would infect others.

This was certainly a case of self-stigmatization. Most of the children could barely bring themselves to mention HIV/AIDS. Grace an eight year old girl from the Kamba ethnic group was typical:

Q: You mean you were not told why you take this medicine?

A: I was told it is because of this sickness.

Q: Which sickness?

A: (Silent for some time). Because of HIV/AIDS.

Some of them such as Paul asked themselves why they got the disease:

Q: Do you normally wonder why you got this sickness and not other children?

A: I do ask myself.

Q: When you do, do you normally think about it very much?

A: Yes, I think about it a lot.

The researcher found out that the fear of HIV/AIDS stigma and its attendant discrimination did deter people at risk for HIV/AIDS from being tested or seeking information and assistance on risk reduction in agreement with Chesney and Smith, 1999 (as cited in Herek, 1999). When James, a 10 year old, boy from Luhya ethnic group was probed, he portrayed a sense of fear at the mention of HIV/AIDS, which he calls "that disease", exhibiting a pained facial expression he stated:

I went to hospital..... (Silent) ... because of that disease....My aunt told me I have the disease.....She did not tell me the meaning of HIV/AIDS...They hide from me the meaning and that's why I got that sickness.

The last statement also raises the possibility of the strong influence of traditional beliefs and doubts about whether HIV/AIDS is caused by a virus, and not having knowledge of how they got infected. The findings concur in general with ActionAid (2009); Chesney and Smith, 1999 (as cited in Herek, 1999) and Alonzo and Reynolds (1995) all of whom found that stigma affected many of the choices that PWHIVs made about being tested and in seeking assistance for their physical, psychological, medical and social needs. The researcher noted that the children feared rejection and isolation; they tried as much as possible to keep their seropositive status a secret.

Grace, an 8-year-old a girl from Kamba ethnic group told the researcher, while looking down playing with her fingers in a shy way with her tone becoming a bit harsh, indicating that she was ashamed of talking about having HIV\AIDS: "I don't like to hear about HIV\AIDS ... It makes me cry".

It is evident that being infected with HIV/AIDS lead to shame and denial for Grace. When Paul, 11 years old, a boy from Kikuyu ethnic group was asked how he felt when he discovered that he had HIV/AIDS, his response portrayed deep inner feelings of shame and denial; he answered the questions leaning on his left arm and facing down: "I felt ashamed, I was not happy". The findings concur with a seminal research by Goffman (1963) (as cited in Brown et al. 2001, p.4) who noted that stigma was caused by "an undesirable or discrediting attribute that an individual possesses" (Brown et al. 2001, p.4), a characteristic or group membership which diminishes "that individual's status in the eyes of society" (Brown et al. 2001, p.4). Campbell et al. (2005) further opined the community's belief that certain behaviors (e.g. homosexuality or prostitution) which had come to be associated with HIV/AIDS due to high prevalence brought shame to those afflicted, made them feel guilty about the disease, and it also

portrayed their families and the community in a disgraceful light leading to their being despised. Herek (1990) and Klitzman (1997) found that such internalized stigma lead to self-loathing, self-blame and self-destructive behavior.

Stigma, and the resulting fear and shame, arises from the concerns about contracting the disease and the fact that it is incurable. Brenda, an 11year-old girl from Luhya ethnic group, with a sad face and shy demeanor, held her hands and spoke with low voice, and portrayed a deep sense of fear. When asked how she felt about her status, she asserted: "I felt very sad". Furthermore, she could not tell how she contracted HIV/AIDS, since she had never had sexual intercourse. She stated: "I have never had sex".

Brenda's response indicates that the child had prior information on one of the key modes of transmission of HIV/AIDS, namely sexual intercourse. It is instructive to examine more deeply the words used by Brenda. Her answer in Kiswahili "sija fanya tabia mbaya" (I have not had sex) translated literally it means "I have not engaged in bad manners" and conveys the community's attitude of frowning upon liberal sex, and how HIV/AIDS was being judged by the community to be synonymous with being promiscuous which was looked down upon, with the disease being seen as punishment for engaging in prohibited sexual behavior (Olenja, 1999; Gelmon et al., 2009). That at this young an age the children recognize this linkage, shows the belief is pervasive in the society (Odindo & Mwanthi, 2008). Two aspects that emerge from this are the close linkage of HIV/AIDS with sex, and the sense of anger and struggle on the part of the children to understand why they are infected. Hunter (1990) and Olenja (1999) both identified the close linkage between HIV/AIDS and sex as a major obstacle to reducing stigma. There was clear evidence of stigmatization through the association with sex.

Sex in most African societies and certainly in the Luo ethnic group the researcher had experience with, was highly regulated and a woman giving birth outside of wedlock was ostracized. The child born out of wedlock could not inherit any property unless the father chose to recognize the child as his own. This acted as a huge deterrent against having sex outside of marriage. With the advent of colonization, attitudes towards sex changed and sex has become a commodity especially amongst impoverished women (Marumo, 2010). The findings are in concert with Roseval (2007) who found that children in such communities lacked opportunities to discuss their fears and concerns about HIV/AIDS. There is clearly a lack of open discussion and appropriate forums for discussing HIV/AIDS since parents rarely discuss matters of sex with their children. This is further complicated by the fact that public discussions of sexuality are a taboo in most African societies.

The study's findings reveal that other major contributors to HIV/AIDS stigma are fear of infection and death, as well as lack of accurate and appropriate HIV/AIDS information (Olenja 1999). As Goffman (1963) proposed, the society seeks to protect itself by discriminating against, and isolating those perceived to endanger it. The researcher found out that parents of children who have HIV/AIDS were themselves stigmatized, and neither confided their HIV/AIDS status to their children, nor let their children know that they are HIV/AIDS positive. The two surviving mothers (of Ruth and Grace) and James's uncle spoke to the researcher after the initial meeting and confided in the researcher that although they knew they were HIV positive and that their children were infected, they had not disclosed this to them. Without such disclosure it is difficult for the parent to prepare the child for life after their death.

Isolation, rejection and loneliness

A conversation with Paul about what he would say to someone who had HIV/AIDS is instructive:

Q: Paul, as a victim of HIV/AIDS what would you tell me?

A: I don't want to tell you (anything).

Ruth a 10 year old girl from the Luhya ethnic group similarly stated:

Q: What would you tell those people with HIV/AIDS?

A: Nothing.

These two conversations are indicative of the fact that persons with HIV/AIDS may find people not willing to talk to them. When asked the same question Joshua just kept quiet and did not answer. This is a form of isolation and rejection and it is particularly sad that these two children who are themselves infected with HIV/AIDS felt they had nothing to say to another person infected with HIV/AIDS. Interestingly both of them, when prompted further, stated that they would advise a PLWHA to go to hospital.

Clare, a 14 year old girl from the Luo ethnic group stated the following about her playmates in the interview:

Q: Do they know you are HIV/AIDS positive?

A: They are not aware.

Q: If they are aware what do you think their reaction will be?

A: They will hate me.

Q: Once they know you are HIV/AIDS they would hate and not play with you?

A: Yes they would not play with me.

And later she stated:

Q: You have told me nobody knows that you are in infected and that's why you have friends?

A: Yes.

Grace, an eight year old girl from the Kamba ethnic group also confirmed she could not confide in her friends:

Q: Can you tell your friends that you are HIV/AIDS positive?

A: I can't.

Q: Why?

A: Because they will start hating and fearing me, and they will not want me near them.

Brenda similarly stated her belief that she would be isolated and suffer loneliness if her friends knew she was infected:

Q: When you are skipping with your friend would like them to know your status?

A: I would not like friends to know my status because they will not play with me.

Clearly, if the information of their seropositive status became known these children feel that they would be isolated and would have no friends to play with. This was also supported by the answers given by the other participants when interviewed.

The findings concur with Odindo and Mwanthi (2008) who found that 43% of their study population experienced stigma, and that separation and segregation were most common forms of stigmatization. People stigmatize others due to fear of infection from the disease (Engender Health 2004). Olenja (1999) found fear to be an important driving factor for stigmatization. Greene and Serovich (1996) found fear of rejection and mistreatment discouraged disclosure. Crandall and Coleman (1992) and Johnston Stall and Smith (1995) all found that lack of disclosure heightened isolation and reduced social support.

The researcher felt that in a way she provided them with an opportunity to discuss an issue that the children did not have elsewhere. All eight children interviewed expressed fear of playing with others erroneously fearing they would infect them. Nearly all of the children stated that they had not been counseled about HIV/AIDS and stated "No-one told me... I do not know the meaning of HIV\AIDS".

Rehm and Franck (2000) found that HIV/AIDS caused stress in families and death of parents caused trauma for children through the constant awareness of the disease and need to manage the threat of stigma.

Psychosocial impact

Most of the children interviewed were still struggling to come to terms with the death of their parents. Brenda an 11 year old girl from the Luhya ethnic group was a good example:

A: My mother and father are the ones who died.

Q: How did you feel?

A: I felt a lot of pain and sadness.

Paul, an 11 year old boy from the Kikuyu ethnic group was interviewed about his parents:

Q: Are mum and daddy alive?

A: They are not alive. They died.

Q: Did they die when you were a young?

A: Yes.

Q: Did you know what killed them?

A: No.

Ruth, a 10 year old girl stated during her interview:

Q: Ruth you told me you stay with your mum what about your daddy?

A: My daddy is dead.

Q: Do you know what your daddy died of?

A: No, I don't know.

Joshua a 10year old boy from the Kamba ethnic group lost both parents while young:

Q: OK are your Mum and Dad alive?

A: They are not alive.

Q: Do you mean to say that your mum is dead?

A: Yes.

Q: When did she die?

A: When I was a baby.

Q: What about your daddy?

A: He also died when I was young.

Duncan, like many of the participants did not know the cause of his mother's death:

Q: But you told me that your mother died?

A: But I don't know what killed her.

The researcher established that the children were deeply affected by the loss of parental protection, affection and support which are key factors in their development. This concurs with Yamuna (2007) who found the third wave of HIV/AIDS hit the children hard through loss of parental affection, support and protection all are key factors in a child's development. From Table 1, it is clear that the children experienced sibling separation. Ruth's mother narrated how her children were being cared for by different relatives. Interestingly, the relatives cared for the children who were not infected but Ruth who was infected was left with the mother.

The study noted that the attitude of guardians, health workers, and social workers, at the orphanages and children's homes towards HIV/AIDS children determined how they coped with stigma. Most of the children's parents were dead (see Table 1). Children often get stressed and traumatized after the death of siblings and/or parents; they needed appropriate care that would guide, mentor, nurture and direct their social, emotional and psychological growth. As noted before, infection with HIV is linked to mental health issues (Ciesla & Roberts, 2001 and Gallego, et al., 2001). The study found that stigmatization could be reduced if the children are given good care and caregivers built up their confidence and maintained confidentiality, encouraging them to seek medication and counseling, in order to survive the difficult and challenging time in school. This kind of support was appreciated by the children although they sorely miss their parents, and helped them to develop trust and live positively. Duncan, a 15 year old boy of mixed Kisii and Kikuyu parentage is a fitting example of this. When told by his uncle to believe in himself, not to be shy and to continue with his life, he says he then felt "happy".

HIV/AIDS stigmatization which results in silence, secrecy, shame and denial, negatively impacts upon children's parental attachment. As Webb (1997) noted, it not only affects care and treatment, it has serious implications for prevention that is critical in a disease with such a long sub-clinical phase. The strain of HIV/AIDS stigma on parental attachment begins when parents fall ill and children's education invariably suffers as they have to drop out of school to take on extra family responsibilities (Mishra et al. 2005). In the long run many are withdrawn from school due to reduced family income and to provide care for ailing parents. The climax of this is when the parents die and the children experience anxiety and fear, are overwhelmed with grief and feel withdrawn. Of the eight children interviewed six had lost both parents and two had a living mother (see Table 1 for the children's demographic data).

Duncan stated that he missed his parents. He obviously lacked the emotional attachment which is important for the development of the child, and had low self-esteem. The children appeared to suffer from psychological trauma of not having closure regarding their parents' deaths. Most of them lost their parents when they were very young and could barely remember them. According to Duncan, a 15 year old boy who had mixed Kisii and Kikuyu parentage, he missed his parents and doesn't know why his mother died. His only confidant was his Uncle,

> *I can only talk to my uncle not anywhere about my status only in the bedroom... where nobody can hear us... I don't like to play with other children because I will infect them... I miss my parents.*

The findings reveal that disclosure of HIV/AIDS status can lead to negative emotions in children. In the only case of enacted stigma documented during the study, Grace, 8 years old, a girl from Kamba ethnic group, disclosed to someone that she was infected and the person told her "sorry" and walked away. She was so affected by this that she became sick. This is the only case of enacted stigma the researcher came across. The researcher noted that the children faced problems of comprehending why they got HIV AIDS. They were uncertainty about their future and several mentioned their fear of death. Joshua, a 10 year old boy from Kamba ethnic group when asked why he was sad, stated "Because I may die". In the event of their parents' death some children are forced to shoulder the social-economic burden of being breadwinners for the family, receiving minimal the input from caregivers, social workers, medical personnel and guardians. Duncan stated that social workers come to visit them, and brought them food and were good to them "but I still miss my parents". James, a 10-year-old boy from Luhya ethnic group said about the social workers:

They brought food for us... they advised us to take our medicine... took us for a walk in the park... They have been good to us but I miss my parents.

The toll of HIV/AIDS stigma on children is heightened and compounded when their HIV/AIDS status is known by friends, neighbors and peers who may not accept them into mainstream society. As Duffy (2005) notes, people may run away from them, and they remain alone with their problems; they are given separate eating utensils and towels; and any of their leftover food is thrown away (instead of being shared with others). The sharing of food is an important communal activity in many African societies and not being allowed to eat together with others is discriminatory and isolating. This concurs with what most of children in the study alleged that if their friends knew about their status, they would not like to play with them because of fear that they would infect them and would even try to avoid them.

Provision of antiretroviral therapy

All the eight children stated that taking the medication was beneficial and that they felt bad whenever they missed their medication. Ruth looked straight in the eyes of the researcher and stated: "This HIV\AIDS medicine makes me feel better, I take them and I sleep". Clare a 14-year-old girl from the Luo ethnic group stated in the conversation:

Q: So Clare, when you take this medicine how do you feel?

A: I feel good.

Q: What if you have not taken it?

A: I feel weak.

Paul, an 11 year old boy from Kikuyu ethnic group stated:

Q: This medicine which you are normally given, does it make you feel bad or good?

A: I normally feel good.

Q: You mean to say when take the drugs you feel better and when you don't take it?

A: I feel bad.

Joshua a 10 year old boy from the Kamba ethnic group was interviewed about medication and stated:

Q: Do you take the medicine you were given?

A: Yes.

Q: How do you feel when you take the medicine?

A: I feel good.

Q: And what happens if you do not take your medicine?

A: I feel bad.

In short, all the participants confirmed the beneficial effects of anti-retroviral (ART) medication. The importance of anti-retroviral treatment was encapsulated in the statement by Clare a 14 year old girl from the Luo ethnic group in her statement:

Q: What would you like people to know about people with HIV/AIDS?

A: I would like them to know that they are more special than anyone in this world.

Q: Why are they more special than anybody?

A: They are special because they take medicine and people don't know their status, because

they are strong enough and they are not weak.

This shows how crucial ART medication is to these children. Closely tied to the issue of provision of ART is the battle over profits for the multinational pharmaceutical firms and the right of less developed countries to produce generic versions of the anti-retroviral medications. In 2001, 39 Pharmaceutical firms sued the South African government and tried to stop it from

importing cheaper generic versions of patented medicines. The case was dropped after an international outcry (CNN news, 2001).

Kaai et al. (2007) found that internalized stigma was measurably reduced after 12 months of ART. It is important for these children to be given access to ART in order to minimize stigma. Abadia-Barrero and Castro (2006) similarly found a shift in the children's stigmatizing experience over the life trajectory as a result of provision of ART services. Deliberation at the 2010 AIDS conference in Vienna concluded that ART reduced the risk of infections and this concludes my findings section.

Challenges faced in research with children

There are various approaches to research with children depending on the researcher's perspective. Recent trends following the acceptance of the UN Right of a Child have been for researchers to emphasize children's voices and for researchers to listen more to children. The researcher approached the research from a social constructivist approach which subscribes to the notion of "understanding children's experiences in ways meaningful to them as co-constructed within the research interaction" (Freeman & Mathison, 2009, p.vi). Freeman and Mathison posit that this approach is based on the notion that all knowledge are "human constructions" (p.1) and are necessarily "mediated by social, historical, institutional and economic conditions" (p.1) and allow for "competing meanings" (p.1) that are contextual and created by the between every unique set of researchers and participants. This approach takes for granted that the children have knowledge of and can make meaning of their experiences within the context of their evolving capabilities (Freeman & Mathison, 2009) or "competent interpreters of the social world" (James, 2001 as cited in Freeman & Mathison, 2009, p.3). Freeman and Mathison (2009) assert that there can be no understanding "without some consideration for history, society, culture and thus any

universal notions of childhood can only be seen as flawed" (p.7). Following from this the researcher had to undertake a lot of background research to understand the historical and cultural influences that could color and inform stigmatization of children in the setting under investigation. Traditional norms that do not encourage children to voice their opinions had to be overcome. A huge challenge was the lack of written literature on the cultures of the diverse (41) ethnic groups in Kenya and on the history of the regions of the capital city of Nairobi.

The interviews themselves were challenging on two fronts namely the maintaining of confidentiality and enforcement of the conditions for ethics approval which meant excluding the parents from the interviews in spite of their very vigorous protests. Interviewing the children successfully also involved negotiating their attempts to deviate from the topic and evade the questions asked. At times it was clear that cultural barriers were at play and that the children did not fee very comfortable discussing a topic that was linked to sexuality with an adult. At other times it was evident that the interrogation was making the children uncomfortable and the researcher had to call a halt to the proceeding to grant the children opportunity to compose themselves, so as not to unduly stress them.

There was also a challenge in breaking through the barrier of being an authority figure and in trying to separate myself from the situation. Next was the issue of winning the children's confidence and assuring them that all data collected was to be handled confidentially. This was important in order to get them to open up. It was a challenge to be able to hear the children and not to influence their answers during the interviews given the unequal power relations. Some researchers posit that question and answer sessions disadvantage children (Freeman & Mathison, 2009). Conveying the cultural aspects of the research was also a challenge. At times what seemed to be obvious to the researcher turned out to be incomprehensible to a reader from a

different environment. The choice of themes and what to highlight in order to emphasize the children's perspective was also a challenge.

Time was an issue in the sense that the researcher needed a lot of time to get to know the children and build rapport with them yet there was a limited amount of time both because of the time available after the ethics approval, time taken to recruit the participants also because the schools were due to close within two months. One child fell ill during the time that the interviews were being conducted and this delayed the data collection by approximately 2 weeks. Given the already tight schedule this delay was a challenge as it delayed the data analysis. Conducting the research alone was a challenge and I missed having my colleagues to share and discuss with.

Punch (2002) enumerated the main challenges in research with children as the imposition of the researchers perspective, "validity and reliability" (p.325), more careful use of language, research context/setting, building rapport, appropriate interpretation of children's perspectives and the use of "appropriate research methods"(p.329).

CHAPTER FIVE

Conclusion

The study sought to answer the key research question in relation to HIV/AIDS stigmatization of affected and infected children in Nairobi. The researcher formulated research questions from which review of related literature was carried out. Purposive sampling was used to select participants who would help her understand the research problem and answer the research questions through the data collected during interviews. The study adopted a qualitative approach since the study was carried in a natural setting when children's experiences and events which were being investigated occurred. The researcher was the primary instrument in data collection whereby she was able to relate well with the children who gave responses that were analyzed in the study. This way, the researcher focused on the children's perceptions, feelings and experiences with HIV/AIDS, their relationships and daily life with peers, family members, teachers and caregivers. However, one undesirable side effect of this strategy was the heightening of stigma as the children were being interviewed. The researcher noted that as she probed the children, some became aggressive, concealed information, digressed from the interview or decided not to talk at all in line with Crandall and Coleman (1992).

The study highlights stigmatization of HIV/AIDS children as one of the challenges facing HIV/AIDS children in an urban center, Nairobi, Kenya. It found that both felt and perceived stigma (as defined in the literature) existed in the form of denial, fear, shame, rejection and fear of verbal stigma/abuse. The study findings concur with and build upon the research findings of Odindo and Mwanthi (2008), Campbell et al., (2005), Roseval (2007) and Engender Health (2004).

The study findings corroborate available literature on HIV/AIDS in Kenya on stigma, HIV/AIDS education, peer education and HIV/AIDS, stigma and stigmatization amongst adolescents and sex education. The researcher believes that this study will add to the pool of knowledge on HIV/AIDS stigmatization in Kenya and the world at large. The study concludes that HIV/AIDS stigma led to fear of disclosure of status for the children and that they lacked avenues to hold discussions in confidentiality and privacy. They were deeply affected by having to keep their HIV-status secret.

This study concludes that stigma takes huge psychological toll on HIV/AIDS children and even their parents, making them not to confide in their children about their status. HIV/AIDS stigma impacted greatly on the social and personal domains of those affected and infected with HIV/AIDS. The children were deeply affected by the loss of parental protection, affection and support which are key factors in their development.

Policy recommendations

The recommendations in this section are a combination of other research, and where applicable, from the specific findings of my research. The study findings concurs with Chesney and Smith, 1999 (as cited in Herek, 1999, p.1110) that the fear of HIV/AIDS stigma and its attendant discrimination does "deter people at risk of HIV/AIDS from being tested" or "seeking information and assistance in risk reduction". In concert with those findings the researcher suggested key interventions to reduce HIV/AIDS stigma among which was: counseling facilities, re-conceptualized educational campaigns that leverage local cultures and epistemologies, ART provision and forums to discuss sex and HIV similar to traditional setups be established in concert with home based care, community mobilization and empowerment to ensure that HIV

stigmatization is reduced. Stigma once entrenched results in active discrimination (EngenderHealth, 2004)

UN Committee on Rights of the Child, (2003) recommends education and training programs that are aimed at changing stigmatizing and discriminatory attitudes towards HIV/AIDS whilst noting that many such programs are designed with adults in mind. Srilatha Batliwala points out that it is not sufficient to merely supply the power over resources to the oppressed, but that it is crucially important to overcome the ideology, value systems and beliefs that shape and sustain power relations (Batliwala, 1997 as cited in Josefsson, 2006). The components of the ideology including educational, religious, legal and political structures need to change in order to alter the power relations and this begins with creation of an environment wherein the subaltern's perspectives and resistance to oppression can be expressed.

Chilisa (2005) states that people of Botswana (and Africans in general), espouse non-western epistemologies that are "complex and multiple, reflecting the interconnectedness that the people have with the environment, spirits, ancestors and every living thing around them" (p.662). This is in juxtaposition to the western analysis, ways of knowing and imposition of sameness (universality) that constrain alternative thought (Chilisa, 2005). Research based on such imposed frameworks, approaches and methods, Chilisa proposes, is doomed to fail because they fail to speak to the researched communities due to their emphasis on biomedical issues at the expense of real experiences. What if the researchers concentrated less on the statistics and begun to query why there are such wide variations in prevalence of HIV/AIDS amongst the provinces of Kenya? What if instead of using billboards and electronic media, the efforts to fight AIDS concentrated on song, dance, drama and other traditional means of communication? What if the impact of HIV/AIDS was contextualized in terms of its impact on society as opposed to impact on the

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individual and framed in terms of the community's cultural practices? Chilisa (2005) proposes that because the local languages and cultures cannot be converted into capital value they are excluded from the global market. Thus the perspective of the patients who fail to complete their prescribed course for example is suppressed and only the statistics of how many fail to do so is captured.

Re-conceptualized Education and training campaigns

One of the key strategies of intervention against stigmatization is education and training and involves educating or sensitizing the community on transmission modes for HIV/AIDS. It is instructive that with over two decades of HIV related campaigns have not changed peoples' attitudes and knowledge (ActionAid, 2009). ActionAid (2009) 48% of respondents feared infection through casual contact and 55% were unwilling to share a meal with an infected person. This naturally leads to the concept that there needs to be a serious re-examination of the current education programs. Nearly all of the participants feared infecting their playmates through casual contact so there is a desperate need for the right kind education. During the study several children expressed fear of infecting their friends and play-mates not knowing that infection through casual contact is nearly impossible. The recommendation to re-conceptualized education is based on the observation that these children were not aware of the fact that they could not infect others through casual contact thus they were stigmatizing themselves and avoided playing with other children on the erroneous belief that they would infect them. This was clearly expressed by Paul an 11 year old boy from the Kikuyu ethnic group (see findings). All children expressed the fear that if their playmates knew they were infected they would be shunned. These children evidently needed to be informed (and convinced) that it is nearly impossible to transmit

HIV/AIDS by casual contact. Similarly their playmates need to be informed and convinced that they are not at risk of infection whilst playing with HIV infected children.

Targeted media similar to Uganda's *Straight Talk* magazine aimed at the young would definitely have a huge impact due to their key role as identified by Olenja (1999). Another example is the country-specific adaptations of the famous *Sesame street* television series to local conditions and their use to convey messages about HIV/AIDS to the young children as is being trialed in Nigeria (Gambrell, 2010). Such education and training can help communities to change their perception (and stigma) towards people (including children) living with HIV/AIDS, to make them more acceptable to the mainstream society. I concur with Chilisa (2005) that we must begin to use ways that "justify the inclusion of African indigenous ways of collecting, analyzing, interpreting and disseminating findings" (p.666). This means using the communities 'belief systems' (p.666) and concept of connectedness to inform HIV/AIDS education by allowing various cultures to name the disease from their perspective (Chilisa, 2005). Re-conceptualized campaigns should leverage local cultures and epistemologies. An alternative approach advocated by Muyinda et al. (1997) involves training of middle aged women to socialize adolescent girls into sex and marriage in a manner similar to the traditional *Senga* institution where the father's sister socializes an adolescent girl child. These modern Sengas occupy a middle ground providing a mixture of modern sex and health information blended with traditional wisdom. Muyinda reports their acceptance by the community and effectiveness in their intervention. This is in line with UNAIDS (2010) which advocates decentralizing and tailoring of responses to local needs and conditions.

Messages need to be conveyed using poems, stories, songs, drama, use of metaphors similes and analogies and socialization that are similar to the ways in which African

communities collected retrieved and disseminated information (Chilisa, 2005; Mutonyi, 2007). Traditional means of sex education through elderly persons such grandparents needs to be explored since many parents find it difficult to talk to their children about sex. Amongst the Luo, for example grandparents had a special relationship with the grand children who slept in their grandparents house after reaching puberty and were jokingly called 'husband' or 'wife' by the grandparents. Mutonyi (2007) and Nyanzi, Pool and Kinsman (2001) identified difficulties in discussing sexual matters in formal or public settings. Anecdotal evidence indicates that discussions of sexual matters in cross generational forums are rare. One child specifically asked for the mother to leave the interview probably due to such unease.

Mutonyi (2007) reports high prevalence of HIV/AIDS in the age group 15-25 years in Uganda, a neighboring country. Media targeting the specific sectors similar to Uganda's *Straight Talk* magazine could go along way towards reaching the youth and other vulnerable sectors to address identified knowledge gaps (Mutonyi, 2007). Quoting past research, Mutonyi (2007) confirms the use of analogies, similes and metaphors as anchors and bridges to new knowledge and effective instructional tools. This education is particularly important for children who are just below the sexually active age.

The researcher feels that children should be encouraged and nurtured with early, appropriate, and relevant information regarding HIV/AIDS, and other related issues within schools. This is inline with UNAIDS Outcome Framework (2009-2011) which calls for empowerment of young people to protect themselves against AIDS and enhanced social protection for those affected by AIDS. As Roseval (2007) noted, stigma is due to fear of the unknown. Although knowledge alone does not fully counter stigma, it is a necessary pre-requisite (Fawole et al. as cited in Sallar, 2009) EngenderHealth (2004) found the lack of

knowledge and association with a degenerative terminal illness were major contributors to stigma and education could lessen this. School-based peer education programs have worked well and need more support. However, since many children are forced to abandon their formal education because of the financial and care implications of HIV/AIDS in the family, innovative out-of-school programs are a priority. Developing a nurturing and safe community-base that can deliver orphan care is critical.

Counseling facilities and forum to discuss sex and HIV/AIDS

The children were evidently deeply affected by the loss of their parents and had yet to come to term with this loss. There exists a need for counseling facilities to alleviate the psychological impact of the loss of their parents and help them deal with the stress caused in their lives by having to keep their HIV status secret. The establishment of counseling a system with middle aged women would also come in handy in providing a valuable safety valve for the children to discuss sex and HIV transmission. Because of the ability of women as mothers to offer compassion, they would be of great assistance to the children in bringing closure to the death of their parents which appears to have been an issue with the children interviewed. Time and time again they told the researcher "I miss my parents". The researcher also had some of the participants drawing close to her a possible indication that they lacked parental/maternal attachment and support and that their mental health was possibly at risk. Such institutions would also close the gap between the provision of material support currently met by non-governmental organizations and the provision of psychosocial support that is currently largely lacking. A valuable by product of the establishment of such institutions might be the alleviation of poverty since these middle-aged women would have gainful employment in this way.

Poverty reduction

One participant Clare a 14 year old girl from the Luo ethnic group narrated how she sometimes went hungry due to not having food. The very fact that surviving parents gave out their children to care organizations, is an indication of their own diminished capacity to care for them due to poverty. In a traditional African society mother would rarely ever give up their children. Olenja (1999) and Carswell et al. (1989) identified poverty as a major contributor to adolescent transactional sex. Extreme poverty certainly entrenches and reinforces the devastation caused by AIDS. Many have ridiculed former South African President Thabo Mbeki's views on poverty as a cause of AIDS but no-one can deny the close links between poverty and AIDS. Parker and Aggleton found that stigma was deeply intertwined with issues of power and difference. Roseval (2007) found that HIV related stigma was merely a trigger for underlying and pre-existing layered stigma within the community. It certainly seems to be a trigger for the underlying stigma against the poor in this case. Chilisa (2005) confirms that in Botswana HIV/AIDS has poverty dimension with the "less privileged, less educated and poorly paid women and girls" (p.674) experiencing the greatest impact. The effect of poverty is made worse by the erosion of traditional structures that would normally have supported the infected and affected children. Many of the poor die not because of HIV/AIDS but because of lack of money to access medication and nutrition to fight off opportunistic infections such as Tuberculosis and Typhoid.

In Kenya AIDS prevalence by province (Figure 1) mirrors the map of poverty. The children interviewed were all from very poor families. One girl, Clare, narrated how they went hungry if they did not receive the food from the hospital. HIV/AIDS, especially within the context of poor households, results in shame, denial, fear, anxiety and suffering. For a reduction

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in HIV/AIDS stigma, there needs to be understanding and action on the issue of poverty aimed at reducing HIV/AIDS stigmatization. HIV/AIDS infection certainly intensifies poverty by consuming the limited resources of the affected families.

Encouragement of residents of Kibera to form small scale co-operatives to improve their lives would help uplift their living standards and provide a means to afford better nutrition and anti-retroviral therapy. In this way the infected could reduce the visible signs of HIV/AIDS and be able to lead a normal life. This would make them less likely to the stigmatized. Whilst interviewing the children it became clear that they always wanted to go to school to appear normal and avoid friends raising questions about their absence. Successful co-operative groupings of women operating water kiosks in Kibera have been reported in the media. Such cooperative ventures can empower the infected and survivors to mitigate the effects of HIV/AIDS and the stigma associated with it.

Home Based care (HBC)

Nyumbani children's home was mentioned by nearly all participants as providing support for the infected children and their families. This home is closely allied with another organization the Lea Toto program that seeks to use the concept of home based care due to the large numbers of infected children needing support. The numbers far outstrip the capacity of the children's home and this is the reason that home based care has been implemented. The study identified Home Based Care (HBC) as a key strategy to be used to counteract poverty, misunderstanding, misinformation and stigmatization. Home based care has become the most important source of care and support for people living with HIV/AIDS. Roseval (2007) found less stigmatizing attitudes amongst relatives. Researchers such as Aggleton (1996), Mamoto et al. (1996), Levine (1996) and Khan and Lernard (1994) have found that increasing numbers of people with

symptomatic HIV/AIDS disease and limited resources for hospital-based care, throughout the world turn to home-based care which is now advocated by many government intervention programs.

Education can be used to get people involved in Home based care (HBC) activities that would help those in close living with HIV/AIDS (Lock, 1997). In addition to community mobilization, the HBC staff can target different groups to address the HIV/AIDS knowledge deficit which is viewed as crucial to the process of reducing stigmatizing behavior. Capacity building for households, estates and children's homes to provide home-based care is important, provided they can manage the stigma associated with HIV/AIDS amongst children in various settings. They would enable the community to respond positively to the plight of the children and provide sympathy and care as well as emotional and financial support.

The researcher found that Lea Toto Outreach Program that is an extension of the Nyumbani Children's Home which offers assistance to a number of the participants was premised on the HBC philosophy and helps approximately 3,000 HIV-positive children with food, clothing and medical care through clinics in six Nairobi slum communities (Nyumbani Children's Home, n.d.). In this way it enables them to stay within their communities and receive care from their close relatives and to reach more children than the orphanage can handle. The program's core principles are basic medical and nursing care, counseling and psychological support, spiritual guidance, relief for social needs, HIV transmission prevention education, promotion of community empowerment/ ownership and self-help (Nyumbani Children's Home, n.d.).

HBC professionals are important in providing strategies for HIV/AIDS intervention. They are aware of friendly policies that work towards reducing stigma and discrimination such

as: orientation of community health workers on HIV/AIDS, accessibility of health services, educating the community, setting up patient support centers, introduction of ARVs (antiretroviral) drugs and integration of VCT services and patient support center. To achieve these objectives, HBC workers need financial support, good policies and operational planning by the government, local and international agencies to be more effective. These resources are needed to cope with the demand created by their good work and avoid disappointments which negatively impact on a program's long term success.

Provision of antiretroviral therapy

All of the children testified to the efficacy of the medication they were given. It is crucially important to maintain the course of medication. The medication slows the progression of HIV into full blown AIDS and allows the children to lead normal lives. The provision of ART is currently threatened by the Global Financial Crisis and only reaches approximately 15% of children (UNAIDS 2009 updates). Kaai et al. (2007) found a marked reduction in internalized stigma after 12 months of ART and increased disclosure to family members and children. Abadia-Barrero and Castro (2006) found similar decreases in stigma as a result of increased provision of ART.

Another intervention that could help reduce the numbers of such children is the provision of AZT for expectant mothers. This medication reduces significantly the chances for virus transmission from mother to child. The widespread provision of free AZT medication would be a valuable goal.

Suggestions for further research

The research study was carried out among eight HIV/AIDS seropositive children in Joseph Kangethe Primary School in an urban, Nairobi, Kenya. Based in the study topic, the

research questions, the research design, sampling procedure and data analysis of this study, the researcher recommends the following for further research. Firstly, similar studies should be carried out comparing with other groups of children in different locations, in other urban and rural settings so as to bolster the validity of the results. Secondly, other studies using both quantitative and qualitative (mixed) methods should be carried out to enable researchers to gain a better understanding of the issues under study and thirdly, I recommend that further studies include variables such socio-economic status, geographical location and school-based factors to determine how these influence HIV/AIDS stigmatization.

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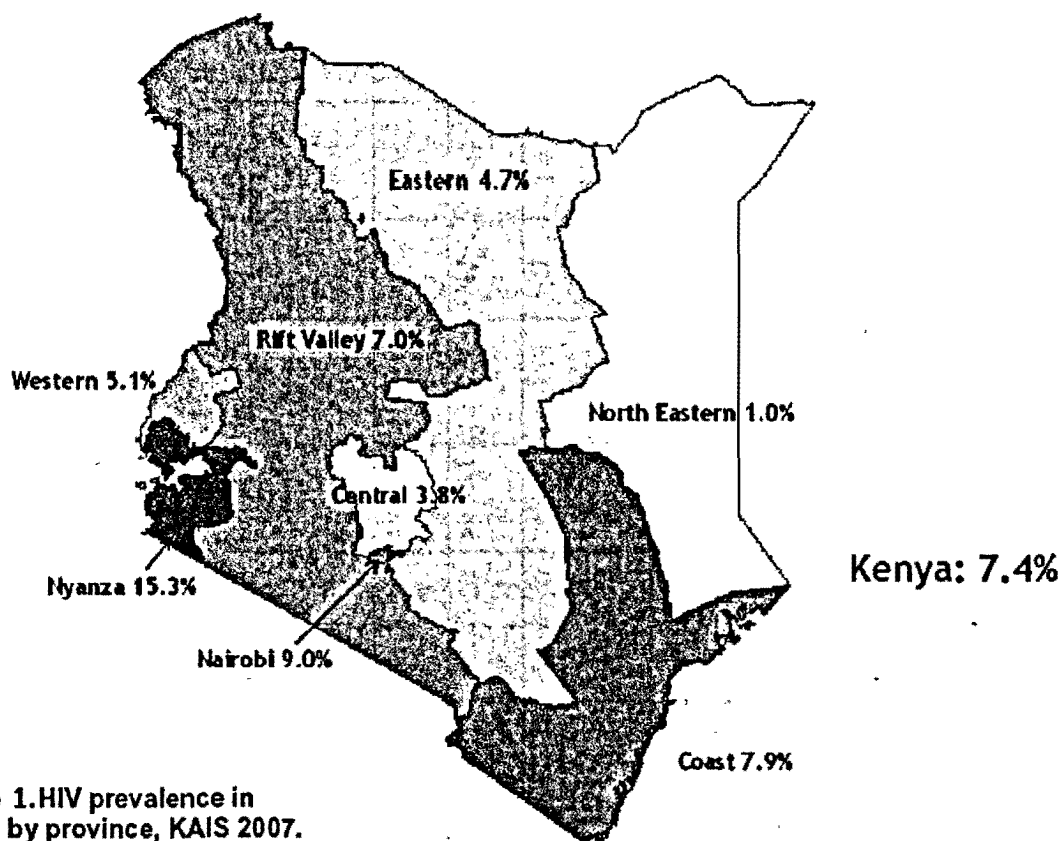
Table 1. Demographic data of the eight participants

Pseudonym	Tribe	Age	Grade	Sex	Siblings	Parents alive?	Principal Caregiver	Income level	Other support
Brenda	Luhya	11	5	Female	5	None	Aunt	< 1 US$/day	Lea Toto / Health workers
Clare	Luo	14	6	Female	2	None	Stepmother	< 1 US$/day	Nyumbani / Hospital
Duncan	Kisii/ Kikuyu	15	7	Male	9	None	Uncle	< 1 US$/day	Nyumbani/ Social workers
Grace	Kamba	8	1	Female	4	Mother only	Mother	< 1 US$/day	Nyumbani
James	Luhya	10	2	Male	2	None	Aunt	< 1 US$/day	Health workers
Joshua	Kamba	10	2	Male	6	None	Uncle	< 1 US$/day	Nyumbani/ Social workers
Paul	Kikuyu	11	3	Male	6	None	Uncle	< 1 US$/day	Nyumbani
Ruth	Luhya	10	5	Female	4	Mother only	Mother	< 1 US$/day	Mother's sister

Nyumbani is short for Nyumbani childrens' home (www.nyumbani.org) caring for approximately 100 HIV positive children.
Lea Toto is short for Lea Toto Community Outreach program helps 3.000 HIV-positive children with food, clothing and medical care through satellite clinics in six Nairobi slum communities. It is principally funded by USAID.

Figure 1

Eastern 4.7%

Rift Valley 7.0%

Western 5.1%

North Eastern 1.0%

Central 3.8%

Kenya: 7.4%

Nyanza 15.3%

Nairobi 9.0%

Coast 7.9%

Figure 1.HIV prevalence in
Kenya by province, KAIS 2007.

APPENDIX A:

Recruitment Flyer

Child HIV/AIDS and stigmatization Study

Be part of Child HIV/AIDS and stigmatization research study

Are you a parent with a child or children who are affected with HIV/AIDS between 5-15 years of age?

Do you want contribute towards making a change in their life, and to be empower them?

If you answered YES to these questions, you may be eligible to participate in HIV/AIDS and stigmatization research study.

The purpose of this research study is to investigate how children with HIV/AIDS are stigmatized. It will inform those who are dealing with children who are infected and affected by HIV/AIDS on ways to mitigate stigmatization and its influence on this vulnerable group and help ensure these children continue to have effective education. Participants will receive a packet of rice as a token of appreciation and refreshments will be served during the interviews.

Both parents/guardians are to accompany their children (5 - 15 years of age) who are eligible to participate. Participation in this study is entirely voluntary and the decision to participate or not will not affect you or your family's future relationship with Joseph Kangethe School or Ryerson University.

This study is being conducted close to Joseph Kangethe School, Joseph Kangethe Road, Kibera, Nairobi. However, information on who participates in the research and any information disclosed during the interviews will not be revealed to the school, the teachers or the head teacher.

Please contact Benta Ogutu Tel. **0721486876** for more information

Ryerson University
Consent Agreement
Research: How are children with HIV/AIDS stigmatized in Nairobi, an urban center in Kenya.

You are being asked to participate in a research study. Before you give your consent for your child to be a participant, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you and you child will be asked to do.

Investigators:

Name of Investigator: Benta Ogutu, B.Ed (ECE), Graduate student, currently pursuing MECS at Ryerson University, Early Childhood Studies, Early Childhood Education, Ryerson University, Toronto, Canada, is the investigator.

Supervisor: Professor Vappu Tyyskä. Dr. Vappu Tyyskä is Professor of Sociology at Ryerson University, and Director of the MA in Immigration and Settlement Studies

Purpose of the Study: To carry out a research on how children with HIV/AIDS are stigmatized in Nairobi, an urban centre in Kenya. In order to help policy makers in the Ministry of Education, Ministry for Children and Youth, NGOs caregivers and parents to understand what happens to children with HIV/AIDS. This will help them to develop strategies on how they can help ensure your child is not stigmatized because of his/her status.

We intend to recruit 4-8 child participants ages 7-15 years for this study and to be eligible the child should be living with HIV/AIDS.

Description of the Study: The researcher will consult your child about their experiences with HIV/AIDS. She/he will be asked to answer questions and the researcher will digitally record the questions asked and the answers the child will give. Your child will be given the first chance to review and edit the material before it is used. The information your child will provide during the study will be kept strictly confidential. The digital recordings will only be viewed by the researcher and her supervisor and will be erased at the end of the study. The child's name will not be used in any report.

The interview and demographic questions will be conducted during one session of 60 minutes duration with a 10 minute break in the middle of the session, which will determine if there has been any changes to the way she/he feels, is treated since finding out she/he is infected.

None of the procedures or interview questions used in this study are experimental in nature. The only experimental aspect of this study is the gathering of information for the purpose of analysis.

Risks or Discomforts: There is minimal risk of harm to your child while participating in this study and there will not be any experimental procedures involved. The researcher will ensure that the questions asked are peer reviewed, ethical and will not make your child uncomfortable. The long-term impact on your child is considered to be minimal. Further risk of harm to the children is to be mitigated by use of pseudonyms, ensuring strict confidentiality, by careful peer review of the methods and close supervision of an experienced researcher. The parent or guardian is to be close by during the interview and easily accessible in case the child becomes

distressed or needs reassurance. Consent and assent is to be obtained from the parent or guardian and the child respectively. Research is to be carried out strictly in accordance with Research Ethics Board guidelines for research involving human participants.

Benefits of the Study: I cannot guarantee, however, that you will receive any benefits from participating in this study. There will be some direct benefits for the child's family, whereby the researcher may carry rice, flour, or beans as a token of appreciation. The child's participation in this study is completely voluntary. The findings will inform organizations working with children and people living with HIV/AIDS, advocacy groups and policymakers on ways to mitigate stigma and its influence upon this vulnerable group and help ensure their continued and effective education. The study aims to highlight and possibly end ways in which children are stigmatized in school settings e.g. in classrooms and at play, in other institutions dealing with children and in the community. The research will give voice and empower the children to reach their potential by talking freely about HIV/AIDS.

Confidentiality: Only the researcher and possibly her supervisor are to have the access to the data, the data is to be locked up until the study is complete or until the research project is successfully defended and then the tapes and video will be erased, or it may be erased immediately the research is over if this is judged by the student and the Supervisor to be prudent.

Incentives to Participate: There will be some direct benefits for the child's family, whereby the researcher may carry rice, flour or beans as a token of appreciation. The child's participation in this study is completely voluntary.

Costs and/or Compensation for Participation: It is not anticipated that the participants will incur any costs during the study. All costs are to be met by the researcher who is to travel to the families' home or any other mutually agreeable and accessible location such as the school (with the parent or guardian's agreement) to interview the children.

Voluntary Nature of Participation: Participation in this study is voluntary. Your choice of whether or not to participate will not influence your future relations with Ryerson University. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty or loss of benefits to which you are allowed. At any particular point in the study, you may refuse to answer any particular question or stop participation altogether.

Questions about the Study: If you have any questions about the research now, please ask. If you have questions later about the research, you may contact.

> Benta Ogutu,
> Graduate student, Early Childhood Studies, Early Childhood Education, Ryerson University, 350 Victoria Street, Room KHS 354, Toronto, Ontario M5B 2K3, Canada
> Email: o2ogutu@ryerson.ca
> Tel. +16479290430

If you have questions regarding your rights as a human subject and participant in this study, you may contact the Ryerson University Research Ethics Board for information.

> Research Ethics Board

c/o Office of the Vice President, Research and Innovation
Ryerson University, 350 Victoria Street
Toronto, ON M5B 2K3
Tel. +1416-979-5042

Agreement:

Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you have agreed for your child/ward to participate in the study and have been told that you can change your mind and withdraw your consent for the child to participate at any time. Withdrawing from the study will not impact in any way on future relations with your school or with Ryerson University. You have been given a copy of this agreement. You have been informed that by signing this consent agreement you are not giving up any of your legal rights.

_____

Name of Parent or guardian (please print)

Consent for the interview and for the taping and video recording of the interview

_____   _____

Name of Parent or guardian (please print)   Date

_____   _____

Signature of Investigator   Date

_____   _____

Signature of Participant or Parent/Guardian   Date

_____

Name of Child (print)

APPENDIX C

Assent Form

Research: - How children with HIV/AIDS are stigmatized in Nairobi, an urban centre in Kenya

Investigators: Names of Investigator: Benta Ogutu, B.Ed (ECE), currently pursuing MECS at Ryerson University is the investigator
Supervisor is Professor Vappu Tyyskä. Dr. Vappu Tyyskä is Professor of Sociology at Ryerson University, and Director of the MA Program in Immigration and Settlement.

Introduction

My name is Benta Ogutu. I am a student at Ryerson University and I am carrying out research.

What is research?

Research is about investigating a problem and collecting evidence so that you and others can know more about the topic. It helps people to understand the topic better.

What is the research about?

The research is about you as a child with HIV/AIDS and, how you are stigmatized and how it affects you. Stigmatization is when people act badly towards you. I will be asking you to tell me your feelings about your status of HIV/AIDS, how people treat you and some of the challenges you as a child with HIV/AIDS face in your school and community.

Why have you been asked to take part?

I have not experienced HIV/AIDS stigmatization and do not know how you feel when you have HIV/AIDS. Am interested in knowing how this affects you. Because you know about HIV/AIDS your views are very important to me.

What will you be doing?

I have planned some activities for us to carry out during the research:-

a.) I will ask you some questions and you can answer the questions if you are comfortable with them. I would like to tape record you voice as you will be speaking to me, after that I will play back the tape recorder for you to hear your voice. If you agree I would also like to video tape the interview

Do you have to take part?

You have a choice whether you want to take part in the activity or not, but I hope you will enjoy being part of the activity and this will be a good opportunity for me to learn from you.

Will anyone be told about what you say?

I will need to talk about the research at the University and to write about it. No one else including your parents and teachers will ever be told what you said.

Name of Child (please print):

I agree to be interviewed and for the interview to be audio and video taped

_____   _____
Signature of Child   Date

_____   _____
Signature of Investigator   Date

APPENDIX D

Interview guide questions

1. What is your name and how old are you?
2. What tribe do you come from and what language do you speak?
3. What is your number in class? What was your number last term?
4. When did you find out that you have HIV/AIDS? Who told you?
5. Has being HIV positive affected your school life?
   Prompts:- Treatment by friends in school, teachers, the Principal.
6. Did anyone talk or educate you about having HIV/AIDS?
7. Do you attend any clinic? Have been given any medication? Have any of your friends said anything about the medicines you take?
8. Does the medicine make you feel different from usual? How?
9. Have you noticed anyone treating you differently after you learned you are HIV-positive? Can you give me an example?
   Prompts:- Parents, brothers and sisters
10. How do you feel about yourself after you learned you are HIV-positive? Do you feel any fear about the disease? Do you feel anger or shame?
11. Can you talk freely about your feelings around HIV/AIDS to anyone? Who would you talk with? Where would you talk with them?
12. Do any social workers come to visit you and your family? If yes, how many times a week or a month do they visit? If no, why not?
13. What do you like to do for fun? Where do you do this? Is it in school, home, church/mosque, or another place?) Do you still do all of these things after you found out you are HIV-positive? Why? Why not?
14. Have you lost a friend because s/he was sick with HIV/AIDS? How do you feel about that?
15. What would you like for other people to know about people with HIV/AIDS?

Interview questions will be the main method of obtaining information. However, if time allows and consent is obtained from the parent/guardians and assent is obtained from the participants and the following data collection tools could also be used in addition

APPENDIX E

DEMOGRAPHIC QUESTIONNAIRE
I would like to start by asking you some background information about you and your family. Some of these questions might not apply to you, and we apologize for this, Please try to be as truthful as possible when answering these questions, but
be assured that the answers you give will be kept confidential

1. Date of Interview: _____ / _____ / 2010
2. Are you Male or Female?
3. What is your age?
4. What grade are you?
5. Who do you live with?
6. What is your religious affiliation?
7. How many siblings do you have?
8. What tribe do you come from
9. What language do you speak?
10. What is your number in class?
11. What was your number last term?

APPENDIX F

Letter seeking permission to contact participants through your school

Benta Ogutu, Graduate student, currently pursuing MECS at Ryerson University,
Ryerson University, 350 Victoria Street Room KHS 354
Toronto, Ontario
M5B 2K3
Canada
Email: o2ogutu@ryerson.ca   Cell: 6479290430

04 February, 2010

Dear Lydia Kagwima, Head teacher, Joseph Kangethe Primary School,

My name is Benta Ogutu and I am in my final year studying for MA in Early Childhood Studies, at Ryerson University, Toronto, Canada. As part of my final year course I need to carry out research with children. Your school, Joseph Kangethe Primary has been chosen since it is the centre of where the type participants required can be found. My topic concerns the ways in which children who are living with HIV/AIDS are stigmatized in Nairobi, Kenya.

My research questions will focus the child's perspective of stigmatization. To collect information for my topic I would like to interview children living with HIV/AIDS. The interviews would take approximately half an hour each.

I will keep you informed of how the research is going throughout the duration of the project without mentioning the names of the children I observed or interviewed. I hope that the research would be of value to your institution in highlighting the ways in which children living with HIV/AIDS are stigmatized.

The study will be a public document, available to library customers. The name of your school and the name of research participants will be kept confidential appreciate your time in reading this letter and will contact you by phone to see if it possible to meet with you to discuss the research further at you institution. If you wish to get in contact with me at any time, my mobile number is +16479290430 and my email is o2ogutu@ryerson.ca

Yours sincerely,

Benta Ogutu

Note: The initial approach to recruit participants through the school was changed to use a flyer and enable the participants to self identify. This was after the initial contact with the gatekeeper.

APPENDIX G

Letter to Parent/Guardian seeking informed consent for a child to participate in a study

Benta Ogutu, Graduate student, currently pursuing MECS at Ryerson University,
Ryerson University, 350 Victoria Street Room KHS 354
Toronto, Ontario, M5B 2K3, Canada
Email: o2ogutu@ryerson.ca   Cell: 6479290430
15 April, 2010

Dear Parent/Guardian,

I am seeking to carry out a research on how children with HIV/AIDS are stigmatized in Nairobi, an urban centre in Kenya

The purpose of the study: - To carry out a research on how children with HIV/AIDS are stigmatized in Nairobi, an urban centre in Kenya. This research will help policy makers in the Ministry of Education, Ministry for Children and Youth, NGOs caregivers and parents to understand what happens to children with HIV/AIDS. This will help to develop strategies on how they can help your child who is being stigmatized because of his/her status.

What your child will be expected do in the study: - The researcher will consult your child about their experiences with HIV/AIDS. She/he will be asked to answer questions and the researchers will digitally–recorded the questions asked and the answers the child will give. The child will be given a first chance to review and edit the material before it is used. The information your child will provide during the study will be kept strictly confidential. The digital-recordings will only be viewed by the researcher and her supervisor and will be erased at the end of the study. The child's name will not be used in any report.

The time required the interview demographic questions will be one session of 60 minutes duration with a 10 minutes break in the middle of the session. There is minimal risk of harm to your child while participating in this study and there will not be any experimental procedures involved. The researcher will ensure that the questions asked are peer reviewed, ethical and will not make the child uncomfortable.

There will be some direct benefits for the child's family, in that the researcher will bring rice, flour, or beans to child's family. The child's participation in this study is completely voluntary. Both you and the child have the right to withdraw form it at any time without penalty, and this will not affect any future relations with Ryerson University. Please read this letter to your child/ward and discuss any questions you may have. Please inform me of any requirements or restrictions you would like me to fulfil. If you agree that your child/ward participates in the study, please sign and return the slip attached below. If you have any questions about the study, please do not hesitate to contact me.

Yours sincerely,
Benta Ogutu

APPENDIX H

Dear Benta,

   Greetings
   Am happy for the interest you have shown to work
 with the children in my school who are HIV positive. We
have quite a number of these children at different levels in
the school.(i.e the children are spread all over the classes... from standard one to standard
seven.)
   You will write and let me know how many of these you> will require, and of course any Other
information you will
 require.

 Regards
 Lydia Kagwima
Headteacher Joseph Kangethe Primary school
P.O.Box 2017-00200
Nairobi, Kenya.

Note: The initial approach to recruit participants through the school was changed to use a flyer
and enable the participants to self identify. This was after the initial contact with the gatekeeper.