Z4, A Slow Puncture: An Autoethnographic Exploration of Language, Embodiment, and Meaning-Making

Charlotte Rose Samuels

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Z4, A SLOW PUNCTURE:
AN AUTOETHNOGRAPHIC EXPLORATION OF
LANGUAGE, EMBODIMENT, AND MEANING-MAKING

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To those I love in Masxha

and to writing which has always been my home
“The ideal, or the dream, would be to arrive at a language
that heals as much as it separates”
(Cixous, 1991, p. 146).
I raise the glass of Hunter’s to my lips which are still burnt and swollen from the pepper I ate the wrong way earlier at lunch (you’re supposed to eat it whole, not chew off little bits in fear while letting it touch your lips). On the TV, South African hip hop has the biggest personality in the room. Men with thick red dreads and fancy sunglasses, women moving their bodies like the ocean. My belly hurts from laughing. It is getting colder now than the days when I sweat through my clothes in Cato during the summer with my leg half way out the window aching for the breeze at night though Mama always asked me to sleep with the windows closed. I laugh even more remembering this now. The pastels are scattered all over the table.
Acknowledgements

I never thought I would come to South Africa. When I decided I would spend my spring semester abroad and began to make plans, I imagined a far different place, nothing like the location I have come to know as my second home, so far away from my home in New Jersey. This piece of writing is an exploration of space and time which would not have been possible without the help of many individuals, communities, and experiences which I encountered in South Africa and elsewhere in my life. First, I would like to thank my parents whose unending love has known no end and who have never doubted me even when I have doubted myself. I would like to thank my partner, Karim, who has been my sounding board and my best friend, whose love has known no distance even from 10,000 miles away and 9-10 hours of time difference during my time here. Thank you to my college community at home, particularly my swim team and my advisor and mentor, Colin Hoag, who told me before arriving here, “expect your research to change, because it always does, and that’s okay.” Thank you to Mamsie, Ntando, Uthando, and Kittynana, for welcoming me into their home and sharing incredible food and stories and laughter and love, I will carry these within my heart forever. To Lungelo and Nkere for helping me arrange my ISP, to all of those who engaged in art and conversation over tea and biscuits and extremely hot peppers. I am indebted to you always. Thank you to Mama and Baba Zuma for giving me the most incredible experience in Nzinga, I will keep these memories with me always -- running for dear life during the hailstorm, the red mud between my toes, the dogs outside our house, the smell of smoke at night as it rained, eating peaches from beyond the fence. It was all the most incredible dream. Thank you to Chihei Hatakeyama, Lomelda, Bellows, Florist, and Yo La Tengo for being the soundtrack to writing my ISP,
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Abstract

In my ISP, I explored language as it relates to the ways in which people living in Cato Manor make sense of HIV/AIDS in their community. With 7.1-7.2 million people living with HIV (PLWHIV) in South Africa, individuals across the country are either infected or affected by illness. KwaZulu-Natal (KZN), the province with the highest rate of HIV, is also the province that was surveyed with the disproportionately highest internal stigma rates for PLWHIV. High prevalence of HIV, particularly in KZN, calls for a constant contextualization of life in the presence of illness.

Throughout the world, metaphor and symbolism is used to help non-medical experts make sense of, and communicate about, illness. I sought to uncover the ways that HIV/AIDS is mediated and expressed through the language and symbols individuals use in their communities. In my research, I conducted interviews with eight Cato Manor residents. I spoke with each person about how they use language and symbols to talk about HIV/AIDS. I incorporated arts-based approaches to afford participants more ways of expressing themselves. Even given its relatively small sample size, and the fact that it may not be representative of Cato Manor, my study still offers a vast breadth of narratives that I believe provide a more nuanced communal
understanding of illness. These lead me to conclude that illness is culturally configured, and that Cato Manor residents’ understandings do not derive solely from a biomedical paradigm.

Because my research was conducted in the form of an autoethnography, I reflected on my own understandings of the power of language and symbolism as a writer and detailed record-keeper throughout my life thus far. Where my initial question sought an answer about “meaning,” I discovered that questions of meaning were better responded to through abstract and indirect inquiries as my broad question of meaning yielded mainly biomedical responses. Some of these alternative questions included color association questions and questions where the participant was asked to create comparisons between HIV and something of their choosing. Other helpful questions were those that shed light on the ways in which individuals’ friends and family members discussed the topic of HIV/AIDS. These complementary inquiries informed and continue to inform me about the importance of signs and symbology, the body, the role of stigma via code, and the ways in which language is employed and deployed in the particular community of Cato Manor.

**Research question and contextualization**

I was drawn to complete my ISP in Cato Manor from the day I arrived for my homestay. When I think about my five weeks living there, I remember the idiosyncratic particularities surrounding my life then and I am overwhelmed with memories. These memories are penetratively warm and deep, standing out more than any of my other experiences in South Africa. I remember sitting outside of our house on the hill eating *magwinya* from the tuck shop looking out at the glowing Pavilion in the distance. I remember my Mama singing to *Narekele Mo* as it played on the gospel channel on Sunday mornings with all of the windows open.

When I think about my ISP as a whole, I still feel the confusion of juxtapositions facing me after weeks and months of my homestay in Cato Manor. I would not have expected stigma to be lingering just below the surface in such a warm and welcoming place. I was intrigued and saddened that a place so beautiful, filled with so much love and outward kindness, could experience the degree of heartache I was able to glance upon when I learned that ~20% of Cato
Manor residents in my age group suffered from HIV. It did not seem right or fair thinking about those who had welcomed me into their community with tremendous hospitality and grace to suffer in such terrible ways. Moreover, upon my arrival in South Africa, I presumed that stigma and discrimination, around HIV/AIDS would have subsided in the 20-30 years since the HIV/AIDS epidemic had ensued, however, I quickly learned that they had not.

Regardless of the fact that KZN has the highest prevalence of HIV in South Africa, survey data reveals that stigma in the KZN province remains extremely high. The 2014 Stigma Index Survey: experiences of people with HIV, reported that the KZN was the province with the highest internalized stigma (50.3% of PLWHIV in this province experienced stigmatization) (Cloete, 2014). In my research, I found that stigma and taboo played an important role in how people and their communities made sense of illness. Moreover, I learned that stigma and taboo had the power to heavily influence the language that individuals and communities use surrounding illness.

During my research I aimed to explore the ways in which Zulu people in Cato Manor were affected by and made meaning of HIV/AIDS, and moreover, aimed to examine the ways in which illness is expressed through language. What does HIV/AIDS mean to community members in Cato Manor in terminology and encounter? What is the role of HIV in the lives Zulu people? What is HIV/AIDS compared to? What words do individuals use when talking about HIV/AIDS? How does one describe HIV/AIDS and why? These questions proffer an alternative to the dominant Western biomedical narrative and language surrounding illness and instead situates illness in the embodied realities of individuals and communities.

Using interviews and arts-based approaches, I learned that one cannot examine meaning-making without also examining the role of the body. Through this process I grappled with my own relationship with language as well as my own body as it occurs within space and time. I also realized the possibilities for continuity in a study like this which employed tools such as crystallization and worked to access as many stories and voices as possible.

**Ethics and methodologies**
When crafting my ISP, I made sure to pay special attention to ethics. Having worked with dying patients in hospice, cardiac patients coming out of the operating room with new heart valves, and psychiatric patients receiving ECT, I knew how important certain guidelines about protecting privacy and dignity were, especially in a place with such a high prevalence of HIV/AIDS. I made sure that participants were fully aware that they did not have to share personal experiences or disclose their status or the statuses of others to me. I allowed for the natural unfolding of experiences and responses among my participants and among my own journey which unfolded after the interviews and in reflection to the ISP process. I made sure that my participants understood the context of my ISP before agreeing to interviews and gave their written consent.

My ISP research in Cato Manor was largely qualitative and drew on lived experiences and understandings as conveyed by individuals in interviews and arts-based approaches. For the purposes of this project I was not interested in counting or particularly quantitatively comparing individuals’ responses as they were largely varied, abstract, and qualitative in nature; this qualitative research data is something that should function in an additive way, instead of one where subjects’ responses can be diminished. As my analysis evolved, however, particular language and themes began to emerge among my subjects. Further, I applied this same theme-evaluation for art pieces which my participants created. The art pieces added another medium for participants to express their responses and reflect on the interview sessions. By employing the crystallized approach, the data is able to remain human. While I may be evaluating trends that appear, I inherently know that the material I am working with is related to people’s lives and memories that they are bringing to the forefront to share. This information is therefore valuable and precious and ought not to be dehumanized or rendered “data” in the traditional sense via methods of medicalization which often dehumanize black bodies for white consumption.

In research that values crystallization, it is important to note that each participant represents a small part of the greater whole. Crystallization, coined by Laurel Richardson (Shagoury, 2011, p. 298), is a three-dimensional data analysis tool which welcomes the many approaches which can be taken to a singular question. This is particularly friendly to “storytelling, art, self-reflection, … metaphor, and imagination to expand the field of data collection and analysis” (Shagoury
2011, p. 297). Crystallization is powerful as it welcomes a cycle of action between the researcher’s self and the work that they are undertaking. It must take into account “a significant degree of reflexive consideration of the researcher’s self and roles in the process of research design, data collection, and representation” (Ellingson, 2009, p. 10 in Shagoury 2011, p. 303). Crystallization is a valuable tool for an autoethnography which aims to examine meaning through multiple viewpoints and experiences.

To answer my questions about language and meaning it was very important that I talk directly with Cato Manor participants. For my sampling plan, I decided on a combination of snowballing and convenience sampling approach with the help of Lungelo Makhathini, a friend in Cato Manor who helped me identify individuals to be my research participants. Individuals were not recruited based on their HIV status although some individuals may have been HIV positive or closely affected by HIV due to the sheer prevalence of HIV in Cato Manor.

It would have been inappropriate and unethical to choose HIV positive individuals solely for their health status in this community for my research as they are a vulnerable population, and I am was aiming to gauge communal views of HIV/AIDS. My research was approved by the Local Review Board before conducting interviews (Appendix A).

My eight participants varied in age and gender, but all of them were black South Africans living in Wiggins or a nearby Cato Manor neighborhood. These participants took part in conversation, art-making, or both portions of the interview. Many of the participants did their interviews in private but some chose to do their interviews together or with others in the room. Participants were stripped of identifying qualities and names. I assigned the participants numbers 1-8 in order to assure anonymity. Data collected through audio recordings have been stored on my locked iPhone and will also be destroyed after my Senior Thesis/Fulbright Fellowship (depending on which takes place last -- for example: I may not be awarded a Fulbright Fellowship in which case the data will be destroyed after my Honors Thesis and participants will be made aware of this). Art drawings were labeled with numbers on the back for reference and will be destroyed after my Senior Thesis/Fulbright Fellowship. However, it is important to note that not all participants chose to partake in art.
I asked for consent from my participants via written consent forms (Appendix B). Within these consent forms was the request to audio record interviews and identify participants by numbers instead of their identifiable names. I got permission from all of my participants for my findings and research material to be used (and stored securely) for my Senior Thesis and possible Fulbright Fellowship. My participants spoke isiZulu and English.

I began by setting the context for my research with a description that went something like this: “HIV has been around in South Africa since the 1980s and we have lots of medicalized ways of talking about it, we talk about condoms and ARVs and prevention. But I’m interested in how HIV is understood in Cato Manor in particular. What language and expressions are particular to Cato that you would not find anywhere else?”

I then went on to ask my participants the following questions and told them that they could participate in art-making in response to the questions, for meditative purposes, or after the interview was done in a reflective exercise:

1. How would you describe HIV or what is “your definition” of HIV?
2. How would you describe HIV in a conversation with friends?
   - How about with your family?
3. How do your friends/family talk about HIV?
4. Do you think HIV has a meaning? If so, what is the meaning?
5. What color do you associate with HIV/AIDS?
6. What would you compare HIV to?

I spent a substantial time with each participant (15-30 minutes) so that they did not feel rushed in either their oral or art-based responses.

Artwork was not originally intended to be used as a data-collection tool, seeing as its original purpose was mostly meditative. However, since my participants chose to draw in reflection to the questions, art became a sort of medium for reflecting and responding to my interview questions.
In this way, art became an additional space for expression. Participants’ art pieces transformed into a living and breathing part of the research. Seeing the importance of art, I also used art as a medium in my own reflections and conclusions of my ISP.

**Introduction and initial reflections**

4/10/19

I thought a search for meaning would be more straightforward. But where I am standing now, I am overwhelmed not just by the information I have gathered from my participants but by the idea of meaning itself. *Meaning* is a heavy word. And an even heavier concept. *What is the meaning of life?* 

You want me to answer that?

The meaning of illness?

The meaning of the HIV and AIDS that has killed so many family members and friends? Possibly the hardest.

Everyone grapples with questions of meaning and I guess that’s okay.

Everything is slightly less muddy in hindsight and that’s natural, maybe. I am writing this realizing I asked all of the right questions even though I did not know I was asking them at the time. I was in fact *on the path* all alone and there was no reason to ask a clear-cut question about meaning with the word *meaning* in it. Everyone, including myself was already answering it.

**How can language and art teach us about meaning?**

A doctor may tell us that HIV is *dangerous, preventable, and not a death sentence with the help of ARVs.* A doctor may lay us down and take our temperature, listen to our lungs. But what about all of the other things that HIV is that the doctor does not have sight of? What about all of the other names it is given when the patient leaves the room? Who is to say that HIV is x but not y or z?
I see now, there is so much more to the HIV/AIDS experience than the biomedical paradigm gives sight to. In fact, to see the biomedical paradigm alone is like looking at the world with blinders, disregarding the reality of individual and communal realities. So much lives in life-worlds of individuals. A life-world is “...not the physical universe that science depicts; rather, it is the world of the everyday that is made up by personal activities and projects. [The lifeworld is] the world that is lived bodily, through which meaning is imparted to life” (Marcum, 2004, 315). So much lives in communities. So much lives in language. Often this is the information that has not been published because it is lived experience and it is outside of the biomedical realm. This lived experience and language often gets pushed to the back burner as biomedicine tries to separate human experience from illness.

Individuals understand HIV/AIDS in many ways that are not strictly biomedical. In “Cultural Meaning, Explanations of Illness, and the Development of Comparative Frameworks,” Garro states, “Illness and suffering are universal human experiences which come to be endowed with cultural meaning” (Garro, 2000, p. 305). These endowments are related to language, community, and the individual lived experience. Communities play a crucial part in maintaining, shifting, and changing the roles of language(s). In this way, languages are belonging to communities and are grounded inside of them. Language serves an epistemological purpose, a method of knowing which is grounded in individual and communal understandings, shaped by experiences and time; a language serves as the heartbeat of a culture, distinctly keeping its own unique time. I hope to offer an elucidation of the role of language in the lives of individuals, particularly in those who are infected and affected by HIV/AIDS in Cato Manor, KZN.
PART I: LANGUAGE INFLUENCED BY LIFEWORLDS

“Meaning”: initial biomedical misunderstandings and limitations

I began my ISP seeking answers about meaning. How is meaning ascribed by community members in the time of such hardships of illness? However, during my ISP I learned that certain questions were better to ask than others. It turns out that perhaps HIV/AIDS doesn’t have a “deeper meaning” as my question was phrased, but rather the way in which HIV/AIDS is talked about can give us clues to communal understanding. Within this is a paradigmatic shift, and there are new and radical possibilities put forth by asking questions of how HIV/AIDS is talked about.
The question I had intended to base my research on seemed to lead the participant to draw a blank. *Do you think HIV has a meaning?* I asked. Participants responded quite differently than I expected. Participant 3 answered: “It does have a meaning, but I don’t know… I always heard it said… H stands for… hmmm…” (Participant 3, 2019, April 1). Similarly, Participant 7 became flustered and said: “I do think it has a meaning, but I have no idea what the meaning is… infected virus is what the I-V means… and the H is…” (Participant 7, 2019, April 1).

The interpretation of this question among my participants was that I was asking them to provide me with the three words that make up the acronym of “HIV.” This was surprising, but perhaps it should not have been. Asking about meaning was easy to misinterpret or perhaps interpret however one wanted. When I realized this was happening in some cases I would try to explain what I *meant* by asking a question about *meaning*. I explained that this question came from the Western medical language used around HIV/AIDS which seemed solely scientific and talked about HIV as a disease that could be prevented and treated vs. what I knew about traditional healers -- that HIV was a sort of curse. After my short explanation some participants answered with the knowledge that I was after what seemed like a binary answer: “My beliefs fall on the medical side. I believe it is strictly a disease. My believing is it’s a disease, yeah, it’s not a curse or anything like that. Because if it’s a curse, we believe curses only happen with black people, that’s how I’ll put it. And white people really don’t have those things. But everybody has HIV so it’s medical.” (Participant 4, 2019, April 1) Similarly, Participant 5 stated, “I think it’s one of the diseases it’s like Ebola, TB, sugar diabetic, all of that. Yeah, I don’t think it’s a curse.” (Participant 5, 2019, April 1). When given an option, my question about meaning was treated in a binary system of medical vs traditional. Here, participants seemed to side with a medical meaning.

Upfront perhaps, individuals described HIV using biomedical language that was not filled with cultural idiosyncrasies. For example, my first question about how individuals would describe HIV yielded other medicalized and proper responses such as “What I can say about HIV is it’s a very, very serious disease and it’s killing people and so many people are scared of that” (Participant 5, 2019, April 1). Alternatively, Participant 6 shared his understandings and beliefs that HIV is a disease that needs to be managed: “How would I define it? What I know about it is
my perception or my understanding of it has changed over the years. First it was a death sentence so to speak and now it is a manageable disease. I do have 1 or 2 family members who have been living with it for a very long time. My understanding of it is that it’s a chronic illness that needs to be managed” (Participant 6, 2019, April 1).

In my questions about personal understandings of HIV and conceptions of meaning, I sought to discover personal responses rather than a reiteration of the biomedical narrative of HIV. By asking about meaning so directly and leading my participants to misinterpretation, I found that perhaps what I was intending to ask were questions of greater communal meaning. These questions were more focused around cultural understandings, emotion evocation, stigma, death, and society. Perhaps I should have been asking some iteration of: what does HIV/AIDS invoke out of Cato Manor residents and this community as a whole? These were answers I had to get in other ways than I first intended with my broad questioning of meaning. In my later questions, I provided alternative routes to invoke responses about meaning that were both abstract and indirect in nature.

Abstract questions lead to meaningful insight

What color is HIV/AIDS?

As it turns out, there were alternative routes into accessing and shedding light on the “meaning” I was intending from my participants. This was the meaning that was related to individual and cultural emotion stemming from lived experiences. It turns out that examining meaning could and should be approached in ways other than asking the direct question, do you think HIV has a meaning?

I believe that I have gained a more nuanced understanding of the meanings of illness through asking abstract questions. I knew that arts-based approaches could and should serve a role in an ISP which was centered around meaning-making, though I never intended to do anything other than a traditional ethnography when first arriving in South Africa. Fully embracing art, I wondered if perhaps art and its possibilities could be integrated into my interview questions.
Two of the questions which helped me examine meaning were abstract in nature.

- **What color is HIV/AIDS?**
- **What would you compare HIV/AIDS to?**

This first abstract question stemmed from my desire to incorporate arts-based approaches into my ISP as well as to examine the connective “metaphor-like” pathways of meaning-making that people may use when discussing HIV/AIDS. Perhaps *color* would be a way to remove from the biomedical paradigm and allow people to think about HIV/AIDS differently. I also wondered if there would be a connection between media and social conceptions of campaign influence and the ways in which people thought about colors and symbols.

I suspected that many responses for the question about color would be “red” because of the red ribbon campaign for HIV/AIDS. I wondered how symbols such as the red ribbon may affect this answer. I considered how a color could, in a way, function as metaphor, both in something qualitative like my research, as well as within the raw experiences and expressions from those I spoke with.

The red ribbon, the international symbol for the HIV/AIDS epidemic, was born out of a New York HIV-awareness arts organization that asked artists to come up with a symbol which would aid in visual support of the epidemic which was highly stigmatized in the United States at the time among homosexual communities. The red ribbon was praised for its power and simplicity, as well as its ability to be produced and displayed readily (Kniel and Wright, 2008, p. 22). The color red was selected because of its “‘connection to blood and the idea of passion—not only anger, but love, like a valentine’” (Visual AIDS website, n.d. in Stolley and Glass, 2009, p. 100). Red ribbons which were originally worn on lapels and became a prime a way to spread social awareness of HIV/AIDS (Kniel and Wright, 2008, p. 22).

According to the Nelson Mandela/HSRC Study of HIV/AIDS, a majority of South Africans are familiar with the international red ribbon as a symbol which is representative of the HIV/AIDS
epidemic regardless of the person’s living conditions (Grünkemeier, 2013, p. 69). The red ribbon has been used extensively throughout the country governmentally, communally, and personally.

I thought that most people would respond “red” for their answer specifically as a result of prevalence of the red ribbon in the AIDS awareness campaign. However, asking this question yielded many different color responses. The responses I got to this abstract question were fascinating and varied. People responded with their chosen colors for a variety of reasons, some biomedical, some symptomological, some emotional. Sometimes people had trouble assigning a specific color and instead chose a spectrum of color: dark or light.

Red

“Red. Red. Because everything goes…with blood” (Participant 1, 2019, April 1).

“Red. Yeah, because of blood. When you touch somebody when you’ve got a cut... when you touch somebody who is HIV positive then you can get infected by the blood” (Participant 5, 2019, April 1).

“Red. Because of the red ribbon. And also, danger. I also think red, when people speak of HIV or are dealing with HIV in different capacities, whether it be medical doctors or… you always hear the word blood. Maybe that’s why I associate with red” (Participant 6, 2019, April 1).

“The red ribbon, red” (Participant 7, 2019, April 1).

“Red. As in the ribbon” (Participant 8, 2019, April 1).

Black/Grey/Dark

“I would say black. Because even the skin. Not black but grey and such, greyish, because the skin tends to be not a normal skin, it looks blackish. Because you’ve lost weight. You become ashen grey” (Participant 2, 2019, April 1).
“What color? Hmm. Eh, it’s something dark. HIV’s like something black. Does that make sense? It’s like a cloud. A grey cloud. And as soon as that comes in the family or between the people that are around you, it’s like a cloud. Like a black cloud over you guys. Because it’s like everybody. If there’s somebody who is HIV, the whole family feels it. Even if you’re not. It affects everybody. We all sort of change, but gradually we will accept. To me it’s like because it’s grey dark cloud over you. Which will eventually we’ll go through it and we’ll see the bright” (Participant 4, 2019, April 1).

White

“Color? Color? Meaning like this color (*points to pastel*). I think it’s…white. Because it’s something you can’t see. Something moving in your blood. Something like…white or something like water because it’s something you can’t see” (Participant 3, 2019, April 1).

In a way, my findings prove to me that colors are a type of metaphors. Searching for colors as representative measures was an interesting exercise. In this act, the participant replaced a color for illness. Through this exercise, the chosen color became a signifier for HIV/AIDS. These responses show the true crystallized nature of this research as my participants chose their association colors for a variety of reasons, each one different than the one that came before.

**How comparative language can help us understand experiences**

*What would you compare HIV/AIDS to?*

My second “abstract” question which led to insight about meaning expanded on the idea of the power of metaphors in language as I asked my participants: *what would you compare HIV/AIDS to?* This question stemmed from my original understanding of illness metaphors as presented by Susan Sontag and others.
Metaphors are examples of comparative language and are frequently used in discussions of illness worldwide. My previous knowledge and research experience with illness metaphors told me that language surrounding illness in Africa and elsewhere was military-related. Because of this, I assumed my participants’ responses would be largely militaristic.

The military metaphor is an example of a conventional and commonplace metaphor, as it helps non-medical experts understand medical procedures and circumstances (Grünkemeier, 2013, p. 91). The military metaphor allows for non-experts to understand the virus as an enemy or an intruder (Grünkemeier, 2013, p. 91); here there is a particular relationship between metaphor and public health communication as public health interventions are created with these “cultural frame[s] of reference” in mind (Grünkemeier, 2013, p. 91).

The military metaphor has come about in other militaristic forms as well such as “Infection is War” which features prominently in popular South African literature. This literature is filled with language which is directly related to warfare such as ‘battle’, ‘fight’, ‘front line’, ‘conquest’, ‘mission’, ‘command’, ‘recruit’, ‘forces’, ‘legion’ and ‘soldiers’” (Grünkemeier, 2013, p. 94). The military metaphor extends to visual representations of metaphor on the scales of personified germs and viruses, and blood cells as seen in books targeted towards children and young adults such as *Ithemba Means Hope*. 
I was interested in the metaphors that would be present in language around illness if people had to come up with a comparison on the spot. Would they also use this war or military language? Would there be a pattern among the responses?

**HIV is like a vampire**
“A vampire. Yeah. A vampire. Because it deals with the blood” (Participant 1, 2019, April 1).

**HIV is like coal**
“Like I said, coal. The changing of the skin, you know the coal? It’s blackish grey, it’s how people used to, before taking HIV. The way their skin changes” (Participant 2, 2019, April 1).

**HIV is like cancer**
“To cancer. Because they are dangerous diseases, both of them” (Participant 3, 2019, April 1).
HIV is like BP
“Let’s see. I think I would compare it to BP. Because once you’ve discovered your status, you can control it. It’s not like if I’m HIV I’m going to die” (Participant 4, 2019, April 1).

HIV is like a nightmare
“That’s a nightmare, I’m telling you it’s a nightmare. When the doctors tell you are HIV positive, you will be thinking I wish I could wake up from dreaming. It’s like a nightmare. It haunts you forever” (Participant 5, 2019, April 1).

HIV is like something that scares the shit out of me
“Something that scares the shit out of me. I can’t really compare it to anything else. Because I’ve seen it destroy families, 1-2 families where everyone went out, and they just left the kids; the children had no homes, so I wouldn’t be able to compare it with anything else at this point” (Participant 6, 2019, April 1).

HIV is incomparable
“I really cannot think of anything that I could compare it to. Because again it is just another sickness and illness, so I find it hard to try to compare it to anything” (Participant 7, 2019, April 1).

HIV is like other diseases
“That’s a disease; I would compare it to other diseases” (Participant 8, 2019, April 1).

While I expected to receive comparative answers inclined towards militarism, my question actually yielded results which were much vaster. These results ranged from biomedical comparisons (“HIV is like cancer”), to uncommon results which I had never thought of or heard about in the literature (“HIV is like coal”). These responses prove to me that comparative metaphors are much more varied than I expected. People do use common illness metaphors, comparing HIV to something terrifying and fear-producing (“HIV is something that scares the
shit out of me”), but the responses as a whole were multidimensional and relied heavily upon personal connective pathways of the participants.

Art-making in the ISP

The art pieces made by my participants were not originally intended to be a part of my research. Rather, the art component was set in place with the intention of being a meditative act for my participants to take part in (for example: doodling) during the interview sessions, a time that I believed could be potentially sensitive and vulnerable for participants given the topic that was at hand.

All of my participants who partook in the art-based portion of the ISP chose to do so after they answered the interview questions. When asked why they chose to do so at that point in time, individuals told me they were drawing in reflection to what they had talked about during their interviews. Many of the drawings also reflected what was touched on in individuals’ interviews, providing another outlet for expression after words had been shared.

In this way, art served as a contemplative process. Some participants shared what their art pieces meant to them. Two of the drawings portrayed individuals who had HIV/AIDS. Participant 2 described her drawing of an HIV/AIDS patient as “angry” and “isolated” as well as characteristic HIV/AIDS symptomological descriptions such as a “large belly.”

This participant believed that these descriptors were indicative of those who were suffering from HIV/AIDS rather than ill-intended biases placed on those individuals by the communities. Participant 1 also drew an individual suffering from HIV/AIDS and described other symptomological descriptors such as skinniness.
Figure 2
Participant 2 artwork

Figure 3
Participant 1 artwork
Participant 5 drew slightly more abstractly and described her drawings to me. For example, this participant explained that the small house in her drawing represented the place where those “affected and infected” lived and when they were inside the house there was sadness and isolation but when they went outside of the house there was sunshine and hope and love.

![Participant 5 artwork](image)

**Figure 4**
Participant 5 artwork

Participant 6 drew mostly with a pen rather than the pastels and colored pencils which were provided. For example, this participant drew Chesterville Clinic in his drawing, stating that “everyone knows what you are going there for if they see you going there” (Participant 6, 2019, April 1). This participant drew an ARV pill bottle with the description “ARVs aka ecstasy,” stating that he had heard some people refer to ARVs in this way, and the interview and drawing made him remember that. The participant also drew a Z4 car which is another way of describing AIDS. This Z4 car was headed to the Chesterville cemetery, indicating that if you have AIDS, you are on your way to death.
I was amazed at how many connective pathways my participants seemed to have used during their art-making processes, making the art pieces able to speak for themselves and be viable pieces of data for my research with the help of my participants’ explanations. As seen by the creative efforts of my participants, art also yielded opportunities for further discussion beyond the confines of my interview questions.

**Unexpected questions lead to insight about meaning**

_How do your friends/family talk about HIV?_

In reflection, as gleaned by the above abstract questions of color and metaphoric comparing as well as the making of artwork, it seems that I learned much of what I now know about understandings of HIV/AIDS in Cato Manor were through questions which were abstract.
Gaining insight into how participants’ friends and family talked about HIV/AIDS opened many doors to understanding how HIV/AIDS is discussed in Cato Manor’s various social circles. Through this process, participants introduced me to the importance of shared communal language and the granted insight into how language shifts depending on who is speaking or being spoken to, and why.

At this point I began to feel my ISP encompass the power of language and naming, both of which I did not intend to explore as I originally thought that my ISP would be much more focused on traditional understandings or folklore surrounding HIV/AIDS.

While color, metaphor, and comparing are useful tools, they can be limiting and concrete. I began to realize the importance of allowing commonly used communal language to come to the forefront rather than looking for a clear-cut answer like “red” or waiting for my participants to provide me with war language and metaphors. Using my questions on color and comparing as a springboard, I began to look beyond metaphor and comparing and towards signifying words and names which are already existent and particular to Cato Manor.

One question which yielded many dense responses and provided insight into how HIV is actually talked about in Cato Manor, was my question: how do your friends/family talk about HIV? Many of my participants’ responses had to do with names that HIV was given that were particular to Cato Manor and the Durban area. I was not familiar with these names before my research and I wondered what the reasoning was for developing these terms to talk about HIV. I later came to understand these terms as “slang” because they were alternative ways to talk about “HIV/AIDS” and “illness” without always saying the direct words themselves.

Since HIV/AIDS is a highly emotive, slang tends to be used in societies where HIV/AIDS is common. Horne suggests that this circumlocution of sensitive and highly emotive subjects is often characteristic of slang (Horne, 2010). In my interviews I found that HIV and AIDS were given a variety of “code words” and “names” in Cato Manor. The following are the code words
and names collected from my participants during interviews. These were the names that my participants believed were the most prevalent in Cato Manor and the Durban area.

**HIV names and codes words and their meanings in Cato Manor**

- **Z3** = signifies that someone has HIV (3 letters make up H-I-V), based on Z3 car
- **Z4** = signifies that someone has “full-blown AIDS” (Participant 6, 2019, April 1) (4 letters make up A-I-D-S), based on Z4 car
- **Amagama amathathu** = isiZulu for “three words”
- **Ishandisi** = isiZulu word for “the thing”
- **Intsholongawane** = Xhosa word for AIDS
- **Ingculazi** = isiZulu word for AIDS
- **Iqhoks** = isiZulu for “high heel” = meaning “iqhoks, like as in a heel...when you contract HIV you become skinny, you know, so you say, this one has got iqhoks, he has lost weight, his bones are showing” (Participant 2, 2019, April 1)
- **OMO** = a type of soap or washing powder, three letters in the word denotes the same three letters in H-I-V
- **Slow puncture** = “It’s a metaphor for a tire. It’s punctured and loses air slowly” (Participant 8, 2019, April 1) = term used in Cato community for HIV/AIDS
- **Isifo** = isiZulu word for “disease”
- **Iyagula** = isiZulu word for “he is sick”

**Nonverbal codes and their meanings**

Code words can also be non-verbal such as signing with three fingers. Signing in this way signifies that someone has HIV. For example, Participant 4 stated, “...if you’re talking about someone who is HIV you use lingo language, sign language, some people say, if I’m talking about you to someone else and I don’t want you to know I’ll say H-I-V (*three fingers -- middle, ring, pinky*). I’d rather just… it happens a lot. If I just can’t keep quiet about it and M is H-I-V and I can’t say it in the other street names because she will understand, it’s like I’m talking about
her while she’s with us! So, it’s like I’ll just sign... like I can’t wait, I need to tell you she’s H-I-V.” (Participant 4, 2019, April 1).

**Fear and awe: code words and stigma**

In a study done in the Cape Town area, HIV/AIDS is often given praise names which invoke respect and fear. These praise names allow HIV/AIDS to be personified. For example, some refer to AIDS as “UDubul’egeqa,” -- he who shoots to kill (Dowling, 2004, p. 2), or a variety of other words in Xhosa, Sesotho, and Zulu which equate HIV/AIDS to the “killer” or “finisher” of a nation (Dowling, 2004, p. 2). HIV/AIDS is referred to a “famous African personality” which is both hated and feared as it invokes a sense of wonder “for its power and ability to wreak havoc on a nation” (Dowling, 2004, p. 2).

Dowling refers to the special euphemistic language made up of substitute words as *(uku)hlonipha*, stating that *hlonipha* evolved due to a “sense of awe surrounding taboos that they may not be named or discussed” (Pinnock, 1988, p. 61 in Dowling, 2004, p. 4). As seen above, my participants refer to this *hlonipha* language the particular “code words” or “names” that they use to speak about HIV/AIDS. It is also noted that illnesses may have euphemisms attached to them so that the speaker is not susceptible to the disease when he or she is talking about it (Dowling, 2004, p. 5).

However, according to my participants there were also other reasons why code words may be used for HIV/AIDS. According to my participants, the official words for “HIV” and “AIDS” carry too much weight regardless of the language that these words are spoken in. Therefore, code words exist for three identified reasons: 1) out of respect for elders 2) out of respect for person who may have HIV/AIDS 3) so that gossiping can take place. Through the usage of code words by my participants, I became keener to the stigma and taboo surrounding the HIV/AIDS conversation in Cato Manor. In no way are these reasons all-inclusive considering that my sample size was only eight Cato Manor residents.
1) Code words out of respect for older family members

According to my participants, there is a different way of talking to family members about the topic of HIV/AIDS which is already stigma-wrought. For example, you would not talk about this topic with your older family members the same way you would talk about it with your friends. Participant 5 stated, “I think if I’m talking to a person in my family, out of respect I would say *isifo* which is more respectful, I think. Even the energy you emit when you say that is more respectful. Dude listen this just happened. When you’re talking to friends, *iqhoks*, Z4, not even talking about a person who has it, you use the code words. Seldom do you hear the word *ingculazi* which is the Zulu word for it” (Participant 6, 2019, April 1). Other participants agreed that language surrounding HIV/AIDS with family members had to be much more respectful. For example, Participant 7 stated, “With my family, *isifo, iyagula*, very respectful, trying to respect the family because they are older you have to use something that is more respectable” (Participant 7, 2019, April 1).

2) Code words out of respect for a person who has HIV/AIDS

According to my participants, code words can be used to replace emotionally charged and raw words, which may be come across as loaded statements. According to Participant 6, using the official words for HIV/AIDS, such as “*ingculazi*” would perhaps be wrought with stigma, “...they used to say *ingculazi* but it sounds so raw. It sounds so charged, emotionally charged, it’s usually used in a context like, you’ve got it. I think *ingculazi* is the one that carried the stigma. So, people are trying to move away from the stigma but it’s still there. Trying to find ways...if you say *ingculazi* it’s so charged. It’s like a loaded statement. So now people use code words” (Participant 5, 2019, April 1).

Participants also described that these words they shared with me were specific to Durban, specifying that one might also hear similar words in Umlazi, a township nearby to Cato Manor (Participant 5, 2019, April 1). Participant 5 stated, “There’s always code words -- *amagama amathathu* which means ‘three words,’ um...and then it’s *isifo*, the disease, there’s so many. And
then there’s *ishandisi*… I think these are specific to Durban. Because I’ve been in Umlazi and people would use the same words. Some people would say Z4. It’s a car actually. There’s definitely code words.” (Participant 5, 2019, April 1)

According to Dowling, “By not mentioning the disease by its name, by treating the disease itself as taboo, one respects the other’s choice to remain silent as well as protecting oneself” (Dowling, 2004, p. 6).

3) Code words so in order to gossip and to talk about people

I learned from participants that in a culture where stigma is common, gossip is also likely to ensue. Code words play a role in Cato Manor HIV/AIDS slang language in order to provide people with avenues to discuss and gossip about HIV/AIDS in a sort of secrecy. According to Participant 6, code words are used “…out of respect for the person who is infected or affected, but also they become coded because people gossip about it.” (Participant 6, 2019, April 1). Participant 2 stated, “they would use words like ‘OMO’ -- that one has got ‘OMO’ -- that way you know they’ve conducted the HIV. OMO, you know OMO soap? Washing powder? So now, in order for other people not to get what you are saying you’ll say, ‘this one has got OMO’ -- words so that other people won’t get to know” (Participant 2, 2019, April 1).

Nonverbally, HIV/AIDS is also gossiped about. For example, Participant 4 stated, “...if you’re talking about someone who is HIV you use lingo language, sign language, some people say, if I’m talking about you to someone else and I don’t want you to know I’ll say H-I-V (*three fingers -- middle, ring, pinky*). I’d rather just… it happens a lot. If I just can’t keep quiet about it and M is H-I-V and I can’t say it in the other street names because she will understand, it’s like I’m talking about her while she’s with us! So, it’s like I’ll just sign... like I can’t wait, I need to tell you she’s H-I-V” (Participant 4, 2019, April 1).

According to Participant 5, community members only discuss HIV/AIDS when they are gossiping about someone who has it. However, if someone is ill or someone who a person is close to is ill, the topic might seldom be talked about (Participant 5, 2019, April 1).
I found it surprising that stigma remained a concern in a community with such a high HIV/AIDS prevalence, even following South African ARV rollout. Prior to my research, I had assumed that after 20-30 years of the HIV/AIDS epidemic in South Africa and countless primary health care and health communication interventions, there would be more openness and normalization around the subject of HIV/AIDS, particularly in a high prevalence area like Cato Manor. However, through my interviews I found that it was quite the opposite. To my surprise, this community seemed to silence the conversation of HIV/AIDS even further, with the creation of code words.

**Frameworks: the role of semiotics in code naming**

Through the examination of color, comparison, metaphor, and code words, the role of semiotics became apparent. Semiotics is the study of signs, the study of how, when, and why something stands in for something else. The term itself was coined by the father of modern linguistics, Ferdinand de Saussure, a man interested in the *signifier* (the thing that stands in) and *signified* (the mental concept that the person communicating is trying to communicate). According to Saussure, the signifier and the signified cannot exist without one another. Moreover, only in conjunction do the signifier and signified make a *sign*. Saussure believed that there was no inherent link between the signifier and the signified, rather they were arbitrary expressions in language. For example, a picture of a tree or the word “tree” were simply concepts that a society decided would be attached to a tree in reality.
Charles Sanders Peirce, a logician who followed Saussure, divided signs into three categories depending on how the sign related to its object or signified: icons, indexes, and symbols. According to Peirce, icons are signs that have direct links to their signified objects. For instance, a photo of a tree is an “icon” of a tree because the photo has an inherent resemblance of its signified tree. For something to be an “index” in accordance with Peirce, it has to have an indirect and recognizable link in a cause-and-effect sort of relationship. For example, smoke signifies that there is a fire nearby. A “symbol” calls for no relationship between its signifier and signified except that the link is reliant on a meaning that it has been given via society. For example, red means “stop” and green means “go.”

The findings of my research are enriched by considering the functions of image and language as put forth by Saussure and Peirce's framings, individually and in conjunction with one another. My research did not originally intend to identify various signifiers which pointed to the signified (HIV/AIDS). However, these frameworks proved to be beneficial in examining my data as I approached topics of metaphor, color, code language, and symbology.

As stated by Peirce, a symbol is a symbol because it has a relationship to its signified that is decided by a society or collective knowledge / consciousness (for example: red = stop). At first, I believed that the term “Z3” was related to HIV not because there was anything in its resemblance or index which related it to HIV, but rather that it was a symbolic relationship that Cato Manor residents had decided to give that word. For example, HIV is not technically a Z3 car or OMO washing detergent. Nonetheless, if people heard these terms in Cato, the terms signify HIV.

However, upon talking with my participants more I realized that terms like “Z3” and “OMO” were actually indexes as well. The “3” in Z3 and the three letters in OMO actually signified the three letters through an index -- a relationship of threes (because this is three, that is three as
well). The more I deconstructed the language I realized that it was full of symbology and indexicality.

Indexical and symbolic words are culturally imbued with meaning where there may have been no evidence of link between signifier and signified before. As an outsider, one might not be able to find a connection between Z3 and HIV, but this specific culture/community has established this understanding of the connections between the terms and the reasoning behind it.

When participants were asked to compare HIV/AIDS to something of their choosing, individuals chose a variety of comparative subjects. The act of choosing these subjects was symbolic as they were bound to Cato Manor community members who were participants in my research and would differ from the comparisons that others may draw elsewhere in Cato Manor, other townships, and the world.

Linguistic theory is a helpful tool to analyze these findings as meaning is made and interpreted via communication and via inherent, determined, or culturally decided link. My research focused on the images generated by my participants. I found that these images were inherently linked to the idea, the signified, of HIV because the subjects were given prompting questions, all of which related to HIV. In this sense, the subjects’ responses and artworks are already suggested as within a web of knowledge pertaining to HIV.

While all of this theoretical deconstruction is important, it is also important to consider that participant responses were rooted in individualized human connections, social webs, and social circles. I made a conscious effort to consider that the responses were not necessarily objective or theoretical, but instead results of lived experience and a slang language which has developed and ensued in the community and will continue to change over time, as well as the inevitable differences produced by the act of interpretation.

Analysis: the question of meaning
Perhaps there is more than the straightforward, comparative metaphors that participants came up with; there is something at play in the language surrounding HIV/AIDS (“HIV is a nightmare”; “HIV is a vampire”) that is rooted in far deeper cultural understandings. These in turn are perhaps wrapped up in language and nuanced complexities, forming a sort of organic biome in which language and meaning may occur. It is the replacement of one word for the word HIV/AIDS or its equivalent in Zulu/Xhosa (for example, HIV referred to as Z3, a car); these analogies cannot exist without the contexts which assist in their definition, the semantics which allow their cultural rooting.

The *hlonipha* language is elaborate and intricate. Mncube states that “when people use a ‘taboo language’ they develop an ‘elaborate system of substitutions’ including ‘substitute words with no traceable associations’ and ‘words from other languages’” (Mncube, 1949, p. 53-57 in Dowling, 2004, p. 7). This is no more apparent than the substitutions we find with words like “iqhoks,” stating that HIV is likened to the high heel of a shoe because it makes one skinny.

The *hlonipha* language of taboo and avoidance is very much at play in Cato Manor as it seems that the code words given to me by participants such as Z3 or Z4 are in fact attempting to relate HIV to everyday objects and activities. Similarly, three-lettered and four-lettered phrases or objects such as OMO, a cleaning product, or the act of holding up three fingers are in fact attempting to relate HIV to a number that is associated with the HIV acronym. I find myself with much more knowledge than when I began my ISP, considering regional and cultural understandings of language as well as the culturally imbued relationships apparent within the symbolic signifiers and signified. In a sense, this wordplay searches to configure HIV’s objective truth into the microcosms it invades, rendering it through language to comprehend its violence.

In fact, when considering my question, “Do you think HIV has a meaning? If so, what is the meaning?” I now realize that this question, especially the use of “meaning”, caused my participants a lot of confusion and misunderstanding. Instead, responses were enhanced by approaching so-called “meaning” through other angles.
Language may serve as part of Cato Manor individuals’ epistemologies for explaining disease. Perhaps this is why I gained the most communally specific responses from asking abstract and indirect questions rather than asking a question with the word “meaning” itself. During my interviews, it was crucial that I examine names HIV/AIDS has been given in Cato Manor, as well as what contexts surround and reinforce those names and what meaning they serve for individuals. I realize now that deriving meaning is as variable in process as in result.

Though certain questions have brought me clarity and led me down avenues I did anticipate myself approaching, my research has left me with even more questions. Do I really have the agency to say what is meaningful and what is not in these community members’ lives? I am wrought with new concerns now -- if language is meaning then was the act of highlighting this language through various interview questions a way situating cultural importance when it came to the topic of HIV/AIDS in the Cato Manor community? Then again, how could I, an American student, say what words and phrases were and were not important? Through an even deeper and more careful reflection of my time in Cato Manor grappling with meaning, I realize that language and meaning-making would be the tools that connect me most to my ISP, tools that were both universal and infinitely intricate.
PART II:
Words and webs

I have learned that an autoethnography may be utilized to render its author more aware of her own subjectivities. I have been in relationship with my research through the positionality of language and analyzed my data based on the importance of language in my own life, only to find the incredible messiness and depth of words and their importance in meaning-making, particularly when a person is uncovering her own lived experience. As an autoethnographer, I realize now that I cannot separate where I am and what I have experienced from the social phenomenon of the language that I am analyzing in Cato Manor; the impossibility of objectivity both strengthens and limits a work’s so-called truth.

I was not named Charlotte after the wise barn spider who helps to save Wilbur’s life in *Charlotte’s Web*, though I like to imagine I was. I have always thought of writing as an act of weaving the pieces together, spinning a web out of the world of language that was surrounding me. I believe that when you write you are weaving the fabric of the universe. This became all the
more apparent in my reflections and in my ISP. Language and words were the tools in my toolbox to do the weaving. I have thought this about the act of language and writing for a long time:

From my weekly notes, week of 6/20/16

i think of writing as weaving
like the words are in this belt in orbit above me and they are sometimes aching for me and
sometimes they dont want me
and so i pull them down and i weave them into the tapestry and the web the ones i want the ones
i ache for the ones that fit the ones that make the landscape violent and afraid and right

Language proves that everything is hitched to a much more complicated web. A single word can signify much more than just what a word might appear to be. For example, a Z3 is a type of car, but it is so much more than just a car. We imbue these connections from within our communities through symbolism according to Peirce. In considering this type of cultural instillment, I am eerily reminded of the ways in which language is spread in cultural networks as well as the largely unknown ways in which slang terms are taken on in communities. People are connected to each other within language webs.

The language and the virus have more in common than I once thought. I have come to realize that language takes on characteristics of a virus both by requiring a human as a host and doing whatever possible to replicate and spread with the eventual goal of being omniscient and all-encompassing (Aoki, 1999, p. 961). In examining language as a virus, one must consider that language is panoramic and forever seeping into the cracks. Aoki argues that language is “between, within and without us - perhaps no area of human experience remains unmediated by language” (Aoki, 1999, p. 961). While I never made this connection before my ISP, I now realize that language is a virus of its own.

Language is inherently related to time, space, our bodies, and our communities. HIV/AIDS and illness is inherently related to time, space, our bodies, and our communities. Where are you and
what is surrounding you? The following section uncovers the ways in which I grappled with my relationship to language, writing, and my own body, particularly during my time in South Africa and in relationship to my research.

For the love of language

With time, a body can be born out of anything. With time, babies grow, and rock formations change, rivers flow into the sea, stars are born. For me language has always been about power. Language has always been about control. As long as I can remember I have been a writer of sorts, though now I am hesitant to call it that. How does one become a writer? Do you write something down and that is that? I do not remember the first day I called myself a writer though I remember wanting to be one. I’ve had so many passions and loves, but writing has stood the test of time, being my companion through all of the days. I’ve used all kinds of mediums and interfaces for my writing -- elegant leather notepads, scrawling in the edges of my Latin workbook, a red Moleskine notebook I carried with me everywhere and kept things tucked inside of, an old boyfriend’s bedroom wall in which I wrote *a piece of gauze to stop the bloodthoughts* when he told me I could write whatever I wanted. I’ve recently found old notebooks on which on the cover I’ve written “do not read or you will die” from approximately age 10. Funny now but not funny then. When I was in 5th grade, at the end of the year my teacher pulled me aside and told me, “I cannot wait to read all of your books one day.” My love for language has always been a warm fire inside of me, keeping me protected, burning through the darkest and coldest days. I’ve written on paper and set it aflame, I’ve scrawled onto bridges and trees, I’ve vandalized. I’ve crafted more letters than I can count to lovers, family members, friends, strangers. I buried my writing in the dirt. I have been called cryptic, creative, confusing. I have a very intimate relationship with my partner but nothing I have ever experienced has been like the love I have known as a result of writing and language. No love has been as consistent and as deeply and thoroughly my own as my writing. Through my writing I have created an archive, a cave of myself. My past, my present, and my future. I have created a home for my memories, my dreams, my fears. Living in my writing are moments I wish to forget, and moments never want to forget. I feel deep connection to Gwyneth Lewis’ poem as she discusses her relationship with language and writing, a strange and confusing love affair of sorts:
Fooled Me for Years with the Wrong Pronouns

You made me cry in cruel stations,
So I missed many trains. You married others
In plausible buildings. The subsequent son
Became my boss. You promised me nothing
But blamed me for doubting when who wouldn’t.
If I knew how to please you — who have found
Out my faults. In dreams I’m wild with guilt. Have pity
Kill it. Then, when I’ve lost all hope,
Kiss me again, your mouth so open —
I’d give anything for one more night —
That I go without thought. Don’t bite. No,
Mark me. My husband already knows
Exactly what owns me.

(Lewis, 2013)

When did I sell my soul to language and writing? To documenting? Why did I do it? What’s the meaning of it? I remember when I first started, the writing itself then came out of fear. I felt the need to create some sort of permanence at that time of my life because of external trepidations -- the feeling of going far away for college, the terrible fear of losing all of my handwritten writing that was not uploaded to the “cloud” in the event of a fire. I was driven by fear and frustration that I couldn’t keep track of everything I possibly wanted to write because I was losing it, or it would be lost in the near future. I was also overwhelmed and scared at the idea of writing taking up physical space in the world through paper or journals. So, I developed a multi-layered digital system. I created weekly documents titled with Monday’s date (month, day, year) and I began to record things that happened in that week. Some weeks were over 30 pages long, filled with copy-pasted conversations from text messages with friends, observations about how the sky looked. Some weeks were much shorter. At first during the short weeks, I became mad at myself because
I was not fulfilling some sort of quota I had set for myself. As time went on, I realized that weeks of life are like that sometimes, you must be kind to yourself no matter how much is observed, documented, collected. Each week is new, yet something is growing. In addition to the weekly document I created one more comprehensive document where I added longer writings which some may consider poetry as well as my dreams. The first long-document was called *Wane of Ridgewood*. I named it this because I began this deliberate writing journey during my senior year of high school, my last year in my hometown.

Sometimes when I look back from the writing of the early days of my archive, I don’t remember what I was talking about. Sometimes I read an excerpt from a conversation or the immediate account of a dream and I am brought back instantly. I do not understand how language has this power. I don’t think I ever will.

Not only have I had a love affair with writing, but language has been the most intimate way to come to know myself and to connect deeply with others. Through writing I have found words for my experience. I have become more grounded in my flesh body, knowing my words exist and they have a place outside of my body.

**A life of its own**

Often, I do not go back to read my writing. It builds up and calcifies indefinitely, taking on a life of its own without me there to see it, deepening and broadening, and I imagine, learning about me and also learning what I do not even realize about myself. I remember the scene in *Annihilation*, a horror sci-fi movie I saw here in South Africa, where a clone-humanoid quickly learns the movements of Lena, the main character, mirroring her every move, becoming more powerful, shimmering until the clone-humanoid is and is not Lena (Garland, 2018). My writing is me and it’s not me. Writing is the closest thing I have to myself. It’s an act of embodiment; it’s me in my most corporeal and material form using the oldest and most familiar form of expression I have of myself: language, expression, putting what happens down on a page, not
trying to make sense of it -- but in this way, letting it free, letting the writing itself take form and make meaning outside of my body. My writing has always been a form of control and yet a form of letting go and letting something exist outside of myself. My writing is an extension of me.

What does it mean for language to take on a life of its own? I saw it do so in Cato Manor, as participants explained how names and code-words evolved and changed with time, falling in and out of use and relevance. This transient nature of this language is an inherent characteristic of slang. Slang is influenced by particular age-sets in communities and by the life of social media, but slang is notoriously difficult to track or trace, as it does not change according to any register nor does it necessarily follow any predictable linguistic patterns (as we can see that symbolic code names are culturally imbued).

“I am my body”

One of the most stimulating and frustrating experiences I had during my time in South Africa was our visit to the Hare Krishna temple, known as the Sri Sri Radhanath Temple of Understanding. During our visit there we spoke with a devotee who asked us the deceivingly simple question: “are you your body?” We went around our SIT group answering the question hesitantly. When it came to my turn, I responded, “yes, I am my body it is more complicated than that.” The devotee cut me off and said that it seemed like I was “op die draad” -- an Afrikaans expression for being “on the fence” or “ambivalent.” The devotee went on to tell us that we were all living in an illusion. He compared our bodies to cars and our souls as the drivers. “Do we mourn when the driver leaves the empty car in the parking lot? No! Because we know that the simply has simply left the car to go elsewhere.” He compared the departed drivers to departed souls and asked why we mourn dead bodies in caskets when their souls had simply “gone elsewhere.” We were told that the illusion we were living was universal and problematic -- an illusion that we were American, that we were women or men, that we were rich or poor. Only through chanting the 16-word mantra could devotees of Hare Krishna be reminded of their “soul-ly” actuality rather than the bodily illusion, the body with the mind inside of the body convincing the soul we are our body in what seemed like a deceptive game:
The devotee spoke of Maslow’s hierarchy of needs, with the highest and fifth level being “self-actualization.” According to him, Hare Krishna devotees were always striving for the fifth level where they would come to an understanding that they were not their lowly-earthly car-bodies but in fact their more heavenly driver-souls.

Listening to this stranger talk to me about my body felt wrong. He didn’t know about my earthly experiences in my body. I felt frustrated and confused that self-actualization was a supposed ascribed phenomenon having to do with the soul’s separation from the body. I sat in the temple in reflection and in confusion. Though we were told to “meditate” I pulled out my little notebook, the one I always carry with me, and I wrote in a confused reflection. *I am my body.*

In my head the devotee’s words echoed. *Prison suit.*
Embodying illness

I wondered if perhaps there were occasions where the body was in fact the prison suit as the Hare Krishna devotee had suggested. When people are confronted suddenly with serious illness, isn’t it common to ask, am I this illness? Is this HIV/TB/cancer me? While the illness is part of the body, what does it mean for the illness to be part of the self? Does illness define the self? Illness threatens everything that we know to be true, putting our lives and life-worlds as we know them into jeopardy. Perhaps it defines characteristics of the body, but does it define what makes someone who and what they really are? This raises questions about the self, the body, and the role of illness. Are there lines that separate the self from the body?

Like Hare Krishna and other religions, biomedicine has done a fantastic job at partaking in the devaluation and the secularization of the body (Kindel, 1985, p. 38). In his piece, “The Challenge of Illness,” Kindel writes, “Our disdain for the body runs parallel to our exploitative attitude to the earth. The flesh should be subdued, renounced for ‘higher things’ or well-maintained like a sophisticated piece of machinery” (Kindel, 1985, p. 38). Kindel discusses the culture of separating the body from the self, in particular towards attitudes of illness and death. The body has become something to be owned as well as something to harness control over (Kindel, 1985, p. 38).

There is a deep-rooted history behind the separation and the mechanization of the body. Descartes states, “I suppose the body to be just a statue or a machine made of earth” (Descartes, 1998, p. 99 in Marcum, 2004, p. 312), devaluing the body and enlarging the value of the mind and the spirit. In medicine, the body follows largely Cartesian values, the body is mechanized, and bodily systems are designated with their own bodily organs which comprise these systems (Marcum, 2004, p. 313). The body is reduced and reduced again down to the single cell. The mechanization and reduction of the body is also responsible for the reduction of the lived experience of the patient who is suffering from the illness. Marcum writes, “Patients as body parts become cogs in a medical machine-world -- a world of interconnected machines in which the patient’s body is but another anonymous and exchangeable device” (Marcum, 2004, p. 313).
Patients are disembodied through biomedicine as they are reduced to what is ailing and needs to be treated within their separated bodies.

If we put value to the concept “I am my body” which the Hare Krishna devotee recommended we deny, we are also honoring the fact that each individual exists in particular lived life-worlds. The life-world is the lived bodily experience, the world that makes up an individual’s subjective life. Marcum states, “The patient is embodied concretely in the here and now… and not abstractly in a universal world that occupies no specific place and occurs at no particular time” (Marcum, 2004, p. 315).

Marcum supposes, “As embodied persons or lived bodies, persons create individual, unique life-worlds. The body, then, is personalized in a lived context or environment; for the person is not composed of separate body parts -- according to the Cartesian model -- but is an integrated bodily unit that is situated in a specific location and time” (Marcum, 2004, p. 315). Thus, we do not possess our bodies as divisible objects -- minds or lungs or hands -- rather we live in indivisible bodies which exist as objects within particular life-worlds. These life-worlds shape our personal and communal understandings of reality (Marcum, 2004, p. 315).

If we consider the HIV/AIDS illness, are physicians treating people for a biomedical disease rather than the lived experience of the person behind the disease? If a person is reduced to their body and the disease their body is suffering from, a person is medicalized rather than humanized. As seen in my participant interviews, it is clear that much stigmatization seems to come with this medicalization of HIV/AIDS in South Africa. People living with HIV/AIDS are reduced to a disease and all that the disease is associated with rather than given the opportunity to have be recognized as people with embodied experiences of illness and people who have life-worlds present outside of illness. People are situated in their life-worlds, even when illness strikes.

I believe that stigma is also amplified when people are disembodied in times of HIV/AIDS and illness. By reducing HIV/AIDS to its medical name and code names, opportunities for personal illness narratives and lived experiences of those suffering from HIV/AIDS are diminished and discredited.
The danger of embodying metaphors

According to Susan Sontag, there is danger in employing metaphors or symbolism when referring to the ill. In *Illness as Metaphor*, Sontag believes that with the stigmatization of war and defense comes the stigmatization of those who embody it. While the war metaphor is a means of health communication, it separates those who are sick and isolates them as “containing the enemy,” thus encouraging a “social death that precedes the physical one” (Grünkemeier, 2013, p. 92-93).

Although the military metaphor and other metaphors and symbols have been crucial in helping non-medical experts make sense of and communicate about illness, these ways of communicating can also lead to victim blaming. By using indirect ways of communicating, victim blaming can ensue. For example, with the military metaphor, individuals are pitied or seen as a disgrace when they do not “win” in the “fight” against the illness they are suffering from. Grünkemeier states, that the military metaphor “‘overmobilizes, it overdescribes, and... powerfully contributes to the excommunicating and stigmatizing of the ill’” (Sontag, 1990, p. 180 in Grünkemeier, 2013 p. 92). The embodying of metaphors and indirect ways of speaking about illness is not only isolated to HIV/AIDS but brings unnecessary and extra hardships to people suffering from other illnesses as well.

We live in bodies, we live in life-worlds

Two summers ago, when my grandfather, Herb, had a stroke in northern California and had to be transported for care; we visited him at a rehab facility far away from his teal-colored home in the Redwood Forest. I remember sitting with my family and Herb around a table in the rehab facility with various speech therapists and doctors as they discussed the trajectory of the damage, all the while seeing my grandfather grow more and more angry, disappointed, and then discouraged. I remember the eagerness as he tried to communicate with us, though he could no longer form words. Herb was cognitively *there* but could not communicate outwardly using the language he once knew as his body could no longer make words come out of his mouth. Herb was eventually
cleared to go home -- the long drive from San Jose to Eureka -- but never regained his ability to speak or communicate the same way.

My grandfather, a witty, peculiar, and handsome man, a doctor with patients who adored him, suddenly had a life which changed forever all due to a blood shortage to the brain. Everything happened so fast. During the weeks that followed the stroke, his life-world was changed forever. In Eureka, California, a small town where everyone knows everyone, word got around fast about what had happened. When Herb’s psychiatric practice had to be shut down, requests flowed in from patients who asked to continue their sessions with my grandfather, imagining that they would sit with him and discuss their problems even though my grandfather could not offer any vocal advice in return. I believe this is a testament to the fact that my grandfather was and still is an incredible listener. These happenings made me wonder even more deeply, where does the body end and the self begin? These happenings also harshened the reality for me that illness is crippling as it changes the life-world that we know.

Through my grandfather’s experience I have come to realize that the reduction of a person to their body’s incapability or fallibility via illness is not right just as it is not right to reduce someone to their HIV/AIDS diagnosis and in turn disregard their individual life-worlds. I wondered what alternatives there could be for people suffering chronic illness or chronic damage as result of an acute illness experience such as my grandfather is. It would be helpful for physicians and other people see those who suffer as their whole experiences and selves rather than just their diagnoses. I believe it may also be helpful to consider the experience that illness brings upon individuals and how it changes their life-worlds. Perhaps doing so may lead to better treatment rather than treating people as cogs within a system (for example, classifying one person among many people who have HIV or have suffered a stroke).

Through these experiences I have come to consider that perhaps there is value that we are not in a perfect system with perfect bodies and beings. We are fallible and must approach with kindness and love as things change in our individual, family, communal, life-worlds. People are so much more than a disease that may limit them by biomedical standards. Herb is his body, I think. The same way I believe that I am my body. And bodies are not perfect, but they are our home. Illness
and mortality come to us all -- they are guarantees -- unlike the “promise of the happy end” which Kindel suggests that each of us carry with us since childhood (Kindel, 1985, p. 39). We ought to value our imperfect bodies as we go through our lives. They are the homes in which we navigate the world and to disregard them is to disassociate from our very existence as human beings.

**Sensuous aesthetic gratification: the importance of the imperfect body**

As a hospice volunteer and an end of life doula, I have always admired BJ Miller, an inspiring palliative care physician who speaks publicly about improving the lives of patients. BJ Miller offers the notion of “sensuous aesthetic gratification” (Miller, 2015) as a way for people to live their lives and honor their bodies even in the face of illness and the alteration of their life-worlds. According to Miller, “sensuous, aesthetic gratification,” is a way of tending to our senses by way of our bodies and “where in a moment, in an instant, we are rewarded for just being” (Miller, 2015). This can be achieved by seemingly small tasks such as petting a dog, or by smelling a scent someone loves. Miller believes that as long as we have access to even a single one of our senses, we have access to way of what makes us feel human. If we consider the importance of sensuous aesthetic gratification, we may have a newfound appreciation for the bodies that we live in even in the face of illness. The body doesn’t have to be perfect to enjoy aesthetic pleasures.

**The body as a machine, the body that goes to the edge of the earth just for you**

I think often about the years when my body was a machine just for me. I was a child when I swam across the English Channel. Thirty-three miles, 11 of the approximately 21 hours in total darkness with the powerful current sweeping up under me, pulling me eastward or westward without a choice. I used to believe that throughout that swim and all of my long swims my “mind” was playing tricks on me. I hallucinated about nets and hands reaching up from the deep for me. Now I think I was trying to make sense of what was happening: is it natural for my body to be out in an open ocean for so long? Probably not. I think about my body that loved and longed for so much outside of the swim, for my body which was home to a person who was a
person and not just a sea-creature. On the boat were my parents and two older friends who had already swam the channel on their own. Though I felt fear, I also felt extreme awe in a way that I never have. I am fascinated about how my embodied self moved like a machine, keeping me safe in the dark water, trying to bring me one stroke closer to France even though the current beneath me had other plans. *I must keep moving*, I told myself like a prayer. My body followed, like an order. Were my soul and body separate then? Ask me then and I would have said yes. Now, I don’t think so. Swimming in this way turned out to be an embodied experience like no other. I remembered this as I looked at my hands, my arms, sitting in the Temple of Understanding. What I understood was that my body and I had been through it all together, we were not separate entities, separate, divided, and reduced pieces that got across the Channel -- arms and shoulders and feet kicking. Instead, my whole self wanted to do it and that self was embodied within the strong determined body, a body that loved and felt pain and fear which swam across. This was not something I knew at the time.

While my body has done things I still cannot fathom, it has also “failed me.” I feel sad writing those words now, thinking about how my body is my home, but I have wanted it to do things it simply could not do, and I had to listen to it. Or how when I write this, I am describing my “self” and “body” as separate: I am not saying “I have often failed myself.” I wonder why I do that.

Alternatively, when referring to HIV/AIDS in Cato Manor, participants spoke about HIV as if it was a describing characteristic of self rather than a separate part of their identity. Participant 4 stated, “if you are HIV, just take the medication,” (Participant 4, 2019, April 1) emphasizing you *are HIV* rather than you *have HIV*. Through this alternate statement, individuals are embodying illness through the language they use in conversation.

This made me consider the way I talk about illness as an American. For example, in America you often hear, “my mother *has* cancer.” My uncle *has* ADD rather than my uncle is ADD. In these possessional linking words such as “has,” we link ourselves to illness from afar, but we do not embody or engulf the illness into ourselves in a way we could with “is” or “are” -- words of identity. We fear the identification with the body and with illness especially those which are fallible, signifying a future mortality.
During the winter of my sophomore year of college on a training trip in Puerto Rico, I started feeling a strange sharp pain in my side whenever I would breathe in. The pain began to travel to my chest and across my sternum and it hurt to swim. I have always been a distance freestyler (hence my marathon swimming), and I could no longer reach forward to grab water without feeling the sharp pain. I have suffered from tendonitis and hypermobility of my shoulders, particularly my left shoulder since high school but this kind of pain was sharp and constant like a knife. It woke me up from sleep. It hurt when I laughed, when I carried my backpack to class, or when I even touched my chest or my ribs. I cried in the shower, anxious, angry, afraid, feeling trapped in my body which I felt had let me down as it chose a life-path of its own. How could my body have failed me when I obviously needed it? When the athletic trainers could not help me, I saw doctors who believed it could be a blood clot or a rib fracture. But I haven’t fallen, I told them. Perhaps it was costochondritis. When the doctor pushed on my side I whimpered. When she touched my sternum, I winced and asked her to please stop. This pain was so bodily and sharp that I can feel it now as I write. Doctors referred me to other doctors. I began guessing what would come out of their mouths and getting it right, a rib fracture, torn intercostal muscles, a mystery. I got chest x-rays and a full torso MRI, all of which amounted to nothing. The doctors told me to stop swimming for the time being. I obeyed, still holding onto the hope of an answer. The pain only partially subsided under heavy anti-inflammatories and a newfound addiction to my heating pad which I began to sleep with turned on to the highest setting. The hardest part about my injury has been the fact that it does not have a name. When people ask, I don’t even know what to say. It lives inside of me. It is a reminder, a mark. It has changed my life-world forever. Over time I have come to terms with it, I have begun to swim and race breaststroke, because it does not have the hyperextension of freestyle, but sometimes the pain catches up to me and I have to stop. I have learned a new language of listening to my body instead of listening to the language of outside, an outside which has no language or diagnosis for me. In fact, Western medicine has tried to separate me from my body, tried to devalue my body and pain as separate from me -- intercostal muscles and tiny bones with floating bones inside of my chest. I have had enough of that.
In my Western mindset, it would be ridiculous to say I am this injury because that would be an act of giving up, of succumbing to “my body’s downfall.” Rather, I have been conditioned to say I have this injury and take the medicine that is supposed to make it better. But I am my body. I am my injury. Whether it gets better or heals, it is part of my embodied experience. I am me because of it -- good or bad. Just as life-worlds are changed because of HIV/AIDS and other illness, a new language must be taken on to embody these changed life-worlds.

As I approach a career in medicine and continue my life as an athlete, I will be very cautious of this devaluation of the body within the scientific biomedical realm. I realize the importance of considering the HIV patient, the athlete, as situated within a particular life-world rather than just a mind attached to a body which is suffering from illness or injury. It is crucial to realize that life-worlds are currently evolving and may be evolving to include illness, injury, and ultimately change and mortality. The way that life-worlds change reminds me of the ultimate plasticity and resiliency of humanity. I would liken illness or injury to a type of scar tissue or a shift in the music’s key -- changes that alter the life-world’s composition and landscape. We walk through the world with our life-worlds as our homes until something goes and changes them, and we have to reconfigure ourselves in our life-worlds again due to the alteration. Events that change our lives are in turn changing our life-worlds -- the spaces and realities that surround our everyday lives. These shifts can be small or big, like a new job, the advent of being diagnosed with HIV, or an ongoing process of living with a chronic injury. All are embodied and not short-lived or as “fixable” as biomedicine may suggest. These scars and shifts are fully felt, taken on by the person’s whole being.

If we only consider the classification of human and earthly pain by scientists, doctors, and academia we are devaluing the human body to anatomic flesh which we treat separately from our own beings. I think I will never forget that lingering feeling that I knew once like an old sad friend. It was a pain that knew me inside and out. Sometimes I laugh, and I’m reminded of all that I’ve been through with my body, and in that moment, I feel the sharp shooting again like a knife. I used to think, how strange that at 19 I had chest pain. But now I realize that I would not know a different body. This is the body that is mine. We make sense in our bodies so much so that to not be our bodies is to not be at all.
Language as a body, the “worded-world”

“You're living for nothing now, I hope you're keeping some kind of record” (Cohen, 1971)

I would argue that by keeping track of my life, my pain, my joys, my dreams -- that somehow what has happened in life, my bodily and physical experiences, have been transferred to the body of my writing. Because of this, the act of writing, and what writing amounts to is inherently meaningful to me. It exists to preserve, to archive, to account for what happened. In writing I am recording accounts of what has happened, though sometimes in a sort of abstraction, be it through poetry or experiences that haven’t been documented in the way they happened -- memories remembered not exactly, not perfectly factually -- an imperfect record. Perhaps writing is a sort of record as suggested by Leonard Cohen in his song, “Famous Blue Raincoat.” Records are meaningful and provide a glimpse into a time in one’s life.

When I revisit these writing and dream records of mine which inhabit a space and time of their own, I see language I lived in and also language that lives without me. Observing this writing now, in preparation for my ISP, I see that my writing is multi-layered in this record. Over time it changes, time adds another layer to grapple with. I find myself asking, what do I feel now -- oftentimes to find that I feel wildly different from before. By making my writing into a material record, my writing takes up space in a material world. This material form can be grappled with, interpreted, and felt. If someone else were to read my writing just as if someone else were to listen to someone else’s music, the meaning might be different than intended. Similarly, in my preparation upon reviewing my writings I realize I feel differently than how I felt when I wrote them, especially those writings from long ago. To me, writing is a snapshot of time and space. Writing, whether intended or not serves as a memory. Writing is a means of time-travel, bringing us back to a place, but also to new and unseen continents time and time again. I see myself within my writing, in conversation with it, in relationship with it. I find myself in relationship with my writing and my language in a brand-new way now than when I first began my ISP and began interrogating the role of language. This process which I began engaging with before I can remember is the most honest form of self-connection that I know.
In this revisiting of my records, I find myself wondering, how would I describe myself then? How would someone else describe me if they were to read my work? Am I a different person now? How did these experiences that I wrote about come to affect the living, breathing person that I am today? Perhaps I’ve done myself a big favor, saving my memories and these pieces of me. Richardson states, “When we view writing as a method, however, we experience “language in use,” how we ‘word the world’ into existence” (Rose, 1992 in Richardson, 2000, p. 923). Through wording the world into existence, have I perhaps worded my body into existence as well? Has my writing affected my life-world? The more I consider this, the more I come to think that everything is in fact worded. In fact, perhaps through my massive documentation and record-keeping I also worded a body of writing into existence.

During my time in Cato Manor I have considered that slang and particular language used in a community might also be a body or record of a particular of time or space. I now find myself asking, is it possible that individuals in Cato Manor have also worded their bodies into existence through the language they use in communities? Am I catching a glimpse of this in notions of slang, color and metaphor? In their responses, I realized that people were also “wording their
worlds into existence” as a result of living in particular communities and having particular experiences.

I find myself in awe of the opportunity to bear witness to these records, these glimpses of others’ life-worlds in a place so far away from mine. In fact, the existence of recognizing these as records makes the world feel smaller, tangible, less scary and reminds me that universally, we make sense of the world on account of our own life-worlds and this sense-making often results in a relationship with language.

**Language, space-time, and memory**

My favorite poet, C.D. Wright, was one to understand the power of language and memory in her writing and poetry. Through Wright’s work I learned about the capability of language as a tool to harness time and space. Wright worded her world into existence as a poet. I have always admired her ability to make her poems portray idiosyncrasies and intricacies of her own life-world, while also making her words available to others to consume with their unmatchable style.

By consuming Wright’s poetry, I have learned that writing serves as a memory, something to tell you where you were at a certain time, whether it is secret and coded or clear-cut and accessible to the reader. I believe that writing can be a way to access a particular time and space, regardless of whether the writing was published or unpublished, or whether the author of the writing went back and revised it or left it alone. Writing and its language are laden with memory as they linger with the specificities of moments in one’s life. Wright becomes a vessel for the flow of space-time and memory.

I remember listening to an interview with C.D. Wright a long time ago regarding the work of revision. Where I have always seen my own documentative writing as a “first-thought, best thought” process (Ginsberg, n.d., in Wright, 2015), C.D. Wright takes a much more articulate process surrounding her writing. Wright states, “it takes me so long to formulate a thought worthy of articulation,” and likens writing to a bear hunt, stating, “my mind takes in and idles for a time before it can contribute to the surround sound” (Wright, 2015). In order for Wright to be
able to create her poems she explains that her writing process is quite difficult and lengthy. Wright states, “...for myself I have to make a lot of notes, do a lot reading, watch films, listen to music, collect little totems, I usually have a whole shelf full of stuff that is somehow for me resonant with my project and then I have to create a clearing” (Wright, 2015). Through the very different writing processes which writers inhabit I have come to know that regardless of how poems and writings are created, they are inherently servers of memory through their processes and their content. C.D. Wright writes often about the body and embodiment as she weaves in memories. In C.D. Wright’s poetry is the essence of kinesthesia, the understanding and awareness of where one’s body is in space and time.

Personals

Some nights I sleep with my dress on. My teeth are small and even. I don’t get headaches. Since 1971 or before, I have hunted a bench where I could eat my pimento cheese in peace. If this were Tennessee and across that river, Arkansas, I’d meet you in West Memphis tonight. We could have a big time. Danger, shoulder soft. Do not lie or lean on me. I’m still trying to find a job for which a simple machine isn’t better suited. I’ve seen people die of money. Look at Admiral Benbow. I wish like certain fishes, we came equipped with light organs. Which reminds me of a little known fact: if we were going the speed of light, this dome would be shrinking while we were gaining weight. Isn’t the road crooked and steep. In this humidity, I make repairs by night. I’m not one among millions who saw Monroe’s face in the moon. I go blank looking at that face. If I could afford it I’d live in hotels. I won awards
in spelling and the Australian crawl. Long long ago.
Grandmother married a man named Ivan. The men called him
Eve. Stranger, to tell the truth, in dog years I am up there.

(Wright, 2002)

I have always been fond of memory which is why I created my weekly and collective documents in the first place. I was so afraid to forget things which I felt so heavily and deeply, and writing became a way to preserve them. Writing and a control of language was a way to hold on for dear life. For me, writing was also a way to cultivate space in an uncontrollable world and to tend to issues that were pressing and needed to be worked through. In her poetry, Wright includes a detailed record of her own memory, even though these aspects might be somewhat coded or secretive to the observer.

Cato Manor is place which is laden with cultural and collective memory. The language used around HIV/AIDS in Cato Manor is inherently related to the memory of HIV/AIDS from generations past to generations future. Participant 6’s artwork depicts a timeline showing the years 1996 to the present, stemming pre-ARV rollout to the time that followed. In the year of 1996, the participant explained that his grandparents were diagnosed with HIV. This is illustrated by sad faces and the words “bad news.” The participant went on to tell me that 2006 was the year when ARVs were just becoming available for his grandparents to have consistent access to. In the year 2016, the participant’s grandmother is alive, well, and happy, living with HIV that did not become AIDS. The last frame shows “old age grandchildren” which my participant explained was himself and other family members.
Those living in Cato are born into cultural and collective memory with particular language surrounding that memory and situation. I realize now the ways in which this existence of cultural and collective memory relates to a term coined by philosopher Paul Ricoeur called “narrative identity.” Narrative identity is defined as a person’s “internalized and evolving life story” (McAdams and McLean, 2013) and is essential to comprehending how illness manifests in the individual and the community as it helps to understand the ways in which one explains HIV/AIDS within the contexts of embodied lives.
During my 2018 summer scholarship program at the Hastings Center for Bioethics, I pursued independent research on end of life legacy work for hospice and dying patients in the United States. In this process, I became interested in narrative identity -- how people view their own identities and where they are situated in their worlds, and the ways in which this could potentially be harnessed to create end of life projects for dying people. This was particularly important to me as a hospice volunteer and end of life doula. In South Africa, I realized that this work of narrative identity and narrative time could be applied to language and embodiment with regards to illness. While at the Hastings Center, I was introduced to the work of Ricoeur, and read a piece about his theories of narrative. However, the sources including the author of this writing were unidentifiable even after extensive research to find more information. I still decided to include this source in my ISP as it was filled with crucial information. I have marked the unknown title and the unknown author by asterisks in the paragraphs that follow.

According to Ricoeur’s narrative identity, one’s narrative is shaped by three types of time: cosmic, historical, and mortal. Cosmic time refers to the seemingly endless time of the cosmos in terms of astronomy and physics, while mortal time refers to the time comprising an average human lifespan. Historical time is referred to as a “fracture zone between mortal and cosmic time” (*, *, p. 64). Historical time becomes the place where mortal time is “reinscribed” among cosmic time through the means of storytelling (*, *, p. 65). I believe that individual life-worlds exist within the confines of mortal time. We are born into stories and we are born into histories. None of us enter into the communicative matrix of a community unconnected to the stories handed down to us by family and culture (*, *, p. 77). This storytelling which is made up of language is a “trace” that makes its way through generations and calls upon the present human beings to “recount the past” (*, *, p. 65). [Unknown author] states that it is within historical time where one begins to recount the past that one is actually beginning to “understand the narrative embodiment of our temporal experience” (*, *, p. 65). It is by understanding and parsing the “trace” that an individual can truly begin to understand and explain his or her own life, particularly with regards to a disease that has historical and mortal elements as HIV/AIDS does in South Africa.
Understandings of illness and languages surrounding illness are influenced and built in relationship with these three types of time. Take for example, the realities of collective historical time, such as AIDS denialism and apartheid. These realities are not only historical in nature but also stem into mortal time as individuals conceive of illness in their lives in the present day. The three types of time are interwoven. Participants used language particular to their own age groups and noted that they changed their language depending on if they were speaking to older relatives or with those who were suffering from HIV/AIDS.

**Language and writing as a way to cope with illness and mortality**

Perhaps it can be argued that the particularities of language and writing are not only a body or a record of time and space, but a way to cope with realities of our very humanity such as illness and mortality. I have found much connection to Don DeLillo’s *White Noise* during my ISP period. *White Noise* is a story about a man named Jack and his family living within a growingly post-modern world. Language and sound play a key role in the story as the novel is framed by a collection of background sounds -- the humming of Jack’s wife, Babette, the familiar grocery store, the TV which always seems to be on. The novel allows for a deep rumination on fears surrounding death -- Jack and his wife Babette are terrified of dying and frequently debate with each other: “*who will* die first?” Jack and Babette eventually come to the conclusion that the death they are so deeply pondering about must be *white noise* -- an endless and consistent series of background sounds like the ones which are already filtrating their lives. Language, sound, and the constant discussion of death become a way to make sense of impending ruination. These devices serve as a comfort in a doomed world.

In *White Noise*, sounds, words and language are not given the same deep weight that I believe I have found in them in my writing -- guardians of memory. Instead, they serve a different purpose -- one of *self-preservation*. As suggested by Ricoeur, stories "*shape*" the shapeless ice of time even though deep time itself is not affected by language (*, *, p. 73). Here, stories become a tool for humans who must cope with lives filled with many highs and lows including illness and an eventual mortality. I would argue that particularities of communal language can also provide the same sort of self-preservation. Having a recognizable communal language is perhaps like having
familiarity in the dark. Searching for footing in the face of devastating illness, people find home in language.

This makes me wonder, is there anything wrong with self-preservation? Is it human to self-preserve and is slang or communally specific language a way to do so? Is it only human to create a language that feels like home, particularly in conversation with a deadly illness which is usually ascribed Westernized medical language?

In her analysis of *White Noise*, Bonca suggests that perhaps DeLillo meant that “language [was] not a system of signifiers and signifieds” as seen in a system of denotation, but perhaps instead that language serves to be “a massive human strategy to cope with mortality” (Bonca, 1996, p. 27). I believe that that there is something beyond the signifying indexicality and symbology of slang words like “Z3” or “OMO” and would argue that perhaps using such terms actually serves as a part of the “a massive human strategy to cope with mortality” with the advent of illness in communities.

Is the creation of language a form of self-preservation? Are Cato Manor residents using particular slang language as a way to cope with mortality and the reality of a ~20% disease prevalence in their community? Can this language tell us anything about meaning-making? Is using communal code language simply a way of inhabiting the world around us? Is the Cato Manor language for HIV/AIDS a sort of white noise as people try to make sense of impending doom and live their lives in the face of illness and death?

In reflection am I also writing as a means of self-preservation and a need for permanence? Is writing a way to cope with my own mortality in a world that I will one day have to leave? Are language and memory a way to feel less alone? I have come to believe that communal idiosyncratic language may be a way to cope with loneliness and that language may be a tool to help us feel less alone in our life-worlds.

“Misunderstandings” in language revisited: beyond Saussure
Language, in its many types, forms, and instances, is irreducibly filled with misunderstandings. During my interviews, I quickly found how easy it was for misinterpretation and miscommunication in language to occur. I believe now that this miscommunication was due to the differing life-worlds that my participants and I occupied, life-worlds that contributed to how we conceived of different words. I wonder now if someone else read my documents, or if I read my own writing from long ago, if the writings would be misunderstood or misinterpreted due to the ways that life-worlds vary or have changed over time. Language leaves a lot of room for mistake in what is said and what is meant, as seen earlier in the initial biomedical misunderstandings during my research in Cato Manor where individuals assumed that I was asking for them to define the disease from a medicalized standpoint.

![Diagram: The Disconnect](image)

**Figure 10**  
*The Disconnect*  
2019  
Paper, oil pastel

The disconnect displayed in the above diagram happened not only with the direct question regarding meaning, but also at one point in time when I attempted to clarify my question "how
do your friends/family talk about HIV?” When my participant was struggling to understand what I meant by this question, I instead reworded it and asked, “how do your friends/family talk about HIV in an informal setting?” By using the words “informal setting” I intended to clarify that I meant a casual conversation space. However, in that moment the Cato Manor participant assumed that I meant something entirely different. He later explained that he thought I was talking about informal settlements, shacks made of corrugated iron. I now believe it falls on the researcher to have a sense of the participants’ life-worlds and words that might make up their language context. How would my ISP have been different if I had included an isiZulu-speaking translator? Would instances like this have been avoided? Would other findings about language have been gained? Has language failed here? Language is idiomatic to a (researcher’s) fault, and it surely can drastically affect the results of these kinds of studies if that is not carefully considered in every step of the process. I believe this reveals much about life-worlds and how they must be taken into consideration during interviews of all kinds.

I wonder if these misunderstandings are actually opportunities for a multitude of understandings rather than a closed system of thinking about things with a singular right answer and wrong answer or a closed “signifier → signified” system where there is only one signifier and one signified. Perhaps understanding is not a box that gets filled up but is instead multidimensional and paradoxical in nature, as seen by the various ways in which people interpreted my interview questions and came to make meaning of what they meant. I have come to know that an infinite number of things can happen between what is said and what is meant. In order for all responses to be considered, I came to a new understanding that “what is said” and “what is meant” did not have to have a disconnect. Here, I came to realize a new way of thinking about what Saussure and Peirce thought were concrete systems of denotation and instead crafted a new diagram consisting of a multitude of arrows (none of which are disconnected). I believe that this indicates the true multidimensionality of life-worlds which must be considered when conducting research which involves crystallization.
Concluding thoughts; language and life-worlds are changing moons

I have come to believe that meaning-making is what happens when humans are faced with illness and mortality, when life-worlds are threatened and altered. I have come to believe that this meaning-making is encountered in an embodied sense and through the multidimensional outlets of languages. However, this is no way a complete study or a complete way to think about meaning-making.

This ISP has taught me more than I could have ever imagined about paradoxes and the very paradox of conducting qualitative research. Meaning itself is paradoxical and multifaceted, calling on the lived and embodied experiences of so many to make a picture which can never be...
completely whole, a narrative which is continually avoiding completion. Through my findings and reflections, I have come to believe that particular language used around HIV/AIDS, illness, and our experiences is crafted based on our particular life-worlds and the communities which we are always interacting with, which in turn continue without pause to shape us. However, I do not believe that I necessarily reached any final answers or completed ideas about what “meaning” is to those living in Cato Manor who are infected and affected by HIV/AIDS because that is not my place to do so. Further, my sample size of eight is in no way indicative of an entire community.

Throughout my ISP process I grappled with what it meant to uncover meaning. Is meaning something that an outsider should have anything to do with at all? Who gets to define meaning? Who am I to say that one thing provides meaning, but another thing does not? Rather than stating that I have the answers or that my answers provide a conclusive way of thinking about meaning, I hope that my ISP has shed light on the power of language, the role and importance of bodies, and all of the complexities that are seemingly woven into language, the role of the lived body, and the individual life-world.

I suspect there can be issues with “ascribing meaning” or saying, “this is meaningful.” In fact, the act of doing so seems a privilege, invalid as an outsider to a community that is not my own where people are suffering from diseases that I do not suffer from or have the same communal connection to. Rather I am honored to bear witness and be in relationship to others’ experiences, in particular in Cato Manor, a place that was so important to me during my time abroad.

I have come to know that when asking about meaning someone should do so indirectly and perhaps ask questions about evocation and emotion rather than a broad and confusing question which can leave people confused or filled with difficult misunderstanding. In asking about meaning, one should always do so via other questions which are perhaps abstract or indirect. This will invite and leave space for the participant’s own expression rather than making the participant feel like they have a huge gap to fill (as seen in the initial question I asked my participants about meaning).
During my ISP, my participants and I struggled, separately and together, and ultimately found common ground in language and art. There is validity and truth in all of it. As this draws to a close, I would like to revisit the art pieces which my participants produced during their interviews. My participants gave of themselves as they engaged with the art, many of them starting off the drawing process by saying, “I’m not a good artist!” Even so, this did not discourage them from picking up a pastel and starting to create. Never having given of myself to art before arriving to South Africa, I decided to challenge myself as my participants had challenged themselves by creating a complementary culminating set of art pieces to my autoethnography. This artwork helped me reflect on the autoethnographic process and my work with my participants. Below I am attaching this artwork.

Figure 12
On the idea of this paradox, I do not wish to conclude with any conception that this work has been finished. Where I left off, someone else can continue in the same way or in new ways. This is the work of crystallization, as one works to examine the many places where the light reflects on a singular crystal, always finding that there are more surfaces and that each one is unique like a fingerprint. I realize now how sacred this work truly is. I am aware of how open and vulnerable
someone must be when sharing of self, community, and life-world. To my participants and those living in Cato Manor I am forever indebted and truly grateful. Thank you.

**Afterword**

Memories are alive in the language we use and preserve for safe keeping. This is a gift. The following is a poem I wrote after visiting Nzinga and the Pholela Community Health Clinic. The title is with credit to Dr. Gumede who remarked in his lecture to us, “some anthropologist must go to the sun!” I look forward to all of what is left to come as I welcome the mystery that is for certain.

**The anthropologist who went to the sun**

Strapped in, in it for the long haul with myself and myself only, fearing nothing, bearing white snaggleteeth, bearing pretty hands, bearing only myself, a person stuck between a few worlds, keep dreaming I'm trying to get to Los Angeles by truck or train in the middle of the night, complicated warm sleep filled with the emanating kernel of a dragon's egg at the bottom of the ocean reminding me I am still me in the dream and I get to wake up and go on, thinking of the ones who came before and were brave enough to jump or push others out of love out of burning windows, epigenetically afraid of burning to death and intrigued by fire, signs and breadcrumbs, steamed bread *ngiyabonga* I love you I miss you thank you thank you thank you, becoming more tender, Real Love and Real Faith are the same -- both feel like traveling far away from home for something, admitting that writing was just a means to an end long ago I want to go back and swallow my words for the me that I am now, for the me that I will become when I am old and grey and braided, life has always been a downpour, Mama tells me to sit properly but I can't stop sitting like the *ixoxo* I threw out of our room who landed bony back first with its soft white belly exposed to the outdoor night light (I'm so so sorry), a cluster headache, a cluster of stars I could only find in Nzinga in the middle of the night, right there -- that's where I'll meet you, we still have a chance, a choice, I am going to be brave for Ma and Dad and Rog and Trace and Otto sleeping in England and everyone else back home, the captain plays the American national anthem as the flag is whipped back and forth like an uncontrollable rope, I am laughing now
imagining a mind and body disconnected when people have kept on living after being chosen by
a bolt of lightning, something precious, look, a hook for a hand, beads of light for eyes, my Dad's
gentle voice singing a song to me in a dark room, I am still surprising myself with memories

References


Marcum, J. (2004). Biomechanical and phenomenological models of the body, the meaning of illness and quality of care. Medicine, Health Care and Philosophy, 7, 311-320.


* Ricoeur article author, title, date, publisher, etc. is unknown and has been marked in an in-text citation with an asterisk.
List of Primary Sources

Participant 2. (2019, April 1). (C. Samuels, Interviewer).
Participant 5. (2019, April 1). (C. Samuels, Interviewer).
Appendix A: Local Review Board Approval
Human Subjects Review
LRB/IRB ACTION FORM

Name of Student: Charlotte Samuels
ISP/Internship Title: "What does HIV mean to you?: An autoethnography of communicative disagreement and meaning-making"
Date Submitted: 3/5/19
Program: SIT: Community Health & Social Policy
Type of review: Expedited

Institution: World Learning Inc.
IRB organization number: IORG0004408
IRB registration number: IRB00005219
Expires: 5 January 2021

LRB members (print names):
John McGladery
Robert Jambert
Clive Brizas

LRB REVIEW BOARD ACTION:
√ Approved as submitted

Approval pending changes

Requires full IRB review in Vermont

Disapproved

LRB Chair Signature: [Signature]
Date: 25 March 2019

Form below for IRB Vermont use only:

Research requiring full IRB review. ACTION TAKEN:

√ approved as submitted

approved pending submission or revisions

disapproved

Appendix B: Consent Form for Adult Respondents in English
CONSENT FORM

1. Description of the purpose of the project
   My name is Charlotte Samuels and I am a student at Smith College in the United States studying in South Africa this semester. You are being asked to be a participant in a study on the way that people in Cato Manor talk about HIV and the language they use to do so. The purpose of the study is to gain deeper understandings of the role of language in helping individuals and communities make meaning of illness. If you agree to be in this study, you will be asked to answer some questions in an interview which also has an art-making component. I would like to let you know that you do not have to share anything that you do not wish to share, especially if it causes you discomfort or distress. I would also like to ask for permission to audio record this interview for my own records and take pictures if you choose to participate in the art-making.

   The risks to participants in this study are minimal but may include emotional discomfort or distress around topics of illness. There may be unknown risks. The benefits of participation are possible companionship and an opportunity for discussion. You will receive refreshments while participating in this study. The information that I collect will be kept strictly confidential. Your identity and private information will not be shared with anyone. I intend to use the information collected in a research project during my time in South Africa and in the United States during my next academic school year for my senior honors thesis. There is also a possibility that I may use this information during a Fulbright fellowship year in Lesotho during 2020-2021.

2. 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.
   a. Anonymity - all names in this study will be kept anonymous unless you choose otherwise.
   a. 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.

   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 ___________________________ Your signature and date ___________________________

Charlotte Samuels 4/1/19 Charlotte Samuels 4/1/19

Interviewer’s name printed Interviewer’s signature and date

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.

Appendix C: Consent to Use of Independent Study Project (ISP)
Access, Use, and Publication of ISP/FSP

Student Name: Charlotte Samuels

Email Address: crsamuels@smith.edu

Title of ISP/FSP: Z4, *a slow puncture*: An autoethnographic exploration of language, embodiment, and meaning-making

Program and Term/Year: Spring 2019

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.

By signing this form, I certify my understanding that:

1. I retain ALL ownership rights of my ISP/FSP project and that I retain the right to use all, or part, of my project in future works.

2. World Learning/SIT Study Abroad may publish the ISP/FSP in the SIT Digital Collections, housed on World Learning’s public website.

3. World Learning/SIT Study Abroad may archive, copy, or convert the ISP/FSP for non-commercial use, for preservation purposes, and to ensure future accessibility.
   - World Learning/SIT Study Abroad archives my ISP/FSP in the permanent collection at the SIT Study Abroad local country program office and/or at any World Learning office.
   - In some cases, partner institutions, organizations, or libraries in the host country house a copy of the ISP/FSP in their own national, regional, or local collections for enrichment and use of host country nationals.

4. World Learning/SIT Study Abroad has a non-exclusive, perpetual right to store and make available, including electronic online open access, to the ISP/FSP.

5. World Learning/SIT Study Abroad websites and SIT Digital Collections are publicly available via the Internet.

6. World Learning/SIT Study Abroad is not responsible for any unauthorized use of the ISP/FSP by any third party who might access it on the Internet or otherwise.

7. I have sought copyright permission for previously copyrighted content that is included in this ISP/FSP allowing distribution as specified above.
Withdrawal of Access, Use, and Publication of ISP/FSP

Given your agreement to abide by the SIT Policy on Ethics, withdrawing permission for publication may constitute an infringement; the Academic Director will review to ensure ethical compliance.

☐ I hereby withdraw permission for World Learning/SIT Study Abroad to include my ISP/FSP in the Program’s office permanent collection.

Reason:

☐ I hereby withdraw permission for World Learning/SIT Study Abroad to release my ISP/FSP in any format to individuals, organizations, or libraries in the host country for educational purposes as determined by World Learning/SIT Study Abroad.

Reason:

☐ I hereby withdraw permission for World Learning/SIT Study Abroad to publish my ISP/FSP on its websites and in any of its digital/electronic collections, or to reproduce and transmit my ISP/FSP electronically.

Reason:

Charlotte Samuels 4/30/19
Student Signature Date

Academic Director has reviewed student reason(s) for withdrawing permission to use and agrees it does not violate the SIT Study Abroad Policy on Ethics.