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What lay illness narratives reveal about AIDS-related stigmatization

ABSTRACT

The main purpose of this contribution is to broaden the understanding of variables surrounding the stigmatization of people living with HIV/AIDS by analyzing a corpus of Afrikaans-speaking teenagers' narratives on HIV/AIDS. Support is given for the hypothesis that lay illness narratives are interdiscursive constructions, based on media discourses about HIV/AIDS, and mapped against the mental schemas of the narrator's own life and identity. Instances of convergence as well as dissonance between reported illness narratives (media narratives) and lay illness narratives are highlighted, with specific reference to the clustering of stereotypical features, constituting three archetypes of people living with HIV/AIDS, namely the AIDS carrier, the AIDS victim and the AIDS survivor.

1. INTRODUCTION

All over the world, the epidemic of HIV/AIDS is having a profound impact, bringing out the best and the worst in people:

They trigger the best when individuals group together in solidarity to combat government, community and individual denial, and to offer support and care to people living with HIV and AIDS. They bring out the worst when individuals are stigmatized and ostracized by their loved ones, their family and their communities, and discriminated against individually as well as institutionally (UNAIDS, 2002).

People living with HIV/AIDS react to, and cope with, stigma in different ways. Some display offensive, deliberate and malicious maladaptive behaviours, such as infecting others through forced sexual contact (rape), discarding used syringes where they could infect others, or deliberately and violently attacking others with used syringes, dripping blood on them or biting them (compare Brown *et al.*, 2001; Lupton, 1999; Stanley, 1999:103). Maladaptive reactions to stigmatization could also include defensive behaviours, such as the avoidance of, or succumbing to, the stigmatized identity. Succumbing to stigma may entail hiding in fear of discrimination and ostracization; experiencing debilitating embarrassment, shame, guilt, depression and hopelessness; living in denial; not disclosing your serostatus; being unwilling to test; not seeking health care; and not soliciting social support (Brown *et al.*, 2001; Stanley, 1999).

On the other hand, stigma control, or positive adaptation to a stigmatized identity, is achieved by accepting responsibility for one's mental and physical health, developing an optimistic counter-discourse (e.g. by inverting demoralizing metaphors), personalizing and/or spiritualizing the meaning of AIDS (Stanley, 1999:106), and embracing disclosure by participating in identity politics, engaging in advocacy, etc.

One would expect stigma to decrease with the increased visibility of HIV, but this is not the case in much of sub-Saharan Africa (Brown *et al.*, 2001:16). Moreover, relatively few interventions to reduce the AIDS stigma have been conducted in developing countries. In a country like South Africa, where 24% of the adult population is currently infected with HIV, stigmatization of the infected constitutes a tremendous barrier in managing the epidemic.

Culture-specific research is necessary to determine the variables that constitute stigmatization in the various communities, which could on their part form the input for designing group-specific interventions.

2. PURPOSE AND GOAL

The main purpose of the research was to broaden the understanding of the variables surrounding HIV/AIDS stigmatization among white Afrikaans-speaking teenagers from middle and high socio-economic class backgrounds by analyzing the narratives they had written on HIV/AIDS.

3. OVERVIEW

Firstly, the theoretical framework used as the basis for the research (narrative analysis) is described, followed by an exposition of the typology proposed for "stories" about HIV/AIDS. In the ensuing descriptive overview, special attention is given to media narratives (reported illness narratives) about HIV/AIDS, since it is hypothesized that lay illness narratives (of which the AIDS poems are instantiations) are largely based on media reportage. The literature review is followed by a description of the research design and research methodology, upon which the research results are discussed in relation to the theoretical framework within which the article is embedded. The conclusion summarizes tendencies observed in the data, their convergence with, and divergence from, those in other types of illness narratives, and the insight that has been gained into how HIV/AIDS-related stigma is perceived and mentally constructed by the members of the sample population.

4. ANALYTICAL FRAMEWORK

4.1 The narrative as unit of analysis

Narrative analysis was selected as the primary analytical framework for the research. From the narrator's point of view, the narrative's importance lies in its being one of the main forms through which the narrator perceives, experiences and judges his/her actions and makes sense of the social world (Hydén, 1997:49; Somers, 1994). Narratives create frames for understanding and judgement and link them to the everyday circumstances of the narrator's life (Hydén, 1997:49). Moreover, the story structure guides people's assimilation of information, especially textual input, and facilitates the retrieval of that input from memory (Viney *et al.*, 1991:757). From this perspective, the narrative constitutes a data unit that reliably reflects the interdiscursive mix of decoded information and internalized value and belief systems regarding various domains of social life, including health and disease.

From the researcher's point of view, narrative inquiry can have either a descriptive or an explanatory purpose. If the purpose is descriptive, the aim is "to produce an accurate

description of the interpretive narrative accounts individuals or groups use to make sequences of events in their lives or organizations meaningful" (Polkinghorne, 1988:161-162). An explanatory purpose would be to account for the connection between events in a causal sense and to provide the necessary accounts that supply the connections (Clandinin & Connelly, 2000:16). In the present study, the purpose is explanatory and interdiscursive, particularly to explain the relationship between different types of narratives that play a role in the lives of a certain group of people.

4.2 Illness narratives

A specific type of narrative, which is increasingly being analyzed in social science and medicine, is the so-called illness narrative. Depicting illness in the form of a narrative is a way of contextualizing illness events and illness symptoms by bringing them together within a biographical context (Hydén, 1997:51). The prototypical narrative is therefore a first-person narrative, and the "illness biographer" is a person who is ill. A personal experience of illness, articulated in and through a narrative, is termed an illness as narrative by Hydén (1997). In this contribution the term 'autobiographical illness narrative' will be used for this subtype of illness narrative.

The biographer of an illness narrative may also be a family member or close friend of the affected person, or a medical professional who is treating the patient. In this case illness is experienced through the primary narrative of the sick person or by co-experiencing the illness as a result of close interaction with the patient. Hydén (1997:54) terms this subtype a narrative about illness. In this contribution, narratives resulting from personal or professional contact with an AIDS patient will be termed a 'co-experiential illness narrative'.

Media narratives about HIV/AIDS, e.g. a news story reporting on an incident involving a person living with HIV/AIDS or a feature story about such a person (compare Hydén, 1997:64; Lupton, 1999), may also be subsumed under the category of 'narrative about illness'. This type of narrative differs from co-experiential illness narratives in that it is not built on personal experience or an empathic relationship with the person who is ill. Media narratives about HIV/AIDS are narrative reports (displaying varying degrees of objectivity) of, or reflections based on, the lives and experiences of people living with AIDS. This type of narrative will henceforth be referred to as a 'reported illness narrative'.

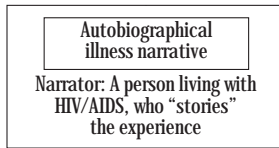
If one assumes that the common denominator of narratives about illness is "the narrative's theme, namely illness" (Hydén, 1997: 51), the narrator could also be a person who is not HIV positive, and has never been in contact with a person living with HIV/AIDS. The narrative of such a person will henceforth be termed a 'lay illness narrative'¹ The term

'lay illness narrative' was coined analogous to 'lay illness cognition', a term suggested by Dr. Henk Boer, a health psychologist from the University of Twente, The Netherlands for non-experiential cognitions about illness as perceived by a healthy person, and it is this subtype that constitutes the main focus of the present contribution.

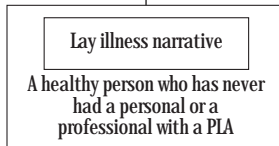
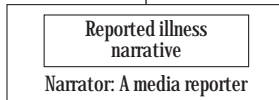
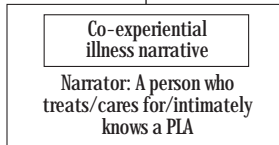
The last category of Hydén's typology is narrative as illness (Hydén, 1997:55), in which case the narrative generates the illness or acts as a symptom of the illness, e.g. a patient suffering from a brain injury that impedes his/her ability to use the medium of the narrative to connect experiences with particular events. This category will not feature in the context of HIV/AIDS since very little is known about the effect of AIDS on the brain (so-called 'neuro-AIDS'), particularly the language faculty (compare Pert, 1999:199-200; 202). This subtype will be labelled a 'symptomatic illness narrative'.

Illness narratives are summarized by the following diagram (author's categorization):

Illness as narrative



Narrative about illness



Narrative as illness

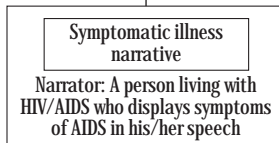


Diagram 1: A typology of illness narratives

According to Frank (1995), as quoted by Hydén (1997:55), illness narratives have the following functions with respect to the individual's interaction with others and to his or her own construction of social realities:

1. To transform illness events and construct a world of illness
2. To reconstruct one's life history in the event of a chronic illness
3. To explain and understand the illness
4. As a form of strategic interaction in order to assert or project one's identity
5. To transform illness from an individual into a collective phenomenon

Lay illness narratives share at least two of the above functions with autobiographical illness narratives, notably:

1. To help the narrator understand and make sense of an illness against one's own life schema
2. To help the narrator assert or project his/her identity in relation to the illness

In addition, lay illness narratives are thought to have the following functions:

- To integrate the voices of medicine, the media and personal value systems in order to construct a mental map representing healthy people's attitude formation about, and behavioural intentions towards, people living with HIV/AIDS.
- To help the healthy person find an appropriate role for him- or herself in a society where illness and death have become part and parcel of everyday life.
- To enable health professionals, psychologists and communication specialists to study the experience of illness as a social and a cultural construct by unveiling dominant stigmatizing discourses, and thus indicate areas that need to be addressed by intervention programmes; and to identify counter-discourses that may serve as vehicles for therapy and destigmatization.

With the exception of Good (1994) and Marshall and O'Keefe (1994), little attention has been devoted to making comparative studies of the different types of illness narratives, e.g. the relationship between primary and secondary narratives about illness (compare Hydén, 1997:64).

In order to determine the extent to which lay illness narratives resonate with, elaborate and distort media representations, it is necessary to give an overview of the construction of HIV/AIDS-related stigma in the media, focusing on stereotypical features, which cluster together to construct certain archetypes.

4.3 Media narratives about AIDS

4.3.1 Representation of people living with HIV/AIDS in the international media

On the basis of news reports in the Australian media, three archetypes of people living with HIV/AIDS have been identified by Lupton (1999): the AIDS carrier, the AIDS victim/sufferer and the AIDS survivor. The representation of people living with HIV/AIDS as AIDS carriers and AIDS victims reflects maladaptive coping behaviours, namely arousal of fear (offensive behaviour) and hiding or succumbing to negative feelings (defensive behaviour). In contrast, the AIDS survivor is an archetype arising from optimistic counter-discourse, by, for instance, inverting demoralizing metaphors and focusing on coping behaviours. A brief overview of each of these archetypes will be provided.

- *The AIDS carrier*

The AIDS carrier is the individual maliciously or carelessly spreading HIV to others. Here, gay men, injecting drug users and bisexual men have often been represented in the international media. News reports typically portrayed such individuals as out of control, vicious and violent, e.g. drug addicts attacking people with their syringes or biting them, or carelessly leaving the syringes around where innocent others might come across them (Lupton, 1999:46). Other narratives of the AIDS carrier portray the person with HIV/AIDS as a calculating and devious villain, deliberately seeking to pass on their infection to hurt and harm others out of a desire for vengeance, often because of bitterness about the person's own infection. Another type of AIDS carrier includes those who pass the virus on via unprotected sexual activity. These people are portrayed as a threat to others not because of vengeance, but because of loose morals and the lack of self-control (Juhasz, 1990; Sacks, 1996).

People with HIV/AIDS falling within the AIDS carrier archetype tend to be positioned as the source of infection (an agent) rather than a victim (a patient). Therefore, the AIDS carrier is regarded as a criminal: he/she has abrogated the trust of others and placed them at risk. This linking of criminality with HIV/AIDS infection brings with it a double source of stigmatization, fear and loathing. These individuals' inability or lack of willingness to contain their bodies was represented in the media as dangerous and contaminating, and they were therefore subject to moral censure (= blame).

A subtype that does not seem to have received international media coverage as an AIDS carrier is the HIV-positive mother who transmits the disease to her child during labour or by breastfeeding.

- *The AIDS victim*

The AIDS victim constitutes the dominant representation of people with HIV/AIDS, namely as "ravaged, disfigured and debilitated by the syndrome [...], generally alone, desperate and 'resigned' to their inevitable death" (Crimp, 1992:118). This type of representation fits into broader discourses about illness and disease, in which ill people are portrayed as the marginalized and dependent others (Sontag, 1989). Images that were vivid in the media during the late nineties were emotional suffering, e.g. distress at discrimination despair; anguish and fear when waiting for test results; guilt by those who lived a promiscuous life or believing that one is invulnerable to HIV infection; indignity and humiliation resulting from a loss control over certain bodily functions; physical suffering; discrimination; and a potential early death.

The archetype of the AIDS victim is typically portrayed as the person with no guilt, represented by several sub-types in the international media:

- The gay man in despair and suffering guilt at his illness
- People with HIV/AIDS (gay or otherwise) who have suffered discrimination
- People who feared that they had contracted HIV from discarded syringes
- Victims attacked by deviant others, specifically injecting drug users
- Elite sportsmen whose distress at being HIV positive presented a bleak contrast between their supreme health and physical fitness as successful athletes and the grim future that awaited them in terms of physical deterioration and a potential early death (e.g. American basketball player Magic Johnson)

According to Lupton (1999:41), all the people falling within the victim archetype were dealt with sympathetically by the press; their suffering was emphasized over their culpability for their infection. In the Western media babies born with HIV seemingly did not emerge as a subtype of the AIDS victim, which is understandable in the light of the emphasis on the politics of antiretroviral drug distribution, rather than on the recipients of antiretroviral drug therapy.

- *The AIDS survivor*

During the second half of the nineties, the AIDS victim archetype started to become prominent in the media (Lupton, 1999:44). People living with HIV/AIDS who remained healthy for years, without apparent immune dysfunction, started to feature in the news media and a growing emphasis was placed on individuals' emotional and psychological approach to their infection and their self-care routines in staving off the effects of HIV/AIDS.

Unlike the people with HIV/AIDS falling into the 'AIDS victim' archetype, 'AIDS survivors' were portrayed as demonstrating stigma control by successfully fighting against despair

and illness. In most of these reports, a positive attitude (optimism), the right diet, a good 'constitution' and spiritual well-being (e.g. by meditating) were portrayed as the reasons for good health despite being HIV positive. Interestingly, little distinction was drawn between the people who were gay or the ones who were heterosexual in this representation.

4.3.2 Representation of people living with HIV/AIDS in the South African media
Analyses of HIV/AIDS reporting in mainstream South African newspapers by Gevisser (1995) and Stein (2001) indicate that local coverage until the mid to late nineties was largely dominated by the AIDS victim, particularly people dying of AIDS. Images of emaciated people, often referred to as 'victims' and 'sufferers', were prolific in almost all the newspapers. The focus often fell on sordid detail and the danger of caretakers being infected (contaminated) by working with bodily fluids from very sick patients.

The AIDS carrier archetype was initially represented primarily by gay men, but between the mid-eighties and mid-nineties, this representation gradually gave way to an image of HIV as a disease 'exploding' among black heterosexuals (Gevisser, 1995). Gevisser found that black women were almost invariably depicted as HIV-positive mothers or pregnant women who are of concern only insofar as they may infect their babies or leave their children orphans, who were then implicitly portrayed as victims. This archetype therefore became tainted with racism.

In the South African media, only sporadic reference had been made to AIDS survivors until the new millennium. Two initiatives – the Beyond Awareness Campaign's Mediawokers Project, and Health-E – reacted to the overall negative reportage (Parker & Kelly, 2001:5). The Mediawokers Project was aimed at promoting greater emphasis on the reporting of social action by individuals and organizations, while at the same time exploring an expanded role for photographic images depicting various aspects of the epidemic. According to Parker and Kelly (2001:5), "there was widespread uptake of the materials produced", and the project dramatically shifted the approach to photographic images, other than pictures of people who were ill. It was only after 2000 that the AIDS survivor archetype became more prominent in the SA media, particularly resulting from the advocacy campaigns initiated by a handful of HIV-positive individuals, notably the 12-year-old Nkosi Johnson (who passed away in June 2001), supreme court judge Edwin Cameron who disclosed his HIV status in the late 1990s, and Treatment Action Campaign head Zachie Achmat who refused to take antiretrovirals until the Government allowed affordable generic antiretrovirals into the country. Between January 2000 and December 2002, more than 40 news stories exclusively on the life and actions of Nkosi Johnson were published in the Afrikaans daily newspaper, *Beeld*, and twelve in the Afrikaans Sunday newspaper, *Rapport*, for the same period. Fifty-five stories in *Beeld* mention

judge Edwin Cameron's name in connection with his HIV status and his advocacy regarding the availability of antiretrovirals free of charge to HIV-positive people (News24.com). This may explain why the AIDS survivor is an archetype featuring prominently in the lay illness narratives analyzed.

5. RESEARCH HYPOTHESIS AND RESEARCH DESIGN

In the light of the fact that 92% of South Africans have access to the radio, 76% to television and 55% to newspapers (Stein, 2001:5; Coulson, 2003:1), it could be assumed that the news that the media provide plays an important role in providing content for discourse about HIV/AIDS among literate people in South Africa (also compare Parker & Kelly, 2001). However, it is also generally accepted that people do not interpret news in a purely objective way. All new information is assimilated relative to existing cognitive structures, which owe their configuration to all the various discourses to which a particular individual has been exposed (Schema Theory, 2002). It can therefore be purported that narratives on HIV/AIDS produced by a particular community of newspaper readers (primary or secondary readers) will converge with media narratives to a certain extent, but also differ to some extent.

An overt aim of this research was to pin down the important similarities as well as the differences between the lay illness narratives of a particular social group and prominent reported illness narratives on HIV/AIDS in order to provide qualitative data that may guide future research into the stigmatization of people living with HIV/AIDS.

6. METHODOLOGY

The database consisted of twenty-two poems written by Afrikaans-speaking high school learners aged between 14 and 17 years (Grades 8 to 11), which were entered for a country-wide Afrikaans language expo². The use of the data was kindly consented by the Foundation for the Advancement of Afrikaans. Poems were chosen as the units of analysis since it is generally accepted that they embody the innermost cognitions and emotions of their authors (compare Goleman, 1996:54).

The research endeavour relied on convenient sampling (Babbie & Mouton, 2002:166; Strydom & Venter, 2002:207). Although convenient sampling is regarded as risky (Babbie & Mouton 2002; Strydom & Venter, 2002:207), and all the respondents "selected themselves", the use of this method can be justified on the basis of the research purpose, namely *to broaden the understanding of culture-specific variables surrounding the stigmatization of people living with HIV/AIDS* (and not to make grand generalizations that are valid for the total population, i.e. white Afrikaans-speaking teenagers from middle and upper socio-economic class backgrounds).

7. ANALYZING THE HIV/AIDS POEMS AS LAY ILLNESS NARRATIVES

7.1 Introduction

Although co-experiential illness narratives fall outside the scope of the present research, this article will draw on the terminology used by Marshall and O'Keefe (1995) for analyzing medical students' first-person narratives on HIV/AIDS. Two terms, in particular, will be borrowed for describing the similarities and differences between different subtypes of illness narratives, namely 'convergence', and 'dissonance'.

Convergence is the mirroring that occurs between different representations by a primary and a secondary narrator at the ideational, relational or affective level. Dissonance refers to divergent constructions or reconfigurations of the social world described by the primary and the secondary narrator at either of the levels mentioned above (compare Marshall & O'Keefe, 1994:70).

Similar to medical students' co-experiential narratives (as described by Marshall & O'Keefe, 1994), which are secondary in relation to the patient's autobiographical narrative, high school learners' lay illness narratives are secondary to reported illness narratives or media narratives, in that the former draw on the latter for factual (ideational), emotional and relational (interpersonal) input. However, other than autobiographical illness narratives, the "source narrative" in this case is not a single narrative, but an interdiscursive mix of narratives that draw on a multitude of other discourses (political, economical and medical). Similar to co-experiential illness narratives, lay illness narratives also superimpose relational and emotional content on the primary or source narrative and partially also reflect their author's understanding of, and beliefs about, the social and affective experience of AIDS.

7.2 Archetypal clustering of features

7.2.1 *Reinforcing stigma*

- *The AIDS victim*

Stigmatization and certain maladaptive reactions thereto are vividly portrayed in the poetry corpus. Not surprisingly, the dominant visual image is that of the AIDS victim, particularly the emaciated, lonely and desperate person, resigned to an inevitable death. The most striking aspect of divergence (if reported illness narratives are taken as the primary narrative) is found in the thematic content of the poems: the general focus in the poems is not so much on the ailing patient, immobilized and dependent on caregivers, but rather on the (purported) emotional suffering the infected person has to undergo. Only three poems describe the physical effects of a compromised immune system, such as fever, weight loss, skin infections and infections of the respiratory tract (poems 3, 4 and 8).

Table 1 summarizes the emotional effects represented in the poems under six prominent sub-categories, namely powerlessness and hopelessness, loss of identity, sadness, isolation, shame and fear:

POWERLESSNESS AND HOPELESSNESS		
Original Afrikaans citation	English translation	poem no.
Sy's magteloois sonder krag	<i>She is powerless and has no strength</i>	1
My dae is hel	<i>My days are hell</i>	3
(Hy is) magteloois	<i>(He is) powerless</i>	4
Hy is hulpeloos	<i>He is helpless</i>	4
Ek kan my nie uit dié een help nie	<i>I cannot redeem myself from this one</i>	5
Waar sal my hulp vandaan kom?	<i>Where will (my) help come from?</i>	15
Ek is in nood	<i>I am in trouble</i>	
Wie sal my red?	<i>Who will save me?</i>	
Gee my 'n helpende hand, maar kan ek dit aanvaar?	<i>Give me a helping hand, but can I accept it?</i>	15
my nagte is swart	<i>my nights are black</i>	15
Ek kan dit nie meer vat nie gedagtes pleeg selfmoord	<i>I can't take it any longer (my) thoughts commit suicide</i>	15
Ek kan my nie uit dié een red nie	<i>I cannot free myself from this one</i>	15
Original citation	English translation	poem no.
Haar trane smelt saam met die wind	<i>Her tears unite with the wind</i>	1
Is daar iets agter die treurigheid?	<i>Is there something behind the sadness?</i>	15
In 'n tyd van diepe droefheid As die smart hierbinne brand	<i>In times of profound sadness When grief/sorrow burns inside</i>	20
Die nimmereindigende verlanse na vreugde	<i>The endless longing for happiness</i>	21
Die pyn, die hartseer	<i>The pain, the sadness</i>	21
Die hartseer in hul oë bly by my	<i>The sadness in their eyes stays with me</i>	21
En soms as sy lag	<i>And sometimes when she smiles</i>	1
Is haar oë dié van 'n mishandelde kind	<i>Her eyes are those of an abused child</i>	
Original citation	English translation	poem no.
maar as die son sak droom sy dat hulle steeds na haar staar	<i>but when the sun sets she dreams that they are still staring at her</i>	1
Nou is sy stoksielalleen	<i>Now she is all alone</i>	5
jy voel negatief nes 'n dief sonder enige lief	<i>you feel negative like a thief without any love</i>	12
Ek wens iemand sal opmerk	<i>I wish that somebody would notice</i>	15

LOSS OF IDENTITY		
Original citation	English translation	poem no.
Wie is ek?	<i>Who am I?</i>	15
Hou ek van myself?	<i>Do I like myself?</i>	15
Original citation	English translation	poem no.
... 'n mislukking	<i>... a failure</i>	15
Om vir hulp te vra sal my dom laat lyk	<i>To ask for help will make me look stupid</i>	15
al is hy van sy selfrespek gestroop	<i>even though he has been stripped of self-respect</i>	22
Original citation	English translation	poem no.
Maar dink aan die Wat in vrees nog wag	<i>But think of those Who are in fear still waiting</i>	3
In hulle oë dwaal 'n angskreet	<i>In their eyes dwells a scream of fear</i>	21
Die vrees beheer my dat ek 'n lewe moet ly vol siekte en swaarkry	<i>The fear controls me that I must live a life full of sickness and suffering</i>	11
maar steeds sterf jy 'n verwerpte eensame jy	<i>but still you die a rejected, lonely you</i>	11
Maar dink aan die Wat in vrees nog wag; dat VIGS hulle lewens verkrag	<i>But think of those who are in fear still waiting that AIDS violate their lives</i>	3
dan sal daar baie minder mense vir hul lewens vrees	<i>then many people will fear for their lives</i>	9
maar steeds sterf jy 'n verwerpte eensame jy	<i>but still you die a rejected lonely you</i>	11
'n Lewe is verkwis Ek wil nie weet ... weet dat ek vroeg dood gaan nie	<i>A Life wasted I don't want to know ... that I will die young</i>	18
Wie sal my verlos uit die kloue van die dood?	<i>Who will save me from the claws of death?</i>	21

Table 1: Instances of perceived stigma in the poetry corpus

Affective convergence occurs particularly with regard to fear: fear of suffering and rejection, but particularly fear of death, which is disproportionately related to the representation in reported illness narratives. The word *death* and its inflections, compounds, derivatives and synonyms occur no fewer than 15 times in the poems. Over and above these, there are ten references to loss of life or the termination of life as a result of AIDS. This seems to be in line with the findings of Marshall and O'Keefe (1994:75) in connection with the relationship between medical students' co-experiential narratives and the primary (in this case autobiographical) narrative, which they attempt to mirror. The medical students, for instance, vividly portrayed the patient's fear of being left alone to die a painful and loveless death, which stood in stark contrast to the patient's actual references to death, which were quite limited.

Apart from the fear of death, the high school learners' lay illness narratives also diverge from the reported illness narratives regarding the intensity of emotions and the overlexicalization³ of hopelessness/powerlessness, sadness and isolation. Metaphors such as "My days are hell" and "My nights are black" (my translations) indicate a hyperbolic reconstruction of reported media narratives. The prolific references in the poems to profound sadness and isolation (see table 2 above) seem to be in contrast to the non-representation of this emotion in reported media narratives. A possible explanation for this dissonance may be an age-related construction of meaning: people from different age groups have different mental schemata for the different stages of life, namely birth, childhood, teenage years, adolescence, adulthood, mid-life, old age and death; and death does not fit into the teenage or adolescent phase. Isolation, loss of hedonistic pleasure and premature death probably constitute a youthful person's worst fears. In the poems, metaphoric constructions such as the following dramatize the emotional paradox of happiness and sadness:

- Poem 1: *En somtyds as sy lag, is haar oë dié van 'n mishandelde kind* (And sometimes when she smiles, her eyes are those of an abused child)
smile (of a happy child) x (sad) eyes of an abused child;
- Poem 20: *Die smart brand binne my* (Grief burns inside me)
passionate fire of love/life x the agonizing fire of sadness.

It is interesting to note that absolutely no reference is made to racial group or sexual orientation. Neither gay men, nor black heterosexuals are mentioned, even in the poems dealing with descriptions of physical suffering. This dissonance seems to be of an affective nature, since discrimination and stereotyping – which are always affectively charged – do not occur. Instead, one finds mostly personalized constructions, referring to the emotional trauma of AIDS as "experienced" by the author.

A subtype of the AIDS victim archetype, which occurs surprisingly many times in lay illness narratives (as compared to reported illness narratives), is that of the baby born with AIDS. Five poems (2, 9, 11, 17, 19) refer to babies born with AIDS. In two poems, passive constructions are used to exonerate the babies from blame:

Poem 2: *Duisende babas word daaglik besmet* (Thousands of babies are infected daily)

Poem 9: *Talle babas word met vigs gebore* (Scores of babies are born with AIDS)

Poem 11 explicitly blames the mother for sentencing her baby to "a life of illness and hardship" (my translation). Poem 17 goes even further by emphasizing the fact of "no choice":

Sy is 'n baba, en haar ma is 'n vigslyer (She is a baby, and her mother an AIDS sufferer)
Sy het nie 'n keuse nie (She has no choice)

Van haar geboorte af sal sy begin sterf (From the day of birth she will start dying)

This dissonance, when compared to reported illness narratives, could be related to upper and middle class white South Africans' beliefs about family planning. While middle and upper class white people take it for granted that parents of the in-group will remain faithful within marriage and assume responsibility for the quality of their offspring's lives, they often attribute "animal-like sexual lust" and "lack of capability to plan for the future" to parents of out-groups. These beliefs shimmer through in Poem 17, entitled 'Ongewenste baba' (Unwanted baby), in which the narrator exclaims: "As haar ma net verstandig was" (Had her mother only been wise), "sou sy 'n kans gehad het!" (she would have had a chance).

The prominence in the poetry corpus of this subtype (HIV-positive babies) is possibly related to the fact that teenagers psychologically view themselves as people whose lives have just begun, and whose futures lie ahead. The image of a child suffering from a terminal illness, which will deprive him/her of "deserved" opportunities, simply does not fit their expectations.

Dissonance of an ideological nature is found in the fact that no reference is made to the ethnic group of the babies, whereas these babies and their "carrier" mothers have typically been portrayed as black people in the SA media. This tendency towards a generic or colour-blind perspective on mother to child transmission is further substantiated by a first person advocacy poem (Poem 19), entitled 'Nevirapine – daar is hoop' (Nevirapine – there is hope), in which the author assumes the identity of an unborn baby, and acts as a first person narrator who begs his/her mother to take Nevirapine:

Ek is 'n baba (I am a baby)
in my ma se baarmoeder (in my mother's womb)
my ma ...? (my mother ...?)
my ma het vigs (my mother has AIDS)

Ek wil nie vigs hê nie (I don't want to get AIDS)
ek wil nie die pyn die (I don't want the pain)
lyding hê nie. (the suffering)

Daar is hoop, daar is pille (There is hope, there is medicine)
Nevirapien!!! (Nevirapine!!!)
Vat dit Ma, asseblief vat dit!!! (Take it mother, please take it!!!)

Ek wil nie pille my lewe lank drink nie (I don't want to drink pills for life)
Ek wil nie weet ... (I don't want to know ...)
weet dat ek vroeg dood gaan nie (that I will die young)
Ek wil nie my lewe lank (I don't want to wonder)
elke dag wonder (every day of my life)
is dit vandag of is dit môre (whether is it today or tomorrow)
volgende week of hierdie week (next week or this week)
dat my lewe tot 'n end (that my life)
gaan kom nie (will end)

Daar is hoop, daar is pille (There is hope, there are pills)
Nevirapien!!! (Nevirapine!!!)
Vat dit Ma, asseblief vat dit!!! (Take it mother, please take it!!!)

Jy kan 'n lewe spaar, (You can save a life)
myne, jou skepping (mine, your creation)
jou kind (your child)
luister na my! (listen to me!)
Asseblief luister na my! (Please listen to me)

This is the only poem in which the mother is not portrayed as a careless carrier; at most she is implicitly portrayed as ignorant.

- *The AIDS carrier*

Stigmatization and blame go hand in hand. In media narratives the AIDS patient who has been infected without committing an immoral or thoughtless deed is vindicated, whereas the deliberate and malicious transmitter of infection receives no mercy and is stereotyped as an AIDS carrier.

The malicious "syringe-wielding" carrier does not feature in the poems. Although two poems refer to syringes (2 and 9), they occur in the context of self- or incidental contamination (by donating blood or injecting oneself with drugs).

Only one poem (no. 18) features AIDS carriers demonstrating violence and malicious intent. The carriers are described as "tough guys" (*brekers*) entering a party scene. However, the protagonist, who is a teenage girl, is not blameless since she flirts with one of them (through eye contact and dancing). His malicious intent is demonstrated by the fact that he abducts her, after which she is raped by the foursome. Later she is diagnosed with HIV. This poem demonstrates relational dissonance in that the "victim" is not totally blameless. Although she seemingly flirts harmlessly ("their eyes met"), and seems to be physically attracted to her abductor (compare the title 'HIV with love'), it is suggested that her succumbing to lust resulted in tragedy.

The carrier in poem 16 is portrayed as a loose woman, who also falls into the subcategory of "the careless/promiscuous partner". As in the previous example, the author (the victim) shares the blame with her, since he is fully aware of his foolish acts: he concedes that the hedonistic pleasure drives him to keep returning to her for sex. Relational dissonance is manifested by the fact that archetypal boundaries between carrier and victim become fuzzy. Although the girl may fall into the archetypal category of carrier, the author is a poor example of a victim.

The portrayal of HIV-positive mothers who infect their babies at birth seems to be affectively dissonant with their media representation. Although the media portrays them as carriers, the media focus is set on the inability of the health infrastructure to handle the crisis and the obstacles caused by indecisive politicians. The poems, in contrast, lay the blame solidly on the mother, e.g. through rigid categorization (lexicalization):

Poem 11: *Die arme kind, dit was sy ma se skuld* (poor child, his mother is to blame)

Poem 17: *Dit is als haar ma se skuld* (Her mother is to blame for everything)

In poem 3 the father shares the blame:

Dis my vonnis deur my ouers gevel (It's my prison sentence passed by my parents)

In poem 17, blame is not lexicalized, but implicated by describing the mother as unwise: "had her mother only been wise, she would have had a chance" (my translation). Her imprudence could be due to her non-insistence on the drug Nevirapine, her promiscuity or her succumbing to male pressure.

7.2.2 *Stigma control*

- *The AIDS survivor*

In at least six poems more optimistic counter-discourses, which evoke images of the AIDS survivor archetype, are found. Although none of the poems construe images of people living reasonably normal lives with HIV/AIDS – thereby still ignoring the effects of advances in medical science – there is evidence of a slow awakening belief that coping with HIV/AIDS can be facilitated by a positive emotional and psychological approach as well as responsible self-care. Moreover, adaptive coping behaviours can be beneficial to the community if the survivor engages in identity politics and inspires others to embrace self-efficacy and behavioural control. The belief in life after death constitutes a third survivor subtype: even if you die and your body is subject to decay you can look forward to a disease- and distress-free life in heaven. This exposition suggests that there are three subtypes of the AIDS survivor that feature in the poems, namely the coper, the advocate/role model and the spiritualizer.

- *The coper*

The coper is a subtype that is situated on the boundary between the victim and the survivor archetypes. Poem 5 reverses the stereotype of PLA as morally compromised, by firstly claiming that people living with HIV/AIDS are not always bad, and secondly stressing that "nobody asked for getting AIDS". He expresses his anger at the fact that all AIDS sufferers are forced to drink "this gall bitter goblet of so much suffering" (my translation). Yet despite pessimists' emphasis on the fact that there is still "no cure" for AIDS, the writer pronounces the victim's right to good health. He then calls on healthy people to support PLA physically and emotionally, and to "touch their hearts".

Poem 12 implores AIDS sufferers not to worry about the ugly/bad things other people say about them, but to take responsibility for their own lives by eating healthily, looking after themselves and fighting the disease. Poem 21 verbalizes the social conscience of the writer as she says that she feels the obligation to help AIDS sufferers. She feels that they need her, and that it is her duty to help them "fight the monster" (= AIDS).

- *The role model/AIDS advocate*

One subtype of the AIDS survivor that features prominently in the poems is that of the AIDS sufferer who becomes an advocate and a role model; who instead of wallowing in sadness and self-pity uses the illness to inspire others. It is encouraging that two poems (6 and 22) are entirely devoted to the twelve-year-old teenager, Nkosi Johnson, who died of AIDS in June 2001. These poems have a strong epic thread. They sing the praises of this young boy who has become a symbol of heroism. Poem 6 says that through his love he taught us (the healthy people) how to live although he himself was dying. Poem 22 celebrates Nkosi as an inspiration for the entire nation. This, says the poem, he

accomplished by "counting his blessings" (my translation) and through determination. In the eyes of the poet he is a 'survivor' despite his eventual death. The portrayal of an AIDS activist such as Nkosi Johnson as a hero and a survivor is convergent with, e.g., the positive portrayal of American basketballer Magic Johnson, who was represented in the US and the Australian media as a role model in his courage and optimistic approach to life (compare Lupton, 1999:45).

- *The spiritualizer*

Another subtype of the AIDS survivor that features in the poems is the person who spiritualizes and individualizes the illness: consciously, or subconsciously, or through verbal construction by the author (compare Stanley, 1999:113).

In poem 4 the AIDS sufferer is portrayed as experiencing no sadness or worry despite his physical condition. The freedom of his soul is metaphorized through words such as *butterfly*, *light* and *fire*, and the protection his spirit affords him against stigmatization (described as "the cold") is metaphorized as a *blanket*:

Sy siel, 'n vlinder in die duisternis (His soul, a butterfly in the darkness)

'n Lig wat die donkerte uithou (A light that keeps out the dark)

'n vuur wat die koue blus (A fire that extinguishes the cold)

Sy gees, 'n kombers wat die koue toevou (His spirit, a blanket that enwraps the cold)

A similar reference to the emancipating power of the psyche is found in poem 22. Here the child activist Nkosi Johnson is praised by saying that although his body may be destroyed his soul is for ever free through his courageous fight against AIDS.

In the majority of the poems that portray the PLA as a spiritualizer, AIDS is construed as an instrument that creates awareness of a higher power (compare Stanley, 1999:113). Eight poems contain either an implicit or an explicit reference to life after death or refuge in God. These references seem to be connected to the ancient Christian narrative, referred to by Freccero (1986), which include the following phases: a life of sin, a realization of sinfulness, and the experience of regret and awakening to a new life. Some of these references serve to subvert metaphors of doom to become admonitions from God:

Afrikaans citation	English translation	Poem no.
<i>Moet ons oorlog teen die sonde verklaar? Moontlik word ons lewens dan gespaar Het God hierdie vreemde plaag gestuur Om ons te waarsku teen die vuur?</i>	Must we declare war against sin? Perhaps our lives will then be saved. Has God sent this alien plague To warn us against the fire?	2
<i>Wat is die doel van hierdie kwaal? Is dit om ons sondes te vergeld? Om die populasiesyfer te laat daal? 'n Bewys van Lucifer se geweld?</i>	What is the purpose of this illness? Is it meant to repay us for our sins? To decrease population figures? Proof of Lucifer's violence?	13
<i>Die virus word deur 'n sondige lewe uitgedeel 'n Manier hoe die Here ons tigtig. Moenie jou kans op 'n lang lewe verspeel En jou aan sondes verlustig!</i>	The virus is spread through a sinful life A method God uses to punish us. Don't miss your chance of living long And indulge in sinful practices!	

This type of transformation rhetoric views HIV as a wake-up call sent by God or a Higher Power to relinquish self-destructive behaviours and attitudes. It becomes a moral strategy to make sense of and renegotiate the meaning of the disease. This strategy is also found in the discourses of people living with HIV/AIDS who revert to spiritual themes to manage a stigmatized identity (compare Stanley, 1999). Stanley's research showed that middle class white women with HIV/AIDS used moral strategies such as AIDS as a 'calling', 'redemption' and 'gift from God' to reclaim their moral identities.

However, not all the references to God in the poems serve as wake-up calls. Some are spiritual consolations assuring people with AIDS that they are not alone in their suffering – God is there to support and guide them, even while they are suffering on earth. Poem 5 encourages them through the words:

ons moenie dat dit ons onderkry (we must not let it overpower us)
want God se hulp is altyd naby (because God's help is always near).

A good example of a consolation poem is no. 20. Each stanza ends with the line *Sien jy hom nog op die pad?* (Do you still see Him on the road?). The poem culminates as follows in the last stanza:

Alle hoop kom van die Here (All hope is from God)
En ons weet verseker dat (And we know for sure)
God woon in gebroke harte (God lives in broken hearts)
Hy alleen lei op die pad. (Only He shows us the way)

Another type of spiritual consolation found in the poems is the reassurance of life after death. In poem 4 the author poetizes the freedom of the AIDS victim's (his friend's) soul

amid the suffering; and then, on his friend's death bed, assures him that they will meet again (probably in heaven). In poem 14 the poet comforts himself with the words "Net een nag dan's ek in die hemel" (only one night, and I am in heaven); and in 17 he consoles the baby born with AIDS by saying that heaven is waiting for her innocent body.

The spiritualization of AIDS is dissonant with mainstream media reportage, both from an affective and a relational point of view. It is, however, widely used in religious discourses of the traditional reformed Afrikaans churches in South Africa, as well as certain charismatic churches. In a context where no cure exists and antiretrovirals are only affordable by the elite, it is understandable that a spiritual redemption will be advocated as a substitute for physical recuperation/regeneration in illness narratives.

8. CONCLUSION

For many infectious diseases, reduction in stigma is connected to the availability of drugs that have cured, masked or delayed the onset of final illness or at least treated the worst symptoms of the diseases (Macintyre and Macdonald 2000 in Brown *et al.*, 2001:15). Since protease inhibitors are not yet available to AIDS patients in South Africa free of charge, this stigma-reducing factor does not exist for a large section of the population. Moreover, the majority of people with AIDS also lack the symbolic capital (social position) to assist them in reasserting a safe and coherent identity. This is an untenable situation since freedom from discrimination is a fundamental human right founded on principles of natural justice that are universal (UNAIDS, 2002).

While it may be unrealistic to think that stigma can be eliminated altogether, research has shown that it can be reduced through a variety of intervention strategies (Brown *et al.*, 2001:16), provided that both stigma-reinforcing and stigma-reducing factors can be isolated.

This contribution aimed at utilizing a qualitative method, namely narrative analysis, to identify stigma-reinforcing and stigma-reducing elements in the discourses of white South African teenagers. The main findings were that they tend to translate symbolic stigma into feelings of fear, distress and hopelessness, and try to make sense of the negative feelings by employing two strategies:

- (a) *Negative coping strategy*
Blaming an external source (mother or partner/rapist);
- (b) *Positive coping strategy*
Appealing to a divine power and/or spiritualizing the disease

These strategies are not unproblematic: blaming may reinforce stigmatization, and spiritualization may lead to a fatalistic outlook, being judgmental or denying personal responsibility. Yet knowing that these strategies are used selectively by learners and that there are significant traces of stigma control in the narratives document designers can carefully formulate and position persuasive arguments in order to change stigmatizing intentions. Moreover, an appeal can be made to deeply entrenched values in order to change more superficial beliefs.

Messages may include the following:

- HIV/AIDS is not a death sentence. People with HIV/AIDS can live healthily for many years by eating a balanced diet, through positive self-discourse, by taking antiretrovirals and through community support.
- If every individual is committed to values such as "quality of life for all" no seropositive person will have to experience feelings of loneliness, sadness and shame.
- Communities that claim to be religious should not live by double standards, i.e. claiming to serve a divine power that is gracious and just, yet ascribing HIV infection to sexual sin, which is punishable by death. (On the other hand, the role of religion in destigmatization campaigns should not be devalued, since believing in the providence of a divine power can promote survival through a positive emotional state and altruistic intentions.)

However, in line with the purpose of the research stated in paragraph 2, the above suggestions are not conclusive. They merely provide future researchers with an indication of the types of messages that may be effective in culture-sensitive programmes aimed at HIV/AIDS-related destigmatization. Verifying the salience of possibly harmful cognitions by making use of probability sampling, applying alternative (qualitative or quantitative) research methods, and pretesting possible messages are essential steps in the process of designing effective interventions.

From a different angle the results of this restricted survey can be viewed as personalizations of stigma, which may be useful to challenge or verify general conceptual models of stigma.

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- 1 *The term 'lay illness narrative' was coined analogous to 'lay illness cognition', a term suggested by Dr. Henk Boer, a health psychologist from the University of Twente, The Netherlands for non-experiential cognitions about illness as perceived by a healthy person*
- 2 *The use of the data was kindly consented by the Foundation for the Advancement of Afrikaans.*
- 3 *Fairclough (1992:193) uses the term 'overwording' (following Halliday 1978 who uses the term 'overlexicalization') to refer to the relative density of the number of words used to name the concepts from a particular domain, which may be "a sign of 'intense preoccupation', pointing to 'peculiarities in the ideology' of the group responsible for it" (See also Fowler et al., 1979:210).*