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MAPPING BODIES: CORPOREAL ERASURE AND RE-PRESENTATION IN AIDS-RELATED STIGMA

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Aids and Society Research Unit

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Anya Subotzky is an Honours student in Psychology at the University of Cape Town. After completing an undergraduate degree in Fine Art and Psychology, she spent a year working for the *Memory Box Project* of the AIDS and Society Research Unit, University of Cape Town. During this time she facilitated a number of body mapping workshops, presented this work in various forums and helped develop the technique in new directions. A brief description of body mapping is provided in the inserted *Memory Box Project* leaflet.

Mapping Bodies: Corporeal Erasure and Re-presentation in AIDS-Related Stigma

Abstract

This paper investigates how body mapping workshops, for HIV positive persons, can be used as an effective tool for therapy as well as advocacy to address AIDS-related stigma. The paper explores how two core theoretical issues, namely the construction of stigma and the reception of stigma, relate to the socio-psychological processes of stigma.

'The failure of the state to address the health care needs of its citizens is mapped out on the bodies of people suffering from AIDS-related diseases in South Africa today and results in their premature and painful deaths' (Thomas, 2001).

'Since the body is our vehicle for interaction with the world and others, it is through it that people experience the HIV epidemic. In social interactions, in which bodies are embedded, the consequences of infection are evidenced particularly in the case of stigmatization' (Varas-Diaz *et al*, 2003).

Introduction

This paper explores the central role of the body, particularly its in/visibility, to processes of AIDS-related stigma¹. Recognising that the AIDS pandemic operates at the level of individual bodies as well as the broader body politic, two corresponding psychological and social cycles are interpreted through a psychodynamic lens.

The first cycle constitutes a process of stigma construction; the second cycle constitutes a process of stigma reception, understood as the implications of the former for those who are stigmatised. Each cycle culminates in an erasure of the bodies, lives and identities of people living with HIV/AIDS. Means of resisting and eroding this erasure are explored through the re-presentation of bodily images and life narratives in the form of body maps. Body mapping (used to address each cycle of stigma in turn) as both a therapeutic and advocacy tool is then examined.

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¹ The term *AIDS-related stigma* was coined by Herek and Glunt (in Varas-Diaz *et al*, 2003, paragraph 17), and has been defined as "all stigma directed at persons perceived to be infected with HIV, regardless of whether they are actually infected and whether they manifest symptoms of AIDS or AIDS-related complex" (Herek and Glunt in *ibid.*, paragraph 18).

Context

At present, there are approximately 5 million South Africans living with HIV/AIDS. In November 2003, the government announced the adoption and details of an operational plan for comprehensive HIV/AIDS treatment and care. While the plan certainly signifies a long-awaited shift in government policy, its implementation is controversial, and the majority of South Africans living with HIV/AIDS still await treatment. In the meantime, an estimated one thousand people are dying each day (Sapa, 2004). This constitutes an effective erasure of large numbers of our population, and it is in this context that the act of making manifest the self-representations of people living with HIV/AIDS assumes particular pertinence.

The term *body map* has been used in various contexts to denote a range of practices that involve the self-representation of bodies, particularly those which penetrate beyond their surface to picture previously hidden depths, be these in the form of the workings of internal organs or subjectively held feelings. The body maps that prompted these reflections were made by the *Bambanani collective of the Memory Box Project*² as part of a collaborative project called *Long Life*³, and were developed and facilitated by Cape Town artist Jane Solomon. They are life-sized paintings in which participants trace the outline of their bodies and picture the ways in which their life stories have left their marks within them. They include anatomically referenced images alongside personal symbols, and depict physical symptoms together with emotional experiences. To examine the use of body maps as therapeutic and advocacy tools, I draw on my own experiences of working with the women who created the *Long Life* images and of co-facilitating body mapping workshops with members of this collective.

Malan (1979) encapsulated diagrammatically his conception of psychodynamic theory in the form of two inverted triangles. Between them, he articulates, "they can be used to represent almost every intervention that a therapist makes" (Malan, 1979: 80). Of particular interest here is the *triangle of conflict* (see above), in which painful or uncomfortable emotions are concealed from

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² The Memory Box Project is an outreach programme associated with the AIDS and Society Research Unit of the Centre for Social Science Research at the University of Cape Town.

³ Long Life is a participatory action research and advocacy project that was conceived and driven by Jonathan Morgan and Kylie Thomas of the *Memory Box Project*, and involved collaboration with *Medicins Sans Frontiers*, *Otherwise Media* and artist Jane Solomon. Many aspects of the body maps project are outlined by Morgan *et al.*, 2003.

consciousness in the form of *hidden feelings*. These give rise to *anxiety*, in response to which *defences* are employed. According to this picture of depth, therapists are presented with the surface, conscious layer of defence and anxiety. The primary challenge of psychodynamic therapy is to move beyond these defences and access the unconscious emotions below (Jacob, 1994). If this occurs in a safe and supportive context, resolution can follow (Malan, 1979). As shall be seen, this notion of revealing what is rendered invisible assumes a particular resonance for a phenomenon characterised by concealment.

Psychodynamic framework

DEFENCE
ANXIETY

HIDDEN FEELINGS

Corporeal erasure

In order to an explore of the social and psychological processes through which AIDS-related stigma can be understood to develop, I adapt and expand Malan's *triangle of conflict* so as to picture two related psycho-social cycles. The first explores the construction of stigma, and the second the reception of stigma.

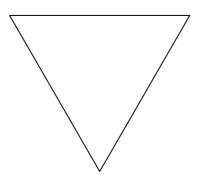
Triangle one: Stigma construction

DEFENCE:

Denial/projection: Erasure

ANXIETY:

Contagion



HIDDEN FEELING:

Fear of disease/death + deviance/disgrace

HIV/AIDS is directly related to two topics fundamental to questions of human existence: death and sex. Perhaps because of this, these constitute two of the greatest social taboos (Sabatier, 1988), giving rise to deep-rooted fears around disease and dying on the one hand and social disgrace and deviance on the other (Marais, 2000). Because their status as taboo serves to conceal these fears, they can be understood to constitute the hidden feelings at the base of this triangle. This relationship of HIV/AIDS to notions of sex and death also gives rise to its complex association with sickness, contagion, loss and bodily death on the one hand and sexuality, pleasure and survival on the other (Varas-Diaz *et al*, 2003). All are experienced through, and so intimately connected with, the human body. It is thus understandable that the body is positioned "at the centre of discourses surrounding the epidemic" (*ibid*. 2003, paragraph 1).

The suppression of these hidden feelings may give rise to anxieties around contamination through exposure to, acknowledgement of, or identification with HIV positive bodies. As "it is through the body and its 'fluids' that people are exposed to the epidemic" (Varas-Diaz, 2003, paragraph 21), HIV positive bodies come to be seen as invasive agents who threaten social order and place public health at risk (Sontag, 1988; Varas-Diaz, 2003). More generally, through their association with a state of decay, diseased bodies become sites of social unease, representative of "the contamination of life by death" (Kristeva, 1982: 149). It follows that the HIV positive body is conceptualised as,

'...a site of death and contagion, an instance of prejudice, an entity suspended between health and sickness, as something that succumbs as it faces the epidemic' (Varas-Diaz *et al*, 2003, paragraph 24).

These anxieties around contamination by HIV positive bodies can give rise to the associated *defences* of denial and projection, which might in turn be expressed through AIDS-related stigma⁴. Denial is acknowledged as the prevailing response to HIV/AIDS in this country (Martindale, 1990), in which the disease is located "beyond a series of perimeters in order to retain and defend spaces in which normality and 'the known' reign..." (Marais, 2000: 56). This leads logically to projection, widely recognised as the global tendency to externalise blame and responsibility for HIV onto the stigmatised other (Sabatier, 1988; Joffe, 1999, and Gilman, 1995). In this way, AIDS-related

⁴ While this stigma manifests both through *mis*representation of people living with HIV/AIDS in the form of negative stereotyping and *non*-representation through their effective erasure, my focus is on the latter.

stigma has come to reflect existing prejudice and social norms (Hook *et al*, 2002: 15). In South Africa particularly, "codes of sanction... [have] slotted neatly into moralistic narratives of deviance, accountability and just punishment" (Marais, 2000: 9).

Stigma can be defined as a recognition of difference that is evaluated negatively, and which resides largely in the body (Varas-Diaz *et al*, 2003). The significance of notions of both visibility and corporeality to this phenomenon has prompted Varas-Diaz *et al* (2003, abstract) to identify "the visual dimension of the body" as central to AIDS-related stigma. Drawing on Foucault's understanding of the regulation of bodies through regimes of discipline and punishment, attempts are thus made to discipline sick bodies into health (*ibid*. paragraph 14). This is especially true of HIV positive bodies, which are "[r]ead as unfathomable and out of control" (Thomas, 2001: 64) and so "inaugurate a crisis in those systems of power concerned with the regulation of bodies" (*ibid*.).

In South Africa, this crisis has resulted in what Thomas (2002: 1) has identified as the "discursive erasure of HIV positive bodies", which she later articulates as, "... regimes of representation which make the lives and bodies of some visible and place others under erasure" (Thomas, 2003: 1). The government's failure to meet the health care needs of its citizens has thus exacerbated and reinforced the stigma surrounding the bodies of those living with HIV/AIDS (Thomas, 2001, p.64): "Nowhere is the power of the state over the bodies of its citizens made clearer than on the bodies of those dying of AIDS without access to medication and care" (*ibid*).

These patterns of stigma surrounding the bodies of people living with HIV/AIDS may become internalised in their targets in the form of bodily shame and guilt (Joffe, 1999; Varas-Diaz *et al*, 2003 and Sontag, 1988). The discomfort of these emotions means that they in turn might be suppressed, and so constitute the hidden feelings of this second triangle.

This cycle of internalisation and repression is reinforced through the intimate association of identity with bodily perceptions. Understanding the body as a "socially constructed entity through which people develop identity discourses" (Varas-Diaz *et al*, 2003, paragraph 16), bodies come to be seen as visual signifiers of our selves, constantly on display, where they are interpreted and decoded by ourselves and others (*ibid.*). This means that hidden feelings of (particularly bodily) shame and guilt give rise to anxieties around exposure as HIV positive with its implications of a tarnished identity.

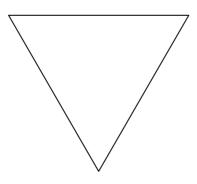
Triangle two: Stigma reception

DEFENCE:

Concealment

ANXIETY:

Exposure



HIDDEN FEELINGS:

Shame, guilt

This anxiety may precipitate attempts to mask signs of dis-ease, which constitutes a defence of concealment. As Soskolne *et al* (2003: 6) note, the common tendency to cover up physical imperfections takes on the additional meaning for people living with HIV that they are "also hiding what these symptoms represent... to others." These attempts to "hide signs of deteriorating health [so as to] 'pass' as healthy" (*ibid*.) often negate private or public

disclosure and so leads to further social exclusion and isolation, and the continued invisibility of HIV positive bodies.

I have suggested that patterns of AIDS-related stigma manifest firstly through defences of denial and projection that lead to an erasure of the bodies and stories of people living with HIV/AIDS, and secondly that this may become internalised in their targets into similar patterns of concealment. The implication of both cycles is therefore an obscuring of the visibility of HIV positive bodies and, by association, lives and identities.

Body maps resurrect and reclaim this visibility. As many layered self-portraits they make manifest the ways in which our life stories inscribe themselves on our bodies, leaving their traces in scars, laugh-lines, stitches or wrinkles. Shifting between depictions of the body's visible surface and imaginings of its hidden depths, they map internal organs, rashes on the skin, unborn children, experiences and memories of violence, love or loss; the HIV virus blossoming in the bloodstream. Body maps are mirrors and X-rays and shadows and idols all at once, allowing us to explore and record and reinvent the ways in which we picture our bodies and, through these, see ourselves.

Through both the visibility of the medium and the corporeality of the content, the making of body maps thus resists the erasure implicit in each of the two cycles of stigma pictured above. As an act of resistance, it becomes a two-fold tool that can be used to challenge each of these cycles in turn. Firstly, the process of making a body map constitutes a therapeutic intervention that could address the implications of the pattern of stigma reception. Secondly, the completed products could be used as advocacy material to address the pattern of stigma construction. While this distinction between process and product, and therapeutic and advocacy tool is theoretically useful, in practice, the boundaries may be blurred. The question of whether therapeutic interventions can or should coincide with advocacy agendas is beyond the scope of this paper, but warrants further investigation. Similarly, questions need to be asked about the coupling of therapeutic functions with the generation of income and of qualitative research material.

Tool one: The process as therapeutic intervention

In highlighting the therapeutic potential of the body mapping process, I look briefly at how it could address each of the three related processes depicted in the triangle of stigma reception. In so doing, I draw on my own experience of working with the technique as developed by Jane Solomon. Firstly, the act of self-representation implicit in body mapping resists *defences* of concealment and so constitutes a form of disclosure. If this occurs in a safe and contained context, particularly within a support group, it may break cycles of isolation and social exclusion as people share their stories and recognise that others have undergone similar experiences. This is reinforced through the practice of having a partner with whom one can reflect throughout the body mapping process, and whose body is represented as a "shadow" figure underlying your own: a source of support, as well as a reminder of the social dimension of the pandemic.

Secondly, in breaking the defence of concealment, participants of the body mapping process may be confronted with *anxieties* around exposure as HIV positive persons and the associated implications for their sense of identity. The creation of self-images that embody stories of pain and suffering as well as images of strength and resilience might allow people living with HIV/AIDS to face these anxieties while reinforcing alternative narratives of hope and allowing for the exploration of coping strategies. Thus participants are prompted to depict the virus in the bloodstream, as well as other markings on the body that record stories of living with HIV/AIDS, but alongside this are helped to develop personal symbols of strength that remind them of and reinforce a sense of their own resilience.

Finally, challenges to the defences of concealment and the confrontation of anxieties around exposing an HIV positive identity may enable participants of the body mapping process to access *hidden emotions* that lie beneath these, particularly around bodily shame and guilt. This might occur through the very act of exploring and recording one's life story and having this witnessed, all of which are acknowledged as particularly therapeutic in the case of narratives centred on illness (Kleinman, 1988). The act of art-making may itself facilitate the accessing of emotions that lie below the surface of consciousness (Warren, 1984). In this way, the body mapping process resonates with the central goal of psychodynamic therapy, which Malan (1979: 74) articulates thus: "The aim of every moment of every session is to put the patient in touch with as much of his [sic] true feelings as he can bear". Resolution is understood to occur through the expression of this emotion in a safe and supportive context (*ibid*.). The body

mapping process usually culminates in a ritual sharing and exhibition of the completed body maps. There is often a sense of catharsis when participants stand back and look at their completed self-representations. The striking and specific beauty of each seems to instil a sense of pride and affirmation that runs counter to perceptions of guilt and shame.

Tool two: The product as an advocacy implement

The visibility, corporeality and humanity of self-depiction makes the 'product' of the body mapping process a potentially powerful and provocative advocacy tool in addressing the threefold cycle depicted in the triangle of stigma construction. Firstly, and perhaps most obviously, the presentation of images and stories of people living with HIV/AIDS challenges the *defences* that serve to erase them: The assertive and graphic presence of these body maps confronts patterns of denial, while the individual and fleshed-out voice of each dodges projection onto a faceless other. Through thus asserting the subjective experience and humanity of people living with HIV/AIDS, body maps "transgress the silences imposed on HIV positive bodies and serve as visible markers of the forms of injustice to which they are subject" (Thomas, 2003: 1).

Secondly, in confronting viewers with their own corporeality, body maps are likely to aggravate *anxieties* around vulnerability and contamination. This is because "[s]ick bodies remind us of our own bodies and the fragile hold we have on our own health" (Thomas, 2001: 66). Thus the re-presentation of HIV positive bodies constitutes for Thomas (2003: 5), "the scandal of HIV positive bodies that speak: their speaking is a means for the dissolution of the boundary between the body that speaks and the body that listens". This provocation may however prompt viewers into a new kind of identification with the bodies and lives that are mapped before, one of acknowledgement and empathy rather than denial or disdain.

Finally, these challenges to the defences and aggravation of anxieties may allow viewers to access the uncomfortable *hidden feelings* that underlie them. This can be seen in the intense visceral and emotional responses that body maps seem to elicit. If this occurs in a constructive context, some kind of resolution may result, which in turn may contribute to the challenging and breaking of individual and collective cycles of stigma.

In addition, completed body maps create powerful counter-narratives to media and popular portrayals of HIV positive bodies as "sick and fragmented entities... in a constant deterioration process..." (Varas-Diaz *et al*, 2003, paragraph 58) which have reflected and reinforced this cycle of stigmatisation. The creation of strikingly beautiful art objects also poses a challenge to common associations of illness with ugliness (Gilman, 1995), and begins to build resilience and restore confidence and dignity.

Conclusion

The social and psychological cycles through which stigma can be understood as constructed and received have been seen to culminate in the literal and metaphoric shrouding of HIV positive bodies and stories. Body mapping has been exposed as a potentially powerful therapeutic and advocacy tool through which these patterns of concealment can be revealed and resisted: in the words again of Thomas (2003: 1), body maps "[a]s bodies that speak out, to, and against those who would silence them... can be understood as resisting bodies, as bodies of resistance". As such, they force us to recognise that we are all embodied creatures, and to engage with one another on the level of the corporeal (*ibid*).

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The Aids and Society Research Unit (ASRU) supports quantitative and qualitative research into the social and economic impact of the HIV pandemic in Southern Africa. Focus areas include: the economics of reducing mother to child transmission of HIV, the impact of HIV on firms and households; and psychological aspects of HIV infection and prevention. ASRU operates an outreach programme in Khayelitsha (the Memory Box Project) which provides training and counselling for HIV positive people

The Data First Resource Unit ('Data First') provides training and resources for research. Its main functions are: 1) to provide access to digital data resources and specialised published material; 2) to facilitate the collection, exchange and use of data sets on a collaborative basis; 3) to provide basic and advanced training in data analysis; 4) the ongoing development of a web site to disseminate data and research output.

The Democracy in Africa Research Unit (DARU) supports students and scholars who conduct systematic research in the following three areas: 1) public opinion and political culture in Africa and its role in democratisation and consolidation; 2) elections and voting in Africa; and 3) the impact of the HIV/AIDS pandemic on democratisation in Southern Africa. DARU has developed close working relationships with projects such as the Afrobarometer (a cross national survey of public opinion in fifteen African countries), the Comparative National Elections Project, and the Health Economics and AIDS Research Unit at the University of Natal.

The Social Surveys Unit (SSU) promotes critical analysis of the methodology, ethics and results of South African social science research. One core activity is the Cape Area Panel Study of young adults in Cape Town. This study follows 4800 young people as they move from school into the labour market and adulthood. The SSU is also planning a survey for 2004 on aspects of social capital, crime, and attitudes toward inequality.

The Southern Africa Labour and Development Research Unit (SALDRU) was established in 1975 as part of the School of Economics and joined the CSSR in 2002. SALDRU conducted the first national household survey in 1993 (the Project for Statistics on Living Standards and Development). More recently, SALDRU ran the Langeberg Integrated Family survey (1999) and the Khayelitsha/Mitchell's Plain Survey (2000). Current projects include research on public works programmes, poverty and inequality.