The Effects of Early Social Representations of HIV/AIDS

A Narrative Analysis

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Tiivistelmä – Referat – Abstract

Social representations are formed when a particular object or phenomenon is considered problematic by a particular group. In trying to make sense of the object or phenomenon, the group forms socially shared concepts allowing it to become part of the group's social world. Because of these features, Social Representations Theory has been used extensively in the area of health and illness, particularly in the area of HIV/AIDS and the stigma that surrounds the disease and those affected. However, few researchers have looked to the narrative to examine the social nature of social representations and have focused mainly on other methods to explore their internal structure. This article explores history of HIV/AIDS and the early social representations of disease. Narrative analysis is used to determine how the early social representations, particularly the process of objectification, has affected the identities of those recently diagnosed with HIV. It concludes that the narrative is a useful tool at examining how the early social representations of a disease can have long-lasting effects on the identities of those newly diagnosed.

Avainsanat – Nyckelord – Keywords

HIV/AIDS, Identity, Imagery, Narrative, Objectification, Social representations, Stigma, Themes, Tone

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1. Introduction

The emergence of the HIV/AIDS epidemic in the early 1980's brought with it both a worldwide public health panic and a media inspired moral panic that has had long lasting effects on how society views certain groups of people in terms of their sexual orientation, sexual practices, lifestyle choices, and cultural and ethnic backgrounds. The panic has long since faded in the developed world, and with the availability of better treatment options and increased life expectancies for those living with HIV/AIDS in wealthier countries, it is now akin to a chronic but manageable condition rather than a death sentence (The Lancet, 2008).

Research suggests there is an increasing attitude of complacency in the developed world about the disease, especially among young people who were not yet born when the epidemic first emerged in the 1980's (Valdiserri, 2004). In the United States, Collins et al (2002) suggest a decrease in risk perception with regard to contracting the disease, as it is still regarded as a disease that affects only certain segments of society. Others argue that improved medications for the disease have resulted in the disease rarely being associated with a deadly condition but rather something that can be managed effectively with powerful medications (Midgley, 2010). Additionally, in the United States, some attribute the complacency to ignorance stemming from a lack of education, especially in the aftermath of Bush-era abstinence only sex education programs, which was the norm for about 35% of public school systems (Collins et al, 2002; Midgley, 2010; The Washington Post, 2009). Within the abstinence only model, the prevention of pregnancy and sexually transmitted infections focused primarily on messages of abstaining from sex until marriage. Conversations about contraception either did not occur at all or were discussed in terms of failure rates (Collins et al, 2002). In other developed countries, such as Finland for example, there has been a more comprehensive sex education policy in its schools. However, Clarke (2002) suggests that over the years, Finns have often associated HIV/AIDS with "gays, foreigners, foreign prostitutes and drug users, those excluded from 'normal' society who seldom have public faces, lives or voices" (p. 21). Clarke argues that, among Finnish society, there is a certain level of denial but also an increasing perception that HIV/AIDS affects only deviants and foreigners, particularly since foreigners make up a large percentage of those infected with the disease in Finland (National Public Health Institute [KTL], 2008).

Regardless of why this complacent attitude about HIV/AIDS currently exists, the fact remains that diagnoses of HIV/AIDS is on the increase throughout the world and new strategies must be adopted in order to stem the increase of infection rates. However, much

of the information and prevention strategies surrounding HIV/AIDS that dominated in the early years of the infection were based mainly on ideas of fear and stigma against groups that were viewed as responsible for the disease. While later campaigns acknowledge that everyone is at risk for infection, and efforts at trying to reduce the stigma associated with the disease continue, the perception of HIV/AIDS as a stigmatizing condition still exist in the United States, Finland and elsewhere.

Society has had to learn the hard way that the early scare tactics used to educate people on issues such as HIV/AIDS have contributed to the fear and stigmatization associated with the disease. While the approaches used to inform and educate have mostly changed, particularly in the West, these early methods of education and prevention have had long term consequences, not only on the identities of those who have been living with the virus for decades, but also on the identities of the newly diagnosed, regardless of the fact that the disease is no longer considered a death sentence for most. Goffman (1963) suggests that those who are considered what he calls "normal" tend to create a "stigma theory" to justify how they believe the stigmatized person is inferior and to describe the danger that they signify. Goffman asserts that we will use stigma terms in our everyday dialogue as a source of "metaphor and imagery" (p. 15).

Nevertheless, with the awareness of increased complacency about the disease, there are growing questions as to whether there needs to be a return to the heavy-handed, fear laden prevention strategies that, for the most part, have long since been abandoned (Midgley, 2010). But, one wonders whether this can be done effectively while avoiding the mistakes of the past, which resulted in the disease being seen as primarily an affliction of "the other," and if that association can ever really be changed.

One answer to this question could lie in the use of Social Representations Theory, which was developed by French social psychologist Serge Moscovici (1961). Bauer and Gaskell (2001) argue that Social Representations Theory is appropriate to examine the development "of content, structure and functions of the voices and images of public concern" (p. 163). For the purposes of health education, looking at the structure and content of the social representations of a particular issue opens the opportunity to identify "not only the networks of meanings surrounding an object, but also the visibility of possible spaces for its transformation" (Reis, et al, 2006, p. 2308). Within the area of HIV/AIDS, pictorial images of the disease in the 1980's "parallels depictions of the syphilitic in pictures produced from the 14th to the 19th centuries that emphasize visual stigmata, degeneracy, sexual transgression, pollution, plague, isolation, suffering, and victimization" (Gilman, 1988 cited in Schoeneman et al., 2002, p. 14).

Clearly, analyzing visual images is one of the most utilized methods of examining social representations. However, Murray (2002) suggests that narrative psychology is also useful at looking at social representations, though it is often dismissed as a worthwhile tool when examining the structure of social representations and how those representations are shared. While narrative psychology focuses on the story of the individual experience, it is a suitable method to examine how the "social" influences the stories we tell about our lives and the positive and negative situations we encounter. Additionally, the late Janos Laszlo (1997) was an instrumental figure in applying the personal narrative into the study of Social Representations Theory. He argues that that verbal communication (i.e. the stories we tell about events, ourselves and others) is what shapes representations and allows them to share them with others. Therefore, the purpose of this paper is to perform a narrative analysis of personal narratives of individuals who have recently been diagnosed with HIV. Through the messages in these writings, the goal is to examine how the social representations, particularly the objectification, of HIV/AIDS has changed over time, but has managed to maintain elements of "othering," victimization, fear, stigmatization and prejudice.

In the following chapter, I will discuss the historical background of HIV/AIDS. In chapter three, I will discuss the theoretical background of Social Representations Theory, including the history of its development, its relationship to other social psychological theories, the formation, structure and processes of social representations and the relationship of social representations to other theories. In this chapter, I will also look at Social Representations in terms of HIV/AIDS as a social phenomenon, objectification of HIV/AIDS, and the function and consequences of social representations related to HIV/AIDS. In chapter four, I will discuss my research material. In chapter five, I will discuss my methodological choices for analyzing the research material followed by my results of analysis in chapter six. I will conclude with chapter seven with a discussion of my analysis, including how the results relate to previous research in the field and their relation to a societal context as well as a discussion on methodological strengths and weaknesses.

2. Historical Background of HIV/AIDS

The following subchapters will discuss the historical background and epidemiology of HIV/AIDS.

2.1 Emergence of a New Disease

It has been well established within the medical community that the AIDS virus likely has its origins in Africa and was transferred to humans sometime between 1884 and 1924. However, AIDS was given worldwide attention when the first case was detected in the United States in 1981. The way in which the United States initially presented and reacted (or under-reacted) to the disease when it was first identified has significantly influenced the fear and stigma surrounding the disease, which continues today (Avert, 2010).

In the United States, the Centers for Disease Control (CDC) is the primary agency responsible for leading HIV/AIDS prevention initiatives in the United States. The CDC works in conjunction with numerous NGOs and community organizations as well as state and local health departments in providing strategies, resources and management for the prevention of HIV/AIDS (CDC, 2011).

2.1.1 The 1980s

During the 1970's, doctors in Africa began to see an increase in the prevalence of opportunistic infections, such as rare types of pneumonia and Kaposi's sarcoma, a rare form of skin cancer, in patients not usually found in young individuals with healthy immune systems. In 1981, doctors in New York and California reported treating a number of individuals, primarily males having sex with other males, with the same types of opportunistic infections that were seen in Africa Avert, 2010). The CDC released a report specifying that five gay men in Los Angeles were hospitalized with a rare but serious pneumonia along with other rare infections. After this announcement by the CDC, a report was released that stated 41 homosexual men in New York had been diagnosed with Kaposi's sarcoma. Of the 41 diagnosed, eight of the individuals had died less than two years after the diagnosis (CDC, 1981, New York Times, 1981)). Up until this point, the disease still did not have a name. While the CDC referred to it in terms of the presenting symptoms, many were referring to it in terms of its associated link to the homosexual community, such as Gay Related Immune Deficiency (GRID), gay-compromise syndrome and gay cancer New York Times, 1982). It was not until the summer of 1982 that the acronym AIDS (Acquired Immune Deficiency Syndrome) was created (CDC, 1982a).

By June of 1982, it became evident that groups other than homosexual men were also at risk for infection. The CDC received approximately 355 new diagnoses of these rare opportunistic infections in otherwise healthy young people. While the majority of these were diagnosed in gay men, a small number of heterosexual men and women were diagnosed with these infections, of which half had reported using intravenous (IV) drugs (Avert, 2010). This suggested to clinicians that the disease was both sexually transmitted and blood borne. In December 1982, the CDC had received reports of three heterosexual hemophiliacs dying after developing symptoms of the rare opportunistic infections associated with AIDS. While there was no evidence that any of these individuals used IV drugs or had homosexual contact, what they did have in common was blood transfusions from a similar transfusion product that combined blood from hundreds of different donors (CDC, 1982b). The CDC also began to receive reports of the disease in a small number of Haitian migrants and added "Haitians" to the list of groups at risk for contracting the disease. Some members of the media and the public termed these risk groups the "4-H Club:" homosexuals, Haitians, hemophiliacs and heroin addicts. However, there was little mention that some of the cases had been among individuals who were not members of these particular groups. The Haitian community in the United States argued that the CDC's comments were racist and contributed to the stigmatization of Haitians (Altman, 1983; Grmek, 1990).

By 1983, doctors in France reported that they had isolated the virus that was believed to cause AIDS, which they named lymphadenopathy-associated virus (LAV) (New York Times, 1984a). In 1984, the National Cancer Institute in the United States announced that they had also isolated a virus, HTLV-III, and that it was likely the same virus that had been isolated in France the year previous. The Institute also stated that a commercially available test would soon be available that would test for the virus with near 100 percent confidence (Avert, 2010).

In 1985, over 20,000 cases of the disease had been reported to the World Health Organization (WHO), of which 15,948 were in the United States (Bureau of Hygiene and Tropical Diseases, 1986). In addition, it had been discovered that mother to child transmission was possible through breastfeeding. The United Stated Food and Drug Administration (FDA) granted a license for the first commercial blood test to reveal the presence of the LAV/HTLV-III antibodies (Avert, 2010). In 1986, there was disagreement within the medical community as to two names of the virus. It was decided that the names LAV and HTLV-III would be dropped and replaced with the name HIV (human immunodeficiency virus) (Coffin et al., 1986).

The way in which the initial outbreak of the AIDS epidemic was handled by the medical community, the United States government and the media undoubtedly contributed the fear, stigma and discrimination associated with the disease. From the beginning, the disease was associated with groups that were already highly stigmatized in society, homosexual men and IV drug users. In addition, the lack of reliable information as to how the disease was contracted and spread contributed to the fear and stigmatization of these groups among the general public. There was also speculation that some in the medical community were averse to researching the causes of the disease because of their own personal beliefs and prejudices. Initially, the United States government ignored the epidemic. It was not until 1985 when President Ronald Reagan publicly discussed AIDS for the first time, but would not discuss or promote safe sex or encourage condom use. Instead, his plan for preventing the spread of the disease in the United States was to impose a travel ban on HIV positive immigrants and to push for abstinence from pre-marital sex (Associated Press, 1985; Avert, 2010). While the United States government appeared to have been doing very little, several non-governmental organizations (NGOs) were established that provided support services for those affected by the disease and distributed information about the disease to health centers, clinics and hospitals. One such group, ACT UP, organized a demonstration on Wall Street in New York City to demand an end to discrimination on AIDS, better treatment and education, as well as a national policy on AIDS (Avert, 2010).

In 1986, the United States Surgeon General published a report that was the government's first official statement on how to prevent the spread of the disease and encouraged parents and schools to start having open discussions with young people about the virus (Boffey, 1986). Also, the first public service announcement (PSA) aimed at educating the public about AIDS was aired on television and featured celebrities Meryl Streep and Robert De Niro. In 1987, the CDC launched the "America Responds to AIDS" (ARTA) campaign, which was the first government sponsored campaign designed to educate the public about the disease and to dispel myths and fear (HIV-AIDS in the Media, 2009). In 1988, with over 83,000 cases of AIDS now identified in America, the government mailed a brochure entitled "Understanding AIDS" to every American household. As with the ARTA campaign, this campaign was designed to provide Americans with factual information about the disease while attempting to allay fears and address misinformation about the disease (CDC, 1988). Interestingly, six other nations had produced similar campaigns before the United States created theirs (Avert, 2010). At the same time, ARTA began to target "high risk" groups such as minorities, sexually active young people and IV drug users. Other NGOs were creating their own AIDS prevention ads that ran along with the

CDC campaign and were the first ads to promote condom use and use the word "condom" in their ads (HIV-AIDS in the Media, 2009).

After promising results from clinical trials with the drug AZT in 1986, the United States Food and Drug Administration (FDA) approved it for use as an antiretroviral in the treatment of AIDS in 1987 (Public Health Service, 1989). In 1988, over a thousand members of the ACT UP organization demonstrated at the FDA headquarters demanding quicker drug approval times, as there was concern that it was taking too long for the FDA to approve new treatments for the disease (Avert, 2010; FDA, 1988). The FDA announced changes to their regulations eight days later, announcing that drug approval times would be reduced. However, makers of the drug were being accused of price gouging, as a year's supply of the drug would cost over $7000 for one person. Most American's lacked sufficient health insurance to cover such costs (Kolata, 1989; Hilts, 1989). After public pressure, the cost of the drug was eventually cut by about 20 percent in 1989 (Avert, 2010). By this time, it had become evident that diagnoses in women were on the increase as well diagnoses in smaller towns and rural areas (Avert, 2010).

2.1.2 The 1990s

In response to the death of Ryan White, a young HIV positive hemophiliac who was at the center of a controversy in the 1980s when he fought for the right to attend the school from which he had been banned, the government created the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act in 1990. This new act was implemented to improve the availability of treatment and care to low income and uninsured individuals living with HIV and their families (Avert, 2010). Also, the ARTA campaign began to create ads that encouraged parents to communicate with their children about the dangers of HIV/AIDS (HIV-AIDS in the Media, 2009).

In 1991, AIDS had become the second leading cause of death among American men aged 25-44 with approximately 45,500 cases of AIDS reported to the CDC (MMRW Weekly, 1991). One of the most significant turning points in the history of HIV/AIDS in the United States was the announcement by celebrity basketball player Earvin "Magic" Johnson that he was HIV positive. The star retired from professional basketball at the urging of his doctors and instead used his position in the public eye to raise awareness and educate young people of the dangers of the disease, emphasizing that everyone was at risk, not just the homosexual community (Stevenson, 1991). His announcement had a significant impact on the country's understanding of the disease. The number of individuals being tested for the disease soared by 60 percent in New York City alone (Sims, 1991).

In 1993, the United States House of Representatives voted to keep the 1987 ban on HIV positive individuals entering the country, including both immigrants and visitors While President Clinton was opposed to the ban, his administration did nothing to counter the vote (Clymer, 1993). There was also controversy in early 1994 regarding a government sponsored condom campaign led by the CDC and Department of Health and Human Services which was more open about sex and condom use than it had been in the past. The campaign produced a number of advertisements that were aired on television and radio stations. However, many individuals were upset claiming that the ads promoted sex among young people (Avert, 2010).

The NGOs continued to lobby the United States government on AIDS related issues throughout the 1990s. In the early 1990s, ACT UP created two illegal needle exchanges for approximately 1,000 IV drug users. By 1995, there were around 75 needle exchange programs located in 55 American cities. While experts agreed that making available sterile needles and bleach to IV drug users was useful in reducing HIV transmission among this group, the programs could not receive any federal funding for their work (Avert, 2010).

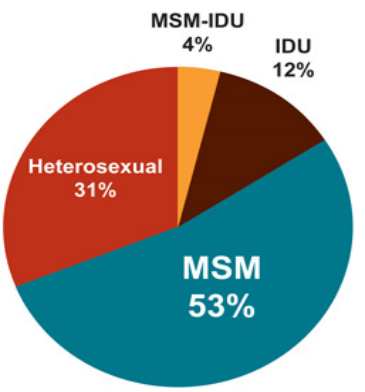
By 1993, AIDS was the fourth leading cause of death among American women aged 25-44. In addition, around 2,000 children per year were becoming infected with HIV through mother- to- child transmission (CDC, 1995; CDC, 1996). In 1994, researchers discovered that the use of the drug AZT reduced the risk of mother- to- child transmissions by two thirds. As a result, the Department of Health recommended universal counseling and voluntary HIV testing for all pregnant women and treatment for those who tested positive. This resulted in a dramatic decline in infant HIV infections (Avert, 2010). However, by the mid-1990s, the CDC reported that AIDS was the leading cause of death among all Americans aged 25-44, with over 500,000 people having the disease, of which half had died (Altman, 1995; CDC, 1995).

While AZT was proving beneficial for the prevention of mother- to- child transmission of HIV, research in the early part of the 1990s revealed questions as to the overall effectiveness of the drug. There was evidence that HIV could become resistant to the drug and that it provided no benefits to patients in the early stages of the disease (Avert, 2010). However, over the next few years, researchers discovered that taking AZT in combination with other drugs provided promising results. In 1995, researchers made a significant advance in HIV treatment with the discovery and approval of a new class of drug called protease inhibitors. When used in combination with other drugs, the treatment was highly effective at suppressing HIV, reducing the amount of virus in the body by as much as 99

percent (FDA, 1995). While there was uncertainty as to how effective these drugs would be in the long-term, there was a dramatic decrease in AIDS deaths over the next few years which were attributed to these new treatments. However, fewer deaths meant more people living with HIV, highlighting the need for improved and affordable ongoing access to treatment and care (Avert, 2010).

2.1.3 The 2000s

Table 1. Estimates of New HIV Infections in the US, By Transmission Category, 2006



Source: Centers for Disease Control (CDC), 2010.

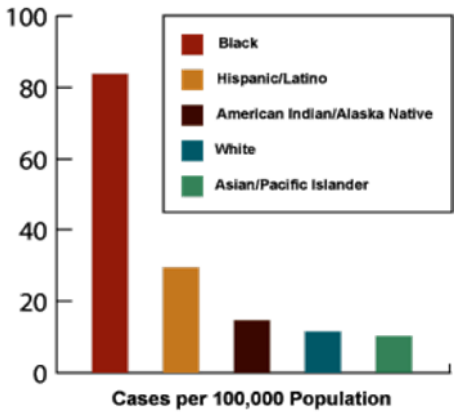
At the turn of the century, there had been over 400,000 deaths from AIDS (CDC, 2001). The Institute of Medicine (IOM) published a report in 2000 that faulted the United States government for failing to create effective HIV prevention programs and criticized the federal government's spending on abstinence only education policies, citing that there is no evidence that these programs are effective. The report emphasized the need for more federal funding for prevention plans, such as needle exchange programs (Altman, 2000). While the CDC set a goal to halve the number of HIV infections to 20,000 per year by 1995, the government ignored many of the main recommendations of the report (Avert, 2010).

In 2003, the CDC's goal to halve the number of HIV infections by 2005 was already showing signs of failure, as the number of new infections was not declining. This caused the CDC to change its prevention strategy and unveiled a new initiative called Advancing HIV Prevention: New strategies for a Changing Epidemic (AHP). Rather than focusing "persons at risk," this program targeted people who were already infected with the virus but were unaware of their HIV status. In doing so, the aim of this strategy was to prevent onward transmission of the virus (CDC, 2003).

In 2006, the CDC estimated that one-quarter of people living with HIV were unaware of their status. The agency distributed guidelines recommending routine HIV testing for all adults and young people using healthcare services in an attempt to identify these individuals. In 2007, more federal funds were allocated to purchase rapid HIV test kits to be provided to communities with the majority of newly discovered HIV cases (CDC, 2006; Avert, 2010).

Currently, the CDC (2010) suggests that while HIV rates among heterosexuals and IV drug users continue to rise, men who have sex with men (MSM) are still the most severely affected of all the risk groups (Figure 1). Black Americans accounted for nearly

Table 2. Estimates Rates of New HIV Infections, By Race/Ethnicity, 2006



Source: Centers for Disease Control (CDC), 2010.

half of the new HIV diagnoses between 2000 and 2006 though blacks account for only 13 percent of the United States population (Figure 2). In 2007, the CDC targeted the black community after acknowledging the past unsuccessful efforts at prevention within that community. The CDC also acknowledged that the United States was falling short on the amount of money being invested in prevention programs, only five percent, while there were still around 40,000 new HIV infections per year (Avert, 2010).

Throughout the 2000s new drugs have been developed and approved by the FDA and have improved the quality of life for many HIV positive individuals. However, despite the improved treatments available, attention has been drawn to the significant disparities in access to treatment among ethnic and racial minorities (Avert, 2010). A report published by the IOM in 2002 stated that white Americans were often given more advanced treatments than black Americans, even when money was not an issue. This meant that black Americans were not only at an increased risk of contracting the illness, but that they also faced obstacles in accessing treatment, testing and prevention education (Villarosa, 2004).

In 2006, President Bush extended the Ryan White HIV/AIDS program (Avert, 2010). However, while more cities were to start receiving funding, no additional funds were being allocated to the program. Instead, funds were being taken away from areas such as San Francisco and New York and being allocated to more rural areas and the southern part of the United States (Riechmann, 2006). In 2008, the Senate approved $1.4 million to develop a National AIDS Strategy, which was designed to increase support and medical services for individuals living with HIV. In 2009, President Obama signed the Ryan White HIV/AIDS Treatment Extension Act, which will extend to 2013 (Avert, 2010). In 2010, the United States saw the end of the travel ban on HIV positive travelers to the United States that had been in existence since 1987 (BBC News, 2010).

3. Theoretical Background

The following chapter gives an overview of Social Representations Theory and goes on to discuss the theory in terms of its influence on the understanding of HIV/AIDS.

3.1 Overview of Social Representations Theory

Social Representations Theory (Social Representations Theory) was developed by Serge Moscovici (1961) and was heavily influenced by Durkheim's notion of collective representations. Collective representations are described as historical experiences of a collective group over time and include concrete symbols as well as the ideas that determine how the individual relates to the world and common sense knowledge. They serve as a way for a social group to express collective ideas and beliefs, which result in unique features of a society and generating unity and social solidarity and assume that the psychology of different groups take on universal thought processes with regard to making sense of the concrete world (Moscovici, 2001). However, Moscovici suggests that social representations are different because in primitive societies, the intellectual universe is unified and myth explains all, whereas in modern society, social representations are but one way that societies make sense of their world (Moscovici, 1976 cited in Jahoda, 1988). Moscovici takes on the view of Levy-Bruhl, whose concept of collective representations suggests that there is a significant difference surrounding primitive thought and modern thought and he disputes that the two are concerned with the same problems suggesting that, contrary to Durkheim's theory, primitive mentality is significantly different to the modern and scientific mentality (Moscovici, 2001). Moscovici (1961/2008) built upon this idea in his work entitled *La psychanalyse: Son image et son public.* In this classic study, Moscovici looked at how the scientific concept of psychoanalysis was circulated and constructed among different social groups in 1960s France. He analyzed how psychoanalysis was represented in the mass media by looking at how various media groups structured their communication of psychoanalysis based on the group's particular interests, such as the Catholic church. From this study, the Theory of Social Representations was born, bringing a different perspective to the field of Social Psychology.

In addition, the work of theorists Jean Piaget and his *psychology of children's representations* and Lev Vygotsky and his *psychology of higher psychological function*, contributed to Moscovici's development of Social Representations Theory. While Piaget and Vygotsky differ as to how they view the influence of culture, social aspects and language on cognitive development, they both highlight the importance of social

interaction to varying degrees on the formation of representations and how people make sense of the world around them (Moscovici, 2001).

3.2 Social Representations Theory in Relation to Alternative Social Psychological Theories

Social Representations Theory supports Baldwin's early argument that knowledge is intrinsically social and must be studied in terms of a social phenomenon and that individual thought cannot be understood without first examining societal thought (Markova & Wilkie, 1987). While Social Representations Theory does have some similarities to some of the major social psychological theories, such as attitudes, attribution theory and social cognition theory, Wagner et al. (1999) suggest that Social Representations Theory addresses the problematic issue that many of these other social psychological theories share, which tend to be individualistic in nature, separating the individual from the social. However, it has also been suggested that many of these different theories are not in fact separate and distinct from social representations, but are actually components of social representations (Allansdottir, 1993 cited in Sakki, 2010).

Within the area of attitude research, Fraser (1994) argues against several criticisms as to how attitudes and Social Representations Theory are different, such as his disagreement with Moscovici's assertion that attitudes are static and argues that attitude change is of primary concern to the study of attitude theories. Fraser also argues against Moscovici's suggestion that attitudes are purely cognitive and maintains that attitudes also "possess affective or evaluative and conative or intentional elements as well as cognitive ones" (p. 4).

However, Moliner and Tafani (1997) argue that while both attitudes and social representations look at the perception of a specific object or phenomenon, social representations is also concerned with the formation of the object or phenomenon. Attitudes, on the other hand, are not necessarily concerned with the formation of the object or phenomenon, but are mainly concerned with the peripheral elements of social representations. Attitudes are said to be concerned with individual cognition, while social representations are concerned primarily with social knowledge (Gaskell, 2001). Fraser (1994) also emphasizes that while attitudes are mainly studied in an experimental setting and are often analyzed quantitatively, social representations are generally studied in a more qualitative fashion.

Wagner et al. (1999) suggest that, on the surface, social representations and social cognition appear similar in the way that both have cognitive systems that work to help

individuals make sense of the world. However, the major difference between the two theories is that social representations stress the importance of the social aspects and the way in which communication constructs knowledge. In contrast, social cognition focuses mainly on cognitive information processing in the construction of knowledge.

Moscovici and Hewstone (1983) argue that while social representations and attribution theory both deal with common sense knowledge, attribution theory is primarily an individualist theory that focuses only on "*how* explanations are made, but not *why*" (p. 121). They argue that attribution theory is concerned with causes of a specific behavior and whether those causes are personal or situational, but fails to take into account the "why" question.

3.3 What is a Social Representation?

Wagner et al (1999) describe a social representation as a "collective phenomenon pertaining to a community which is co-constructed by individuals in their daily talk and action" (p. 96). Social representations are formed when a particular object or phenomenon is considered problematic by a particular group. In trying to make sense of the object or phenomenon, the group forms socially shared concepts allowing it to become part of the group's social world (Moscovici, 1981). In this section, the structure of social representations and the processes involved in the formation of social representations will be discussed, as these concepts must be understood in order to fully grasp the importance that social representations play in our everyday social world.

3.3.1 Structure of Social Representations

Abric's (1996, 2001) theory of the central core suggests that all social representations consist of a relatively stable central core along with peripheral elements that are less stable and subject to change, giving concreteness to the core. He follows the structuralist approach of the School of Aix-en-Provence (see also Claude Flament, Christian Guimelli, Pascal Moliner and Eric Tafani) where the central core is the primary factor that determines the importance and meaning of the overall representation, which is referred to as its generating function. In addition, Abric (1996) suggests that the core also determines the representations structure, which is referred to as its organizing function. The peripheral elements control how the representation functions as well as its dynamics and gives concreteness to the central core with regard to position taking and behaviours. As the central core is relatively stable and not easily alterable, the more changeable peripheral elements provide an environment where the core can adapt to the constraints and features of a particular situation. The core is controlled by the group collective

memory and its value system. It is "shared by virtually all members of the group that created the representation" (Moliner & Tafani, 1997, p. 689) and is context invariant (Wagner et al., 1996). There have been various methods put forth for locating the central core such as that presented by Guimelli (1993) whereby counting the associations made to the representation's object make the core known.

Moscovici (2001) suggests that within the core exist themata that are organized and interrelated with the core of the representation. Moscovici adds that themata are information and beliefs that are shared among members of a group and are talked about in conversation or taken for granted. Markova (2000) asserts that themata are oppositional pairs that for one reason or another become focused on and develop tensions and opposition. Examples of the oppositional pairs of themata are sick-well, happy-sad, etc.

However, the existence of core themata as a concept is vague in the literature. Moscovici and Vignaux (2000) suggest that themata may never be clearly identified and their existence open to interpretation. Abric (1996) argues that themata "is only a hypothesis which to be confirmed, and a process to be discovered" (p. 78). In addition, it is not clear whether core and core themata are combined into one concept or if they are separate concepts (Huotilainen, 2005). Therefore, in this study I will focus mainly on the structuralist approach to the central core without emphasis on the concept of core themata.

3.3.2 Processes of Social Representations

The two main processes in the origin of Social Representations are *anchoring* and *objectification.* In addition to these processes, Moscovici (1981) proposed a third process known as *naturalisation.* Anchoring combines a new, unfamiliar concept or thing into familiar categories (Moscovici, 1984). For example, the villagers in Denise Jodelet's (1991) study of the mentally ill, Moscovici (2001) suggests that the patients placed in their community were "judged by conventional standards and compared to idiots, tramps, spastics or to what in the local dialect were known as 'loonies' ('bredins')" (p. 42). Moscovici (2001) adds that if the classification is more or less accepted among the social group, then any judgment that makes reference to the particular category will also make reference to the given object or idea. Thus, the process of anchoring brings the representation into our frame of reference, which is heavily influenced by social values, allowing the group to classify and name something. It creates a method for interpretation and allows for a way of determining behaviours "in creating expectations, needs and anticipations" (Abric, 1996, pg. 78). Things that are not named are considered foreign and both non-existent and frightening to the social group. Group members resist and distance

themselves from the given situation or object when they are unable to evaluate and talk about the new and threatening object or situation. Categorizing and naming it something that is familiar to us is the first step in overcoming this resistance. By doing so, group members become capable of imagining the situation or object and representing it (Moscovici, 2001).

Objectification gives concreteness to the new situation or event, allowing for the use of preexisting worldviews and the connection of words to "things" in order to make sense of the new situation or event. In essence, objectification takes the abstract and turns it into something tangible, which transfers "what is in the mind to something existing in the physical world" (Moscovici, 1984, p. 29). Moscovici and Hewstone (1983) suggest that the *objectification* process includes three sub processes. The first process of *objectification* is *figuration*, which is the transformation of metaphorical concepts, or anchors, into clear images, or the figurative nucleus. Once society has attained the figurative nucleus for the once abstract concept, it becomes part of our everyday reality and a topic of communication for the group (Moscovici & Hewstone, 1983; Moscovici, 1984). The second process of *objectification* is *personification*, which connects the concept to a person. The final process of objectification is *ontologizing,* which makes a concept real giving it tangible qualities. For example, in their longitudinal study of social representations of AIDS in abnormal psychology textbooks, Schoeneman et al. (2010) argue that these three sub processes are represented by taking a complex concept and transforming it into a metaphorical image *(figuration),* associating AIDS with celebrities who have publicly admitted their HIV positive status or who have died from disease *(personification),* and showing a picture of the virus under the microscope *(ontologizing)*.

Naturalisation is a newer term and the third and final process necessary for the way in which social representations are formed and transformed (Moscovici, 1981; Philogene, 1994). Philogene (1994) explains that *naturalisation* occurs when the object of the social representation has to become part of our everyday conversation and language and people are compelled to talk about it. During these conversations, the explicit images given to the object are projected and externalized to the figurative core of the social representation. Philogene asserts that during this process, "the images assume an independent existence beyond their original intent, lose their purely symbolic functions, and get fused with reality to become part of it rather than remaining thoughts" (p. 102).

3.4 Social Representations and HIV/AIDS as a Social Phenomenon

Social Representations Theory has contributed significantly to the field of health psychology by increasing the understanding of how lay people make sense of health and

illness. Health is certainly one of the most common fields of application and Joffe (2002) suggests that Social Representations Theory is centered around group-based, "symbolic understandings and communications regarding health issues" (p. 560) by way of socio-cultural and historical influences. One of the main ideas of Social Representations Theory is the notion that social representations emerge in times of crisis or when new discoveries or conceptions become popularized in every day speech (Moscovici, 1984a). Many social representations have their roots in the reified universe and scientific knowledge (Moscovici, 1984b), but they can also originate out of ordinary phenomena such as gender and eating (Duveen & Lloyd, 1990; Wagner, 1998). However, it is more or less accepted that within the area of health and illness, specifically HIV/AIDS, lay knowledge of health issues are usually derived from the medical sciences. For example, Herzlich and Pierret (1989) assert that the media transmitted information about HIV/AIDS from the medical and scientific sphere of the laboratory to the social sphere leading it to become an issue of social concern.

The surfacing of HIV/AIDS in the early 1980's resulted in much more than a medical crisis. It quickly evolved into a social crisis fueled by irrational emotional responses, moralization and stigmatization. While the social representations that resulted from the initial panic and fear about HIV/AIDS may have metamorphised as time has gone on, Sharma, Singh & Mishra (2006) assert that the risk of HIV/AIDS has presented itself well beyond the traditional risk groups and is now a concern for the general population. They argue that it is essential to look at new "ideas of HIV/AIDS, risk and coping among the lay persons so that people can be educated and protect themselves and those already affected can be rehabilitated in the community where stigma against AIDS is very strong" (p.2).

3.5 Objectification of a Disease

Over the last 29 years, many social psychologists have turned to Social Representations Theory to gain an understanding into how the mass media and prevention campaigns have influenced lay people's perceptions of how HIV/AIDS is contracted and spread, its influence on the portrayal of so called "high risk" groups, and how the profound effect of early media representations of the illness have had on public perceptions of the disease and those afflicted. In their 1989 article *Construction of a Social Phenomenon: AIDS in the French Press,* Claudine Herzlich and Janine Pierret explain that in the years leading up to the HIV/AIDS panic, the French press was already printing "ethical, social and cultural interpretations" (p. 1237) of another sexually transmitted disease, genital herpes. Media articles most often pointed to the stigmatized individuals who were infected with

the disease and sought to use themes of immoral sexual practices as a means of spreading themes of panic surrounding the "herpes psychosis" (p. 1237), and moralizing sexual behavior. Herzlich and Pierret assert that these themes set the stage for the anchoring and objectification of new information of what eventually became the disease known as HIV/AIDS, to these existing ideas and beliefs that people already held about genital herpes. Joffe (1995) suggests that the mass media, in an attempt to attract viewers and readers, used the "plague" social representation to associate the disease to specific out-groups, which has been done throughout history. The transfer of information about this intangible concept between science, media and the lay public shows that this anchoring and objectification was not simply limited to "plague imagery" (p. 2) but in a plague, which was anchored to immoral and deviant behavior affecting the other," and objectified specifically to homosexual men and drug users. Schoenenman et al. (2010) found that the images in abnormal psychology textbooks that were produced between 1984 and 2005 use social representations of AIDS that emphasize the anchoring of the disease in concepts like "Otherness, death, victimization and culpability. They do so unwittingly and, in fact, unavoidably" (p. 32). They argue that once our social communication creates our understanding of a social phenomenon, such as AIDS, it is very difficult to avoid using metaphorical anchors of the phenomenon.

Herzlich and Pierret (1989) claim that there were two main processes by which the identification of this new "mystery disease" came to pass. The naming of this new medical mystery was the first of these processes. Since the majority (but certainly not all) of the initial cases of AIDS had been discovered in homosexual men, the illness was immediately identified by scientists and western media as a "*gay plague*," "*gay pneumonia*," "*gay cancer*," and the somewhat more official sounding, gay-related immunodeficiency (GRID) (Altman, 1982). In fact, even after the official neutral acronym, AIDS, came into being in 1982, media articles continued to refer to the disease as a gay disease. In a 1982 article in the *New York Times* entitled "New Homosexual Disorder Worries Health Officials," the author states early in the article that "researchers call it A.I.D., for acquired immunodeficiency disease," (Altman 1982, para. 4) but goes on to refer to the disease as GRID throughout the rest of the article.

The second process of identification of this new, unknown disease was through statistics. Herzlich and Pierret (1989) state that as the number of articles regarding the disease continued to increase, the statistics being reported, some real and others projected, were placing emphasis on the accelerated rate at which the disease was believed to be spreading. They argue that by 1983, what was initially thought of as an "accidental event that would go away," (p. 1237) was now being forced into acceptance as a reality that was

not going away and was, in fact, being discussed in terms of an epidemic. They argue that the disease was now being seen as a potential worldwide catastrophe that would likely get worse. Despite the fact that there was still very little known about the disease, the view was that "something had to be done even though no one was sure of what" (p. 1237).

Stockdale et al's (1989 cited in Markova and Farr (eds), 1995) looked at individuals' reactions to the specific messages of HIV/AIDS prevention campaign posters and the representations that people use to organize their response to media messages. By comparing the early HIV/AIDS prevention campaign posters in the UK, they found that the early campaigns were useful in reaching the target groups, but they in had very little impact on those groups. They found that the posters aimed at the heterosexual target group provoked fear. However, the messages targeting the homosexual population were found to be more erotic. By eroticizing safer sex practices, these messages portray such practices as behavioral norms rather than negative and fear inducing. The research also found that while homosexual and heterosexual respondents agree as to which groups are more at risk, they suggest that each group holds a different 'cognitive map' (p. 40) of themselves in relation to how they perceive their risk of contracting the virus. They assert that homosexuals, including those in monogamous relationships, are aware of their possible risk of contracting the disease, but they feel that they 'got the message' (p. 40). They found that heterosexuals, on the other hand, still don't see themselves at risk for contracting the disease and consider it someone else's problem. They consider those at risk unlike themselves and that those "others" only have themselves to blame if they do contract the disease. If by some chance a heterosexual does contract the disease, it is not their fault.

Stockdale et al (1989 cited in Markova and Farr (eds), 1995) go on to suggest that the differences in how the groups view themselves has implications for the way that media messages are designed. They argue that a blanket message targeted at everyone does not allow the individual to relate the message to their own behavior. The authors maintain that until heterosexuals are able to change the way they perceive their own behavior and are able to relate it to those considered to be at risk, they will continue to represent HIV from the standpoint of "observer, rather than that of a participant with a positive role to play in preventing its spread within the sexually active population" (p. 41).

Their findings are further supported by a more recent study conducted by Marston and King (2006) who reviewed 268 qualitative studies of the sexual behavior of young people between 1990 and 2004. The aim of the study was determine why campaigns all over the world, even where condoms were freely available and knowledge of sexually transmitted

diseases was high, were having disappointing results. Their findings revealed sexual behavior is strongly shaped by social forces and this phenomenon is universal across cultures. They discovered seven major themes in their findings: 1) Young people subjectively assess the risks from sexual partners on the basis of whether they are 'clean' or 'unclean'; 2) Sexual partners have an important influence on behavior in general; 3) Condoms can be stigmatizing and associated with a lack of trust; 4) Gender stereotypes are crucial in determining social expectations and behavior; 5) There are penalties and rewards for sex from wider society; 6) Reputations and social displays of sexual activity or inactivity are important; 7) Social expectations hamper communication about sex (pp. 1582-1584). They argue that historically, social influences on sexual behavior have not been addressed by policy makers. The researchers suggest that these seven themes are a "useful, evidence-based checklist of social influences that can be a starting point for local needs assessments and developing programmes" (p. 1584).

The results of both studies show how the social representation of HIV/AIDS being an affliction of the "other" has remained consistent over time and shows how a group's collective memory and value system control the core of a social representation. It is the peripheral elements that have changed and perhaps altered the group's idea of who the "other" is to some extent, particularly when speaking cross-culturally and from a heterosexual point of view. It is these peripheral elements that control the dynamics of the central core with regard to position taking and behavior (Abric, 1996; Moliner & Tafani, 1997).

Goffman (1963) identifies three different types of stigma in his seminal writing, *Stigma: Notes on the Management of Spoiled Identity*. These three types of stigma include, "abominations of the body – the various physical deformities. Next there are blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behavior. Finally there are the tribal stigma of race, nation, and religion, these being stigma that can be transmitted through lineages and equally contaminate all members of a family" (p. 14). He suggests that those who are considered what he calls "normal" tend to create a "stigma theory" to justify how they believe the stigmatized person is inferior and to describe the danger that they signify. Goffman asserts that we will use of stigma terms in our everyday dialogue as a source of "metaphor and imagery" (p. 15), which contributes to the objectification process as defined in Social Representations Theory. For example, the use of such stigma terms is shown in Jodelet's (1989), *Madness and Social Representations*, where mentally

ill patients were categorized by stigmatizing terms based on their particular affliction such as ” *the innocent, the nutter, the epileptic, the crackpot and the head case*” (p. 167). By categorizing patients in this way, the stereotypes contribute to the collective imagery of what a mentally ill looks like even if there is no clear outward sign.

3.6 Social Representations of HIV/AIDS and their Functions and Consequences

The human immunodeficiency virus (HIV) was identified in 1983 as the virus that eventually causes AIDS, and AIDS is the final stage of the HIV infection (CDC, 2009). It is now widely accepted that a person that is infected with HIV does not necessarily have AIDS and may, in fact, never develop AIDS as a result of HIV infection. However, in the early years of the infection, HIV was often overshadowed by the association made by the media between AIDS itself and homosexuality, which has contributed to the stigma surrounding the disease that has lingered until present day.

Such social representations render the world controllable by restricting HIV/AIDS to risk groups and blamed identities. Doing so permits those who do not posess the blamed identities to detach themselves from the threat (Joffe, 1994 cited in Joffe, 1995). She found that the idea of AIDS as a “gay plague” was already anchored in the bubonic plague, an earlier known threat. It referred to the threat of AIDS in the out group (homosexuals), hence making it seem less threatening to the ingroup. Public health centers and those involved in the gay movement went to great lengths to remove the association of AIDS as a gay disease by emphasizing that *anyone* who practices certain behaviors is at risk. However, since the static core of the representation (incurable illness) was already linked to specific outgroups, it prevented the comprehension of this message (Joffe, 1995). As an example, in 1988 the US Surgeon General and the CDC mailed a brochure to every American household, entitled *Understanding AIDS,* in what now would seem to be a somewhat naïve and slightly misguided attempt to address concerns and misconceptions about AIDS among the American public. The brochure is filled with “frequently asked questions,” such as “How Do You Get AIDS?” (CDC, 1988, p.2), “Do Married People Get AIDS?” (Ibid, p. 4), and “What Does Someone With AIDS Look Like?” (Ibid, p. 5). However, despite the fact that the CDC was attempting to allay public fears and clarify misinformation about the disease, the brochure, read by millions of Americans, briefly refers to the actual HIV virus, only once, as the virus that causes AIDS with no further explanation (Ibid, p. 2) even though it had been five years since HIV was identified. In addition, the brochure states in no uncertain terms that, “*Married people* (my emphasis) who are uninfected, faithful and don’t shoot drugs are not at risk” (Ibid, p. 4) and the authors waste no time in reminding the reader that *gay men* (my emphasis)

were first affected by the disease (Ibid, p. 2). In addition, the brochure cites "anal sex, with or without a condom" or "vaginal or oral sex with someone who shoots drugs or engages in anal sex" (Ibid, p. 3) as risky behavior when performed with an infected person. The implied message being that if an individual takes part in such immoral behaviour, they *will* get AIDS, which *will* result in death. In addition, the overall wording and emphasis placed on certain behaviours does little to dispel the association that the general population already had with blaming AIDS on homosexual behavior and misleads people into thinking that they are not at risk unless they engage specifically in what the CDC and the Surgeon General consider risky. Despite the efforts on the part of the CDC and the Surgeon General, Herek and Capitano (1993, cited in Joffe, 1995) conducted a random sample of Americans which showed that 46.2% believed that AIDS could be transmitted by two homosexual men even if both men are HIV negative. Joffe (1995) argues that the social representations that associate AIDS with homosexual men acts as a defense mechanism because by anchoring the disease into the familiar, the individual is protected from the "potentially threatening 'shock of the new'" (Kaes, 1984 cited in Joffe, 1995, p. 2). Joffe (1995) argues that the irony of the blaming of "the other" is that the blaming actually causes those who blame to be at a higher risk of the disease because they do not feel it is necessary to take precautions against it.

Society now undoubtedly has a much better understanding of how the disease is contracted and spread and new generations of children are being born into a society where, at least for them, HIV/AIDS has always existed. HIV/AIDS prevention campaigns have evolved and have moved away from associating it specifically with gay men and intravenous drug users exclusively, but HIV/AIDS still carries with it the stigma that, "it only happens to those types of people. It could never happen to me," or that it is some sort of divine punishment for individuals who engage in immoral behavior.

According to the UNAIDS AIDS Epidemic Update 2009, there are approximately 33.4 million people living with HIV worldwide. Children under the age of 15 account for approximately 2.1 million of the HIV population and women now make up approximately 50% of the adult population living with HIV. These numbers show that the disease can no longer simply be associated primarily with the traditional out-groups. However, even with these sobering statistics, the stigma associated with HIV, nevertheless, still exists. Therefore, using the theory of social representations, this paper will deal with the question of how the images in HIV/AIDS prevention campaigns in the United States and Finland have evolved from the 1980's to present and how these images have changed the objectifications of the disease over time, but continue to perpetuate the stigma, "othering," and fear associated with it.

4. Research Material

Personal illness narratives will be gathered from two HIV positive individuals, Clyde and Jeff. Clyde's story came from Avert.org, which is a non-profit international AIDS charity based in the UK. The website offers comprehensive and up to date information on the lastest in prevention and treatment of the disease as well as an area for those affected to share their personal stories. Jeff's stories came from the website ExperienceProject.com, which is an open forum where individuals share experiences on a particular topic. All entries are in a diary type format, public and freely accessible to all users of the website. While it is unclear as to whether first names are used by the authors, surnames are not used and no contact information is listed for the authors, allowing for anonominity. However, rather than use the names that the authors have listed on the website, I have changed both authors' names in order to ensure complete anonominity. Both Jeff and Clyde have been diagnosed as HIV positive within this decade. I will look at three different personal narratives (one from Clyde and two from Jeff) and evaluate them line by line. In addition, the quotations that I use are the originals as written by the authors. Misspellings and typos made by the original authors will not be corrected.

5. Methodology

The methods used in this analysis was narrative analysis. The following chapter discusses how the method was applied to the data.

5.1 Narrative Analysis

The qualitative method of narrative analysis will be employed in order to gain a deeper understanding of how early social representations of HIV/AIDS have affected the identities of individuals recently diagnosed with and living with the disease and how these individuals make sense of their illness. I will look to social psychologist Dan McAdams' (1993) theoretical and methodological approach to personal narratives, where he argues that individuals *are* the stories that they tell. McAdams suggests that each of us try to make sense of our lives and experiences through storytelling. Doing this allows us to discover our own truths and determine what is important to us and gives our lives meaning. As human beings, we are natural storytellers and this attribute allows us to organize information in such a way so that we may fully express ourselves.

During the analysis, I will attempt to identify three main elements, which McAdams (1993) cites as the the most important when analyzing a personal narrative : narrative tone, imagery and themes. Repeated reading of each story will allow me to identify and

map out the various elements and themes, which, hopefully will result in a coherent analysis in relation to my research question.

5.2 Why Narrative Analysis as Opposed to Discourse Analysis?

I chose the narrative method of analysis, as opposed to another language based approach, because narrative approaches pay great attention to the "inextricable interconnection between 'self' and 'social structures'" (Crossley 2000a, p. 9). Trauma and the study of identity, have traditionally been looked at through various social constructionist, language based approaches such as discourse analysis. Narrative psychology itself is loosely based on a constructionist premise with the importance both discourse analysis and narrative psychology place on the importance of language and qualitative analysis (Smith et al. 1997). However traditional social constructionist approaches will often leave out human subjectivity (Crossley, 2000b) when, in fact, the ability for us to be reflexive is at the center of human agency and understanding. It is what binds the individual and the social (Parker 1991 cited in Crossley 2000b). Similarly, Bruner (2004) argues that we as individuals have no other way of describing our lived experiences except in the form of naarrative. He goes on to suggest that "narrative imitates life, life imitates narrative" (p. 692) and and that life and narrative are constructed out of the same logic and reasoning, a selective narrative achievement narrative achievement of memory recall. While the ability to tell one's story makes for a both opportune but problematic narrative in that it is reflexive in nature where the narrator and the main character in the story are the same. However, Bruner points out that the "culturally shaped cognitive and linguistic processes that guide the self-telling of life narratives achieve the power to so structure perceptual experience, to organize memory, to segment and purpose-build the very 'events' of a life" (p. 694).

Narratology, especially in psychology, is based upon the belief that we need to investigate the systems and structures of meaning in order to understand ourselves and to understand others (Polinghorne 1988 cited in Crossley 2000a, p. 10) and that it poses important questions as to the relationships between the actual events of the lived experience and those events that are expressed in a narrative (Mishler 1986 cited in Ezzy 1998). McAdams (2008) suggests that the stories that we create to make sense of our lives are "fundamentally about struggle to reconcile who we imagine we were, are, and might be in our heads and bodies with who we were, are, and might be in the social contexts of family, community, the workplace, ethnicity, religion, gender, social class, and culture writ large. *The self comes to terms with society through narrative identity* (p. 242-243). He goes on to remind the reader that narratives have been used throughout history in the

field of psychology by those such as Freud who wrote about dream narratives, Jung who focused on universal life myths, and Adler who studied narrative descriptions of early life memories.

Some researchers argue that there is a dichotomy between what is considered objective experience that has been uniterpreted and subjective interpretation (Linde 1993 cited in Ezzy 1998) and they often create a clear distinction between what is narrative and what is lived experience (Ezzy 1998). In fact, Linde argues that the actual realities of a person's life are immaterial to an analysis. However Ezzy argues that this dichotomy is false, as it suggests that language is either "transparent and reflects lived experiences accurately, or it is a distorting screen that always projects experience out of its own categories" (p. 171). Ezzy argues that that to divide lived experience and interpretation "demonstrates a misunerstanding of the hermeneutic point about the nature of reality" (p. 172), regardless if the assertion is made by positivist, interactionist or cultural theorists. He argues that this results from "lingering positivism that attempts to deny the linguistically mediated nature of the events of lived experience" (Bruner 1990 cited in Ezzy 1998, p. 172).

Drawing on Ricouer's (1991 cited in Ezzy 1998), philosophy of hermeneutics, Ezzy suggests that it is incorrect to assume that life is simply lived but not told and that action and the plot of a narrative are understood in a similar way and that language is what makes the human experience real (Merleau-Ponty, Polkinghorne 1988 cited in Ezzy 1998). Ezzy suggests that positivists tend to circumvent the influence of subjective understandings. However, Rosenwald and Ochberg (1992) argue that it is the subjective understandings that are the primary focus of narrative analysis. It is not so important that individuals present their lives accurately but it is enough that they believe that that they are. Ezzy asserts that the focus of the narrative method is the way in which people tell their stories. Accuracy of the story is a secondary issue. Crossley (2000a) asserts that, especially in a narrative interview context, the discourse or rhetorical analyst's main interest is "in the social functions achieved by particular responses (p. 87) and is not concerned at how a particular response may influence the events surrounding psychological or social reality if it is not within the particular interview context. However, she adds that while not *everything* that people say is necessarily important, she argues that one should reflect on the idea that what a person says does have some significance for them and we must accept that it is their own reality and ongoing story, which is a "manifestation of their psychological and social worlds" (p. 88), even outside of the interview environment.

5.3 Narrative Psychology and Social Representations Theory

Murray (2002) suggests that there has been little research into connecting narrative into Social Representations Theory. However, he argues that narratives not only help us tell a story of certain events but also of the social context within which narratives are constructed. Murray further asserts that Social Representations Theory is similar to narrative psychology as both approaches are "concerned with the popular means of making sense of the world" (p. 654). Both narrative psychology and Social Representations Theory can both be traced back to Wilhelm Wundt and his method *Volkerpsychologie*. This method considered narratives, such as myths and legends in everyday life. Farr (1996) has shown how Wundt's *Volkerpsychologie* influenced Thomas' work into the study of social attitudes, where he and Znaniecki developed their own narrative approach to studying immigrant experiences in the early 1900s.

Murray (2002) argues that Social Representations Theory can also be traced back to Wundt's *Volkerpsychologie* because of its concern with collective representations. However, Moscovici was more interested in "how scientific concepts were integrated into everyday thought and not with the narrative content and structure of popular thinking" (p. 656). And while Moscovici did look to Bartlett (1932) whose study into the social processes of remembering took into account narrative transmission between people, he did not think about the role that culture and narrative might play in Social Representations Theory. And while Herzlich's (1973) study on workers' views of health and illness using ethnographic interviews can be considered groundbreaking, Laszlo (1997) argues that she ignored the narrative aspects of the interviews instead choosing to focus only on the concepts of anchoring and objectification by categorisation. However, Murray goes on to argue that Herzlich's categorical coding scheme has several similarities to many narrative structures described by other researchers.

Murray looks to Ricoeur's (1991) processes of *configuration* and *refiguration* to show how we constantly move between the two in order that structure is brought to the world (*configuration*) and how we define who we are through narrative (*refiguration*). He suggests that narrative identity is societal as well as personal. Narratives help communities define themselves. Likewise, he argues that social representations are also important characteristics of communities, but that it is the sharing of personal narratives that helps to establish social representations.

6. Results

In this section, I will show the results of the narrative analysis of my research material.

6.1 Narrative Tone

McAdams (1993) suggests that narrative tone is the most primary feature of the personal narrative. It is expressed not only in the content of the story but also in the manner in which it is told.

The narrative tone that is most prevelant throughout all three texts that were analyzed was of a pessimisitic nature. Even though, some of the authors made an attempt to draw something positive out of their situation, the negative undertones were stll present. For example, Clyde tells his story of when he found out he was HIV positive and how life has been for him since the diagnosis. He ends his story with the following:

> *I do believe in God and this allone has kept me going along with the love I have for my dad who because of bills now live with. I still manage to work everyday but I do not know for how long." (Clyde, HIV + male)*

In an attempt to give himself hope and to bring something positive into a situation that he preceives as very dire, Clyde cites that his belief in God and the love for his father are what keeps him going. And he is clearly thankful that he is still able to work. However, Clyde's pessimistic tone is consistent here, as he implies that his father has to live with him simply because of moutning bills that he is unable to pay. The positive tone that creeps up around the fact that he is still able to go to work is overshadowed by his fear that he will one day be too ill to continue to do so.

Jeff, an HIV positive male, actually submitted his story in two parts. His second story was more of an apology for having had "vented" to the reader in his first story. However, both of his submissions were clearly pessimistic in tone. Similar to Clyde, even where Jeff attempts to look for the positives in his life, negativity still prevails:

> *Yes, I can still find the right woman to fall in love with and marry and I can still share my first real sexual experience with her, but we will never be able to experience intimacy without protection. We will never be able to have children together. She will have to invest into a man and a relationship that has limits, and that's not fair for her."*
> *(Jeff – Part I, HIV + male)*

Jeff expresses some sort of hope that he will be able to live some sense of what he considers to be a normal life but will always somehow be lacking that which, in his mind, is what"normal" people do, or more specifically, "normal" men. It is as though he has has already let down a person that does not yet exist, implying that if he did not have HIV and if he was what he considers to be a "normal man," his relationship would have no limits.

Jeff continues:

> *"I know I shouldn't think so negatively. I've only been positive a few years and men and women have lived many years with HIV. But I don't think I'm the only person that gets scared. (Jeff – Part I)*

Again, Jeff attempts to weave in a positive statement, acknowledging that individuals can live many years with the disease but the overall message that Jeff gives is not one of hope in the face of adversity, but fear in the face of the unknown.

In Jeff's second posting the next day, he begins his story with what at first seems like an attempt to be less pessimistic.

> *"I believe it was yesterday I wrote my first story in this group. I was angry yesterday, however, my angers has subsided." (Jeff – Part II, HIV + Male)*

Later, he seems to try to make a futile attempt try and put things into perspective and to make sense of his situation:

> *"Perhaps it's one of those things that happens for a reason? I hate when people say that but sometimes, it's true, althogh never what anyone wants to hear, and almost as difficult to accept."(Jeff – Part II)*

The negative undertones prevail for both Jeff and Clyde, and they are unable to convince the reader that either of them believes that anything remotely positive could come from their situation.

6.2 Imagery and Themes

Crossley (2000a) asserts that looking at both imagery and themes together is most useful because they often overlap with one another. She argues that certain images in a text most often points to the prevailing themes. The stories of both Clyde and Jeff are clear examples of how imagery and theme overlap and contribute to one another.

Clyde consistently speaks of the loneliness that has felt since being diagnosed:

"The hardest part was going through all of it alone." (Clyde)

"Spending the holidays alone is really rough." (Clyde)

"HIV is a lonely life no matter what anyone tells you." (Clyde)

The negative imagery of loneliness and isolation is prevalent throughout Clyde's entire text. Clyde continues with the images of judgment and humiliation that he has experienced because of how family and friends have reacted, not only to his HIV status but also to his sexuality:

"I have had so called friends throw away plates, forks, spoons etc that I had ate off of (they did not know I saw them take a towel, throw it in the trash and spray Lysol in the bag, that hurt the most and by the way I have never been invited back." (Clyde)

"Dating has been almost non-existant. I see or have a good looking guy approach me just to have him walk away once he finds out I am positive." (Clyde)

"Spending the holidays alone is really rough. Sitting in my living room and watching neighbors families gather with presents and smiles while knowing my siblings are gathering at their homes doing the same however they do not want the fag brother with aids in their home because I am going to hell for being gay." (Clyde)

"The looks from doctors and dentists when you tell them…"(Clyde)

These images that Clyde invokes lead to the prevailing themes of "acceptance versus non-acceptance"," me (the other) versus them (the un-infected friends, the 'straight' siblings)" and even betrayal by friends, family and doctors.

However, the humiliation image for Clyde does not end with the HIV:

"……. the dread of having to go on some kind of public assistance."(Clyde)

In this instance, Clyde has again invoked the "me versus them" theme but in his eyes, it is "other people" who receive public assistance and for him to do so would mean that he is associated with yet another out-group.

In Jeff's stories, the main images that come up are images of anger, mistrust and victimization . In both of his texts, these images are brought up consistently:

> *"This man took so much from me that can never be replaced. He took my purity. And then, when I got sick and found out I was positive, I realized he took my life." (Jeff – Part I)*

> *"So that's me right now. Scared and angry, and going to smoke another cigarette." (Jeff – Part I)*

Even in Jeff's second entry, which was written after he had apparently "cooled off" a bit, these images present themselves again:

> *"I wish I could forgive him. He said he didnt' know he was positive. That's not what I'm angry over though. He shouldnt' have done what he did in the first place." (Jeff – Part II)*

For Jeff, these images have constructed themes of "loss of control" over one's life and situation, and betrayal buy a trusted adult.

Jeff is also quite quick to point out the images of who does and does not get HIV:

> *"I never, in a bazillion years, would have ever thought I would be effected by it when I consider the type of family I grew up in. I never even put a thought toward the idea that I could ever contract the disease." (Jeff – Part I)*

> *"I don't drink or do drugs. I've never had a girlfriend or a boyfriend, and just to clear it up, I would be looking for a girlfriend." (Jeff – Part I)*

> *"I can be at ease knowing that I could go out today and get hit by a bus or be struck with some other disease that was uncontrollable. I am not, however, at ease knowing that I have one that I shouldn't." (Jeff – Part II)*

As in Clyde's story, the theme of "me versus them" becomes evident in both of Jeff's stories. Jeff associates HIV with out-groups such as drug-users and people who did not grow up in the "type of family" that he grew up in. He feels compelled to inform the reader of his sexual preferences, presumably so that he is in no way associated with homosexuality. Finally, he goes on to refer to how getting hit by a bus or a different "controllable" disease would be easier to deal with, as he is not someone who *should* get HIV. Only *other* people get HIV.

7. Discussion

Within the area of health psychology, Moscovici's (1961) Theory of Social Representations has played an essential role in explaining how scientific information about a newly discovered illness is transformed, primarily through mass media, into lay knowledge. With the emergence of HIV/AIDS in the early 1980's, psychologists have looked to Social Representations Theory for an understanding into how the early dominant representations of the disease affected the identities of those who tested positive as well as on the identities of those who were members of the particular out-groups, such as gay men, regardless of their HIV status. Many of these dominant social representations have been attributed to much of the mass media presentations of a disease that even scientists knew very little about at the time of its emergence. The information that was being transferred to the lay public resulted in mass hysteria and fear rather than providing informative, useful information about the disease.

As Moscovici pointed out, once formed, social representations take on a life of their own. As scientists discovered more information about the disease, the type of information being presented about the disease also changed. One could conclude that once the information being presented changed, the social representations somehow changed as well. This was evident in some of the later media campaigns that emerged in the late 1980's, that emphasized that those who practice certain behaviors are at risk, while the rest need not worry about the infection. However, it would seem that the initial representations that were formed out of the initial fear and panic about the disease merged with the new representations that formed, which have allowed for the stigma surrounding the disease to remain, even to this day. While these campaigns acknowledged that the disease was not contained to only homosexuals or intravenous drug users, it was emphasized that *normal* people who partook in specific behaviors *with* these risky individuals were at risk for getting the disease.

The main goal of this research paper was to look at how the identities of individuals diagnosed and living with HIV/AIDS in the new century have been influenced by the early social representations and stigma that surrounded the disease in the early 1980's., and how these individuals make sense of their illness. I performed a narrative analysis on three stories written by two separate individuals, Clyde and Jeff, in order to evaluate a possible connection, particularly with the objectification process. Narrative analysis was chosen as method for looking at this issue because, as Ezzy (1998) suggests, it is language that makes human experience real. What a person says has significance for that

person and it must be understood that it is that person's own reality. Their story is the manifestation of their psychological and social worlds.

I would argue that the early social representations of HIV/AIDS has impacted the identities of Clyde and Jeff and has also influenced the way in which they each make sense of their illness. Clyde makes it quite clear that many of his friends have shunned him for being positive, as though they would contract the disease simply by eating off of the same utensils that he used. Clyde's interpretation of his friends' behavior, whether real or imagined, is consistent with the hysteria and fear that surrounded the disease in the early 1980's. In addition, he maintains that his siblings have also rejected him because he is, in his own words, "*the fag brother with aids."* While intellectually Clyde knows that one does not necessarily mean the other, the early association of AIDS with homosexuality is still prevalent, even in Clyde's own mind.

Jeff's quick announcement that he is not gay and does not drink or do drugs is quite consistent with the early representations made that link HIV/AIDS with particular outgroups. His assertion that "people like him" who have families "like his" do not deserve AIDS is also quite consistent with this early representation.

The consistent negative tones in both stories, even when attempting to be positive, suggests that both Clyde and Jeff are experiencing significant turmoil in their lives as a result of how see themselves as HIV positive males. While writing these narratives may be a first step in trying to make sense of why this has happened to them, it is evident that these are two men whose identities are in crisis. I would argue that it is precisely the stigma and the initial social representations that were formed early on that have remained over the last 30 years that have directly affected how these men view themselves in terms of their illness. This analysis has shown that the objectification of the disease that resulted in the early days of its discovery continues to pervade the talk surrounding the disease, and continues to influence the way in which society views those who are affected. Furthermore, it is clear that the early objectification process still influences the way in which those living with the disease view themselves. While the peripheral elements of the early social representations have morphed over time and HIV/AIDS is now considered a manageable condition, the early representations surrounding the disease are still in our collective consciousness.

As Jeff put it,

> *"I can be at ease knowing that I could go out today and get hit by a bus or be struck with some other disease that was uncontrollable. I am not, however, at ease knowing that I have one that I shouldn't."*

The issue is not having *a disease*, the crisis has emerged at having *this particular disease."*

Future research in this area could include more in-depth analysis of the stories of individuals living with HIV/AIDS in an unstructured interview setting. While the narratives that were used for the purpose of this project contained quite rich information, an unstructured interview would provide far more insight into early identity formation before the HIV diagnosis and to look for any transformations that took place after the diagnosis. Also, using narrative analysis in addition to another methodological approach, such as a more in-depth look into media campaigns surrounding HIV/AIDS, both early and recent, could provide the researcher more insight into how or if these areas link.

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APPENDICES

JEFF

Nobody should have this disease. I never, in a bazillion years, would have ever thought I would be effected by it when I consider the type of family I grew up in. I never even put a thought toward the idea that I could ever contract the disease.

I just became an adult, and most wouldn't even consider me to really be one yet because I'm still, as my older sibling say, a pup. I don't drink or do drugs. I've never had a girlfriend or a boyfriend, and just to clear it up, I would be looking for a girlfriend. I'm a total victim here and right now, today, it's really bothering me, truly making me angry again.

It was someone whom I trusted, a youth minister, that gave it to me. Nothing about the encounter was concentual.

When I first found out, not long after I returned home from a personal mission trip, I was so angry. This man took so much from me that can never be replaced. He took my purity. And then, when I got sick and found out I was positive, I realized he took my life. It would no longer be the same.

Yes, I can still find the right woman to fall in love with and marry and I can still share my first real sexual experience with her, but we will never be able to experience intimacy without protection. We will never be able to have children together. She will have to invest into a man and a relationship that has limits, and that's not fair for her.

My parents may have to bury me. I can't even handle thinking about that idea.

I'm just really upset today about the whole thing, all spawning from a cold that I feel like I'm coming down with right now. Colds scare me. They scare my family. I'm not afraid to die because I'm secure enough in my faith and my service to God that I will go to Heaven. I'm just afraid to do it so soon.

I know I shouldn't think so negatively. I've only been positive a few years and men and women have lived many years with HIV. But I don't think I'm the only person that gets scared.

So that's me right now. Scared and angry, and going to smoke another cigarette.

JEFF – PART II

I believe it was yesterday I wrote my first story in this group. I was angry yesterday, however, my angers has subsided. While, in the back of my head and heart, I still hold anger, it doesn't always come forefront in my average day.

I wish I could forgive him. He said he didnt' know he was positive. That's not what I'm angry over though. He shouldnt' have done what he did in the first place.

I have come down with the cold I was trying to avoid. Every cough reminds me that things will, at some point in my life, be much worse. I can be at ease knowing that I could go out today and get hit by a bus or be struck with some other disease that was uncontrollable. I am not, however, at ease knowing that I have one that I shouldn't. I guess the best way to describe my feeling toward it, today, at least, is that I am hurt and disappointed.

Perhaps it's one of those things that happens for a reason? I hate when people say that but sometimes, it's true, althogh never what anyone wants to hear, and almost as difficult to accept.

The Experience Project, 2010

CLYDE

My life with HIV started in November of 2006. I was 37 had only been out of the closet for three years and wham! I had gotten a routine test done and knew it would be negative because it was the year prior. Well that was not the case, it was positive. The hardest part was going through all of it alone. My father was and is supportive and that was my saving grace. I have had so called friends throw away plates, forks, spoons etc that I had ate off of (they did not know I saw them take a towel, throw it in the trash and spray Lysol in the bag, that hurt the most and by the way I have never been invited back.

Three years later I am know dealing with extreme fatague, neuropathy, sore muscles etc. I was placed on a drug holiday (stopped taking my meds for three months) because my numbers were good. I feel like the HIV has come back stronger then ever but I will know more when I go for blood tests next month.

Dating has been almost non-existant. I see or have a good looking guy approach me just to have him walk away once he finds out I am positive. Spending the holidays alone is really rough. Sitting in my living room and watching neighbors families gather with presents and smiles while knowing my siblings are gathering at their homes doing the same however they do not want the fag brother with aids in their home because I am going to hell for being gay.

HIV is a lonely life no matter what anyone tells you. The looks from doctors and dentists when you tell them, friends and co-workers who dont understand why a 40 y/o man is worn out all the time, potential dating partners who run when they find out, all the pills, my Lord the co-pays and bills, not knowing how much longer I will be able to keep working, the dread of having to go on some kind of public assistance.

Sorry to depress you but this is what life is like for many of us and it sucks! I do believe in God and this allone has kept me going along with the love I have for my dad who because of bills now live with. I still manage to work everyday but I do not know for how long. Thanks for letting me vent.

A*vert, 2010*