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Narratives Towards Ending Stigma: HIV-Related Stigma in the Netherlands from the Standpoint of Those who Experience it First-Hand

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Narratives Towards Ending Stigma
HIV-Related Stigma in the Netherlands from the Standpoint of Those who Experience it First-
Hand
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Abstract

While there is a decent amount of research that has been done regarding HIV related stigma in the Netherlands, little has been done qualitatively, working from the standpoint of individuals who have experienced that stigma first hand. This research uses qualitative methods, weaving the stories of individuals as well as participant observations to understand what people believe are the most essential methods in erasing HIV stigma. It also looks at what people see as the types of stigma and conflicts within HIV positive communities that are the most detrimental to the larger erasure of stigma. Through interviews and volunteer work at HIV Vereniging, it was found that education and ending self-stigma are necessary to end stigma as a whole. It is important to work from the inside out, starting with HIV positive individuals who feel shame about themselves or their stories. There is a lot more work to be done in this field, namely in finding a more diverse group of participants.

Introduction:

For my ISP I wanted to do HIV related research that was heavily influenced by peoples' lived experiences. I wanted to share peoples' experiences and work from the standpoint of individuals who were exposed to HIV, HIV care, and HIV stigma first hand. I also wanted to incorporate my studies in cultural and medical anthropology into my research. It was really important for me, both in terms of getting access to interviewees, but also in my ethnographic research to volunteer for an organization that worked with HIV positive individuals. This allowed me to gain the trust of my interviewees and to break down the rigid barriers that may have existed between my interviewees and myself. It also allowed me to perform participant observations, which would have been extremely limited had I interacted with these individuals solely during our interviews.

My research question explores the methods in which HIV positive individuals in the Netherlands see as being most indispensable in combating HIV related stigma. My sub question looks at the types of HIV related stigma individuals see and experienced both in care settings with individuals who, by societal standards, are supposed to show constant compassion for those receiving care as well as in society as a whole. Most studies that I have read regard care as medical care, or care related specifically to one's physical health—their CD4 count, opportunistic infections, AIDS Dementia, and other illnesses that are treated and dealt with by doctors. But I want to look at other forms of care such as self-care and care that comes in the form of peer support, so how are people cared for by their families, their friends, and their communities beyond those rooted in biomedicine? Additionally, how do HIV positive people face stigma in the communities or spaces that are targeted specifically towards HIV positive people?

Self-stigmatization has come up numerous times in my discussions at HIV Vereniging. How does an individual's self-stigma affect the care that they receive and how does disclosure of the fear of disclosing play a role in this? Additionally, how are people met with multiple forms of stigma? An individual cannot be looked at for one aspect of their identity. They are not just HIV positive, but may be disabled or experience other more invisible forms of marginalization. How does this impact the care they receive?

Context:

What is the situation of HIV-positive individuals in the Netherlands? As of 2014, 19,065 individuals in the Netherlands tested positive for HIV. Of that cohort 17,750 are in care (Ard van Sighem, 2014). Within this number 60% of those diagnosed were Dutch and 39% were of a different ethnic origin (Raad Voor Gezondheidsonderzoek, 2001). One of the biggest HIV related issues that the Netherlands faces is the fact that HIV positive individuals are not being diagnosed with HIV until the later stages of their illness. Additionally, certain people have trouble adhering to their medications. Research by SOA AIDS Nederland has shown that heterosexual ethnic minorities often have a greater chance of receiving care late because they are being diagnosed late. This research also makes the point that culture plays a big role in adhering to one's HIV medication, due to a lack of trust in Western medicine or issues concerning one's faith. SOA AIDS Nederland is planning to get people into care faster and to make sure people stick to the care they are receiving. But what I want to look at takes these issues one step further. As mentioned before, the legacy that HIV carries is not free from stigma, but stigma is not homogenous. Different people with different identities and different histories experience stigma in their own ways. Additionally, people may not experience stigma at all.

Literature Review:

What I found in most of the literature that existed regarding HIV stigma in the Netherlands was that while it provided relevant and important information, it did so in a very impersonal way. Few of the journal articles were qualitative in nature and none of the articles that I was able to find incorporated interviews with individuals who were HIV positive and had experienced the stigma the researchers were talking about. This fact might say something about the nature of privacy regarding HIV, but it is also a gap that I am going to try and begin to fill with my research. The purpose of the literature review is to provide context and background for the current academic information that exists surrounding the topic of HIV related stigma in the Netherlands. This is important for situating my research. To find this literature I used key word searches on various databases, used the bibliographies of sources regarding HIV that I have used previously, and looked at existing literature from authors who frequently write about this topic.

“Making a Difference: The Construction of Ethnicity in HIV and STI Epidemiological Research by the Dutch National Institute for Public Health and the Environment (RIVM),” by Alana Proctor, Anja Krumeich, and Agnes Meershoek

Alana Proctor, Anja Krumeich, and Agnes Meershoek discuss how biomedicine and public health measures often reduce ethnic minorities to a single category of “migrants” that are then categorized as dangerous to the native heterosexual Dutch population. Because of the words that are often used when describing HIV risk groups, “...persons of any Dutch Caribbean or sub-Saharan African heritage (even when born and permanently residing in the Netherlands) as a possible bridge between HIV at ‘home’ and the Netherlands,” (Proctor, 2011, p. 1838). Although in public health measures this may seem to be an effective way to represent the populations that are contracting HIV, in practice it creates a connection between anyone who physically

resembles the ethnic minorities listed and HIV. As Proctor, Krumeich, and Meershoek write, “Socially constructed notions of ethnicity are enacted in science and professional practice and treated as apolitical variables, through these institutions scientific and professional merit is ascribed to analyses of these variables and factual knowledge is produced,” (Proctor, 2011, p. 1839). This research made me critically examine SOA AIDS Nederland’s “The Way Forward” policy paper. In the piece, for example, they write about certain cultural behaviors that interfere with adherence to HIV medications, such as wariness towards Western medicine and religious justification for denying medication in the first place. Does this lead to “biological essentialization, ethnic stereotyping, and victim blaming?” (Proctor, 2011, p. 1839). How do individuals experience stigma both related to their HIV status and their supposed cultural practices and beliefs? Although Proctor, Krumeich, and Meershoek’s research speaks to institutional issues, speaking mostly about RIVM and other public health organizations, I want to investigate how this is experienced on an individual level. While it is important to look at the gaps in the public health system, it is also important to take a more micro level approach, listening to the lived experiences of individuals who the aforementioned public health programs target. This is useful because it provides insight into the ways in which current measures may or may not be succeeding. Progress cannot be made within public health measures unless you listen to the beneficiaries of those measures.

“HIV and Sexual Risk Behavior Among Commercial Sex Workers,” by Maaïke G. Van Veen, Hannelore M. Götz, Petra A. Van Leeuwen, Maria Prins, and Marita J.W. Van De Laar

Van Veen and her fellow researchers sought to investigate the prevalence of HIV among commercial sex workers (CSW). Within this study three groups of CSW were looked at. These

included CSW who used hard drugs, male to female transgender CSW, and female assigned at birth CSW. One of the most interesting methods used in this study was that interviewees were matched with interviewers of the same ethnicity. This is something that will not be possible to execute in my research, and it will be interesting to reflect on how it may impact the answers I receive. An interesting point is brought up here though and resonates with points made in Proctor's article. This study reads, "African CSW were reluctant to participate which may be due to a taboo on HIV infection in their community or because of their often illegal status. In addition, distrust of public health authorities in medical research may also have increased the refusal rate and unfortunately we were not able to employ African interviewers, who might have stimulated the participation of African sex workers," (Van Veen, 2010, p. 722). This furthers the cultural essentialization that Proctor and her fellow researchers speak about. The researchers make overarching statements about "African CSW" with no qualitative information from individual African CSW. The research refers to a large and diverse group with very specific and unsubstantiated claims. But in opposition to this idea, how is one supposed to break away from essentialization when it is impossible to find interviewees to relay their individual experiences? On another note, the researchers write, "...sex workers might not want to disclose their HIV status because this may have consequences for their working permits in clubs or brothels. Sex workers with an illegal status might be reluctant to get in touch with official health care services and this may also influence both testing behavior and their knowledge regarding HIV status," (Van Veen, 2010, p. 720). Although I will not be able to interview CSW, this notion of HIV as being stigmatized in the workplace is a topic that comes up repeatedly in my conversations with individuals at HIV Vereniging. How does an inability to disclose one's HIV status at work lead to issues with receiving care? This is a question that I hope I can gain some

insight into with my interviews. The second point here regarding one's illegal status is extremely salient. What this article does not speak about is how one may experience multiple layers of stigma. How might one's immigration status, or rather perceived immigration status, impact their access to care? These notions of perception, essentialization, and stereotyping frequently come up in studies regarding HIV stigma in the Netherlands. In my interviews I am going to ask individuals about stereotypes and assumptions they may have encountered. How does stigma play into presumed identity and how do people move past this initial stigma?

“Report of the Stigma Research Workshop for the Development of Scientific Consensus Papers and Field Guidelines on Health-Related stigma, Held in Amsterdam, the Netherlands from 11-14 October 2010,” by Carlijn G. N. Voorend, Wim H. Van Brakel, Hugh Cross, Valsa Augustine, and Bassey Ebenso

This report was the product of a four-day workshop in Amsterdam that looked at various conditions that were often stigmatized and tried to formulate ways to combat this health-related stigma. This piece will be extremely valuable for my research because it outlines the origins of stigma and distinguishes between different types of stigma. This is important because one cannot simply see stigma as a monolithic entity, but rather something that, in order to be understood and subdued, must be interrogated. Patrick Corrigan, one of the speakers at the conference, said that there were three notions that need to be established when looking at stigma. These include “i) stereotypes...ii) prejudice...and iii) discrimination...He suggested further that four different types of stigma can be distinguished; i) public stigma...ii) self-stigma...iii) label avoidance...and iv) structural stigma,” (Voorend, 2010, p. 190). When thinking about this it is also important to understand how society regulates bodies. We can take Corrigan's model one step further and look at how different types of stigma can inform us about which bodies different

cultures deem as valuable, and how individual bodies are “disciplined” (Scheper Hughes and Lock, 1987, p. 8). This is salient when thinking about self-stigma because our phenomenological experiences—the way we experience the world and experience our bodies in the world—are informed by internalized notions of what bodies are seen as productive by society. So how do structural and public stigma inform self-stigma?

Another conference attendee, Jayashree Ramakrishna, said that “there was a reluctance to disclose HIV status, and the consequences of disclosure were modulated by gender, social status and affiliation to a minority group,” (Voorend, 2010, p. 191). This brings up the notion of social capital. Stigma differs based on different intersecting identities that individuals may hold. Stigma cannot be viewed statically. It varies based on one’s social position. So disclosure, or rather lack thereof, may seem to be attributed to self-stigma, but in order to understand the root of that self-stigma it is important to recognize how different bodies and identities are privileged in the society that is being looked at. Ramakrishna goes on to say, “a higher level of stigma was common among female sex workers, and since some of them practice secretly, this leaves them hiding double identities. Female sex workers...thus face redoubled discrimination and stigma. Such factors promote self-stigma or internalized stigma and leaves some affected people convinced that their disease is a retribution for moral depravity,” (Voorend, 2010, p. 191). Multiple stigmas is an issue that very few studies introduce. While this paper is extremely useful, it is missing the perspectives of individuals who actually experience the stigma being discussed. This is where my research comes in. I will use the points brought up in this paper in my interviews, and see how issues such as double discrimination play a role in the lived experiences of individuals living with HIV in Amsterdam.

“Evaluation of the Dutch AIDS Information Helpline: An Investigation of Information Needs and Satisfaction of Callers,” by Arjan E.R. Bos, Gerard C. Visser, Bertus F. Tempert, and Herman P. Schaalma

This study was conducted in 2000 and it involved asking people, at the end of their calls to the Dutch AIDS Information Helpline, if they would participate in an “anonymous evaluation” (Bos, 2004, p. 202) of the helpline’s services. The interviews consisted of a questionnaire, background facts about the interviewee, the content of the phone call, and an assessment of the helpline as a whole. While most of the people interviewed felt positively about the helpline and the help they received on their phone call, the study found that the helpline reached very few lower educated individuals (Bos, 2004, p. 205). In addition to further exploring why lower educated individuals may be hesitant towards calling the helpline, this study calls attention to the private nature of anonymous hotlines, and how keeping HIV behind closed doors may effectively promote stigma. This is something that will be valuable to bring up in my interviews when getting a sense of the way my interviewees feel about current measures of prevention and care. This also relates in a sense to my time volunteering with the campaign Out of the Closet. The objective of that campaign is to bring HIV out from behind closed doors. Its aim is to show that individuals living with HIV are not simply their HIV, but are people with stories and experiences that go beyond their illness. Additionally, how does the use of “AIDS” in this context rather than “HIV” promote stigma? AIDS can bring up associations with the illness that are no longer relevant. Is this something that occurs often in prevention and harm reduction tools? How does language play a role in stigma? In my interviews I spoke with two people who have worked and still work on the HIV Helpline. This will be an important point of comparison for my research.

“Psychological and Social Correlates of HIV Status Disclosure: The Significance of Stigma Visibility,” by Sarah E. Stutterheim, Arjan E.R. Bos, John B. Pryor, Ronald Brands, Maartje Liebregts, and Herman P. Schaalma

This study examined three groups of HIV positive people—those who revealed their HIV

status to a selective group of individuals, those who were completely open with their status, and those who had symptoms that were visible and thus made it difficult to keep their status a secret (Stutterheim, 2011, p. 382). It explored an interesting dimension of stigma, which is that if you “pass” (Stutterheim, 2011, p. 382), or rather if your illness is not written or visible on your body, unless you disclose you have the privilege, or supposed privilege, of avoiding stigma. This privilege though is double sided because internalizing your HIV status and keeping it to yourself can lead to inner turmoil. As the researchers state though, in order to get social support people frequently have to disclose their HIV status. What this study misses though is an examination of associative stigma. Do people who keep their HIV status a secret from non-HIV positive individuals associate in public with individuals who may have visible HIV symptoms? How do visible symptoms affect one’s access to community? This is something that I will explore in my interviews. The researchers write, “Perhaps full disclosers possess certain attributes and coping mechanisms to a greater extent than limited disclosers. This corresponds with the work of Paxton who has shown that public disclosure can lead to psychological release,” (Stutterheim, 2011, p. 389). This is something that is going to be extremely important in my research as well as something that I will expand upon. The lunches at HIV Vereniging are a space for HIV positive people to come together and speak freely about their experiences. One of the recommendations for further measures to be taken in stigma related research is that it is important to not only look at visible symptoms that may marginalize an individual, but also those that are less visible. How is illness perceived in the Netherlands, and what determines a legitimate illness? A paradox that exists in this research is that while one may face increased psychological distress living with visible symptoms due to that inability to hide one’s illness, society may privilege people who are visibly impaired in certain ways. How does one deal with this inconsistency? I am going to

investigate this further in my research.

“Public Reactions to People Living with HIV/AIDS in the Netherlands,” by Arjan E. R. Bos, Gerjo Kok, and Anton J. Dijker

For this study Bos, Kok, and Dijker created a telephone survey that looked at how knowledgeable people were about highly active antiretroviral therapy (HAART), how people behaved towards HIV-positive individuals, and how willing people were to have contact with HIV-positive people (Bos, 2001, p. 219). 751 people participated in this study and it was found that “people tend to respond with less pity, stronger anger, and more stigmatization to HIV infected individuals who are to a high degree responsible themselves for their infection,” (Bos, 2001, p. 220). But how does this play out in society? One may know that someone is HIV-positive, but most likely will not know how they contracted HIV. This study did not analyze the assumptions people have about HIV positive people. Additionally, which HIV-positive people do receive pity? Those who are visibly suffering? It’s also one thing to respond to a hypothetical situation abstractly, but when one is confronted with the situation in reality, how will one know how they will actually respond? In this sense I think it is important to hear stories about interactions that HIV positive individuals have had to get a sense of how people really react. Something that this study may not address is the fact that people who are hostile towards HIV positive individuals could be the people who refused to participate in the interviews. What opinions did this method leave out?

“HIV-Related Stigma Within Communities of Gay Men: A Literature Review,” by Peter J. Smit, Michael Brady, Michael Carter, Ricardo Fernandes, Lance Lamore, Michael Muelbroek, Michael Ohayon, Tom Platteau, Peter Rehberg, Jergen K. Rockstroh, and Marc Thompson

The purpose of this research was to fill a gap that existed in existing literature that studied HIV stigma within gay communities and specifically between men who have sex with men. The

study pointed out that within gay communities it is common for HIV negative men to associate with other HIV negative men and for HIV positive men to only associate with other HIV positive men (Smit, 2012, p. 405). This is known as serosorting. Although some studies say that this tactic can lead to the prevention of transmission, it also has the potential to lead to an increase in transmission. “HIV negative men who serosort [are] inadvertently placing themselves at risk for HIV through infrequent testing, lack of HIV status disclosure, acute HIV infection as well as co-occurring sexually transmitted infections,” (Smit, 2012, p. 407). As this literature review points out, serosorting is in most situations actually “seroguessing” [because] selection [is] based on perceived rather than actual HIV status,” (Smit, 2012, p. 907). How do people guess others’ HIV status? What physical features or attributes accurately or falsely illustrate one’s status? This furthers the question of how people’s perceived identities may cause them to be stigmatized in one way or another. One of the biggest reported rifts within the gay male community occurs along age lines. Often times younger HIV positive men describe a certain hostility coming from older generations of both HIV positive and negative gay men who feel that because of the knowledge and prevention materials that exist today for HIV, younger gay men should be more responsible when having sex. There is a lot of judgment placed on younger gay men who have HIV. This study does not explore this issue further, but to what degree does this have to do with older generations of gay men feeling anger towards younger generations for being ignorant to what older generations experienced during the height of the AIDS crisis? Does their supposed lack of responsibility symbolize apathy towards their elders’ history? This is where qualitative data will be helpful. How do the individuals who experience this issue articulate it?

Methodology:

I wanted to capture peoples' stories as told by themselves, but also through the more understated stories that became apparent in individuals' interactions, comments, and anecdotes I witnessed during the month of November. Storytelling is extremely powerful in the sense that it creates a mutual exchange between the listener and the storyteller. Telling stories, especially our own, can be cathartic, and hearing stories can be one of the most powerful ways of learning. It is a technique that can deconstruct prejudice, which often stems from fear. It is easy to fear someone that you have never met and have never communicated with, but when you see someone in the flesh or hear their story that person no longer becomes their illness or their sexuality, they become human. Stories can also bridge gaps in humanity. By learning about each other's experiences, we can find commonalities. I wanted to be a channel for this way of learning, combating prejudice, fear, and creating change (Dean-Duncan, 2014). Stigma is deeply rooted in distress and unease of what we don't know. I wanted to make people known, and humanize their experiences in the eyes of others who may never have met an HIV positive person. I wanted and needed to do this in a way that still worked from the standpoint of the interviewee. I wanted to use their words and their feelings without exhibiting my own judgment or analysis. Additionally, HIV positive individuals are a vulnerable population. Speaking about one's HIV status has the potential to dredge up unwanted memories, anger, sadness and a well of other emotions. For these reasons I had to be cautious and sensitive in my research and the way I went about recruiting interviewees.

For each interview I had a list of interview questions, but often times I got the best information from listening to my participants tell their stories. I had guiding questions such as, "can you tell me a little bit about yourself and the HIV related work you do," and "have you

experienced stigma related to your HIV?" I knew a bit about each interviewee before I interviewed them, so this help me to structure more personal questions. I asked about the organizations they worked for and the campaigns they had and have been a part of. I recorded all of my interviews and transcribed them from those recordings on the same day of the interviews, so everything was still fresh in my mind. I also took notes during the interviews when possible to record body language and things that the tapes would miss. In one of my conversations with a participant she thanked me for taking interest in her story. Although this may seem minute, it really zeroed in on why this type of research is so valuable. People want their stories to be heard

As mentioned above, for a little over a month I volunteered at HIV Vereniging making lunch for and with HIV positive individuals. Every Wednesday I went to their office, started cooking at 11:00 and left around 3:00 after we cleaned up. It was very important that I was extremely transparent throughout my time volunteering there. I was introduced to everyone by a man who worked there named Peter, and together, both in Dutch and English, we explained that I was doing research about HIV related stigma and that throughout my time there I would conduct informal as well as formal interviews, which would inform my research. These informal interviews took place while chopping vegetables, drying dishes, and mopping. They were conversations, meaning that it was not simply a one sided discussion in which I drilled someone with questions, but was more of a give and take where we asked each other questions and learned about each other's lives. It was made very clear though that I was doing research, and every time I had a conversation with someone I would be open and honest about the work I was doing, the questions I was looking to answer, and my interests regarding this extremely personal topic. People were very willing to engage with me and often times told me that I could ask them anything that I wanted.

I wanted to do a CVE for multiple reasons. Firstly, my goal of this research was to hear people's stories and learn from people who had first hand experience with HIV related stigma. There's only so much you can learn from charts, graphs, and statistics that are relatively detached from individual's lived experiences. Secondly, one of the most important tools in anthropological research and more specifically ethnographic research is participant observation. I wanted to write and research about something that I had experienced first hand. I also wanted to build rapport and have relationships with my participants. One of the key aspects of participant observation is establishing a connection with participants and making sure that people are comfortable with you in their environment so that act as naturally as possible. This does not go to say that I was an insider, but I was definitely not a complete outsider. I did not stand by and watch while everyone cooked, but rather cooked, cleaned, and spent time with my participants. Because I spent weeks working with people in this field I was also invited to events that I most likely would not have been able to attend had I simply conducted interviews and done nothing else. This allowed me to meet a wide range of people, but also let me see different actions that were being taken in Amsterdam in order to combat HIV stigma. As Greg Guest, Emily E. Namey, and Marilyn L. Mitchell write in their manual, "Collecting Qualitative Data," "being embedded in the social context helps researchers learn what questions are relevant and to ask them in terms that make sense to the 'natives,' ...participant observation teaches you what to ask about and how to ask it," (Guest, 2013, p. 80). My participant observations thus informed the questions I asked in my interviews. Additionally, it should be noted that all of the participants are referred to with pseudonyms.

Interviewees:

In order to get my interviewees, because of the IRB's ethical guidelines, I had to essentially work through a middleman. This was the logical way to go about getting participants though because as I mentioned before, this is an extremely vulnerable group and I wanted to do everything in my power to protect their privacy and not breach ethical conduct in any way. Peter introduced me to two of my participants, Wouter and Evert, who attend HIV Vereniging lunches. Wouter was diagnosed with HIV in 1994, but believes he was infected in 1984 by his Norwegian boyfriend. In 2007 Wouter started an organization for HIV positive orphans in South Africa called the Will and Do Foundation. Evert is 58 years old and was diagnosed with HIV in 1984. In 1994 he was diagnosed with AIDS. Evert also has a peripheral arterial disease, which can be caused by HIV medication, and ten years ago he lost his legs because of issues with his veins. The illness has now spread to his neck and carotid artery, so the risk of having a stroke is very high (Kokkelkoren, 2014).

My third interviewee was with a woman named Riella who is 57 and diagnosed with HIV 27 years ago. At the time of her infection she was living in Spain with her lover, who was also HIV infected. He passed away in 1990 and she returned to the Netherlands where she had access to health insurance. She was the project manager for HIV Vereniging's "Positief Geluid," or rather Positive Sound. This research was conducted on a peer-to-peer basis where HIV positive people interviewed other HIV positive individuals. The research was looking to make the needs of HIV positive people visible—it was looking to uncover information and certain forms of HIV related stigma that were not present in other studies and studies that had been conducted using different and less qualitative methods.

My fourth interviewee was a man named Luuk who was diagnosed with HIV in 1997. During our interview Luuk said that at that point in the Netherlands the policy surrounding testing was to not get tested. This was because there was no treatment. He said that the overarching belief was that finding out you were positive would just bring you more grief. Because of this Luuk was not tested for a long time. At the time he was also a prevention worker, and after his diagnosis he felt that he was standing on the outside looking in. He said, "I was looking over as a prevention worker I thought, well, these messages that I am spitting out for gay men are not for positive men. I felt that some of the messages were actually offensive to people living with HIV," (Luuk). In 2006 he started Poz & Proud and now he is the coordinator and editor in chief of the Hello Gorgeous foundation, which publishes a magazine four times a year that works to fight stigma and normalize HIV. Hello Gorgeous also just launched a new campaign titled, "HIV Uit De Kast," or HIV Out of the Closet, which seeks to make HIV visible and fight discrimination and intolerance. The campaign profiles individuals who are living with HIV and refers to them as "role models," (Hello Gorgeous, 2015). They have posters with individual's portraits and messages, as well as more detailed stories about their lives in the magazine.

My last interview was with a woman named Hellen who is 50 years old and has known that she has been HIV positive since 1989. During those years she spent a lot of time travelling throughout Africa. She had many STIs and when she got back to the Netherlands she had them treated. She asked for an HIV test to be done, but her physician told her she was white and a woman, so she had nothing to worry about. So she buried it. A few years later she became pregnant and during an appointment with her midwife, she was told that a study regarding HIV was being done. She was not obligated to participate in the study, but the midwife insisted that it

would be the best thing to do for the baby and that if in fact she were HIV positive, she would need to have an abortion, which is what ended up happening. She now has two children who are 20 and 22, and she is an editor at Hello Gorgeous, runs an HIV helpline, has workshops for people who have been recently diagnosed, as well as a host of other forms of HIV related activism. With my interviews I sought to portray HIV related stigma in the Dutch context from multiple perspectives. I wanted to hear from people who work on the organizational level as well as those who face stigma themselves. For my interviews with individuals at HIV Vereniging I had Peter establish a connection for me with them because I wanted to make sure that these were people who were comfortable talking about their stories and answering my questions. The other three people that I interviewed had been published regarding their HIV in very public sources, and were more than eager to speak about their research and activism in the field. It is important to note that while I was able to interview two women, all of my participants were white. Additionally, all of the men I interviewed identified as homosexuals.

Description and Reflection of CVE:

At 11:00 on Wednesdays I would meet around six other volunteers, the vast majority of whom were HIV positive, and we would each prepare a section of the meal. People had their roles set in stone and I was the floater—I would cut, clean, peel, and whisk things when needed. At 12:45 people would filter into the dining room and at 1:00 we would begin to eat. When most of the people had finished we would begin cleaning. I am not sure if I'll ever be able to articulate why volunteering at HIV Vereniging was such a valuable experience, both for my ISP as well as for my life as a whole. Everyone I met was so unbelievably welcoming and willing to assist me in any way they could.

I was recently telling a close friend about volunteering and I realized that in a lot of the work that I have done both regarding HIV as well as my work this summer at a psychosocial treatment center for mentally disabled LGBT identifying adults has involved being in the kitchen. While this may seem like a negligible detail, it is something that I see as being hugely important in the results of my research and more specifically my ability to connect with the people that I was working with. At the treatment center this summer there were many people who were HIV positive, were intravenous drug users, and many individuals who had been in and out of psychiatric hospitals for their entire lives where they were told that kitchens were not the place for them and that they could not handle the responsibility of cooking—it was not safe for them and the people around them.

Cooking may seem inconsequential to those who take it for granted, but handling knives and being able to provide for oneself are not tasks that everyone has the privilege or performing, for various reasons. In some cases it gives people a sense of agency as well as confidence in the fact that people trust them. It also gives people a purpose. They have a responsibility to provide

for people. To a certain degree cooking also serves to combat self-stigma. Throughout my interviews and conversations I heard people speak about how at they once saw themselves as dirty. They could not see a future for themselves because everyone around them was telling them that their lives would be cut short. Many people including one of the women I volunteered with had been fired from previous jobs after disclosing their HIV status. Having work and not being challenged in one's ability to work has the potential to lift a huge weight off one's chest.

Another facet of cooking and cleaning was that in some ways the roles were reversed. Being a researcher comes with a lot of power. You are in charge of the questions being asked and of the final product—the research paper. But in the kitchen I was not in charge. It was not that there were hierarchies in the kitchen, but I was working with people who had been there for years. Everyone knew each other, had built rapport, and knew what their jobs were. I worked next to people, doing what they needed me to do and cleaned when the meal was over. In this sense a reciprocal relationship was formed. I am by no means saying that my participants owed me something after I assisted in making lunch and cleaning, but rather I don't believe they saw me as a complete outsider. They saw that I was willing to help out in whatever way I could, that I was interested in what they had to say, and that I did not simply want to take their stories and run. I worked hard both to provide a good meal and a clean kitchen, but also to form trusting relationships with the others at HIV Vereniging. An important part of these friendships stemmed from the fact that not all of our conversations revolved around HIV. We shared many facts about our lives, experiences, our families, as well as other minute details that came up. We did not form our relationships around HIV, but rather around points of similarity. These people were not their HIV, but people who had HIV and I think that being able to see that allowed me to gain more insight into who these individuals were as people.

One of the first things that I was told while eating lunch was that it is extremely important for people living with HIV to be open and be able to freely discuss all of issues they are facing, HIV related or not. They cannot keep anything on their chests because that makes you sick, it weighs down on your spirit. This was visible during the lunches. People spoke about everything ranging from health care problems to sex, from death to jobs, parties to side effects of their HIV medications. While many of the topics were heavy, they were frequently spoken about in a lighthearted manner. People said that this was how they coped—it was important to stay positive, even when facing distressing situations. At one point though I was in the kitchen with a woman who also volunteered making lunch, and she said that something she feels that she cannot bring up among other HIV positive people is that she knows she is going to die young. She can feel it deep inside her. Yet she does not feel sad about it—she has accepted it. But people do not want to hear that—they don't want to think about dying. So this woman has to stay silent about something she is coming to terms with. This goes to show that not everything is an acceptable topic.

One of the most notable characteristics of the lunches was the demographic of the people who came to eat. I worked in the kitchen with three women, but other than that all of the attendees were men and, as I understood it, they were all gay. Additionally, only a small portion of the individuals coming were people of color. This was an issue that came up frequently in my interviews and discussions at HIV Vereniging. I asked why people thought so few women and heterosexual men came. The answers were scattered regarding women. Some people figured that it was because they were busy with children, husbands, and boyfriends, while others figured that they did not feel they had a place at the lunches. The responses for why heterosexual men were not frequently present at the association stemmed more from stigma. People felt as though

heterosexual men living with HIV saw the lunches as a space for homosexual men, and that they did not want to be seen as homosexuals. According to people that I spoke with heterosexual men are often still in the closet because they view their illness as a homosexual illness. They have an internalized stigma that stems from HIV challenging their own perceived identity. While we can question the legitimacy of this fear, it is not so far fetched. In Hello Gorgeous' new campaign, Out of the Closet, the magazine featured photographs and the story of one heterosexual HIV positive man named Kenny. Hellen who works for Hello Gorgeous was saying that shortly after the campaign was released people were making comments about Kenny being gay. The individuals in the campaign are supposed to be role models for those who are afraid to disclose and those who have internalized shame. But how are more heterosexual men supposed to feel comfortable disclosing when they see the response that Kenny is getting?

During my second to last time volunteering at HIV Vereniging I was in the kitchen cleaning with two women, one of who was HIV positive and another who was not. The woman who was not HIV positive, Ingrid, was talking about what it was like to work there while not having HIV. She then turned to the other woman, Christina, and asked if Christina saw her as an outsider. Christina responded by saying no, everyone is here for a reason and that reason brings us together—it is what we have in common.

Interview Analysis:

Although each interviewee had a distinct story and brought new experiences with and ideas about stigma to the table, there were also commonalities that existed between all of them.

Stigma Over Time:

HIV related stigma is not something that has stayed static in the Netherlands throughout the years. Over time it has shifted. One of these shifts can be seen in Luuk's interview. He saw the way HIV was being portrayed, and the images that were being shown regarding HIV. He highlighted the paradox that existed within the gay community. Luuk saw this as something that needed to change. When describing stigmatization in the early days of medication he said

When medication came it was springtime. People got their lives back. People who thought they were going to die were faced with a situation where they had to get jobs again. There was also the time that especially gay men got back in the sex scene, and then we found out that there was a lot of stigma in the gay scene. We were surprised because the gay scene was the most affected scene regarding HIV so you would expect that we were the most informed regarding HIV, but there was a lot of stigma towards people who disclosed. That's when people started to serosort¹ to avoid stigmatization.

A lot of the change in HIV stigma came with the introduction of new forms of media and the advancement of technology. Before the Internet there were many people who could not find others like them. People felt alone. They did not have anyone to talk to who understood exactly what they were going through. This was especially the case for women and heterosexual men who did not know people in their immediate circles who were HIV positive. In her interview

¹ Choose sex partners who shared your HIV status

Riella brought this issue to light by reflecting on her experience right after she was diagnosed.

She said

In those years I think I met the first woman with HIV, also living in the same city as me. She was a medical student and she got HIV in her first sexual contact when she went to France. She is a doctor now. In those days it was quite difficult to find each other because there was no Internet, and we really depended on the hospital to bring us into contact.

Hellen also reflected on this issue in her interview, speaking about how she happened upon a television advertisement for a meeting group for HIV positive women. She said that was the best thing that could have happened to her—that finding community, a support system, as well as those who understood her circumstances was incredibly powerful. Hellen also spoke about the discrimination she experienced in medical establishments early in her diagnosis. She reflected upon these times and then contrasted them with the tolerance she experienced with doctors more recently. This does not go to say that medical establishments are stigma free, but the degree to which certain HIV positive patients are stigmatized these days in the Netherlands is shifting from the way it was during the 1980s and 1990s. Hellen experienced this specifically during her first pregnancies. When she first became pregnant her midwife told her that an HIV study was being conducted, and that while the HIV test was optional, it was highly recommended because it could determine the viability of her baby. If the test came back positive, the midwife told Hellen that she would have to have an abortion for the child's safety. She went on to say

She gave me all the wrong information. She said for sure your baby will have HIV too. For sure you will develop AIDS when you carry this pregnancy to term. They were saying you wouldn't be a good mother if you kept your child. I had an abortion against my will—I felt like I had no choice. After that I became depressed about the fact that I was never going to become a mother.

This was in 1989. For the next few years Hellen never stopped thinking about having a child. It was something she had always dreamed of and, against the judgment of her doctors, she continued trying to conceive. She had a miscarriage, a premature birth, but then in 1993 she had her daughter. Along with her general practitioner who she found to be extremely supportive, she decided that she would not test her daughter immediately. In 1995 she found out her daughter was HIV negative and gave birth to her son who was also negative.

Conflicts Within Stigma Fighting Campaigns:

In her interview Hellen spoke about two HIV campaigns, one conducted by AIDS Fonds in 2012 called, “Hoe Positief Ben Jij,” or “How Positive Are You,” and *Hello Gorgeous*’ new campaign, “Uit De Kast.” The AIDS Fonds campaign was a consciousness raising operation. It involved posters, an interactive website, and television ads in which photographs of well known people had text over them saying things like, “would you still let me tattoo you if you knew I had HIV?” (AIDS Fonds, 2012). The tattoo artist pictured was not in fact HIV positive. At an AIDS Fonds dinner Hellen went up to the tattoo artist and said, “would you still tattoo me if you knew I had HIV?” According to Hellen he paused for a long time and she said, “I know enough,” and walked away. She then spoke about the Uit de Kast campaign, in which she said she believed you had to work from the inside out. You have to combat people’s internal stigma before you work on those who do not have HIV.

Luuk also spoke about *Hello Gorgeous* and the new campaign. He said

In 2011 I came together with a group of people and the idea of *Hello Gorgeous* came up. We found that the news and images of people living with HIV were very somber, dated, and depressive, so we wanted to do a makeover of the image of HIV, showing

people's faces. A lot of the times the interviews with people living with HIV were always of their backs because no one wanted to be seen. We changed that. We only put people in the magazine who were willing to be photographed fully.

This resonated with what Stutterheim, Bos, and Schaalma wrote in “HIV-Related Stigma in the Netherlands,” They say, “In short, there is a lot of work to be done if HIV-related stigma is to be effectively reduced. We need to tackle the various manifestations from various perspectives and in various contexts. We need to keep learning and improving efforts together. Most importantly, we need to give HIV a human face,” (Sarah E. Stutterheim A. E., 2008, p. 72). When addressing this campaign Hellen mentioned some of the criticism that has since come forward. She said that people are upset because all of the individuals being photographed are beautiful, successful, have families, jobs, and objectively good and happy lives. People are saying that this invisibilizes the people for whom medication does not work, the people who have been visibly affected by HIV. This was a criticism spoken by individuals at HIV Vereniging as observed during my CVE as well. One woman mentioned that she saw the campaign as glamorizing HIV. She believed the campaign had the potential to convince people that HIV was not in fact a harmful disease and that people did not need to be as precautious as they may have originally thought when having sex or participating in “risky behavior.” She did not want this to hide the fact that people are still dying from HIV and that people still struggle, physically, emotionally, and politically. She said that it is a privilege to be able to come out of the closet. This notion of privilege is echoed in Maaïke G. Van Veen, Hannelore M. Götz, Petra A. Van Leeuwen, Maria Prins, and Marita J.W. Van de Laar's piece, “HIV and Sexual Risk Behavior Among Commercial Sex Workers.” As stated above, they write about how certain people, in this case sex workers, may not be able or have the privilege to disclose their HIV status out of a fear of losing their job. Some people have

too much at stake (Maaike G. van Veen, 2010). Hellen said that she can see this and can see it as a potential issue, but that you have to start somewhere. People will not pick up a magazine with unfortunate looking people on the cover. Riella also touched on this issue and said, “When telling stories we cannot show people that are in the deepest deep down misery, but we can tell that we have been there. And that is what we can show.” It seems as though in order to fight stigma it is somewhat necessary to conceal the more gruesome and harrowing stories people still have. As Riella said

What I do now is I try to show that I am living with HIV, but hey, I also have effects from the illness. It's not like it's a piece of cake. I am doing fine, but I am working very hard on it. I don't smoke, I try to sleep a lot, I have concentration problems. My appearance seems okay, but people don't know how I feel. And there are many people like me who have been living for over twenty years with HIV that are not able to work as an effect of having lived so long with HIV. It is a struggle. I know we show very strong and successful people, but how else would we reach the general public? We try to give some more nuance.

Self-Stigma:

One of the most common issues relating to HIV stigma brought up by the participants was what they called “self-stigma,” which can be defined as an internalized shame regarding one's own HIV status. This appeared to be a hot button issue within organizations and campaigns working to combat stigma. Many interviewees cited it as the reason for working from the inside out—combatting internal stigma before targeting the general public. Hellen viewed self-stigma as one of the most detrimental factors in the prolongation of HIV related stigma. She saw it as something that many HIV positive people have, whether they can see it or not. She said

I do a series of workshops—six times in seven locations in the country—twice a year for people who have recently been diagnosed with HIV. It's for about eight people...last time

everybody at the retreat was on medication...but there were two guys, one of 21 and the other of 56, and we talked to both of them before they joined the group. They were both full of self-stigma, saying things like 'I'm dirty' and 'I cannot have sex anymore.' One workshop that we did was so interesting because there was one guy saying 'oh my God, I thought I didn't have self-stigma, but now I realize I'm always trying to make up for my HIV. I'm always trying to prove that I am still a useful person.'

As Hellen went on to say, self-stigma is not something that is always apparent to the person who experiences it. I can become innate—routine almost. This is why it can be so hard to combat. In Hellen's interview she gave an example from her own life in which she was shocked by the stigma she held internally—she could not see it until it was right in front of her. She spoke about a time seven years ago when she had protected sex with somebody who knew she was HIV positive. The man she slept with had a girlfriend at the time and the next day he told Hellen that he was furious with her and scared that now he would infect his girlfriend. Hellen said that her response was to feel dirty. She was terrified by the notion that by having nice sex she could do that to someone. This entire interaction shocked her, but what was most shocking was the fact that she realized her self-stigma was still there, after years of feeling rid of it.

In Luuk's interview he did not specifically speak about his own experience with self-stigma, but rather what he was doing to combat self-stigma in others. He also saw the solution to ending stigma as ending self-stigma. When speaking about *Hello Gorgeous* he said

You hear people that aren't willing to have their photograph taken because they *might* lose their job. The key word here is might. Because you might even keep your job, but people anticipate stigma. That is a marker of self-stigma—if you anticipate a lot of stigma. A woman told me that she had a gay male friend who wanted to like our Facebook page, but was afraid that his friends would see that he liked the page and would ask questions about his status. I think that is a very good thing because then you see the internal processes going on in peoples' minds.

This adds another layer to what Hellen was speaking about. If people cannot see their own self-stigma, how are we supposed to combat it? Not only does Luuk's campaign work to provide role models that empower and motivate others to "come out of the closet," but also calls attention to forms of stigma that frequently go unnoticed and that are extremely difficult to tackle. As Riella said

I think that what is shown as well in our research is that our circumstances in the Netherlands are incredibly good. Access to care is not a problem. We have a lot of access to things that other countries do not have access to. If you are feeling side effects you can always go on a new regimen. For the physical parts we have it good, but internal stigma is still very strong. And it takes a while to get over that, and most people don't get over that by themselves, because if you are feeling like a victim and feeling dirty or feeling guilty or sinful or whatever, then it is very difficult to get back from that.

This was interesting because it played into a paradox that Luuk introduced. One of the questions asked during our interview was about whether people speak about how they contracted HIV, or if that is seen as irrelevant. He said

It is almost the number one question from people who you tell that you have HIV. People are always very curious about how you got it. At HIV Vereniging there's an unspoken rule that you are not to talk about how you got it. It's not important. But I'm always curious about why that is. If you are not talking about it then you are always pushing the blame or guilt away. Let's face it—it's very important to process that as well. I'm all for openness. Groups are *so* important.

One of the reasons for why self-stigma is so hard to locate and battle is because in some settings people are not allowed to speak about the factors that perpetuate it, such as subconscious shame towards the way one became infected. If people cannot speak openly about everything feeling they have, how will people process their self-stigma? In order to understand this it is also important to think about what Carlijn G.N. Voorend, Wim H. Van Brakel, Hugh Cross, Valsa

Augustine, and Bassey Ebenso write in their report. Self-stigma is not simply something that randomly occurs, but is rather the product of cultural norms that become drilled in our minds and bodies. In addition to combatting self-stigma it is also important to look at the roots of where the internalized shame came from. In their piece “HIV Related Stigma in the Netherlands,” Stutterheim, Bos, and Schaalma write, “Stigmatization is related to perceptions regarding personal responsibility. When PLWHA are considered personally responsible for acquiring their HIV infection through, for example, sexual risk taking, people tend to respond with less pity and more anger,” (Sarah E. Stutterheim A. E., 2008, p. 10). How do people internalize this and how do people disclose or not disclose based on whether they themselves believe that their behavior was “risky?”

Processing self-stigma and getting rid of self-stigma also came up as an important tool when dealing with stigma from people other than oneself. Many of my interviewees spoke about how those who do not experience self-stigma often do not experience stigma from others. Luuk spoke about this relationship and said, “A lot of stigma has to do with how much you are receptive to it.” Evert also echoed this notion when recollecting his experiences with stigma. I asked him how his family reacted to him disclosing his HIV status and whether he had ever faced HIV related discrimination. He said

When I told my mother she was in absolute shock, but besides that it was no problem at all. Everything was still the same. Really I never felt discrimination. Maybe that is because I’m open about it. I think if you are hiding it then people think there is something wrong there, and then you get problems. Don’t hide it, just be open about everything.

When people can sense that you are ashamed or feel guilty of something, they may feel as though there is something to feel shameful about. Not everyone has the privilege to be open about everything, and not to hide, but it seems as though this was a common opinion among my

interviewees. As Stutterheim, Bos, and Schaalma write, “PLWHA who had disclosed their status to most family, friends, acquaintances and colleagues scored significantly lower on perceived stigma than those who had not,” (Sarah E. Stutterheim A. E., 2008, p. 22) Hellen expressed this to by reflecting on an experience she had in a workshop with a woman who disclosed to her partner. She said

The other day a woman called me and she wanted to talk about how to tell her partner about her HIV status. I said to her, the main thing is that you cannot make it a big deal. Keep it small—make it a non-issue. Tell him that you just need to get something off your chest, but that it in no way needs to impact your relationship. That is exactly what she did and it went perfectly. She shared it in the group and some of the other participants said that it was the biggest lesson they had learned since being diagnosed with HIV. This was not because they needed to know what to say to their partners, but because it taught them that they were not infectious scary people after all. It is not about what others think, but rather that themselves they know it now, and that they can thus bring it to others in that way.

This shows that both the way you present your HIV status as well as being able to speak openly in a group and having group support can be one of the most valuable tactics in combatting self-stigma as well as just generally getting support. Hearing from other peoples’ experiences can bring things to light that you did not know were buried in your psyche. This ties into peer-to-peer contact and support, which was utilized by Riella in her research. In fact she said that this was one of the most compelling conclusions she and her colleagues made.

People are empowered by contact with other people living with HIV, for exchanging experiences, for advice, and for partner search. Many people said that they missed the possibility for direct contact with other HIV positive people right after their diagnosis (Riella).

Intergenerational Stigma and Hostility:

A big topic that came up with participants regarded stigma and hostility existing within communities of HIV positive gay men and, more specifically, between younger gay men and older gay men. A lot of this hostility stemmed from older generations seeing younger generations being ignorant of what happened in the 1980s. Evert spoke about this in his interview saying

Gay men still do not use protection. I don't know much about the scene anymore, but I have heard terrible stories of people barebacking² everywhere, and then I think wow, you're stupid. The new generation has no idea what was going on in those days.

Some of the tension between older and younger generations of gay men come from this ignorance regarding the past, but are also driven by the fact that younger men have access to medications that were not available during the 1980s and 90s. In his interview Wouter said "Younger generations, they say, 'who cares!' There are medications. They are more reckless." This tension was also present when talking about how to educate younger generations and people who had just been diagnosed. Often times in communities people share their stories and talk about how they have overcome certain obstacles. Hellen spoke about this after I asked about whether the past is something that she spoke about often and conversations she has with younger generations and people who have been more recently diagnosed. She said

It is difficult because you don't want to neglect the past, but you don't want to scare people. People ask what happened to me and I say I can tell you but it is not going to help you because I literally got a death sentence. But it is hard when people complain about medication and about side effects. I just want to say at least you have medication!

² Sexual intercourse without the use of a condom

This was a common tension. People want to educate, share their experiences, and help others, but to a certain degree what happened many years ago is no longer that relevant to what is going on now. The people I interviewed spoke about how they could not blame people for not knowing what happened in previous years, but that it was hard to see people be so oblivious to what they went through. But at the same time, how do you tell people about it without terrifying them and creating stigma?

Not Disclosing to Family Members as a Method of Protection:

Many interviewees spoke about not disclosing to their families because they did not want to worry them and because they wanted to protect them, both emotionally as well as socially—they did not want their HIV status to have an impact on the way society saw their family. While the participants did not necessarily highlight stigma as the cause of this, if HIV were normalized and didn't carry the stigma and taboo that it does, maybe these measures of secrecy would not be taken. This can be seen in Riella's interview when she spoke about not disclosing to her community. She said, "I lived in a small village and did not keep my HIV status a secret, but very private because I did not want it to backfire on my daughter." Wouter said something similar in terms of protection. He said

When I came back to the Canary Islands in the 2000s I had not told my family that I was HIV positive. They would have worried—they would have thought that I was going to die. I thought it would tell them when I got back to Holland. And then I had to tell them. It was an obstacle to create a situation that I could tell my sisters in. There is a certain something you feel—uneasy.

This reflects an idea presented by Bos, Stutterheim, and Schaalma when they write "An additional reason for non-disclosure is that the HIV positive person wants to spare others from

worrying about him or her or from being subjected to stigmatizing reactions as a result of their association with PLWHA³. One final reason is that the person with HIV believes that his or her status is a private matter that does not need to be shared with others,” (Sarah E. Stutterheim A. E., 2008, p. 8). This idea of privacy is also something that was reflected in my interview with Hellen. She spent a long time speaking about how open she was with her HIV status, and how being silent and in the closet was negative, yet she said

My boyfriend prefers that I don't talk about my HIV with his family and friends. It has never been an issue with him—not at one level—but when his friend comes here with his white wife who is a doctor, my boyfriend hides my medication. And it is because I think he does not want people to think he has it. It is not because of stigma, but because he doesn't want to worry people and he wants it to be our business.

But this seemed to be antithetical to what she as well as other participants were saying was necessary to eliminate stigma. Selective openness was not an option, but rather one had to be open in all contexts for HIV stigma to be eliminated. They said that by being open in all contexts it would show that there was no person, no place, and no situation in which they felt ashamed. But then again this calls attention to the idea that not everybody has the privilege to be open.

Educating to End Stigma:

Towards the end of each interview participants were asked about the tactics they saw most fitting for ending HIV related stigma. As mentioned before many people believed that it was imperative that we tackle self-stigma—that in order to end external stigma it is important that we work from the inside out. Additionally, many participants believed that education was also crucial in ending stigma. Both Wouter and Riella spoke about incidents that emphasized just how important

³ People Living With HIV/AIDS

education is. In his interview Wouter spoke about an experience he had that highlighted a serious lack of knowledge regarding HIV.

There were some guys in the street who were trying to be bad towards me. I told them to be careful of what you do because I have HIV and if you hit me and get my blood on your hands you will get HIV. And they backed off.

Riella also expressed a need for education in medical facilities when she said

What we found striking was the discrimination people with HIV experience in the regular healthcare. Especially for gynecologic treatment and dental exams. The precautions taken when the HIV status was known were ridiculous and insulting. The knowledge and awareness about the very low transmission risk when people are aware of their status and on treatment is very low... There should be more education in schools. It needs to get the same kind of attention that other chronic conditions get. We need to focus on responsible behavior, not fear. The medical sector needs to be informed about the current state. That people are not infectious. If we as women go get normal pap smears and they see we are HIV positive, they start doing miraculous things, like protecting themselves—dentists as well. The general public should be educated like they are with ALS or diabetes.

Many interviewees reflected on what Riella brought up regarding people being educated about HIV like they are with other illness such as diabetes and cancer, as other interviewees mentioned. It is important though, as Luuk brought up, that this education happens in a certain way. During his interview he spoke about an exhibit he went to recently at Micropia, a museum in Amsterdam. He said

Yesterday we were in Micropia and they have a beautiful exhibition with dangerous viruses and bacteria that stand on top of closets. So you have Ebola, the measles, and HIV as well. When you opened the closet for HIV there was an old, run down condom machine with dirty stickers. It was not offensive, but it is such a stupid thing to do. They also had text there that said AIDS medication. It's not AIDS—it's HIV.

Luuk went on to say that yes, it is incredibly important that we bring HIV into the open and out of the closet. But pairing it with dangerous viruses and using outdated fear tactics such as run down condom machines and acronyms that evoke old memories is not the way to education.

Where are the Women? The Heterosexual Men?

As mentioned before, it was mainly gay men who were attending HIV Vereniging lunches. There were a few women and, according to people I spoke with, no heterosexual men. This was one of the questions that I asked my interviewees: Where are the women and the heterosexual men? Hellen, Riella, and Christina all said that women were busy doing other things. They have children, boyfriends, and husbands to take care of. This does not go to say that women do not organize and come together to support one another, but they do so less visibly. When talking about how HIV positive women meet other HIV positive women Riella said

We use social media, we have private and secret groups of women, and that really works well. I am part of that as well, and I am public, but many women do not out themselves. It's fine—I don't want anyone to do it if they are not ready.

None of my interviewees seemed to feel as though people should be forced to be open about their HIV status, but there was a sense of urgency that people spoke about—that maybe people who were not open or out of the closet were holding up the movement towards eradicating stigma.

Regarding heterosexual men every participant spoke about how straight men seemed to have trouble finding their place in spaces for HIV positive people. Additionally, they do not want to be perceived as being gay for having HIV. In his interview Wouter said, “I think many heterosexual men just don't talk about HIV. They say many times in Holland that they think it's

a gay disease.” Evert also echoed this notion saying, “Heterosexual men do not come to HIV Vereniging lunches because of the stigma. If a straight man is infected it is assumed that he has had contact with a man.” As Riella pointed out, this issue is also present at the organizational level. She said that she saw little hostility in most HIV support spaces, but said

I do see hostility from some earlier heterosexual men who have been involved in the association. They feel deceived by the gay men. They say it’s an HIV association, not a homosexual association. Heterosexuals are not used to being the minority.

Another reason for the lack of presence of straight men seemed to be attributed to gay men’s history of organizing. As Evert said, “Gay people were always standing on the barricades, fighting for their rights. It’s almost in our genes. We are so used to it, and I think that is the difference between heterosexuals and us.” Riella said something similar.

I think heterosexual people do not organize as a group because we are so many. Homosexuals are a minority and have found their strength in organizing, so there is a lot of activism within groups of homosexual men. I think the fact is that this minority group already has a very strong basic organization. HIV is targeting heterosexuals so randomly that if HIV is the only shared association you have with other heterosexuals, it is harder to organize. It is easier, for example, for women to associate because we can talk about practical things, that’s what women do when they seek support. For heterosexual men, this is not the way to organize. They want to meet with women as well—just to be in a normal situation. So they will not come to this association or meetings where it’s predominantly homosexual men because then they will be automatically addressed as a homosexual man. They have this internalized stigma that they are carrying this disease of homosexuals. It does not tell anything about what they have done, but they think it attributes to their perceived identity, and that is quite a big problem.

Discussion

Something to note is that initially for my ISP I wanted to incorporate a creative feature in which I would take portraits of each of my interviewees as well as people who were willing to be photographed at HIV Vereniging. This idea was rejected by the IRB because it violated ethical codes and infringed on peoples' privacy. I understand the reasoning behind this, but I also see this as a culprit in the furtherance of HIV stigma. If people are willing to be photographed and see openness as an important tool in the erasure of stigma, why should an institution such as the local review board be able to take that privilege away from them? By making these interviewees anonymous and not allowing their faces to be shown, we are inherently saying that we still need to protect these peoples' identities. Research has the ability to promote tolerance, knowledge, and education. But how much tolerance can we realistically promote if we keep the narrators of these stories veiled? Who are we protecting if we are putting people back in the closet? As explained above, people want their stories heard and people want to be seen. This does not go for everyone, but why should we deny those that want to be heard that right?

Assumptions:

When thinking about my positionality in conducting this research I must acknowledge that in doing my research I was always an outsider. No matter how many hours I worked at HIV Vereniging, how close I became with my participants, and how comfortable my interviewees felt with me, I never felt as though I was completely inside because I was not HIV positive. I also do not speak Dutch, and it is possible that not everyone could communicate with me in the way they were able to or wanted to. It was also important for me to be reflexive during this research and to constantly ask myself questions. What does it mean for an HIV negative woman to critically examine HIV related stigma among a community of HIV positive individuals? I also had to be

careful of assuming that stigma was essential in the experience of having HIV. This was an assumption I made and one that I initially did not question. But this preconceived judgment had the potential to invisibilize the stories of those who maybe did not experience their HIV in this way.

I found that in my interviews I often drew on my experience in HIV related work, such as on GMHC's HIV hotline and as an HIV peer tester and counselor at my college. In this sense I manipulated situations based on how close I could be to becoming an insider. This is a power dynamic that I must acknowledge. Positionality is not static, but has the potential to be used distinctly in differing situations. On many occasions during my interviews I was maybe too sensitive about my power as a researcher and the power differential that existed between my interviewee and myself. In a couple of my interviews I refrained from asking certain questions because I did not want to make my interviewee uncomfortable and I did not want to trigger them. Many people often took the conversations further without my prompting, but I was hyperaware of how my power and my position as someone who will never understand what it is like to have HIV affected what questions I felt comfortable asking. This discomfort limited the information I was able to receive.

Death was a topic that came up a lot during the interviews. It is a heavy topic, and it was not something I wanted to continuously ask people questions about. For this reason I was transparent with my experiences with death. It seemed to make people feel more comfortable and also let them know that I could in some ways relate to what they were saying. In this sense I was able to gain access to a certain depth of information and emotion that I maybe would not have had access to had I not shared this aspect of my life.

Conclusion:

This research demonstrates how meaningful and informative working from peoples' stories and standpoints can be. The participants saw education and targeting self-stigma as two necessary means in ending HIV-related stigma in the Netherlands. But these two tactics highlighted other issues, such as the fact that most HIV positive communities were comprised solely of gay men. Heterosexual men and women rarely dominated these spaces. In the future it will be important to hear more from those two communities, as well as from individuals who may fall out of those binary categories. While everyone's story is equally valid and important, it is important that there is representation from more diverse demographics when hearing about HIV stigma. This also calls attention to another issue, which is that there is often tension within communities of HIV positive individuals. This can be seen intergenerationally between gay men, as well as between homosexual men and heterosexual men. Women were infrequently at the forefront of these conflicts, but this research did not look into HIV positive support groups and communities specifically targeted towards women, so it is possible that this understanding comes from a lack of data within that network.

In the future hopefully the IRB will loosen its reigns and see the validity in granting people the right to choose whether or not they have their photograph taken, rather than making a sweeping rule that HIV positive individuals can only have their portraits taken if their identities cannot be recognized, thus undermining their agency and fostering HIV related stigma.

Bibliography

- Agnes Meershoek, A. K. (2007). Judging Without Criteria? Sickness Certification in Dutch Disability Schemes. *Sociology of Health and Illness*, 29 (4), 497-514.
- AIDS Fonds. (2012). *Hoe Positief Ben Jij?* Retrieved 2015, from AIDS Fonds: <http://www.aidsfonds.nl/hoepositiefbenjij/>
- Akke K. Van der Bij, N. H. (2008). Low HIV-testing Rates and Awareness of HIV Infection Among High-Risk Heterosexual STI Clinic Attendees in the Netherlands . *European Journal of Public Health* , 18 (4), 376-379.
- Alana Proctor, A. K. (2011). Making a Difference: The Construction of Ethnicity in HIV and STI Epidemiological Research by the Dutch National Institute for Public Health and the Environment (RIVM) . *Social Science and Medicine* , 72, 1838-1845.
- Ard van Sighem, L. G. (2014, November). *Monitoring Report 2014: HIV in the Netherlands*. Retrieved November 24, 2015, from Monitoring Reports: <http://www.hiv-monitoring.nl/nederlands/onderzoek/monitoring-reports/>
- Arjan E. R. Bos, G. C. (2004). Evaluation of the Dutch AIDS Information Helpline: An Investigation of Information Needs and Satisfaction of Callers. *Patient Education and Counseling* , 54, 201-206.
- Arjan E. R. Bos, G. K. (2001). Public Reactions to People with HIV/AIDS in the Netherlands. *AIDS Education and Prevention* , 13 (3), 219-228.
- Arjan E.R. Bos, A. J. (2007). Sex Differences in Emotional and Behavioral Responses to HIV+ Individuals' Expression of Distress. *Psychology and Health* , 22 (4), 493-511.
- Carlijn G.N. Voorend, W. H. (2011). Report of the Stigma Research Workshop for the Development of Scientific Consensus Papers and Field Guidelines on Health-Related Stigma, Held in Amstrdam, the Netherlands from 11-14 October 2010. *Leprosy Review* , 82, 188-201.
- Dean-Duncan, R. (2014). *Tap the Power of Storytelling*. Retrieved 2015, from Forbes: <http://www.forbes.com/sites/rodgerdeanduncan/2014/01/04/tap-the-power-of-storytelling/>
- Edwin J. M. Oberjé, A. L. (2015). Looking Beyond Health-Related Quality of Life: Predictors of Subjective Well-Being among People Living with HIV in the Netherlands. *AIDS Behavior* , 19, 1398-1407.
- ELM Op de Coul, T. W. (2014). Sexual Behavior and Sexually Transmitted Infections in Sexually Transmitted Infection Clinic Attendees in the Netherlands, 2007-2011. *International Journal of STD & AIDS* , 25 (1), 40-51.
- Fleur van Aar, I. S. (2012). Current Practices of Partner Notification Among MSM with HIV, Gonorrhoea and Syphilis in the Netherlands: An Urgent Need for Improvement. *Bio Medical Central Infectious Diseases* , 12 (114), 1-11.
- Foppen, R. (1995). Let's Form a Club of 'Sexally-Disabled' Women. *Reproductive Health Matters* , 3 (5), 54-55.
- Harry J. A. van Haastrecht, P. J. (1997). Estimating the Size of the HIV Epidemic Among Injecting Drug Users in Amsterdam . *European Journal of Epidemiology* , 13, 261-265.
- Henna L Toppenberg, A. E. (2015). HIV-Related Stigma in Social Interactions: Approach and Avoidance Behavior in a Virtual Environment. *European Journal of Social Psychology* , 45, 169-179.

Jay, S. (2012). Enhancing Dignity for Older People in Health and Social Care Setting. *Journal of Clinical Nursing* , 19, 70-92.

Kokkelkoren, E. (Director). (2014). *The Time There-After* [Motion Picture].

M.G. van Veen, M. K. (2009). Disassortive Sexual Mixing Among Migrant Populations in the Netherlands: A Potential for HIV/STI Transmission . *21* (6), 683-691.

M.N. Wagener, S. v. (2014). Employment-Related Concerns of HIV Positive People in the Netherlands: Input for Multidisciplinary Guideline. *Journal of Occupational Rehabilitation* , 24, 790-797.

Maaïke G. van Veen, H. M. (2010). HIV and Sexual Risk Behavior Among Commercial Sex Workers in the Netherlands . *Archives of Sexual Behavior* , 39, 714-723.

Madelief G.B.C. Bertens, M. E. (2008). Negotiating Safe Sex Among Women of Afro-Surinamese and Dutch Antillean Descent in the Netherlands. *AIDS Care* , 20 (10), 1211-1216.

Newman, A. P. (2008). Making Monsters: Heterosexuality, Crime and Race in recent Western Media Coverage of HIV. *Sociology of Health and Illness* , 30 (4), 632-646.

Peter J. Smit, M. B. (2012). HIV-Related Stigma Within Communities of Gay Men: A Literature Review. *AIDS Care* , 24, 405-412.

Raad Voor Gezondheidsonderzoek. (2001). *Advies HIV-surveillance in Nederland*. The Hague: The Hague: Health Council.

Sarah E. Stutterheim, A. E. (2008). HIV-Related Stigma in the Netherlands . *AIDS Fonds* , 1-86.

Sarah E. Stutterheim, A. E. (2011). Psychological and Social Correlates of HIV Status Disclosure: The Significance of Stigma Visibility. *AIDS Education and Prevention* , 23 (4), 382-392.

Sarah E. Stutterheim, I. S. (2011). HIV Status Disclosure Among HIV-Positive African and Afro-Caribbean People in the Netherlands . *AIDS Care* , 23 (2), 195-205.

Stefano Conti, A. M. (2011). Modeling of the HIV Infection Epidemic in the Netherlands: A Multi-Parameter Evidence Synthesis Approach. *The Annals of Applied Statistics* , 5 (4), 2359-2384.