The Aha Moment(s)! - What Prompts HIV Positive Individuals to Transition from One Life Narrative to Another

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Abstract

What prompts an individual who has had a positive HIV diagnosis to undergo the transition from a limiting life narrative to an empowering life narrative?

With HIV positive individuals living longer lives, it is important that individuals are able to integrate the HIV/AIDS identity into their sense of self and life narrative. Diagnosis of HIV creates a shocking rupture within an individual’s life narrative. Integrating the HIV/AIDS identity requires a shift away from a life narrative that initially limits HIV positive individuals from having a positive outlook on the self and life. This qualitative study incorporates a narrative interview approach to understand what events and experiences prompt an HIV positive individual to transition from a limiting life narrative to an empowering life narrative. Narrative interviews were conducted with 3 HIV positive individuals who have utilized HIV resources available at the Blue Roof Life Space located in the Wentworth township of Durban, South Africa. The results from these interviews showed that while there is a similar progression of phases that HIV positive individuals, as a collective community, go through while incorporating HIV into their life narrative, the events that take place within this timeline are greatly varied based on each individual’s societal context. These results will continue to refine our understanding on the relation between chronic illness and the composition of life narratives at an individual level.
**Introduction and Background**

In life we make meaning through the stories we tell others and ourselves. When something changes in our life, the stories we tell must also change. Learning of one’s HIV positive status causes a rift in one’s life that requires changing one’s life narrative in order to understand, cope, and accept the diagnosis. I am interested in understanding what prompts an HIV positive individual to undergo the transition from a limiting life narrative to an empowering life narrative. The Blue Roof Life Space located in the Wentworth community of Durban is an NGO that provides support, care, and resources to HIV positive individuals. Many who come to Blue Roof are in the process of editing their own life stories. This study examines the process of shifting narratives of 3 HIV positive individuals who’ve sought out support from Blue Roof.

HIV/AIDS has shifted from a terminal illness into a chronic illness after the discovery of an effective combination antiretroviral (ARV) drug in the mid 1990s. Currently, South Africa touts the highest prevalence of HIV/AIDS in the world. In 2015, South Africa had an estimated 12% of the population (approximately 7 million people) actively living with HIV. The prevalence of HIV varies from province to province, with KwaZulu-Natal bearing the greatest prevalence of the disease. While there are many campaigns to reduce the incidence of new cases, the number of individuals living with HIV has increased by 2.17 million between 2002 and 2015 (AVERT, 2016).

Although an effective ARV drug was created in the mid 1990’s, South Africa was unable to introduce this drug into the public sector due to domestic political AIDS denialism amongst other issues. “Throughout Nelson Mandela’s presidency, HIV and AIDS were never prioritized and took a backseat to an array of other issues facing the new government [post-apartheid],” and “Under Thabo Mbeki…oversight progressed to unqualified denial [of the epidemic]” (Kautzky and Tollman, 2008, p. 25). However, in 2003 a nation wide public rollout of ARVs was introduced. Currently, South Africa continues the rollout of the world’s largest free ARV medication program (AVERT, 2016).

The Wentworth township of Durban, South African is located on the eastern coast of KwaZulu-Natal, in an area called the South Durban Basin. During the apartheid era, the Group Areas Act of 1950 had the Wentworth region partitioned for colored people
Colored individuals identify as a person of mixed ethnic background. Today, the region is still predominantly home to colored people. This area is also home to Engen and SAPREF, the area’s largest fuel refineries. With the oil refineries on one side, Wentworth remains sandwiched on the other side by the Jacobs industrial area. This has resulted in horrific air pollution that has taken a toll on the health of the Wentworth residents (Naidu, 2014, p. 22).

Over the years, Wentworth has unfortunately taken on an infamous reputation for having the highest rates of crime, violence, and drug trade in Durban. In 2015, 629 drug related crimes were reported in Wentworth (eNCA, 2016). A resident of Wentworth comments on this reputation by stating that, “Even if you are not involved in gangs, you are still classified with them” (Naidu, 2014, p. 24).

Nestled within the Wentworth community is the Blue Roof Life Space which serves ~3,000 HIV positive individuals from the surrounding areas. Before Blue Roof was founded, the space had been an indoor sports bar that was eventually shut down and converted into an HIV center. The Keep A Child Alive Foundation, which is based in New York City, funded the center’s 2005 renovations. Both Alicia Keys and the Stephen Lewis Foundation founded the vision and mission of the center. In the beginning, the center’s goal was to provide access to comprehensive HIV testing, treatment, and care. However, with evidence showing that the current rise in new HIV cases is due to the youth’s sexual practices, there has been a shift from HIV treatment to HIV prevention (Rhona Buckley, In-Person Interview, November 2, 2016). Additionally, in May 2016 the Blue Roof Life Space has transitioned management from Keep A Child Alive to Zoë-Life, a South African Capacity Building and Development organization that works within the realms of Public Health and Social Transformation. The space is now in the process of transitioning to a broader mission of creating a safe space for children, youth, and families to seek health care, support, and an outlet for creative after-school programming. Health issues that the center will be dealing with are not limited to HIV, and instead will include care for abuse, malnutrition, and mental health illnesses (Zoë-Life, 2016).

To provide context to the foundation of this study it is important to understand that throughout life, our experiences become encapsulated in the stories we tell others and ourselves. These stories become organized within distinct lifetime periods, and when
strung together build the meaning of our life story. “...the stories we construct to make sense of our lives are fundamentally about our struggle to reconcile who we imagine we were, are, and might be...” (McAdams, 2008, p. 242). Therefore, self-identity is intricately intertwined with one’s life story. In response to life changes, new stories and dialogue must be created. Many times, life changes mark the beginning of a new chapter, or lifetime period, in one’s life story. Furthermore, traumatic life changes, including the onset of chronic illness or life threatening disease, forcefully require an individual to reevaluate their previously “normal” relationship with life and self (Crossley, 2000, p. 528). These personal evaluations can result in the development of a disempowering, limiting self-narrative (Millen and Walker, 2000, p. 3). This negative narrative potentially leads into internalizing a sense of discouragement, failure, and lack of enthusiasm. This prevents transition into the next distinct life period following the traumatic event. Some sort of turning point is required to prompt an individual to begin the process of transition from one chapter to another.

With HIV positive individuals living much longer lives, there is more time to incorporate their illness within their life narratives (Baumgartner, 2007, p. 919). ARVs require HIV positive individuals, “to incorporate both the disease and the treatment regimen into their lives” (Russell and Seeley, 2009, p. 4). The incorporation of both remains crucial to positive long-term management of the chronic condition.

While there have been many narrative identity studies analyzing the overall process of accepting and incorporating the diagnosis of a chronic illness such as HIV within oneself, this research study focuses on understanding the nuances present in an individual’s experience with incorporating HIV into their identity. While collective narratives about chronic illness patients, specifically HIV patients, provide insight into the general phases a patient may go through, the individual narrative provides a more powerful insight to reality of staggering differences in experiences from person to person. This study seeks to understand the experiences, specific to each individual, that prompt them to embark on a journey from a limiting life narrative toward acceptance and incorporation of an empowering HIV life narrative. Furthermore, this study served to explore the turning point(s), or aha moment(s), between diagnosis and integration of HIV
into the identity of HIV positive individuals who have utilized HIV services at the Blue Roof Life Space.
Literature Review

The construction of a personal narrative of one’s life begins in our childhoods as we tell stories to attempt to find meaning, justify, and explain our experiences (Richardson, 1990, p. 126). These stories aid us in formulating a ‘life-story model of identity,’ which was developed by McAdams in 1985. This model outlines the way individuals build their life through a series of stories that attempt to fuse the “reconstructed past and the anticipated future” in order to find significance and purpose in life (McAdams, 2008, p. 243). Narrative identity is related to McAdam’s ‘life-story model of identity’ since it “refers to an individuals internalized, evolving and integrative story of the self” (McAdams, 2008, p. 242). Ultimately, the identity of the self assumes both the role of the storyteller and the collection of life stories (McAdams, 2008, p. 243).

However, when the sense of significance and purpose in life is disrupted by a traumatizing event, such as the diagnosis of a chronic illness, individuals attempt to regain a sense of their identity through the utilization of narratives (Crossley, 2000, p. 528). Some refer to the diagnosis of a chronic illness as an ‘ontological assault’ on the self, which radically shifts fundamentally held beliefs about oneself, the world, and life. Others refer to it as a ‘biographical disruption’ on the self, which refers to the physiological impact of the illness on the individual (Crossley, 2000, p. 539).

“Disruption, transition and transformation are broad concepts that feature strongly in people’s narratives of chronic illness experience and management…” (Russell and Seeley, 2009, p. 5). For example, “disruption can affect numerous aspects of life [such as]: daily routines, work and leisure, relationships and identity…” (Russell and Seeley, 2009, p. 6).

When the onslaught of physical illness disrupts the former taken-for-granted sense of oneself and the world, we attempt to rebuild it through the use of storytelling and the process of ‘narrative reconfiguration’ in order to re-establish “a renewed sense of meaning, order and connection to…life” (Crossley, 2000, p. 541). This transition phase includes people actively engaging in actions to cope with the life change. These actions could be through strengthening meaningful relationships, joining a social group, or becoming an activist (Russell and Seeley, 2009, p. 6). Ultimately, transformation occurs
once the illness is integrated into one’s identity and “…perceived as an opportunity to learn and live a better life…” (Russell and Seeley, 2009, p. 6).

When specifically analyzing the traumatic event of an HIV diagnosis, narrative analysis is important in understanding how to live positively (Mooney, 2005, p. 72). Diagnosis of HIV creates a sudden, traumatic rupture to an individual’s life story, which can initially limit one’s outlook on life and self. After the initial shock of the diagnosis, HIV positive individuals find it difficult to make meaning from the new component to their identity. This results in an uncertainty of how to incorporate HIV within their existing life narrative and sense of self. As Rohleder and Gibson found in a study with HIV positive individuals from Cape Town, the time after an HIV diagnosis is a time that threatens the self, sometimes resulting in the incorporation of “the ‘bad’ identity, which is attached to the disease” (Rohleder and Gibson, 2006, p. 25).

In a study done by Baumgartner on incorporating the HIV/AIDS identity into the self, the diagnosis of HIV acted as the initial marker in the incorporation of HIV/AIDS into one’s identity through first challenging participants’ identity as healthy individuals. The disruption of the diagnosis affects HIV positive individuals “notably because of stigma, and, before antiretroviral treatment (ART) was available, shattered hope and assumptions about one’s future” (Russell and Seeley, 2009, p. 6). In order to further advance through Baumgartner’s model of HIV/AIDS identity incorporation, participants experienced a turning point at some point in time after initial diagnosis. For participants in Baumgartner’s study, this turning point occurred anywhere from 6 months to 5 years after being diagnosed. The turning point presented itself in different forms unique to each individual. For one participant it was a conversation about miracles. For another, it was an emotional conversation with a fellow HIV-positive individual (Baumgartner, 2007, p. 924). These turning points resulted in participants embodying a sense of empowerment, enlightenment, and control of their lives (Baumgartner, 2007, p. 920). As stated in the Russell and Seeley piece, the turning points discussed in Baumgartner’s study lead to the transition and transformation phases of integrating chronic illness into one’s life narrative.

Focusing in on how this transition process unfolds within HIV positive communities within a South African context, a study titled Rights passages from “near
death” to “new life”: AIDS activism and treatment testimonies in South Africa completed by Steven Robins in 2005 can provide some deeper insight. The research found that in South Africa, “ART and social reintegration…has stimulated people to take action, make changes in their lives and render new identities meaningful” (Russell and Seeley, 2009, p. 20). This finding coupled with the findings found in Russell and Seeley’s work affirm that “people need to pursue meaningful economic and social lives if they are to incorporate HIV as a long-term chronic condition into their lives and adhere to treatment” (Russell and Seeley, 2009, p. 20).

These particular studies highlight the important relationship HIV has on influencing an HIV positive individual’s sense of self and overall construction of his or her life narrative. Furthermore they point out that a multitude of external factors such as social support and access to treatment greatly affect the process of transition to living with HIV as a chronic condition. While the HIV studies draw upon individual HIV positive experiences, it leads to the creation of a collective HIV positive story. A collective story, “gives a voice to those who are silenced or marginalized in the cultural narrative” (Richardson, 1990, p. 128). The issue with creating a collective narrative is that it ignores the blatant reality that no HIV positive individual’s experience fits a cookie cutter description. This is why it is important to take a deeper look into the untold stories at an individual level in order to better contextualize the ‘HIV positive’ narrative and understand the empowering agents that influence HIV positive individuals living in South Africa.
Methodologies

Design

The approach I used to conduct my ISP is a qualitative method by incorporating a narrative interview approach. Qualitative research is a method of study that seeks to understand the behavior and perceptions present within a defined community. Rather than solely analyzing numerical data to understand a community, qualitative methods allow for a deeper understanding of what underlying opinions, beliefs, and motivations are woven within an individual. Narratives combine life stories and social context. When narrative interviews are coupled with qualitative research, it allows for the production of detailed, subjective content that transcends simple transmission of information or content since it allows the researcher to understand “…both the interviewed individually as [well] as the context in which she/he is inserted” (Muylaert et al., 2014, p. 188).

Utilizing a narrative interview format allows a researcher to collect richer responses to questions because of the semi-structured interview structure. According to Muylaert, a semi-structured narrative interview allows for the interviewer and interviewee to engage in a natural flow of conversation unrestricted from a structured script. This allows interviewees to feel more comfortable sharing personal stories because of the collaborative nature of the interview which facilitates stories to emerge through “…interaction, exchange, and dialogue between [the] interviewer and participants” (Muylaert et al., 2014, p. 185). Furthermore, even though the structure of the interview is less formal than a traditional interview, the outline of pre-prepared questions allows the interviewer to focus the conversation on specific topics of interest (Muylaert et al., 2014, p. 188).

Sampling

In order to collect life narratives of HIV positive individuals while simultaneously looking into the impact Blue Roof has on said HIV positive individuals, participants for this study were recruited from the Blue Roof community. Rhona Buckley, the Communication and Client Liaison Manager of Blue Roof, personally recruited 3 HIV positive individuals over the age of 18 who have sought support from Blue Roof and were willing to share their life stories. There is no restriction to gender of the participants
in order to prioritize recruiting individuals who are most willing to open up about their experiences.

**Data Collection**

A narrative interview structure was used to organize the outline of questions to be used in the interviews. As the interviewer, I had an outline of questions printed out and on hand during the actual interview, which were used to prompt participants to share the construction of their life narrative. There was a focus on creating a comfortable space that allows for conversation between the participant and myself by not tying myself to the questionnaire outline. I encouraged the development of a collaborative conversation to allow for a less formal setting. This was to help the participants feel they have the ability to share their life narratives in a candid manner. Additional follow-up questions were formulated while conducting the interviews in order to further question, challenge, and clarify participant’s responses. This was to help better understand the context of their feelings and actions relating to the incorporation of HIV/AIDS into the self. This comprehensive narrative interview strategy allowed me to not only guide the direction of the conversation by having a questionnaire outlined, but also allow for flexibility in the flow of conversation.

All interviews with the HIV positive participants were recorded on an audio recorder. Using an audio recorder allowed myself as an interviewer to refrain from continuously jotting down notes and instead concentrate on listening to, responding to, and engaging with what the participant shared.

**Data Analysis**

The actual interpretation of narrative data remains a challenge to researchers since there is no single technique (Muylaert, 2014, p. 187). The first step I took in analyzing the information collected from interviews was to separate factual content (the who, what, where, when why) from subjective content (the expression of values, judgments, feelings, and beliefs). Because I am attempting to pinpoint the specific prompts in each person’s life narrative that sparked the transition between life narratives, I textually logged each individual’s life narrative by chronologically organizing the pivotal events. Both concrete
and subjective content were placed within this chronological timeline. Next, I extrapolated meaning from each event within the timelines in order to match up both the experience with an associated significance. At this stage it was important to ask: what is happening here and now? This allows meaning generation to be based on “situational context (here) and the moment of interaction going on (now)” at each event within the timelines (Muylaert, 2014, p. 187). Finally, I compared and contrasted each of the participants’ timelines with one another to see if there are any similarities.

Additionally, I will be ending this written report with a personal reflection on the ways this project has unfolded based on what I thought my initial direction for the project would be. I will also incorporate my personal observational data while at the Blue Roof Life Space interacting with locals, patients, and staff to highlight specific qualities of Blue Roof’s unique approach to providing HIV care.

**Limitations**

It is important to recognize the limitations of this study in order to understand the context of the findings and data analysis sections. The recruited participants are not representative of a randomly sampled population of HIV positive individuals. This sampling strategy places limitations on what data analysis can be concluded about HIV positive individuals as a collective community, but will allow for individualized analysis on HIV positive narratives.

The small sample size was to ensure that there was ample time to thoroughly recruit willing participants, conduct interviews, and analyze data within the few weeks allotted for the project. This allowed for a deeper understanding of each individual’s unique narrative, with the basis that all life narratives that are disrupted by the diagnosis of HIV are complex and varied, while at times exhibiting common themes.

However, because the length of time spent with each participant was limited, the narratives gathered from participants may not holistically encompass all details of their life narrative. It is also important to keep in mind that the depth of detail discussed in Gerard Genis’ narrative may reflect the fact that he has had practice publicly sharing pieces of his narrative as a motivational speaker at events and through participation in a number of interviews over the years.
Finally, my subjective experience of having spent weeks at Blue Roof is emergent in my overall analysis of the data. My personal reflection on my research experience at Blue Roof is placed at the end of this report.
**Ethics**

This study included the participation of 3 adults who identify with the HIV positive vulnerable population. In an endeavor to uphold the ethical standards of human subject research, this study has been reviewed and approved by a Local Review Board (the SIT Institutional Review Board). The narrative interviews were all conducted onsite at the Blue Roof Life Space. Prior to the interview, participants were verbally debriefed about the study as well as the relevant risks and benefits of the study. A written informed consent form was provided to each participant to read and sign. The participants were encouraged to ask the researcher if they had any questions regarding the study or the contents of the consent form prior to signing the consent form. Before the actual interview began, participants were reminded verbally that if at any time they felt uncomfortable, they were able to terminate the interview and retract all previous statements. At the end of each interview, participants were again encouraged to ask the research if they had any further questions or concerns about the study.

All audio recorded files and word processed transcripts of the interviews were labeled corresponding to each participant’s numerical code (01, 02, 03) and are kept in a password protected folder. However, each HIV positive participant granted permission to use their full name in the written up results and analysis of this research study.

Because a Blue Roof employee recruited participants, the 3 HIV positive individuals may have felt pressured to participate in the study since they have received some sort of care from Blue Roof. If someone who is thought to hold an authoritative position asked them if they were interested in participating, they may agree because they feel obliged or indebted to Blue Roof. Additionally, because Rhona recruited participants there is bias in the recruiting process. To combat this, all recruited participants were thoroughly debriefed on the purpose of the study and were told multiple times that their participation must be voluntary and that lack of participation would not be an issue.

**Findings**

Below are the prominent findings collected from the narrative interviews. The sections below are separated into each individual’s narrative. The content of each section discusses the pivotal, relevant, and contextual events found within in each life narrative.
Gerard Genis

At the age of 10, Gerard Genis was sexually abused by his father’s friend, which ended up breaking up his family. Shortly after this incident, he was moved into a children’s home. Before Gerard was diagnosed HIV positive in 1999, he was aware of the disease.

“I just knew that it [HIV] was something related to death. It was so bad to have this disease... It was very scary in the 1990s. Lots of people in my community were dying, and the only talk about it was that I cannot get this thing because I am going to die immediately.” (Gerard Genis, In-Person Interview, November 7, 2016)

When Gerard was in his final 12th year of grade school, he fell sick. After undergoing a multitude of medical tests, the cause was still unclear. A nurse who used to volunteer at the children’s home suggested that Gerard take an HIV test. While Gerard agreed to do the HIV blood test, it was the last thought on his mind that he would end up HIV positive. He was baffled that the nurse had even recommended taking the test since he believed that he didn’t physically look like the AIDS patients that were shown in the news.

“I couldn’t have it because I don’t look like that [an AIDS patient]. The way AIDS looked to me at the time was that you had to be very thin and sick looking, almost like you were gonna die... But I was looking okay, I was still as handsome as ever.” (Gerard Genis, In-Person Interview, November 7, 2016)

When he was first diagnosed he was sure that the test had been wrong because he didn’t feel like he had the disease. Back at the children’s home he was able to have a conversation with a lady who was well educated on the virus. She sat him down and questioned him on his sexual activities. He explained to her that he had been having sex without protection because most of the girls at the children’s home were on the pill or had an injection to prevent them from pregnancy. At the time, he didn’t realize that the unprotected sex left him vulnerable to contracting HIV.

“I wanted to feel it [the virus] and at that time, because I couldn’t feel it, I couldn’t accept it.” (Gerard Genis, In-Person Interview, November 7, 2016)
Because ARVs were nonexistent at the time of Gerard’s diagnosis, he believed that he was going to die soon. The mindset of death looming around the corner led him to make a number of rash decisions as he decided to focus on having a good time. Gerard left both the children’s home and school to live on the streets. He lived with other street kids near bushes on Durban’s beachfront. For the years he spent living in the streets, he had forgotten about his HIV positive diagnosis because he felt he “…didn’t have anyone to complain to” (Gerard Genis, In-Person Interview, November 7, 2016). And even though he lived on the streets, he never fell physically ill.

“I found this newfound freedom and happiness on the streets. No worries, no dishes, nobody…scold me. I could do whatever I wanted to do.” (Gerard Genis, In-Person Interview, November 7, 2016)

This newfound happiness soon diminished when he got hooked on wine. A new life full of excessive drinking and drugging weakened his immune system. Shortly after, he was checked into the oncology ward at the hospital to treat his Kaposi sarcoma skin cancer. After looking at himself in the mirror in the hospital and seeing lesions cover his body, he started to believe that he wasn’t going to make it. But what Gerard felt was the worst part was the facial reactions of the others who looked him.

“…Other people made me feel much worse than what I was actually feeling because of the way they had looked at me…[and] moved away from me… That look was worse than what [the pain] you’re actually experiencing physically…”

(Gerard Genis, In-Person Interview, November 7, 2016)

After recovering from Kaposi sarcoma, he continued to live on the streets, but this time moved to a graveyard site. He recovered his health, but refused to start ARV treatment after hearing stories that the medication had horrific side effects. During his time living at the graveyard he came to learn that the indoor sports bar he used to party at was closing down and that Alicia Keys had bought the building to convert into an HIV/AIDS clinic called the Blue Roof Life Space. When the clinic opened, he went to collect the free soups that were offered. At the clinic he tested positive for HIV and had a CD4 count of 60. Even though Blue Roof employees encouraged him to start treatment because of his low CD4 count, Gerard said, “…since I’ve got the virus I may as well die with the virus” (Gerard Genis, In-Person Interview, November 7, 2016).
Gerard started coming to the clinic often for the free food, but would come drunk and would swear at the employees. But one day, he started chatting with the lady working in the kitchen who was appalled to hear that he was living at the nearby graveyard. The lady asked if he would be interested in helping her out around the kitchen. The next day he arrived bright and early to begin working his first shift at the kitchen. Gerard recalls how he felt after that first day of working in the kitchen: “I never felt so loved, like what this woman had done for me in that day” (Gerard Genis, In-Person Interview, November 7, 2016). This woman was the first anchor of support whose verbal encouragement seemed to translate into Gerard taking the steps to start ARVs. She told him that he might as well live properly, and asked him to observe the patients at Blue Roof who had started medication and notice that those who at first were looking ill were now looking healthy.

While the kitchen lady provided the first push of encouragement that Gerard actually took to heart, he considered starting ARVs. However, he now recognizes that “…there is an event that took place, that had to have happened, in the way that it had happened, in order for me to catch a wake up [call] from this whole mad, unhealthy, dangerous lifestyle that I had been living” (Gerard Genis, In-Person Interview, November 7, 2016). After getting drunk after one of the sessions he attended at Blue Roof, he went out to party at a bar with friends from the graveyard. There he got involved in a fight that landed him in the hospital. After seeing his unrecognizable, beat up face in the mirror he felt ashamed. He left the hospital determined to begin treatment.

He arrived at Blue Roof and explained that he was ready to begin ARVs. However, before starting treatment, the Blue Roof manager persuaded him to sign up for a church retreat that was starting the next day. Gerard hesitatingly agreed to go onto the 4-day retreat. The retreat created a space for him to organize his thoughts on his outlook on his past, present, and future life. At the end of the retreat he felt excited to start living a healthy lifestyle.

“So many of those lessons were…encouraging…me to stop all the things that I was doing in the community and start giving myself the opportunity to live… I wanted to die before but now I wanted to live.” (Gerard Genis, In-Person Interview, November 7, 2016)
After returning to Blue Roof after the retreat, things started falling into place for Gerard. He started ARV treatment, was offered a full time position as the groundskeeper at Blue Roof, and was given a room to live in at Blue Roof. He slowly became close with the Blue Roof staff and noticed changes in his behavior.

“I started speaking proper to people when before...I was so abrupt, rude, and vulgar.” (Gerard Genis, In-Person Interview, November 7, 2016)

While Gerard’s life had already gone through a number of changes, what helped Gerard grow the most was the friendship he forged with Blue Roof’s new assistant manager, Tessa Beaunoir. After meeting Gerard and noticing that he walked with a shuffle due to neuropathy, Tessa brought him brand new gym shoes the following day for him to keep on the condition that he start to walk around the neighborhood to regain strength in his legs. He started with short walks but soon was able to jog around the neighborhood, and the pain he previously felt in his feet lessened. Over the following months, Tessa signed Gerard up to run a 5k, 10k, 21k, and 56k with her at her running club. He ran all those races, finishing in the top categories.

“I was doing something that I never thought I had the strength to do. And the huge difference was that she [Tessa] did not entertain weakness, or ‘I can’t,’ or ‘I wont be able to.’ It was, ‘Yes I can,’ ‘I am going to.’” (Gerard Genis, In-Person Interview, November 7, 2016)

Gerard’s hobby in running led him to qualify for the Comrades Marathon, an 87-kilometer race from Durban to Pietermaritzburg. He trained a full year for this race and completed it without stopping once to walk. Finishing these races brought a new mindset to Gerard.

“I had such big dreams all of a sudden and felt that I could conquer the world all because of finishing these races.” (Gerard Genis, In-Person Interview, November 7, 2016)

Post-Comrades, Gerard found himself embracing his HIV positive status. He became a local celeb, with people amazed that an HIV positive individual was able to complete the marathon. The races shifted his mindset on the illness itself.

“I was able to speak like a strong guy... I always wanted people to feel sorry for me, to understand that I was sick... When I got the [HIV positive] results [I threw
away my whole future,...self respect,...[and] self esteem. It was just a matter of a mind change that I needed to have." (Gerard Genis, In-Person Interview, November 7, 2016)

Gerard shared his current views on the disease as he proudly invests his time as an activist for HIV positive individuals. At Blue Roof he holds the position as the patient committee chairman, which allows him to give input on behalf of the patients in managerial meetings at the center.

“I want to live because I want to show another side to being HIV positive; a strong side. To show others that you don’t need to be recognized as a chronic illness person that’s weak and can’t achieve anything, and is useless and hopeless. NO I want the total opposite. That’s why I flip that HIV word around, and I want everybody to realize that we are still VIH, which is very important human, whether you are positive or negative.” (Gerard Genis, In-Person Interview, November 7, 2016)

Lorna Abrahams

Lorna runs a canteen at Feltex, an automotive manufacturing facility located in the Jacobs industrial area of Durban. Before her HIV positive diagnosis, she was well aware of the disease and supported a number of individuals at her workplace who were HIV positive. In addition to supporting people at her workplace, Lorna also supported her brother who had been diagnosed HIV positive over 10 years before her.

“I was very active at my place of work assisting people that had HIV, not thinking for a moment that it will affect me one day.” (Lorna Abrahams, In-Person Interview, November 11, 2016)

Lorna was diagnosed HIV positive in 2007, and the results came as a complete shock. She had gone in to get herself tested “…to motivate and encourage the other guys at work to get themselves tested” (Lorna Abrahams, In-Person Interview, November 11, 2016). But her test came back imbalanced; it was not positive or negative. But because of all the research she had previously done on being HIV positive, she knew that something was wrong. Before receiving the imbalanced test results, she had previously tested
negative at another clinic. She returned to that first clinic and there she tested positive.

“I was going through a lot of emotions... And when I did get tested, I did, I won’t lie, suicide crossed my mind.” (Lorna Abrahams, In-Person Interview, November 11, 2016)

With a number of emotions swirling through her mind, Lorna kept strong and went straight to her sister-in-law who she is very close to. Her sister-in-law wasn’t home at the time, so Lorna returned to her home and shut herself in her bedroom. Lorna’s sister-in-law came into the room later that night to find Lorna under the blankets crying. But her sister-in-law encouraged her to stay strong in spite of the diagnosis.

“I was under the blankets, I was crying, and I was all broken up. And she just encouraged me. She said ‘You be strong... You were there for others so now it’s your turn to be strong.’” (Lorna Abrahams, In-Person Interview, November 11, 2016)

Knowing that she needed to take the next steps forward, she first went to a hospital accompanied with her sister-in-law to get her CD4 levels checked. Although Lorna lived in the Wentworth area of Durban, she was still scared to come out because of the stigma and instead spent some of her own money to get her levels checked at a private hospital in Addington. Her results came back with a CD4 count of 700, which did not require her to start treatment. Instead, she started the journey to “eating healthy and living a healthy lifestyle” (Lorna Abrahams, In-Person Interview, November 11, 2016).

The transition from an unhealthy lifestyle to a healthy lifestyle is not an easy switch. Before receiving her HIV positive diagnosis Lorna admits that she was not living a healthy lifestyle. She had recently gone through a divorce at the age of 40, which left her on a search for new love. She went out partying, drinking, and as a result went to sleep late. Additionally, she acknowledges that had it not been for the diagnosis, she would have continued living an unhealthy lifestyle.

“After I was diagnosed, I realize[d] that I need to live for me now. I have to live healthy.” (Lorna Abrahams, In-Person Interview, November 11, 2016)

Coming out about her status to her two sons was one of the most difficult steps Lorna had to take towards her integration of HIV into her self-identity. When she was first diagnosed she immediately told her parents, sister-in-law, and brother. Her parents
had been supportive of her brother’s HIV positive status so she felt that they would accept her as well. What prompted her to disclose her status to her sons was knowing that gossip spreads fast in the Wentworth community and she “…felt that it was better that my children heard it from me rather than hearing it from somewhere on the streets” (Lorna Abrahams, In-Person Interview, November 11, 2016). In addition to this, Lorna had a sister that passed away from HIV/AIDS, but her sister had never come out with her status and instead took it to her grave.

“...One of the things I’ve learned is that if you keep it a secret it eats at you slowly... And when I told my kids, they embraced it. They didn’t make me feel like I’m an outcast.” (Lorna Abrahams, In-Person Interview, November 11, 2016)

Lorna had known of the Blue Roof Life Space because it had been present for a couple years before she was infected, and its location near the Wentworth shopping center made it difficult to miss. While she had transitioned to living a healthy lifestyle, she knew that stress could impact her CD4 count. She had begun stressing because of her sons’ party lifestyle, worrying for their safety and wellbeing. Concerned that her CD4 count may have been dropping even though she did not physically feel ill, Lorna chose to get her CD4 count checked out. She deliberately chose to go to Blue Roof for testing because she had heard stories about how the Wentworth Hospital did not treat their patients well or make them feel welcome. After getting her CD4 levels checked over a period of 3 months, it consecutively dropped from 700 to 300 to 199, which ultimately required her to start ARV treatment.

Her first experience at Blue Roof was very memorable. From the moment she walked in she felt welcomed by the staff in a way that made her feel special and comfortable. Furthermore, she noted that the staff knows her by name and has a kitchen that serves free meals, which makes her feel at home.

“And for me, if I’m not welcome, I’m not going to get better. I need to feel at home because that’s where I’m going to be getting my treatment for practically the rest of my life until there is a cure for HIV/AIDS.” (Lorna Abrahams, In-Person Interview, November 11, 2016)

Today she has integrated HIV into her identity, and her own positive diagnosis has driven her to continue to help, advise, and guide anyone she comes across at the
canteen she works at that may also be HIV positive. She’ll reveal her own status in order to give other courage to speak to her.

“Now it’s [HIV] become part of me. It’s routine. It’s like, you gotta brush your teeth, have your cereal, and...before you go to sleep you take your medication.”

(Lorna Abrahams, In-Person Interview, November 11, 2016)

**Helen Fynn**

Helen was on antidepressants when she found out that she was HIV positive in 2000. She recalls throwing a screaming fit and having suicidal thoughts when the doctor told her the test results. Before she was diagnosed, Helen thought that HIV “was a dirty disease” and that “only dirty people got it” (Helen Fynn, In-Person Interview, November 16, 2016).

At first Helen was hesitant about coming out to her family and did not disclose her status to her family until her mother passed away 6 years after her diagnosis. She had seen a lot of her friends die because of HIV who did not end up disclosing their status openly. However, there was a particular emotional event that pushed Helen to finally come out with her status. Her 23-year-old nephew was a lively boy who ended up bed ridden in the hospital dealing with full-blown AIDS symptoms. Watching him deny his HIV status after transforming from a hefty sized young man to skin and bones in a hospital bed completely changed Helen’s outlook on the importance of disclosing. Since disclosing her status, her family has been accepting and supportive.

“[I] saw a lot of my friends pass [away] through ignorance... I believe you must talk about it. You must be open about it... I didn’t want to be a statistic.” (Helen Fynn, In-Person Interview, November 16, 2016)

She had heard about Blue Roof because she lived in a house behind the center. Originally she would receive her medication from the Wentworth Hospital. The trek to Wentworth Hospital was long and physically taxing. She used to leave her home at 2 am to only return at 3 pm in the afternoon the next day hungry and tired from the journey. Blue Roof was much closer so she asked to transfer. At Blue Roof she has felt cared for and supported.
“Here [at Blue Roof] they give good meals and their treatment is 100%, 110%!... You’re just a number there [at Wentworth Hospital], at least here they know me personally.” (Helen Fynn, In-Person Interview, November 16, 2016)

Currently, Helen feels that her HIV positive status has made her a better person. She has become much more compassionate and enjoys talking to others who may be struggling with the diagnosis.

“...When I was at the hospital...this girl had a severe meltdown after begin diagnosed positive. I told her, ‘Look it’s not the end of the world. I’m 16 years [living] with the virus. You can live with it [too].’” (Helen Fynn, In-Person Interview, November 16, 2016)
Analysis

The narratives of the 3 HIV positive individuals in this study support the notion that while HIV positive individuals may share a common broad collective narrative that includes the transition between a limiting life narrative to an empowering life narrative, each individual’s unique narrative is made up of events distinctive to his or her societal and familial context. The analysis below seeks to compare and contrast the limiting and empowering phases of the 3 HIV positive narratives collected in this study.

Limiting Life Narrative

Limiting life narratives lead to the hindrance and/or regression of having a positive mindset about the identity of one’s self, outlook on life, and ability. While Gerard, Lorna, and Helen went through phases of living with a limited mindset, this phase manifested itself differently in each narrative and for different lengths of time.

Gerard had the greatest number of events take place within his phase of the limiting life narrative in comparison to Lorna and Helen. Soon after diagnosis he had accepted that death was imminent, and because of this “…made decisions, wrong decisions, so fast…” (Gerard Genis, In-Person Interview, November 7, 2016). The particular impulsive decision of leaving school for a life on the streets greatly lessened the number of paths that could have allowed him to transition to an empowering narrative sooner rather than later. During his time on the streets he found genuine “…freedom and happiness…” (Gerard Genis, In-Person Interview, November 7, 2016). And because he felt happy, the odds of him engaging in behavioral changes to live a healthier lifestyle would be slim to none since behavior change is fueled by a deep set feeling that another lifestyle is more desirable than the current lived experience.

Gerard wanted others to know that he was sick and dying soon. By telling people this it made them feel sorry for him and they would in turn do their best to make sure he was always having a good time by giving him things for free. While he somewhat embraced this limiting narrative because of the positive gains, he himself believes that the limiting narrative he convinced himself of stemmed from how society viewed HIV positive individuals: “I do believe that it is that [limiting] mentality that I grabbed hold of just because of being HIV positive. Because that is how sick people should behave. Be
weak, be sick, be beggars, be nothing” (Gerard Genis, In-Person Interview, November 7, 2016). And it is important to remember that the social construction of this limiting narrative of HIV positive individuals, while still present today, was very prominent in the 1990’s when an HIV diagnosis was equated to a death sentence and not a chronic illness.

Although Gerard seemed to spend the most time out of all 3 participants within the limiting narrative phase, part of this could be attributed to the fact that he was diagnosed before free access to ARVs was available in South Africa. When Lorna and Helen were diagnosed, their choice to start ARV treatment was an option, whereas Gerard did not even have that choice available to him. Gerard had already adopted the limiting narrative for years before access to ARVs was brought into South Africa’s public sector. So for him to actively choose to transition into living a healthy lifestyle coupled with ARV treatment would have taken much longer for him in comparison to Lorna and Helen simply because he had to disengage from years of a negative mentality that his life was not valuable.

Both Lorna and Helen had similar first reactions to the diagnosis. Suicide crossed their minds, but the time they spent within this limiting narrative phase was different based on when they ended up disclosing their status to their families. I believe disclosure of status and subsequent acceptance from those who are told is a marker for transitioning to an empowering narrative since it requires the individual to recognize that HIV is now part of their identity and a positive reaction allows for positive self-affirmation of one’s new identity. Lorna spent the least amount of time, a couple of months, within the limiting phase because she disclosed to her parents, brother, and sons within that timeframe. Helen waited 6 years till she disclosed to her family members.

It is also interesting to note what prompted Gerard, Lorna, and Helen to disclose to their families, and how their families’ reactions set the tone for the following narrative each individual embraced. Gerard felt he should spend time with family since death was imminent. Lorna had already seen her family accept her own brother’s HIV positive status. Helen was the first HIV positive individual in her immediate family, and for her it was observing many friends dying because of HIV but being unwilling to admit their status. Regardless of how long it took Lorna and Helen to disclose, both had supportive reactions from their families. And these moments began the transition into an
empowering narrative for Lorna and Helen. Gerard on the other hand was completely shut out when he had disclosed to his family: “…I didn’t get a positive welcome, and I immediately made myself unwelcome and left” (Gerard Genis, In-Person Interview, November 7, 2016). While Lorna and Helen started moving toward an empowering narrative, Gerard left to live on the streets, ultimately spending the most time in the limiting narrative phase in comparison to Lorna and Helen.

**Empowering Life Narrative**

Empowering life narratives pave the path towards building beliefs in HIV positive individuals that a fulfilling life is possible despite the somewhat limiting collective story society has already created for the population of ‘HIV positive individuals.’ Again, while Gerard, Lorna, and Helen are currently in the phase of living with an empowered mindset, this phase manifests itself differently in each individual narrative.

Gerard spent years mentally caged in a limiting mindset that undoing that mindset required a number of emotionally moving events to lead him to embracing his HIV positive identity in a healthy way. These events include: getting involved in a fight that disfigured his face, spending 4 days on a spiritual retreat reflecting on his life, the presence of individuals who showed interest in his potential, getting a job, and finishing races, an achievement that would have once seemed impossible to him. These moments slowly carved away at the limiting persona Gerard had embodied until a new, driven individual was uncovered.

Prior to her diagnosis, Lorna was already actively engaging with HIV positive individuals, helping them transition into empowering life narratives. Her previous experience as a support system to help HIV positive individuals cope and come to terms with the illness aided her own transition into an empowering narrative. Her own brother was a living example of living positively with HIV, and this type of role model helped accelerate her transition into living a healthy lifestyle. While Lorna had the advantage of established HIV positive role models in her life, Helen had to become her own role model. Although she had seen many friends pass away ignorant about their HIV status, what struck her the most was watching her nephew on his deathbed in the hospital failing to acknowledge that HIV was the cause of his ill health. This was the turning point event
Helen needed to embrace her own identity publicly, leading her to integrate an empowering life narrative.

Gerard, Lorna, and Helen each followed similar suit in how they have gone about expressing their HIV positive status once in the empowerment stage. Each has been playing a role in breaking down the stigma around openly being HIV positive by giving advice, mentoring, and listening to others who may be going through the journey of integrating HIV into their identities. Within each interview, the three discussed specific examples of helping others understand that HIV does not need to be restrictive to one’s livelihood. As Helen said, “I give a damn what people say…Because it’s [HIV’s] even made me a better person” (Helen Fynn, In-Person Interview, November 16, 2016). The act of taking on an activist role showcases how all three have entered the ‘transformative’ phase discussed in the Robert and Seeley text discussed in the literature review (Russell and Seeley, 2009, p. 6).

To sum up the journey toward embracing an empowering HIV positive life narrative, it wasn’t one singular event or one single individual that gave these individuals the power to embrace an empowering life narrative; it was the conglomeration of multiple emotionally charged moments.

**Support Structures**

Social support structures form the foundation which fuels personal growth. In the context of an HIV positive individual post-diagnosis, social support systems are imperative in one’s transition from a limiting life narrative to an empowering life narrative. As Gill Green’s editorial review finds, “…there is a link between social support and the psychological well-being of people with HIV…” (Green, 1993, p. 87). Woven within each of the empowering life narratives of Gerard, Lorna, and Helen is the presence of multiple individuals who have provided them with unconditional support. Lorna and Helen had the support of people in their immediate family. For Lorna, it was the motivation from her sister-in-law and HIV positive brother that provided the most support: “My sister-in-law was such a tall pillar of strength…[My brother] was like my motivation” (Lorna Abrahams, In-Person Interview, November 11, 2016). For Helen, it was the sense of acceptance from her immediate family: “Everybody around me is fine...
with it [my diagnosis]” (Helen Fynn, In-Person Interview, November 16, 2016). For Gerard, this support didn’t come from his family, but instead came from staff at Blue Roof who loved him during a time society labeled him as unlovable.

The support Gerard received from Blue Roof was paralleled in the lives of Lorna and Helen as well. All three discussed how crucial Blue Roof’s role was in supporting them physically and emotionally throughout their acceptance of HIV. For Lorna and Helen not only was receiving medication and healthy meals a highlight of their choice to utilize Blue Roof, but also the warm hospitality of the center was key to Blue Roof’s unique support system. Lorna explained that “when you walk into Blue Roof you get nothing but love” and Helen used the words/phrase “Caring, supportive, and very prominent in my life” to describe her thoughts on Blue Roof in a nutshell. While Gerard felt supported by Blue Roof in a similar sense, he was eventually integrated into the support system of Blue Roof itself through his work as a groundskeeper and now as the chef at the center. And while all 3 consider Blue Roof a second home, for Gerard, the space itself became his physical home. And while Lorna and Helen had support from their families, Gerard’s lack of familial support eventually grew from the Blue Roof staff that became his family.
Conclusion

HIV/AIDS has been a serious public health concern to the country of South Africa since the beginning of the AIDS epidemic in the 1980s. Early in the epidemic, diagnosis of HIV meant a death sentence. However, once an effective antiretroviral therapy was discovered, an HIV diagnosis no longer meant a shortened life. With HIV positive individuals living longer lives, the incorporation of the chronic illness within one’s sense of self and life narrative has become necessary if one wants to effectively cope with both the emotional and physical side effects of an HIV positive lifestyle.

The process of incorporating HIV/AIDS into one’s identity differs from person to person. While the exact processes may differ, there is a common trend among HIV positive individuals in adopting a negative life narrative after the initial diagnosis. In order to embrace a positive life narrative one must be prompted by some sort of decisive event or experience. While many studies found in literature do analyze the collective process of integrating an HIV/AIDS into one’s self and life narrative, the individual experiences are often overlooked. It is also important to focus upon these experiences from the individual level to understand what types of decisive moments prompt shifts in life narrative.

Based on analysis from the 3 narratives collected for this study, these decisive moments that spark transition from one narrative to another seem to be intimately linked to an individual’s social support system. All 3 narratives did not progress into the transformation stage until each individual felt that a solidified support system was present. The structure of the support system acts as the empowering agent that facilitates progression from one life narrative to adoption of another, and it ultimately bridges the two narratives.

Finally, this research study aimed to expand upon the existing literature by seeking to understand what these pivotal prompts are comprised of within the community of HIV positive individuals that have utilized HIV services from Blue Roof. Blue Roof remained a positive source of support that all 3 individuals give credit to for transitioning from one narrative to another. The center’s ability to make patients feel welcome, cared for, and comfortable remains the cornerstone of its individualized approach toward healing HIV positive individuals both physically and mentally.
In a modest manner, this research can add greater detail to the existing processes used to discuss the relation between chronic illness and the self-construction of life narratives from an individualized perspective.
Recommendations for Future Research

This research lays the foundation for the understanding of HIV positive narratives within a South African context at an individualized level. Further studies should be done to expand upon this study. While the number of individuals interviewed was limited, a clear evidence that social support expedited the process of HIV positive individuals embracing an empowering life narrative was present within each individual narrative. Based on the findings from this study, it appears that it would be beneficial to study to a greater degree the relationship between social support structures and HIV positive patients. These studies could help shed light into what types of social support structures are most beneficial to have in one’s life. Is familial support most important? Or can any third party individual provide adequate support? Ultimately it would be interesting to find out how social structures could be utilized as a source of support within HIV clinics. Is there a way to potentially integrate social support systems into more HIV clinics in South Africa? What would these support systems look like? There are a number of ways that this research could help formulate future research questions regarding the development of HIV positive narratives.
**Personal Reflection**

I am currently a senior at Northwestern University on the pre-med track majoring in Radio/TV/Film and minoring in Global Health. To tackle pressing global health issues, I am interested in blending medicine and media. Visual storytelling has the power to mesh knowledge and emotion, and emotion lies at the heart of fueling behavioral change.

Before coming to South Africa, I hoped that my ISP would allow me to continue growing as a storyteller and filmmaker. Upon arriving in South Africa, I soon learned of the high prevalence of HIV as a pressing public health concern. It was after our program’s site visit to the Blue Roof Life Space that I started to formulate what research topic I wanted to investigate for my ISP.

During our visit to Blue Roof, an HIV positive individual named Gerard Genis, who works as the head chef at the center, shared his inspirational and moving life story with us. His story had many traumatic moments, including the account of his HIV positive diagnosis. After his diagnosis, he told us how he wholeheartedly believed his life was worthless. Instead of seeking further medical care, he continued to live as an alcoholic and drug addict. Gerard believed in the limiting life narrative he told himself until he ended up receiving care and support from Blue Roof. At Blue Roof he told us how he was loved during a time he believed he was unlovable. Eventually, he participated in deliberate, personally motivated healthy behavioral changes prompted by the passionate encouragement he received from the director of Blue Roof. The director gave Gerard a pair of new running shoes on the condition that he would start jogging. This challenge further pushed Gerard to rewrite his life narrative into one that was empowering. Instead of feeding into a negative life narrative, he chose to embody a positive life narrative that motivated him to begin taking ARVs and getting physically fit. Gerard’s story left me astonished at the power of self-narrative to completely transform one’s life. What amazed me most was what triggered his transition from one narrative to another: the passionate support of a person he admired who sincerely believed in his worth. This interaction with Gerard at Blue Roof led me to question what other things prompted HIV positive individuals to let go of limiting narratives and embrace empowering narratives.

During my time conducting research at Blue Roof, I have experienced first-hand
the type of environment Blue Roof fosters for its staff and student volunteers. And while my experiences as a student conducting research at Blue Roof are not at all representative of the patients who utilize Blue Roof’s HIV services, I have found overlap in the language used by both HIV positive individuals and myself when describing Blue Roof. These words include: welcoming, loving, friendly, family. From our first day at the center, each member of the staff made us SIT students feel as if we were part of the Blue Roof team. Throughout the day all individuals’ part of the managerial staff would each check up on us to ask how our day was and how they could help us. Everyone greeted us with a smile and always wanted to guide us to the best of their ability.

Furthermore, the center’s atmosphere does not feel or look like a traditional clinic or hospital. The bold color scheme of wall paint, homey furniture, open floor plan, and large windows that draw in natural light brings an uplifting mood to the setting. Many times, the space in which one receives care affects the quality of the care. A space that gives off “happier” vibes through its color scheme, furniture, and building layout subconsciously influences people in that space to feel happier.

I noticed myself describing Blue Roof as a welcoming environment whenever Uber drivers would drive Kaykay and I from our home to the center. When Uber drivers saw that we were going to Wentworth they would question us to why we would be working in such a ‘dangerous’ area. I found myself telling these drivers that while Wentworth does have high crime rates, we were conducting research at an organization with some of the most hardworking, passionate, friendly individuals and that our experience in the Wentworth was quite positive.
References


Primary Sources

1. Rhona Buckley, Communication and Client Liaison Manager, In-Person Interview, November 2, 2016, Blue Roof Life Space
2. Gerard Genis, HIV Positive Individual, In-Person Interview, Blue Roof Life Space, November 7, 2016,
3. Lorna Abrahams, HIV Positive Individual, In-Person Interview, Blue Roof Life Space, November 11, 2016
4. Helen Fynn, HIV Positive Individual, In-Person Interview, Blue Roof Life Space, November 16, 2016
### Appendices

**SIT Study Abroad**

School for International Training

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**Human Subjects Review**

**LRB/IRB ACTION FORM**

<table>
<thead>
<tr>
<th>Name of Student:</th>
<th>Lakshmi Karuparthi</th>
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<tbody>
<tr>
<td>ISP Title:</td>
<td><em>THE ANA MOMENT: WHAT PROMPTS HIV POSITIVE INDIVIDUALS TO TRANSITION FROM ONE LIFE NARRATIVE TO ANOTHER</em></td>
</tr>
<tr>
<td>Date Submitted:</td>
<td>31 October 2016</td>
</tr>
<tr>
<td>Program:</td>
<td>Durban Community Health and Social Policy- Fall 2016</td>
</tr>
<tr>
<td>Type of review:</td>
<td>Exempt</td>
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- Institution: World Learning Inc.
- IRB organization number: IORG0004408
- IRB registration number: IRB00005219
- Expires: 9 December 2017

- LRB members (print names):
  - John McGladdery
  - Clive Bruzas (PhD)
  - Francis O'Brian (PhD)

**LRB REVIEW BOARD ACTION:**

- [x] Approved as submitted
- [ ] Approved pending changes
- [ ] Requires full IRB review in Vermont
- [ ] Disapproved

**LRB Chair Signature:**

**Date:** 31 October 2016

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**Form below for IRB Vermont use only:**

**Research requiring full IRB review. ACTION TAKEN:**

- [ ] approved as submitted
- [ ] approved pending submission or revisions
- [ ] disapproved

**IRB Chairperson’s Signature**

**Date:** 31 October 2016
Access, Use, and Publication of ISP/FSP

Student Name: Lakshmi Karuparthy

Email Address: lakshmikaruparthy@gmail.com

Title of ISP/FSP: The Aha Moment(s)! – What prompts HIV Positive Individuals to Transition from One Life Narrative to Another

Program and Term/Year: Community Health and Social Policy Fall 2016

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

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Lakshmi Karuparthy
Student Signature

October 20, 2016
Date
CONSENT FORM

Project Overview
You are being asked to take part in a qualitative research study. This form has important information about the reason for the study, what you will do if you choose to enroll in this study, and the way we would like to use information about you.

The purpose of the study is to learn about your personal experience of what events prompted you to transition from your initial HIV diagnosis to your integration of HIV into your self identity, and whether the Blue Roof Wellness Center aided you in this process. You are being invited to take part in this study because you are an HIV positive individual above the age of 18. I plan to interview a total of 3 HIV positive individuals who have reached out to the Blue Roof for HIV services.

You will participate in a sit down interview with the investigator in a closed off room at Blue Roof. The interview will last approximately 1 to 2 hours. The interview may be recorded on an audio recorder and/or video camera if you give permission to do so.

Rights Notice
In an endeavor to uphold the ethical standards of all SIT ISP proposals, this study has been reviewed and approved by a Local Review Board or SIT Institutional Review Board. If at any time, you feel that you are at risk or exposed to unreasonable harm, you may terminate and stop the interview. Please take some time to carefully read the statements provided below.

a. Privacy - all information you present in this interview may be recorded and safeguarded. If you do not want the information recorded, you need to let the interviewer know.

b. Anonymity - all names in this study will be kept anonymous unless you choose otherwise.

c. Confidentiality - all names will remain completely confidential and fully protected by the interviewer. By signing below, you give the interviewer full responsibility to uphold this contract and its contents. The interviewer will also sign a copy of this contract and give it to you.

Please keep in mind:
1. You are free to choose to participate or not to participate.
2. You may choose to stop participating in the study at any time. Even if you consent to be in the study, you are free to stop the study at any time with no penalty.
3. If you withdraw from the study, no more information will be collected from you and you will be free to leave.
4. If you indicate you wish to withdraw the investigator will ask if the information already collected from you can or cannot be used.

Consent for usage. Please circle Y for Yes or N for No
The document containing information from my interview may be published on the SIT World Learning Website: Y/N
I would like my name to appear with my interview responses in the final document: Y/N

I understand that I will receive no gift or direct benefit for participating in the study.
I confirm that the learner has given me the address of the nearest School for International Training Study Abroad Office should I wish to go there for information. (404 Cowey Park, Cowey Rd, Durban).
I know that if I have any questions or complaints about this study that I can contact anonymously, if I wish, the Director/s of the SIT South Africa Community Health Program (Zed McGladdery 0846834982)

Participant’s name printed  
Lakshmi Karuparthi
Interviewer’s name printed  
Lakshmi Karuparthi October 21, 2016

I can read English. If the participant cannot read, the onus is on the project author to ensure that the quality of consent is nonetheless without reproach.
ISP Interview Questions

HIV Positive Individual:

1. Could you describe to me what HIV/AIDS is?
2. Before your diagnosis, what were your views on HIV/AIDS?
3. When were you diagnosed as HIV positive?
4. Could you tell me about what you felt when you were diagnosed?
5. What were your views on HIV/AIDS once you were diagnosed?
6. How did you hear about the Blue Roof Life Space?
7. When did you start coming to Blue Roof?
8. Why did you choose to come to Blue Roof?
9. What types of services have you received from Blue Roof?
10. How has Blue Roof had an effect on your life physically and emotionally?
11. How did you feel about HIV/AIDS once you started utilizing services offered at Blue Roof?
12. Do you feel that you have incorporated HIV/AIDS into your identity?
13. What steps did you take to integrate HIV/AIDS into your identity?
14. What specific event(s) or experience(s) prompted you to begin integrating HIV/AIDS into your identity?
15. How do you feel about HIV/AIDS today?
16. Can you describe the blue roof in 3 words?
17. Anything else you want to say?
18. Do you have any questions for me?