

Fall 2012

# Storytelling and Healing: the Influence of Narrative on Identity Construction Among HIV Positive Individuals in Kisumu, Kenya

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## Recommended Citation

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**Storytelling and Healing: the Influence of Narrative on Identity Construction**  
**Among HIV Positive Individuals in Kisumu, Kenya**

Kimberly Leon

Kenya: Health and Community Development

Fall 2012

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## **Acknowledgements**

I would like to thank Caroline Owiti, Yvonne Okundi, Beatrice Ogolla, Bethsheba Moyangi, Mathems Atembo, Adams Milungu, Lukas Myambok, and Lillian Adhiambo of the Women Fighting AIDS in Kisumu office for all of their help, to the Academic Directors and Donna Pido for advising and supporting me, and my roommates, friends, and family for always being there for me. I would especially like to thank Ruth Okoth for her amazing talents and for helping me turn this project into a reality. And to all of the amazing, inspirational people who shared their stories and experiences with me thank you for your time, your care, and your honesty; this project is dedicated to you.

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## **Abstract**

The principle objective of this Independent Study Project is to investigate the influence of storytelling as a counseling method on conceptions of HIV among HIV positive individuals in the city of Kisumu. Interviews with counselors, community health workers, and HIV support group members were used to determine the role of storytelling in the counseling process. Stories and life experiences were gathered and analyzed in order to extract themes and draw a relationship between the act of storytelling and a person's perception of their HIV status. Data was collected at various support groups in the Kisumu area and through the help of the Women Fighting AIDS in Kenya office. Based on the data collected, this study has found that storytelling is primarily a way of creating positive identity change that both aids in the healing process and leads to a reinterpretation of what it means to be an HIV positive individual.

## **Introduction**

More than 34 million people are currently living with Human Immunodeficiency Virus, making it one of the most pressing international health crises of today. Combating HIV and AIDS (Acquired Immunodeficiency Syndrome), by halting its spread, eliminating mother to child transmission, and reducing stigma, is one of the United Nations' Millennium Development Goals.<sup>i</sup> However, since the widespread distribution of antiretrovirals, which manage but do not eliminate the virus from the body, the nature of this condition and its effects on individuals and communities has changed. Where once a positive status was seen as a death sentence, HIV positive individuals can now look forward to a long and healthy life. However, this change does not undercut the important role that HIV plays within a person's life. HIV continues to have diverse social, political, psychological, and physical effects that are unique to each individual. HIV counseling in particular must acknowledge and integrate these various implications of the condition in order to provide adequate support for HIV positive individuals.

Storytelling is one tactic that can be used in counseling, and more specifically in HIV counseling. Narrative is a universal human way of deriving meaning from experience. The freedom that it allows an individual provides a space within which the complex relationships between the experiences of a person's life can be related, organized, and processed.<sup>ii</sup> Thus, storytelling can be an effective way of comprehending and addressing the complex effects of HIV on an individual. One of the primary objectives of this research is to determine the role that storytelling plays in HIV positive person's life. This paper seeks to examine how narrative fits in the counseling and support group settings, specifically addressing the effect of storytelling on the psychological processing of HIV. Further, this research will use the stories collected to examine not only whether storytelling has an affect on counseling, but how this affect is manifested and how it relates to a person's emotional and physical health.

This paper is organized into five major sections: Introduction, Methodology, Discussion and Analysis, Conclusion, and Recommendations for Further Study. The Introduction includes a background on HIV/AIDS specific to the context of Kisumu, Kenya, as well as information on HIV counseling, the use of narrative in the counseling setting, and the principles of narrative inquiry in the healthcare field. The Methodology details the three main research methods used, including counselor and individual interviews, group interviews, and observation. The Discussion and Analysis section examines the data collected, using the interviews and stories collected to extract themes and determine individuals' conceptions of HIV and its relation to themselves and their lives. The Conclusion summarizes the findings of this study and discusses their significance. The Recommendations for Further Research section proposes possibilities for additional research in this field. Following the major sections of the paper, refer to the Notes, Bibliography, and Appendices for more information.

### **Setting and Context: Kisumu Kenya and the HIV/AIDS Epidemic**

Research was conducted in the county of Kisumu, primarily within the city itself and the nearest surrounding villages. The city of Kisumu has an estimated population of 394,000 and is the capital of Nyanza Province.<sup>iii</sup> Kisumu was an important trading city as a terminal for the Ugandan Railway and due to its location on the shores of Lake Victoria. However, the city's economy crashed in the 1980s along with the rest of the country.<sup>iv</sup> Although trade has picked up since that time, Kisumu has continued to suffer from extreme poverty. 48% of the population lives below the poverty line, compared with 29% nationally. It has the highest incidence of food poverty in the nation, with 53.4% of the population below the food poverty line, compared with 8.4% in Nairobi. Additionally, almost 60% of the population live in slums, in semi-permanent

structures with high population densities and shortages of services including electricity, sanitation and access to clean water.<sup>v</sup>

Coupled with its high rates of poverty, Kisumu also has one of the country's worst set of health indicators. HIV in particular is a health crisis in the area, with a rate of 15.3%, twice the national average.<sup>vi</sup> High HIV prevalence as well as high rates of other STIs have been linked to fishing villages on the shores of Lake Victoria, both inside and outside of Kisumu County. Certain cultural practices and beliefs of the area's largest ethnic group, the Luo, are thought to be tied to the high rate of HIV throughout the region. This includes wife inheritance, widow cleansing, polygamy, "jaboya," a practice where female fishmongers have sexual relationships with fishermen in exchange for fish, and "chira," which is a curse caused by breaking certain traditions or taboos.<sup>vii</sup> Other key social factors in the spread of HIV in this region include early sexual debut and marriage, rate of partner exchange, age mixing between non-spousal partners, and male contact with sex workers.<sup>viii</sup> The prevalence of HIV among commercial sex workers is upwards of 75% in Kisumu City.<sup>ix</sup> There are also strong associations between economic vulnerability and higher rates of HIV/AIDS, especially among young women.<sup>x</sup> These high rates of HIV/AIDS have left 40% of children under 18 without one parent and 11% without both.<sup>xi</sup>

The HIV crisis in Kisumu has shown the prodigious gaps in the healthcare infrastructure of the city, in particular the accessibility and reliability of medical services. The types and quality of medical facilities available to the people of Kisumu County range from expensive private clinics to small public dispensaries to large public hospitals, including the Jaramogi Oginga Odinga Teaching and Referral Hospital.<sup>xii</sup> HIV testing, counseling and treatment including Anti-Retrovirals, Septrin and multivitamin pills are free at many of these facilities, but access to these is not universal. Rural areas within the county have significant disadvantage in



terms of distance, and thus cost of transportation, to health facilities.<sup>xiii</sup> Also, due to the high stigmatization of HIV and AIDS in the region, many individuals either do not seek treatment or report using health facilities farther away from their homes to avoid people they know.<sup>xiv</sup> Some will even travel as far as Nairobi for fear of stigma.<sup>xv</sup> Kisumu also has a significant shortage of doctors and other skilled healthcare staff. In 2008, the city had one doctor per 15,182 people and one nurse to every 2,069 people, compared to the World Health Organization's recommended one doctor for every 5,000 people and one nurse for every 400 people.<sup>xvi</sup> Also, some studies have shown that some health professionals in the area reportedly discriminate against HIV positive patients.<sup>xvii</sup> However, HIV testing is mandatory for all patients seeking medical treatment at the public hospitals in Kisumu, and counseling is provided. Although this has increased the number of people who know their HIV status, it has also deterred many who do not want to be tested from seeking medical care.<sup>xviii</sup>

HIV/AIDS in Kisumu is not simply a health issue, but instead possesses complicated social, cultural, and economic factors and repercussions. Governmental and Nongovernmental responses to the epidemic have been challenged to take into account the many facets of the HIV/AIDS crisis in order to stem its spread, combat its stigma, and provide the support HIV positive individuals need. There are over twenty Non-Governmental Organizations in the Kisumu area dedicated to care and support of HIV positive individuals.<sup>xix</sup> An analysis of the aims of these different organizations highlights the main concerns associated with HIV/AIDS in Kisumu today. Some of these vital issues include social considerations, including stigma reduction and community education, disclosure, and behavior change advocacy, personal support including adherence, treatment of secondary infections and psychological support through counseling, economic issues including financial support and income generation, as well many

other topics, including medical male circumcision, the prevention of mother to child transmission, and the care of orphans and vulnerable children.<sup>xx</sup>

Women Fighting AIDS in Kenya (WOFAK) is one such organization dedicated to the support and care of HIV positive individuals. The organization was started in 1994 by a group of women who, newly diagnosed with HIV, were searching for a network of support.<sup>xxi</sup> Now that network extends through seven centers across the country. The organization attempts to address the breadth of challenges associated with HIV/AIDS, including stigma reduction, counseling services (including individual and adherence), group therapy through the creation of support groups, pediatric nutritional care, home based care, economic support and food basket programs for orphans and vulnerable children, and education and training programs, such as awareness creation, behavior change education, income generation training, and stigma reduction education.<sup>xxii</sup> The Kisumu office of WOFAK provides these services to the city of Kisumu and the surrounding villages. The organization is known for keeping in contact with its members and the support groups that it visits.<sup>xxiii</sup> WOFAK provided an excellent base for the research conducted because of its long standing presence in a variety of locations throughout the Kisumu area. Its attention to the social and economic ramifications as well as the psychological effects of HIV constitute a holistic vision of health that supported the aim of this research.

### **HIV Counseling: Addressing the Social, Psychological, and Economic Repercussions of HIV/AIDS**

For those who are HIV positive, knowledge of their status can be a traumatic, life changing experience. Cultural perceptions of HIV, as well as HIV's affect on an individual's life has changed over the last twenty years. With the widespread availability of ARVs, people are

able to look forward to the possibility of a long and healthy life. However, access to ARVs is not synonymous with good health. Mental health, nutritional health, and physical health remain major issues for those who are HIV positive. A holistic vision of health and health concerns is needed to understand the total affect of HIV on an individual's life and to assess the needs of those who are HIV positive.

Ongoing counseling has been shown to benefit those living with HIV both personally and in developing an understanding of what types of support are needed most by HIV positive individuals. To counsel literally means "to advise, to recommend, to advocate."<sup>xxiv</sup> The interpretations of this word in a clinical setting are many, however counseling, and more specifically HIV/AIDS counseling, has some general goals and guidelines. Counseling is most commonly seen as a means of helping people to explore problems and clarify conflicting issues, and subsequently discover and implement alternative ways of dealing with these problems.<sup>xxv</sup> Counseling an HIV positive person requires applying these principles of counseling to the very diverse issues that HIV can instigate within a person's life. HIV and AIDS counseling is different from counseling for other chronic conditions because HIV/AIDS is accompanied by concerns that are not associated with other diseases. There are personal, social, political, legal, and religious ramifications of a positive HIV status that are unique to the individual and must be carefully considered during counseling.<sup>xxvi</sup>

Counseling in HIV/AIDS care must include information exchange, skill acquisition and unconditional emotional support between the counselor, the HIV positive person, and any other deeply affected persons.<sup>xxvii</sup> Counseling should, firstly, help an affected person define the problems associated with HIV, and then enable them to make realistic decisions to minimize the affect that the condition has on their life. Counseling, at its most basic, should provide

information on the following issues: self care, including information on the infection and any attitudes, beliefs, and actions which will protect their immune system, nutrition, physical fitness and rest, stress reduction and awareness of the relationship between psychological health and immune function, and ways of dealing with stigma.<sup>xxviii</sup> This biopsychosocial framework is a method of counseling developed by the United States Department of Health and Human Services that attempts to address the diverse social and environmental circumstances, psychological factors, and biological aspects that interact to make HIV the complicated condition it is.<sup>xxix</sup>

Specific cultural, economic, and social factors further complicate HIV/AIDS counseling in Kisumu, Kenya. Special attention must be paid to the widespread stigma against HIV/AIDS in the area. Stigma can have disastrous affects on a person's mental and physical health. It can prevent someone from seeking counseling or treatment, adhering to anti-retrovirals, or disclosing to their family or partners.<sup>xxx</sup> Equally important is addressing economic hardships and their affects on living with HIV. Behavior change is another incredibly important topic that should be addressed in counseling with specific attention to the cultural beliefs and social practices common to the Kisumu area. Acceptance, adherence, disclosure, re-infection, and the possibility of joining a support group are all important issues that should be addressed during counseling sessions.<sup>xxxi</sup>

### **Storytelling in Counseling: Narrative Theories of Health and Their Application**

*“Narratives often reveal more about what can make life worth living than about how it is routinely lived.”<sup>xxxii</sup>*

## Storytelling and Medicine

The act of creating stories is a natural human process. It helps individuals organize, relate, and give meaning to their experiences and themselves. The stories we tell as humans explore and interpret everything from the events of everyday life, to past experiences, to the age old stories of our societies. The term “narrative” is used often in academic writing, rarely with a concrete definition or differentiation from the term “story.” In this work, narrative can be assumed to mean “the threading together of a set of events or experiences in a temporal sequence in order to make sense of them.”<sup>xxxiii</sup> Although a broad understanding of the word does not distinguish it from the concept of a story, this definition suits the methods of research and analysis as well as the types of stories gathered in this research.

For an individual, storytelling can be a means of interpreting and defining the self. Current literature in the field of personality psychology asserts that identity among adults nearly always takes the shape of a narrative that incorporates both interpretations of the past and an understanding of the current self.<sup>xxxiv</sup> This narrative provides meaning and purpose to life, and the process of revising or adhering to this narrative identity is central to the development and wellbeing of the individual.<sup>xxxv</sup> Gergen and Gergen coined the term self narrative to describe these identity forming stories.<sup>xxxvi</sup> The components necessary for a good self narrative are similar to the components of any good story, including a story goal, events that relate to that goal and the organization of these events in order to achieve that goal. People are exposed to these general components of storytelling from a very early age, and the ability to create causal relationships and follow these principles is important in the development of an individual’s emotional life.<sup>xxxvii</sup>

The active and continual construction of a self narrative has been shown to be an important part of mental and physical health. Within psychotherapy, stories are often used to

explain and organize major events that are causing psychological distress.<sup>xxxviii</sup> The creation of these kinds of stories involves interpreting not only these events, but their emotional effects and their impact on perception of self.<sup>xxxix</sup> Ultimately this can allow a person predictability and control over their own life. Although the relationship between understanding one's life and being psychologically healthy may be obvious, many studies have shown that storytelling has an affect on physical as well as mental health. One particular study demonstrated that writing about personal experiences leads to a decrease in physician visits.<sup>xi</sup> Another reported that among students writing about traumatic experiences, writing produced positive effects on blood markers of immune function. Other studies have shown that writing stories is associated with lower pain and medication use and lower levels of depression.<sup>xii</sup> Whether in written or spoken form, putting lived experiences into a story is linked to both physical and mental benefits across diverse samples.<sup>xiii</sup>

Considering the widely accepted health benefits of storytelling, it is a wonder that storytelling is not allowed greater legitimacy within the clinical setting, outside of psychotherapy. After all, self narrative works to interpret difficult life experiences and, broadly speaking, illness can be one of the most potent challenges to the construction of identity and the understanding of self. Narrative can be a process of identity re-creation and can lead to the reworking of the illness into everyday life.<sup>xiiii</sup> However, the field of narrative medicine is emerging gradually from the theories of narrative, the psychological studies on writing, and the observed relationship between identity and narrative construction discussed above.<sup>xliv</sup> This new movement attempts to shift the focus of medicine from "disease" to "illness," or, in the words of Oliver Sacks,

*“to restore the human subject at the center--the suffering, afflicted, fighting human subject--we must deepen a case history to a narrative or tale; only then do we have a “who” as well as a “what,” a real person, a patient, in relation to disease--in relation to the physical.”<sup>xlv</sup>*

For the patient this means that a new legitimacy is given to their interpretation of illness and lived events. For the health provider, this means understanding that there is more to being a patient than can be captured by a medical synopsis and expanding healthcare to consider the complicated relationship between physical, psychological, and social wellbeing.

HIV/AIDS is one example of a health concern whose affect on an individual reaches far beyond physical affects to have an impact on every area of a person’s life. However, too often HIV positive individuals are unable to access comprehensive medical care that respects the depth and breadth of their illness experience. Immediate post-test counseling and access to ARVs does not always adequately address the profound implications that HIV can have on a person’s understanding of their own life.<sup>xlvi</sup> Storytelling as a counseling method holds the potential to allow for favorable reinterpretation of the HIV positive self. It can also expedite the psychological integration of all aspects of HIV, including its physical, economic, and social demands, into a person’s life. Also, narrative based counseling has been shown to have a particularly effective relationship with members of a stigmatized group. A recent study showed that, among members of a stigmatized group, writing about being a member of that group led to greater collective self worth (the sense of self worth that is from being a part of the group).<sup>xlvii</sup> HIV affects many people around the world whose relationship with public healthcare systems is not ideal. Storytelling as a type of treatment for HIV positive individuals has potential for improving patients’ psychological and physical wellbeing as well as carry out what many

medical sociologists consider health care's primary duties: *"to bear witness to patients suffering and to honor their experiences of illness."*<sup>xlvi</sup>

### **Narrative Analysis and the Experience of Illness**

Understanding the relationship between storytelling and identity change requires acknowledging the discrepancy between reality and narrative representations of reality. Although life stories are often descriptions of real events and real people, narrative itself is a constructive process.<sup>xlix</sup> *"In both telling and interpreting experiences, narrative mediates between an inner world of thought-feeling and an outer world of observable actions and states of affairs."*<sup>l</sup> In other words, narrative is about perception, and objective truth is often irrelevant.<sup>li</sup> Thus, stories can reveal more about the story teller than the story's subject. Personal analysis is at the core of the psychological benefits of storytelling.<sup>lii</sup> Analyzing the interpretive quality of these stories is the basis of another level of narrative inquiry, that focuses on narration as a means of understanding the narrator as an individual, and as a part of a larger cultural moment.<sup>liii</sup>

Narrative investigation looks at stories on multiple levels of analysis. The analysis of the narrated life story looks specifically at the narrator's present interpretation of past experiences and the connections between them. This form of analysis primarily searches for the mechanisms guiding the narrators choices in relationship to the overall thematic orientation of the interview.<sup>liv</sup> Form, including the structure and sequence of a plot, as well as content, can equally be integral to this type of analysis. Similarly, extra-lingual aspects of a story can have as much interpretive meaning as the words themselves.<sup>lv</sup> Verbal stories must take into account the role of audience in the development of a story. Although ideally life stories would reflect only the narrator's interpretation of events and their relative importance, the effect audience has on the focus, form,



and content of a story cannot be ignored. Equally undeniable is the fact that there are as many ways of interpreting a story as there are of telling one. However, neither stories nor their analysis is interested in the discovery of an objective truth. Instead, narrative investigation is primarily concerned with what subject analysis can reveal about the subject experience of life.

In the field of healthcare, narrative investigation examines the relationship between an individual and their subjective wellbeing. In this context, the analysis of illness narratives can offer unique insight into personal conceptions of a particular illness and larger cultural understandings of health.<sup>lvi</sup> Narrative investigation in this field attempts to identify the mechanism of a holistic process of healing that includes not only the physical process of being cured, but also the necessity of psychological healing and the reformation or reinterpretation of identity.<sup>lvii</sup> As already discussed, narrative can be a means of achieving this psychological health and reconstructed identity. This only underlines how narrative investigation can be an effective means of analyzing the personal experience of health and illness. What subjectively constitutes “healing” as well as what it means to be “healed,” can reveal a great deal about the true ramifications of a disease, and thus the types of care and support an illness requires. Within the context of this research, narrative inquiry is used to examine the meaning of HIV and the broader understanding of health within the lives of HIV positive individuals.

## **Methodology**

Various research methods were used to gather life stories, as well as assess the affect of storytelling and counseling more generally on the lives of HIV positive individuals in the Kisumu area. Almost all research was done through the help of the organization Women Fighting AIDS in Kenya. WOFAK is a national organization with an office in Kisumu that serves all of Kisumu County. WOFAK offers educational, psychological, and occasionally

financial support for individuals and support groups.<sup>lviii</sup> The organization provided a medium through which individuals and groups who would be comfortable discussing their experiences with HIV could be identified and contacted.

Information on HIV counseling was gathered through interviews with the four counselors at the WOFAK office as well as through interviews with counselors at three other health facilities in the area. These interviews were used to identify the structure and aim of HIV counseling methods as well as the effects of this counseling. Special attention was paid to the use of storytelling in the counseling setting and its influence on the outcome of the counseling. HIV counselors in the Kisumu area are almost always HIV positive.<sup>lix</sup> These interviews thus provided a unique conflation of personal experience and professional knowledge concerning the psychological needs of an HIV positive individual.

Eighteen individual interviews were conducted with HIV positive individuals. These individuals ranged in age from the early twenties to women in their eighties. They came from both rural and urban settings within the county, but were connected in that they had in the past received counseling support from WOFAK. Ruth Okoth, a counselor and the head of the Treatment, Care and Support Department of the WOFAK office identified persons who would be comfortable discussing their HIV status, as well as their past experiences. Although many of the experiences and challenges discussed in these interviews are common among many HIV positive people in Kisumu, their openness and their view of HIV as a condition and a force in their lives renders them a very unique group of individuals. Interviews with individuals who were uncomfortable with their status, or who had received no psychological support concerning their condition were impossible. However, the interviews conducted show the true success that narrative based counseling can achieve. These interviews were based from a set of open ended

questions concerning storytelling, counseling, and the challenges associated with living with HIV (see appendix). However, almost every one of these interviews branched from this list of questions as certain topics or stories emerged.

Although the individuals were chosen by Ruth Okoth for their comfort with discussing their status, informed consent was gathered from each interviewee. Furthermore, every interview started with the question, how did you become acquainted with WOFAK? The purpose of this was to allow the individual the option of disclosure. In both these interviews and in the group discussions effort was made to allow the interviewees as much freedom as possible in the choice of topic and freedom of conversation. This was meant as a way of allowing the interviewees to avoid topics that they were uncomfortable discussing, as well as a way of ensuring that their vision of HIV's relationship with their lives was expressed and not the researcher's perception of key issues or topics. Interviews were conducted in the language identified as the most comfortable to the interviewee, and Ruth Okoth provided translation when necessary. However, it should be noted that many of the interviewees chose to speak in English to ease communication between themselves and the researcher.

Five support groups were also interviewed during the course of this research. These group interviews were used to ascertain the role of support groups in the psychological support of individuals, as well as the place of storytelling and experience sharing in these group settings. A number of open ended questions was posed to the support group as a whole, after which anyone who wanted to share a story was invited to present. Originally, a group activity involving the creation of a story about an HIV positive individual from Kisumu was planned. The purpose of this exercise was to determine what details, experiences, and challenges the group thought were important enough to be shared with an outsider. However, this activity proved to be

impossible, as the support group was identified as a “place of reality,” where stories were told, but not made up.<sup>ix</sup> These group interviews were carried out during the groups’ normal meeting time. This allowed the researcher to observe the rest of the meeting, after conducting the interview. From these observations, the use of storytelling in the support group setting could be more concretely identified. Also, these observations were used to compare the types of stories told to an outside researcher and the types of stories told amongst other members of a group.

WOFAK’s interactions in the community were also observed. Meeting with support groups for educational purposes were attended, as well as meetings with the heads of community groups and other NGOs. These meetings and observations were important in determining the kind of language used to discuss HIV and the common issues associated with it at various levels of community involvement.

Finally, observations were made of the healthcare facilities available in the Kisumu area. The East Kisumu District Hospital, the Provincial Hospital, St. Monica’s Hospital and the Rabour Clinic were each visited over the course of the research. Formal and informal interviews were conducted with employees at the different facilities concerning the services they offer, the populations they serve, and the challenges they perceive in the community. Further, informal discussions of these different health facilities was conducted with the workers at WOFAK, exploring their own and their clients experiences and opinions of the healthcare options in Kisumu. These observations and discussions were used as background information to investigate the accessibility of support for the physical and mental health of HIV positive individuals.

## **Discussion and Analysis**

### **Storytelling and the Healing Process: Identity Change**

There are a thousand ways to interpret a story, and the stories gathered during this research contain a wealth of information about HIV, health, Kisumu, and life in general. This paper will look specifically at the theme of identity change as a part of the healing process. A changed conception of self is a striking feature of every one of these stories and a feature, moreover, that guides the path of each story and the chosen outcome. From these initial observations, the stories were analyzed more closely to identify just how this identity change comes about and how it is related to the healing process.

Identity change occurs in almost every one of these stories. However, the initial identity change in many of these stories is imposed. When asked what they would want to tell someone who had just found out that they are HIV positive, more than two-thirds of the interviewees named acceptance as the first step.<sup>lxi</sup> But what is acceptance, and what needs to be accepted? A closer look at these answers reveals that to many there is no differentiation between acceptance of status and acceptance of self. These terms are interchangeable in the narratives.

*At first I denied. I said no, it won't be like that. But as the time goes illnesses come on and off, on and off, and then I just accepted myself. Let it be the way it has been found.*<sup>lxii</sup>

In the first sentence the subject of acceptance is the self. However, the switch to the use of the word “it” in the second sentence represents the change in status as what must be accepted. The seamless shift in subject shows how closely linked self and status are in the narrative. This suggests a conflation of the person and the virus. It is this new HIV positive identity that needs to be accepted. The fact that a change in HIV status necessitates acceptance of oneself at all further shows how truly life changing HIV can be. A positive status becomes a fact of identity that must be accepted as the first step to healing.

This is further represented in the range of conceptions of stigma. Stigma is commonly defined as a mark of disgrace associated with a particular circumstance or quality.<sup>□</sup> However, throughout the course of these interviews, a more complex vision of stigma emerged. For many of the interviews, the first mention of stigma was in relationship to oneself.<sup>lxiii</sup> Although many told stories of family members or friends that stigmatized them and all identified stigma as a problem within their community, these were not as central to peoples' stories as moments of stigma within oneself.<sup>lxiv</sup> When pressed about the meaning of stigma or how stigma could be combatted, many focused on themselves and other HIV positive individuals.<sup>lxv</sup> When asked how her support group works to reduce stigma, one interviewee replied,

*So when you go there you saw many things you saw many people. So I see you, I see this one and you start to feel okay. You don't see you are the only one having that thing.*<sup>lxvi</sup>

She has identified that the main source of stigma reduction is in the members of the group, not in the community. She has also identified that stigma can be something personal, between an individual and their understanding of HIV. One individual defined this a "self stigma," but many mentioned it, simply referring to it as stigma.<sup>lxvii</sup> This understanding of stigma suggests that these individuals think that a person's relationship with their HIV status is more important than the community's opinion of that status.

This does not mean that stigma in the community has no affect on these people. However, when stigma is described, it is often filtered through an individual's understanding of himself.

*Because if you stigmatize yourself, it is even worse. Let people stigmatize you, but don't stigmatize yourself. The first thing you have to do, you have is to accept that I am HIV positive. And this is my way to live.*<sup>lxviii</sup>

This quote suggests a causal relationship between community perception and personal perception. Perhaps misconceptions generated in the community are the basis of stigma, but these individuals' understandings of stigma suggest that it is most detrimental when it comes from oneself. Within an individual, stigma is the opposite of acceptance, and the strive to eliminate stigma is actually just another way of achieving self acceptance. This reinterpretation of the word stigma further suggests how moldable the language of a narrative can be. The evolution of the word in this context emphasizes the true importance of self acceptance and acceptance of status for these individuals.

A change in status is an attack on an individual's identity, but how is this prized acceptance of self achieve? From the narratives at hand, the process of acceptance often emerges as a reinterpretation of this forced identity change. This means another, now purposeful, change in identity, which takes the shape of a recreation of what it means to be a person who is HIV positive. This can be seen in the larger story arcs of sickness and healing that emerge throughout an interview. Almost no interview begins with a person being tested for HIV. Instead, stories start much earlier, usually when they first became sick.<sup>lxix</sup> In some cases, stories start even as much as ten years before the person discovered that they were HIV positive.<sup>lxx</sup> HIV may be a major actor in all of these stories. However, almost every single story begins with sickness and ends with health. Although during most of these stories, finding out a positive HIV status is a part of the illness portion of the narrative, healing is still possible. Many mentioned healing in their descriptions of their life stories,

*In our group we are not sick nowadays. We are healed. We are just living with the condition, but we are not sick. Those who have not gone for the VCT they are the ones*

*who are sick, because they do not know their status. Us, we know our status, so we know how to live.*<sup>lxxi</sup>

In this quote, this individual identifies HIV as a condition, not a sickness. This is common among the interviewees.<sup>lxxii</sup> However, many acknowledged that at first they thought that HIV was not only a sickness, but was synonymous with death.<sup>lxxiii</sup> This means that this person's understanding of HIV has changed. Reinterpreting HIV requires also reinterpreting what it means to be HIV positive. In this quote the interviewee asserts that not only is living with HIV and feeling healthy possible, but that healing is associated with knowing one's status and knowing "how to live."

Another way that these interviews reflect a reinterpretation of what it means to be HIV positive is the common mention of being "free." While explaining her methods of counseling people to accept their statuses, one interviewee demonstrates what it means for an HIV positive person to be free,

*I have asked people, why would you die from HIV? Because you can't leave the virus to kill you, because there is a way to be free from the virus. Even if the virus is not gone out of you, you can leave. You can go back to your work. You can do other things.*<sup>lxxiv</sup>

She expresses a changed relationship with HIV, using the word "free" to connote permanent and meaningful change, much like healing. However, the narrator admits that the virus does not leave your body. Freedom in this case is not literal, but psychological freedom from the common understanding of HIV as sickness and an HIV positive person as sick. This interviewee reasons with her audience "why would you die from HIV?" She, and in fact every interviewee, identified in their relationship with HIV the possibility of choice.<sup>lxxv</sup> They can control their relationship



with HIV. Thus, the HIV positive person changes from being the object of HIV as a sickness, to being the subject of their own story, of which HIV is only a part of plot.

### **Mechanism of Identity Change**

A simple question posed to each interviewee asked, when do you tell stories and why? The answers were overwhelming. Every interviewee and every group identified story telling as an essential part of their relationship with HIV.<sup>lxxvi</sup> The ease with which they shared their stories, even with an outsider, as well as an almost practiced air given to the first lines of their stories demonstrate how common telling their story is for many of these people. However, more important than whether storytelling is helpful, is the question, how is storytelling helpful? Many people cited dissemination of information and encouragement, as well as a feeling of pride and relief, as the main benefits of telling one's story.<sup>lxxvii</sup> However, when examining the stories more closely it emerges that, although these answers adequately explain the role storytelling plays in their lives, there is the possibility of a deeper relationship between storytelling and the healing process. This paper proposes that the link between them is identity change. As a whole, these interviews establish storytelling as a practical method of dealing with the immediate present, a way of organizing and understanding the past, and a means of creating a workable identity for the future.<sup>lxxviii</sup>

When asked how story telling is helpful, the most common answer was that storytelling was a useful way of gaining information. News about medicines and treatments, childcare, financial support, and information dispelling some of common misconceptions about HIV are the main topics of many support group meetings.<sup>lxxix</sup> One individual cites this availability of knowledge as the main reason support groups are helpful:

*It is helpful because we learn many many things in the support group. We learn issues of positive living in the support group. We get teaching from the doctors and medical workers and even social workers, from organizations. They come and teach us, so support groups we meet various individuals. We get experiences from many, many people.*<sup>lxxx</sup>

This focus of education underscores one of the main reasons that support groups are so important. With knowledge, living a healthy life with HIV is very possible. However, HIV is a complicated condition, and from the medicine to the prevention of its spread to the diverse signs and symptoms of AIDS, a broad range of information is needed. Support groups offer a uniquely effective means of disseminating information on HIV, because they are self-initiated and sustainable, a safe and intimate space, and most often separate from NGOs and the public health sector. In one interview, an interviewee lamented the end of his support group but reassured me of its lasting affect, “*New knowledge cannot be rubbed off. What you have heard you will still maintain.*”<sup>lxxxii</sup>

However, personal stories convey much more than just information about HIV and AIDS. People readily remarked that sharing or storytelling can be the difference between dying of AIDS and living happily with HIV.<sup>lxxxii</sup> There are practical reasons why disclosure is so important. Several interviewees explained that adherence is much easier when a person is open with the people they live with. In these open settings, HIV becomes a normal, communal task.<sup>lxxxiii</sup> Remembering medicine, drinking enough water, and keeping proper nutrition, are all essential to good physical health when HIV positive and are less daunting in a group setting. However, some interviews hinted at a more complex relationship between not disclosing and not adhering to the ARVs.

*After you have accepted you will adhere, it is when you will join these support groups. If you don't accept you will keep on doubting yourself. Even you go to a health facility and you see someone you know you will keep running away, you won't take your medications.*<sup>lxxxiv</sup>

This quote suggests that not being able to adhere to the ARVs, much like not being able to disclose their status, is a symptom of self-stigma and thus poor psychological health. This is just a further example of the importance that these interviewees place on acceptance of self and status.

Many interviewees also emphasized the dramatic impact that listening to stories can have on an individual's understanding of HIV and how to live with HIV.<sup>lxxxv</sup>

*I always give them my testimony. What I have seen, what I have passed through. They are simply swayed through what they see from me.*<sup>lxxxvi</sup>

In this quote, a story becomes a way of connecting with another person and finding solace in shared experiences. Occasionally, it even means acknowledging that someone has faced more challenging situations than oneself.<sup>lxxxvii</sup> Many individuals remarked that finding out their HIV status made them feel alone, especially if they felt uncomfortable disclosing to friends or family.<sup>lxxxviii</sup> Hearing other people's stories helps a person realize that some of the challenges of living with HIV are universal. One woman described just such a feeling when relating her first experience with a support group,

*I was totally down and I was very weak. So as time goes, somebody introduce me to WOFAK. They used to have group therapy where people would go to share their ideas. So when I went there I saw very beautiful ladies, very fat and very happy. And you know I thought I was the only one because I had never been into that status... So from there I*

*started picking up, I could see that I was not the only one and I could see that they were very happy. And that also made me to heal faster. So I just picked up from there.*<sup>lxxxix</sup>

This quote suggests how being a part of a support group can dispel the feeling of isolation, common to many newly diagnosed people, and can help to create a sense of communal identity, centered on a shared status and a shared history. This quote also suggests these shared experiences can also engender a sense of hope for the future in the listener. Several interviewees explained that to a newly diagnosed person, being told that it is possible to live a happy and healthy life with HIV is different from seeing a person who surprises you by telling you that they are HIV positive.<sup>xc</sup>

Seeing another person's success combined with knowing of their previous struggles is an effective method of counseling. Many of the counselors and Community Health Workers explained that telling their story was one of their most potent weapons in counseling an individual.<sup>xc</sup>

*I encourage them and I become an example... And then I told her, "You see I am HIV positive and I am not ashamed. Why are you not now talking?" And I told her, "please talk. HIV is not killing anybody unless you close your mouth."*<sup>xcii</sup>

Being an "example" was a common tactic among many of the counselors.<sup>xciii</sup> In fact, in the Kisumu area, it is strongly encouraged that HIV counselors be HIV positive individuals.<sup>xciv</sup> This ensures a greater level of understanding between counselor and patient and also gives the patient a concrete example of the possibility of success. As this quote explains, success with HIV is not just being physically healthy. When this counselor says that she is not ashamed, she is assuring her patient that whatever sense of fear or shame she is feeling can also be overcome. The

previous quote also suggests this, as witnessing other people's happiness helped that individual to feel happy and to heal.

Telling one's own story is equally as beneficial as listening to others. One interviewee described how she felt afterward,

*You feel relieved. You feel good. At times you have a burden with yourself. You think, I am the only one. Where did it come from? Who gave it to me? And if you share, you see that I should not think about that. There is nothing in thinking about that. Life should just continue. You get relieved and you feel very comfortable. Just like now I am sharing and I feel very comfortable. It is very nice. And I really enjoy sharing.*<sup>xcv</sup>

This quote suggests that even talking to an outsider years after accepting one's status still creates a feeling of pride and comfort in some individuals. Several words appeared again and again in peoples explanations of how they feel after telling a story. "Relief," "pride," "comfort," "happy" and "good" were the most common.<sup>xcvi</sup> All of the interviewees said that they felt better after telling a story.<sup>xcvii</sup> This quote suggests that sharing as well as hearing stories enhances a sense of common identity, by explaining that sharing relieves the feeling of being "the only one." Thus, storytelling is a reciprocal process, where the role of audience and narrator alternate freely and sense of belonging and understanding is formed in the face of the communal challenge of living with HIV. Thus, either in a group setting or a counseling setting, one of the major goals of storytelling is the creation of a communal identity. This shared understanding of HIV and self allows the counselor or the counseling members to communicate strength and comfort.

All three of these uses of storytelling relate to understanding and coping with present challenges and situations. However, storytelling is also useful as a process of organizing and understanding one's own past. In the field of narrative psychology, this process of reflecting on

and analyzing a difficult experience with an openness to learn from it is referred to as exploratory narrative processing.<sup>xcviii</sup> Stories in a counseling or support group setting constitute these types of narratives because they require the teller to reflect on past events, draw connections between them and present them coherently to an audience. Many of the stories told in these interviews reflect aspects of narrative processing by including not only stories of life but also explanations of the internal processing that accompanies these stories to the researcher as an outsider.<sup>xcix</sup>

*I always say that being HIV positive is like being saved, like starting a new life altogether. It is like being born again because you have to change everything, from what you're eating, you have to also change friends because there are people who will welcome you and there are people who won't welcome you. It could be your relatives, or even your parents or your siblings, Some can even just deny you because of your status because of the lack of knowledge. So it is upon you as an HIV positive patient, take it upon yourself to tell them that HIV does not kill, it is just a condition.<sup>c</sup>*

Within this quote the teller describes events that have happened in her life. Many are topics that she will describe on a more personal level later in the interview. However, in this quote she introduces them as impersonal events. They are presented almost as steps that must occur to achieve the “new life” that she is describing. This suggests that she has reorganized these past experiences as events that have led her to her current understand of HIV as a positive life changing experience. By explaining them in this way, she is depicting them through the lens of her current understanding of HIV. This is an example of coherent positive resolution, which is the construction of a coherent and complete story of a difficult event that ends positively by

conveying a sense of emotional resolution.<sup>ci</sup> In this case, the story explains and justifies the way this individual feels about her HIV status.

The depth of this positive resolution are demonstrated throughout the rest of the interview. Often when asked about a challenge in her life or how she previously viewed herself or her status, she would answer but quickly redirect her answer towards her current feelings. A reminder of her achieved sense of wellbeing was present in her every answer. This tendency shows her commitment to her current identity in relationship to HIV. This positive resolution is also conveyed in this interviewee's method of repeating certain phrases and concepts, throughout her story and her answers to the researcher's questions. For example, describing HIV as "being saved" is a theme that she will mention many times over the course of the interview.<sup>cii</sup> These commonly repeated phrases suggest that she has found certain concepts that fit her understanding of herself and her status. These phrases allow her to communicate a kind of motto related to her experience. This motto and these phrases as a part of her conception of her experience with HIV are also a part of her identity. They demonstrate how organization and reinterpretation of past events is critical to the recreation of an identity that positively reinterprets what it means to live with HIV.

The affect of storytelling on conception of HIV shows that the creation of identity is both personal and communal. Sharing with others and listen to their stories forges a communal identity, in which people can empower each other to accept their status and their changed selves. Reinterpreting one's own past allows a person to create a life story that reflects and reinforces this new identity. These sources of self empowerment converge to create a workable identity for the future.

*Sometimes you can have so many thoughts in your mind that you just want to die. To stop the drugs and die. But once somebody talks to you and encourages you, and you come back to your senses, and you see again how to continue.<sup>ciii</sup>*

This quote shows that even once a person has accepted their status and themselves, the challenges of living with HIV do not disappear. Seeing a way forward is the reason acceptance is so central to living positively with HIV. Instead of being defeated by the many dimensions of living with HIV, this reformed identity and understanding of HIV provide a base of strength through which these challenges can be met and overcome. This quote suggests how storytelling can be the key to seeing the way to continue. Through the refined identity that the use of storytelling can create, the future is no longer daunting.

### **Manifestations of A New Conception of Self**

Although storytelling was important to every interviewee, and identity change was an aspect of their changed understanding of HIV, identity change did not manifest itself in the same way in every individual. However, some common results of acceptance and a changed sense of self emerged throughout the interviews, including a sense of responsibility for their own and for their community's health, and the integration of HIV into everyday life.<sup>civ</sup> These are aspects of living with HIV they did not have before they accepted their status, but that they now considered the most central to their lives and the most important to communicate to the audience. They are also the features that they use to explain why the way they live is the way to live positively with HIV.

Many of the interviewees, as a part of expressing their successful relationship with HIV, described how they fit HIV into their every day life.<sup>cv</sup> Combating the everyday issues of adherence to the ARVs, being careful to take these drugs exactly twelve hours apart, eating well



and drinking a lot of water, limiting stress and other psychological factors that can lower immunity, and seeking treatment immediately if they feel sick are just some of the ways that everyday life has to be adjusted slightly in order to live positively with HIV.<sup>cvi</sup> However, another aspect of integration is normalizing HIV. For many, normalizing HIV means allowing it to be an everyday affair instead of a scary and deadly foe.

*She is very much ok. She is doing things as normal. She is the way she used to be even before.*<sup>cvii</sup>

This quote suggests how HIV, in order to be completely accepted, has to become not the central concern of a person's life, but just another part of the everyday. One of the central themes of many of the stories of acceptance was the realization that life continues and that an HIV positive person "will just die like other people."<sup>cviii</sup>

Responsibility is another one of the major themes that emerged as a part of people's explanation of their relationship with HIV.<sup>ciX</sup> In terms of one's own health, responsibility is a part of the integration of HIV into everyday life. Although it is very possible to live a healthy life while on ARVs, taking careful care of one's health is more important than it is for a person who is not HIV positive. However, the sense of responsibility that emerges through a person's experience with HIV is not just for one's own health, but also for the health of the community. Many of the individuals interviewed became counselors or community health workers after coming to terms with their status.<sup>cx</sup> When asked why he decided to volunteer as a community health worker, one man said,

*My home is just here so I am interacting in the community very well and I have seen life. I have seen life throughout my days, from the time I know my status up to now.*<sup>cxI</sup>

This quote suggests that he was moved by his own experiences to help others in the community who may be facing the same trials. Many interviewees suggested that the people who helped and encouraged them before they were tested or before they accepted their status were another part of the reason they have decided to volunteer in their community.<sup>cxii</sup> This sense of responsibility may also in part relate to the communal sense of identity that emerges from group membership. A sense of shared challenges transforms into a responsibility to help alleviate those challenges for others if possible.

Ultimately, both responsibility and integration are a part of many of the interviewee's definitions of being healthy. Remarkably many described health as much more than just the absence of illness.<sup>cxiii</sup> One woman described being healthy as being "*physically fit, spiritually fit, emotionally fit, and also financial status.*"<sup>cxiv</sup> She was not alone in including psychological and economic wellbeing in her definition of health. Although it is difficult to know that this understanding of health is caused by a relationship with HIV, there are several reasons why an HIV positive status could lead to this conception of health. CD4 tests, which are available to HIV positive individuals on a fairly regular basis, are a representation of the health of a person's immune system.<sup>cxv</sup> Regular access to these tests allows individuals to understand what affects their immunity. This can include physical changes, such as illnesses, but can also include psychological problems. One woman explained, "*what gets most people is also stress. Once you are stressed your CD4 will automatically go down.*"<sup>cxvi</sup> Economic wellbeing was also commonly mentioned as a health concern. Multiple people explained that this was related to stress and more directly to the ability to buy enough food, and the right kinds of healthy food.<sup>cxvii</sup> Accepting responsibility for one's diet, stress, and the other aspects of living with HIV was mentioned by several interviewees when they described why they feel healthy.<sup>cxviii</sup>

One interviewee was not HIV positive, but instead cared for an HIV positive grandchild. When asked what she thought being healthy was she said she was healthy because, “*I am immune, not having that HIV or certain diseases or other diseases.*”<sup>cxix</sup> This further suggests that HIV positive individuals’ more holistic understanding of health may be related to their status. HIV is at its core a health concern, and thus everything that affects it becomes a health concern as well. Further, as already discussed, feeling healed is a part of the positive reinterpretation of a person’s identity. In order to feel healed, HIV must be reinterpreted as a condition instead a sickness. This reinterpretation can also be a factor in a person’s larger understanding of health. To these interviewees, acceptance is a necessary part of dealing with a positive HIV status.<sup>cxx</sup> Thus, acceptance and the psychological wellbeing that it creates are part of a person’s health. In other words, a holistic conception of health can be a representation of a reformed relationship with one’s HIV status.

### **More Than Just Identity Change**

Importantly, this reformation of identity accounts for more than just the integration of HIV into a person’s life. Reinterpreting what it means to be an HIV positive individual is not just about redefining the self. It is about redefining everything, including HIV itself, in response to a new identity. At its most far reaching, identity change can be a means of creating a “new and enhanced place for the patient within the social world.”<sup>cxxi</sup> Almost all of the individuals interviewed showed this depth of change in relationship to their own lives.<sup>cxxii</sup> This can be seen through a closer look at the role of audience in story formation and delivery.

The question of audience in narrative inquiry asks who a narrator is talking to, but in this case I think a more accurate question is who the narrator is talking against, who they are proving wrong. Resistance is a common theme among many of these stories. People talk of resisting

death, resisting the urge to give up, resisting families and communities who abandon them.<sup>cxxiii</sup>

One of the most common sources of triumph in these stories is the sense of success derived from proving everyone wrong.

*Nobody knew I was going to come up alive, everybody knew I was going to die.*

*Everybody knew that I was dying. But now I am okay, I am able to do my things, I am very able to do things. I am very strong.*<sup>cxxiv</sup>

Within this quote, the interviewee defines her health in opposition to the people who doubted her. Asserting her wellbeing becomes a way of resisting not only HIV as a condition, but the ignorance and stigma of members of her community.

This use of narrative as means of resistance manifests itself in many of the stories as a turning point or moment calculated to surprise the audience.

*I told the counsellor, “I am happy.” And he just looked at me, “What do you mean?*

*You are happy? But why? I thought you were going to cry and to pass.” And I told him,*

*“Look here, ten years down the line I have been suffering and I didn’t know the problem.*

*And now I know the problem. I know what to treat.”<sup>cxxv</sup>*

This example demonstrates multiple levels of resistance, both to a character within the story and to the audience. A dramatic pause after the phrase “I am happy,” gives me, as the audience, time to react to this unexpected statement. As a way of enhancing a narrative, these types of phrases attempt to challenge an audience’s preconceived notions of HIV.

Analyzing these narratives as narratives of resistance contextualizes them within larger cultural and social influences on identity. These narrative can become a source of social empowerment for the storyteller. In one group meeting, a man described to me his journey from drug addiction and homelessness to finding out his HIV status and turning his life around. He is

now a single father caring for four children, but he asserts how healthy he feels.<sup>cxxvi</sup> A feeling of pride in one's change was common among many of the stories.<sup>cxxvii</sup> Finding out one's status can be more than just a turning point in a story of sickness and healing, it can be a more important turning point in one's life.

Another woman found a sense of solace in her husband's death, because she was finally allowed to openly take medication, and she was able to run and expand her husband's shamba (farm) in order to ensure her family's continued economic stability.<sup>cxxviii</sup> Thus for many, resisting stigma and preconceived notions of HIV allows these individuals a means of resisting other norms of identity. Even though this woman found herself disempowered by her gender, her status, and her widowhood, she was able to defy gender norms and successfully run her family's farm. Not every story of HIV is a challenge to common codes of identity. However, even being part of a group is a form of social empowerment, through the income generation activities and informational sessions that they provide. Even this is a challenge to the helplessness that many uniformed people see as the result of being HIV positive.

Several interviewees also suggested that knowing one's status and being HIV positive is better than not knowing one's status,<sup>cxxix</sup>

*And the only worried people are the people who are negative because they don't know when they will become positive. But we are positive, we live when we know because we teach ourselves how to live, and not to infect others, and also how to not be reinfected by others. So we live happily. We are even more happy than the negatives.*<sup>cxix</sup>

This quote focuses on the importance of knowledge in relationship to living positively. The use of the phrase "teaching oneself" suggests that the process of learning how to live with HIV is at least partially internal. Thus, teaching oneself is a way of achieving a kind of final understanding

of one's relationship with HIV that those who are not HIV positive cannot have. Acceptance may be the first step, but reaching a point where one would not look back, where one would not want to change one's status for anything, where one can say that his life is better now than it was before, is true positive closure.

## **Conclusion**

The findings of this research conclude that storytelling is an indispensable aspect of HIV counseling in both individual and group settings. The stories and interviews of this research suggest that storytelling is the main method of achieving positive identity change that reinterprets the HIV's relation to self and integrates the condition into everyday life. Narrative is a method of finding and creating a communal identity in the counseling or support group setting. On a personal level, it is also a way of organizing and interpreting the past to formulate a sense of self that can make sense of current challenges and provide a basis of strength and support for the future. Moreover, the stories of this research suggest that the identity change created by this storytelling is a necessary part of the healing process. It is integral to the process of self acceptance and acceptance of status. Also, by reforming a person's understanding of HIV and influencing a more holistic vision of health, identity change can be a source of personal and social empowerment.

The analysis of identity change in relationship to the healing process contextualizes HIV within not only a person's life, but their large social and cultural moment. The stories of this research express how and why HIV counseling works within the social and economic atmosphere of Kisumu. Storytelling underlines why counseling must address HIV holistically and is, itself, a method of addressing the multiple interrelated repercussions of living with HIV.

Also, communal identity formation is a way of understanding the purpose of sharing in the support group setting. This demonstrates why support groups are so effective at providing emotional as well as educational and social support for HIV positive individuals.

At first, I was hesitant to even use the word healing in connection with HIV. Are the stories HIV positive people tell stories of “coping” or “making due” with HIV? However, from the very first interview that I conducted, my mistake was obvious. Not only are these stories almost always stories of healing, but they are stories of much more than just HIV. Stories are a medium for learning and gaining understanding about others by affording a context for insights into what one has not personally experienced. Storytelling offers a free space, in which the narrator chooses not only what to include but, importantly, what to leave out. Thus, the narratives of this study can become a window into examining the integrated nature of the physical, psychological, and social disruptions created by HIV. Identity change is an effective way of examining these disruptions and their affect on a person, their life, and their conception of themselves. However, identity change is just one overarching theme of these stories. One of the most exciting aspects of life stories is that the information and insight they afford is virtually endless. However the stories are read, they are a means of learning about HIV: more than its biological nature, or how it is transmitted, but what HIV means to an individual and how this meaning can change.

### **Recommendations for Further Study**

Building on the research of this paper, further research could include a wider range of participants using the methodology and questions of this study. A larger number of interviews analyzed for the same themes would allow for more statistically significant data. Also, a control group of HIV negative individuals would allow for a comparative approach to understanding

conceptions of HIV and health. A long term study could ask these questions to individuals over the course of months or years and monitor the changes. Analysis of changed perceptions of past events could be analyzed in correlation to perception of health and identity change.

## **Appendix A: Individual Interview Questions**

Age

Sex

Ethnic Affiliation

Religious Affiliation

1. How/ When did you become acquainted with WOFAK?
2. Have you attended counseling either in a group or individual setting?  
Did you find the counseling helpful? What parts? Why?
3. Did you ever tell stories about yourself or your experiences during these sessions? How often?  
What kind of stories would you tell?  
Could you give me an example of a story that you might tell (it can be about yourself, someone else or made up)  
What about this story makes it worth telling?  
What affect does storytelling have on you?  
Do you feel different after you tell a story? Could you describe that feeling to me?



Do you ever tell stories about yourself and your relationship with HIV outside of a group or counseling setting? When? Why?

4. Have you heard stories about faith healings or healing from traditional medicines? Could you give me an example of such a story?

What do you think about these kinds of stories?

5. When you first found out that you were HIV positive, how did you react/ how did you feel? Did the news make you feel different about yourself? your future?

Has the way you feel about yourself and HIV changed since that time? How?

Why do you think the way you feel has changed?

6. Do you remember what you thought about HIV when you first heard about it?

What did you originally think caused it or what did you originally hear as the cause?

Has your understanding of HIV changed since then? How?

Why do you think your understanding of HIV has changed?

7. What does it mean to you to be healthy?

Can you give me an example of a time when you felt healthy or unhealthy?

Do the ARVs make you feel healthy?

Do the counseling sessions make you feel healthy?

8. If you met a woman who had just found out that she is HIV positive, what would you want to tell her?

Why would you want to tell her these things in particular?

## **Appendix B: Group Interview Guiding Questions**

1. What is the name of the group?

2. What are the groups main activities?

3. What topics are normally discussed during meetings?

4. Why did you join the group? How did you come to join the group?

5. How does the group help you?

6. How do you feel after you tell a story in the group meetings?

7. How do you feel after you give advise or answer a question in a group meeting?

8. Are there things that you feel comfortable talking about HIV/AIDS here but not elsewhere?

9. What does it mean to you to be healthy?

## **Appendix C: Counselor Interview Questions**

Age

Sex

Ethnic Affiliation

Religious Affiliation

1. How long have you been a counselor?
- 2.
2. What are the goals of counseling?
3. How long do the women go for counseling for?
4. How do you explain HIV/AIDS to someone?
5. Is language ever a barrier? Are there words or concepts that you find people have difficulty understanding? How do you explain these things so that people understand better?
6. What are some topics that you discuss most often in counseling?
7. Do people ever come in to tell you about their concerns? How do they approach the issues that they are most uncomfortable with?
8. Do they ever tell you stories about things that are happening in their lives? How do you respond to these stories?
9. Do the types of stories and concerns people tell you change the longer they have been in counseling? Why do you think they change?
10. Have you heard stories of miraculous healing either through prayer or through herbal medicines?
  - What do you think about these stories?
  - What do you tell people when they tell you about these stories?
11. Do the people change over the course of their counseling sessions or over the time you have known them?
  - How do they change?
  - Can you give me an example?
  - Why do you think they change?

## **Verbal Consent Form**

Dear Participant,

You have the opportunity to participate in a research study about HIV/AIDS counseling in Kisumu Kenya, being conducted by Kimberly Leon in conjunction with the School for International Training. Your participation will involve a one on one interview with the researcher that may involve the discussion of different topics related to HIV/AIDS including counseling and coping methods, personal experiences and sources of information on HIV/AIDS. This interview is completely voluntary and your participation will not affect your relationship with WOFAK in any way. You are free to decline to participate in the study and free to end the interview at any time. Anything you say on record during the interview may be used in the study. However, your identity will be protected and your name will not be used.

Thank you,

Kimberly Leon

## **Glossary**

**AIDS-** Acquired Immunodeficiency Syndrome- a disease of the immune system characterized by increased susceptibility to opportunistic infections, as pneumocystis carinii, pneumonia and candidiasis, to certain cancers, as Kaposi's sarcoma, and to neurological disorders: caused by a retrovirus and transmitted chiefly through blood or blood products that enter the body's bloodstream, especially by sexual contact or contaminated hypodermic needles. (Oxford English Dictionary)

**Anti-retroviral drugs-** are medications for the treatment of infection by retroviruses, primarily HIV. Normally several such drugs, typically three or four, are taken in combination. They control the levels of the virus, but do not eradicate it from the body. (Oxford English Dictionary)

**CD4 Test-** CD4 is a cell marker expressed on the outside of T-helper cells, which are a part of immune system. The test is used as a representation of the health of the immune system, when one is HIV positive.

**Chira-** a curse caused by breaking certain traditions or taboos

Coherent Positive Resolution- the construction of a coherent and complete story of a difficult event that ends positively by conveying a sense of emotional resolution.

Collective Self Worth- The self esteem that results from being a member of a group.

Exploratory Narrative Processing- process of reflecting on and analyzing a difficult experience with an openness to learn from it.

HIV- Human Immunodeficiency Virus- refers to either of two closely related retroviruses that invade immune system cells and are responsible for AIDS. There are two types of HIV: HIV-1 and HIV-2. There are many strains of both types and the virus mutates rapidly, a trait that has made it especially difficult for researchers to find an effective treatment or vaccine. In many cases, a person's immune system will fight off the invasion of HIV for many years, producing billions of CD4 cells daily, always trying to keep up with the HIV's mutations, before it succumbs and permits the well-known signs of AIDS to develop. HIV is especially lethal because it attacks the very immune system cells that would ordinarily fight off such a viral infection. Receptors on these cells appear to enable the viral RNA to enter the cell. (Oxford English Dictionary)

Jaboya- a practice where female fishmongers have sexual relationships with fishermen in exchange for fish

NGO- Non-Governmental Organization

WHO- World Health Organization

WOFAK- Women Fighting AIDS in Kenya

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### Interviews

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"Diunga Beach Groups Interview." Personal interview. 13 Nov. 2012.

"Geneva Support Group Interview." Personal interview. 11 Nov. 2012.

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#### Counselor

"Counselor Interview 1" Personal interview. 14 Nov. 2012.

"Counselor Interview 2" Personal interview. 14 Nov. 2012.

"Counselor Interview 3" Personal interview. 15 Nov. 2012.

"Counselor Interview 4" Personal interview. 3 Dec. 2012.

"St. Monica Counselor Interview." Personal interview. 13 Nov. 2012.

“Non-WOFAK Counselor Interview.” Personal Interview. 14 Nov. 2012

#### Individual

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