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# Making life stories visible: an ethnographic study of body mapping in the context of HIV and AIDS in South Africa

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#### **Abstract:**

This paper analyses the lived experiences of people living with HIV in South Africa through the use of body mapping as a visual research method, by focusing on the physical and symbolic use of the body within the broader context of anthropology and medical anthropology. The study consists of an empirical analysis of the body maps themselves and the accompanied narratives of seven participants, six female and one male participant living with HIV in South Africa. Drawing upon the- ories and literature on theorising the body in medical anthropology and visual research, this study explores the significance of this practice as a visual research method in understanding the nuanced lived experiences of people living with HIV by highlighting the individuality of the body and emotions; embodied experiences: a bio-cultural approach; and the body politic: social injustice. The results of this study illustrate that body mapping is a unique visual research method, that explores the body as the vehicle in which we exist within the world, while con-taining a vast amount of layered interpretive and cultural meanings, which are key to understanding the lived experience of people from marginalised groups.

**Keywords:** visual research methods, body mapping, HIV/AIDS, medical anthropology

#### Introduction

The 'body' and embodiment is seen as the one of the most central fields of enquiry within anthropology and its subdiscipline - medical anthropology (Hadolt, 2001; Lock, 1993; Csordas, 1999). A paradigm of embodiment, which also refers to the methodological views which inspire the re-analyses of prevailing data, while suggesting new point of enquiry, can also be elaborated in the study of culture and self (Csordas, 1990). Several authors have problematized the body which was central to future theoretical conceptions within the field of medical anthropology (Singer & Erickson, 2011). This led to an acceptance in medical anthropological discourse in the 21st century, which widely recognised that the body is both a physical and symbolic artefact which is both naturally and culturally produced (Scheper-Hughes & Lock, 1997 in Singer & Erickson, 2011). Medical anthropology has acquired an exclusive view on the body due to its critical engagement with the suffering of the body. It is in within this realm of enquiry that the context of the physical, emotional and social matters triggered by the experience of illness and suffering, calls for a deeper social and cultural analyses (Hadolt, 2001). The study of the body thus relies on providing interdisciplinary problematic dichotomies such as, "...nature-culture, self-other and body-mind" (Hadolt, 2001: 132).



**Figure 1.** Body maps in exhibition being viewed by a child (photo: Author, 16 February 2017).

With curiosity filled eyes, the young girl stared at the life-size artworks that laid in front of her, 'what are they?' she uttered, 'body maps...' replied *Mandy*, a 32 years old female participant who had taken part in the study, 'through them...our life stories are made visible'. *Mandy* has been living a life with HIV for a few years and had endured many traumas as a result thereof. She was unable to read or write and had problems communicating verbally. Body mapping as a visual research method had allowed Mandy to communicate her experiences with illness in relation to her body both physically and symbolically, in a respectful and non-threatening way. Body mapping is a method that incorporates the exploration of memories, feelings, emotions and storytelling that have the body as their main focus (Gastaldo, Magalhães, Carrasco & Davy, 2012).

This study forms part of a broader research endeavour aimed at exploring different visual research methods such as: photo-voice and photo elicitation; mobile phones and internet memes; and drawing as visual research methods to

portray the lives of people living with HIV by highlighting the social, political and psychological challenges they face. Focussing on South Africa, this study by Chernelle Lambert situates itself under an umbrella transnational project led by Favero and Pauwels which focuses on the role of digital visual practices as tools for addressing social invisibility and marginality. The objective of this paper is to analyse the lived experiences of people living with HIV through the use of body mapping as a visual research method, by focusing on the physical and symbolic use of the body within the broader context of anthropology and medical anthropology.

#### Theorising the body

In Kapfere's (1988) article on *Gramsci's body and critical medical anthropology*, emphasis is placed on the body as a metaphor. Within the body and within the suffering of the body, Gramsci had experienced degrading and dividing experiences which had come from the political and historical world he was living in at the time. These internal struggles had allowed him to introspectively examine the role of the body through the suffering he was exposed to (Kapfere,1988). Lock (1993) describes anthropologists initial longstanding uncertainty regarding the theorising of the body as being a result of the assumption of the complexities of the human body, which through time was replaced by new theoretical developments in the field. Anthropologists thus began to become more aware of the theoretical challenges which the body posed by acknowledging the variation and development of human populations over time (Lock, 1993).

In *Medicine, rationality and experience*, Byron Good (1994) emphasises that disease is located within the body as a physical entity or as psychologically extant regardless of the subjective experiences in the minds of the patient or the physician. When medical knowledge is being presented, it remains an objective account of the representation of the disease body. Good (1994) argues for an alternative approach to the analysis of medical information based on the imperative evaluation of the manner in which medical practices and ontologies form the object of medical consideration. When referring to the person who is sick or the clinician, Good (1994) sees the disease as being experienced in the present within the body however, for the sufferer, the body is not necessarily seen as the physical object or as psychologically extant, but seen as a crucial aspect of the self.

In *Phenomenology of perception*, Merleau-Ponty (1962) provides an extensive and critical analysis of the body by highlighting that Cartesian dualism and tradition has required us to disengage from the object which alludes to the notion that the body is the sum of its parts, with no internal substance, with the soul exclusively existing to itself with no detachment. Merleau-Ponty (1962) believes that the experiences of one's own body reveals a certainty that the body is ambiguous but is not an object, even though its harmony is implicit yet also indefinite while being transformed by various cultural influences.

Scheper-Hughes and Lock (1987) present three perspectives in which the body may be viewed within the context of medical anthropology: firstly, as a phenomenally experienced body related to self; secondly, as a social body related to the symbolic reflection on relationships within nature, society and culture and

thirdly, as a body politic, an artefact related to social and political control. The first perspective, emphasises the individual body from within a phenomenological perspective and highlights the lived experience of the bodyself. We all may possess the ability to have an intuitive sense of the embodied self, which exists independently from other individual bodies (Mauss, 1985 in Scheper-Hughes & Lock (1987). Moreover, the fundamental components of the body such as "...mind, matter, psyche, soul, self, etc.-and their relations to each other, and the ways in which the body is received and experienced in health and sickness are, of course, highly variable." (Scheper-Hughes & Lock, 1987: 7). The second perspective and analysis of the body, the social body, is concerned with the representative view of the body as a symbol for the manner in which we think about nature, society and culture (Douglas, 1970 in Scheper-Hughes & Lock, 1987). The body when referring to health suggests a model of "organic wholeness"; the body when referring to sickness suggests a model of "social disharmony, conflict and disintegration" (Scheper-Hughes & Lock, 1987: 7). The third level of analysis of the body refers to the body politic which is related to regulation, surveillance and control of bodies with regard to reproduction and sexuality, work and leisure, sickness and other forms of differences in humans (Scheper-Hughes & Lock, 1987). Thus, it becomes clear that theorising of the body is filled with layered interpretations of the role of the body and the importance thereof. The analysis of theory related to the body consists of several dichotomies that are further explored in other studies, but provide new insights into the accumulating knowledge of how the body is positioned in the field of social sciences more broadly: migration, violence and HIV (Martinez et.al, 2019; the cultural analysis of reproduction (Martin, 1991); the role of the body in the construction of masculinity (Swain, 2010).

## **Body mapping**

Body mapping has been used in an array of contexts within the field of social sciences: embodied pastoral anthropology (Meiring & Muller, 2010); the use of body mapping in interpretive phenomenological analyses (Klein & Milner, 2019); coping with HIV within the context of sub-Saharan migrant women (Nöstlinger, Loos & Verhoest, 2015); exploring reproductive ethnophysiological beliefs and knowledge of contraception (Wallace et.al, 2018).

Body mapping as a visual method resorts under the mode of 'respondent-generated image production' (as opposed to analysing pre-existing or 'found materials' or 'researcher produced' visuals, Pauwels, 2015a, 2010) whereby the researcher (or therapist/facilitator in the case of therapeutic interventions) gives the respondents or participants a particular assignment or series of instructions. This method exemplifies the rising popularity of drawing and painting techniques in visual research in addition to the many and historically dominant camera-based ones. Drawing and painting can also be viewed as another form of communication, and semiotics enables us to turn its representation into an interpretable language through the use of icons, indexes and symbols as categorised by Charles Peirce. People who may not have the ability to communicate solely through verbal means may find this form of communication useful and more importantly, meaningful.

These more 'intentional' imaging techniques also allow to visualize things that are not visible or present: states of mind, feelings, past experiences, concepts. Body mapping also belongs to the wider category of so-called 'visual participatory methods' (along with visual elicitation, respondent- or participant-generated images/photo voice, collaborative video, digital storytelling) whereby the respondents take a more active role in the process and in the final shape and nature of the data (Pauwels, 2015b). Such approaches almost always require verbal elucidation by the participants as well as an in-depth analysis of both the visual and the verbal data by the researcher. In this way they offer genuine opportunities to productively combine an 'etic' and an 'emic' view.

Anthropologists MacCormack and Draper (1987) conducted a study on the social and cognitive aspects of female sexuality in Jamaica using drawing as a research method to explore aspects of the female anatomy. The study was considered pioneering as it was one of the first of its kind to use drawing as a method to elicit women's understanding of the sexual reproductive process.

Cornwall (1992) shared her experiences with Participatory Rural

Appraisal/Rapid Rural Appraisal (PRA/RRA), when she worked with women in a rural area in Zimbabwe. Building upon the work of MacCormack and Draper (1987), Cornwall (1992) used body maps to assess the women's knowledge about reproduction and their perceptions on non-indigenous contraception.

In the field of HIV and AIDS, body mapping was first pioneered by the AIDS and Society Research Unit (ASRU) which forms part of the Centre for Social Science Research (CSSR) at the University of Cape Town, South Africa. ASRU developed a set of unique tools and techniques related to HIV literacy.

The original idea for using body mapping with people living with HIV was started during the Longlife project coordinated by the Regional Psychosocial Support Initiative (REPSSI) in South Africa in partnership with ASRU. The Bambanani group was a pilot study group originally consisting of 13 women who took part in the project and met over a period of three months with Jane Solomon (2007), a graphic artist who guided the workshops by assisting the women in creating life-size body maps which recorded their journey with HIV and the double narrative of dealing with the emotions that come with terminal illness (death) and living with it (life) (ASRU, 2007; MacGregor & Mills, 2011). The Bambanani group produced numerous visually stimulating body maps filled with details related to their author's life experiences with HIV. Since then there has been a vast number of attempts at using body mapping as an art-based therapeutic technique and as a research tool in a variety of contexts: for the treatment and observation of people with mental illnesses (Hughes & da Silva, 2011; Lys, 2018); for organ transplant patients (Skop, 2016); for undocumented workers Gastaldo et al. (2012); and for a sexual health intervention with young people (Lys et al., 2018).

In a pioneering book, *Remembering the body: ethical issues in body mapping research*, Orchard (2017) details her experiences with body mapping as a research method by highlighting the embodied, political, and aesthetic dimensions of transformative research. Orchard (2017) was astounded at how transformative the research experience with body maps were not only for the participants, but for her as the researcher as well. The meanings the men and

women had given to the body maps were multi-layered and allowed them to take control of the terrains of their lives in an embodied way, through explorations of their past using colourful tones and detailed symbols (Orchard, 2017).

#### The context of this study

HIV and AIDS continues to remain a global public health issue which has taken the lives of almost 33 million people world-wide (WHO, 2020). Although the virus has seen a dramatic increase in access to effective HIV prevention and treatment, and has thus become a manageable chronic health condition, the statistics and the societal impact, remain alarming (WHO, 2020). Sub-Saharan Africa remains the region most affected by HIV, with 1 in every 25 adults living with HIV, translating to over two-thirds (25.7 million) of the people living with HIV worldwide (WHO,2020). Eastern and southern Africa remains the regions most affected by HIV, accounting for 45% of the world's HIV infections and 53% of people living with HIV worldwide. South Africa is the sub-Saharan country with the highest distribution of new HIV infections and AIDS-related deaths (UNAIDS, 2018). Didier Fassin and Helen Schneider (2003) describe three main social factors they consider placing South Africa at a higher risk of HIV and AIDS. These are namely: high levels of social inequality in income and employment; the mobility of persons as a well-documented contributor to epidemics; and the history of sexual violence in South Africa

The vast complexities around the historical background of HIV and AIDS in South Africa provides a strong case for a study this nature. The role of stigma and discrimination is in the forefront of recent literature and HIV/AIDS campaigns and provides a rationale for this study.

### Methodology

The participants for this study were recruited through a volunteer healthcare worker known to Lambert due to her prior work in the community as a research psychologist, in a low-income area within the Western Cape, South Africa. The healthcare worker held monthly support group meetings on her own accord with a group of six people living with HIV and her son who has cancer. The participants ages ranged from 19-58 years old, with six females and one male. The vast majority of the participants in this study classified themselves as "coloured". The term "coloured" describes a person of mixed ancestry living in southern Africa. The term "colouredness" refers to the identity and cultural practices which were attributed to the marginalisation of coloured communities (Adhikaris, 2013). Historically labelled coloured communities had a stronger connection to cultural practices and values from the West, as opposed to African cultural practices and values. The negative connotations to being coloured derived from the stereotypical notions that the mix of races was associated to weakness and retrogression. In terms of the researcher's positionality, Lambert has lived most of her life within the designated "coloured" communities. She is therefore well accustomed to the cultural practices and values which have influenced the participants responses and added another introspective, emic layer of analysis to the interviews and the material produced in this study.

The health care worker indicated that the group would be keen to do a body mapping workshop and were willing to participate. The group had known each other for several years and had built a relationship with each other based on mutual trust.

After practical arrangements were made for a suitable time and venue, the participants had arrived ready to begin the body mapping workshop. The materials used during the body mapping workshop consisted of large sheets of white paper which was two meters in length and less than one meter wide, coloured pencils for drawing, a variety of acrylic paints, paint brushes, and water. Upon their arrival the healthcare worker had mentioned that there were two participants who were unable to read and write and had at times had problems communicating verbally. This indeed was an unexpected revelation that required an alteration to the method to suit the needs of the participants, this would be made more explicit later in this paper.

Individual interviews and interviews within a focus group setting were done with participants and were recorded using a voice recorder. Voice recordings were analysed multiple times to validate the findings.

#### **Ethical considerations**

This research study underwent rigorous evaluation and was ethically approved by the Social Sciences and Humanities Ethical Committee of the University of Antwerp. A report on all the procedures involved within the study was provided and evaluated according to the ethical implications. Each participant was first given an information sheet detailing the study and a consent form which they were required to read through or request the healthcare worker to read for them and then sign in order to make certain that they were volunteering at their own free will and were able to withdraw from the study at any moment. Due to the sensitive nature of the stigma and discrimination related

to living with HIV and AIDS, participants faces were blurred when requested by the participants. All participants were given pseudo names to protect their identities. Voice recording made of all interviews and photographs taken by researchers and the participants were kept locked in a safe location to prevent the misuse of information and data. All requests for privacy were adhered to by all means necessary as the participants and healthcare workers were respected and valued for their contributions. The ethical issues experienced in arts-based research are often formed by the context and the conditions in which the research study is based, i.e. in a public health setting, therapeutic, community and is also determined by the type of art that is produced (Orchard, 2017).

#### **Results**

The following is the results based on a thematic analysis of the participants experiences with the body mapping method. These themes have been categorised as: The individuality of the body and emotions; the social and cultural interactions of the body; embodied experiences: a bio-cultural approach; and the body politic: social injustice

## The individuality of the body and emotions

One of the first steps within the body mapping method involved introducing the shadow-support element. Each participant was to choose a partner in the group and allow their partner to assist them (and vice versa) in outlining their body on the large sheet of paper on which their body map was to be completed to create a shadow effect. While participants were lying down on their maps to have their bodies traced, participants would automatically choose

to lie still, without saying anything. The stillness closely resembled a brief but significant period of introspection as seen in figure 2 below where participants first chose a motionless stance with arms and legs spread apart as their bodies were being traced. When asked what they were feeling during the shadowsupport process, there was unanimous agreement that it felt pleasant and satisfactory. This was illustrated when Felicia a 43-year-old administrator, laid on the floor while having her body traced and stated, '...this that I am doing now [the drawing] I haven't done this since I was a child, today, this here, is all about me...'. This moment of stillness gave participants a sense of purpose in what the project was about and in themselves as the subject of this enquiry. The introspection stimulated from the participants was something not anticipated yet proved to be a necessary element in giving the participants time to process what was happening around them and ultimately gather their thoughts on themselves and their experiences with their illness in a transformative manner.



**Figure 2.** participants tracing each other on their respective body maps (photo: Author, 16 February 2017).

In yet another terrain, Favero (2018) has approached a similar topic in his work around long-exposure photographic self-portraiture. Describing the ritualized series of self-portraits, he enacted at the moment of his father's death.

Combining long exposure with the use of a timer Favero (2018) experienced an opportunity to open up time, to stick to the present in an ongoing act of blurring of the difference that separates the photographer from the photographed, the self

from the world. Praising the importance of slowness and stillness and foregrounding 'presence' Favero describes this moment as:

'Long exposure allowed me to feel the present moment, to stick to it, to live it. And as I slowly started inhabiting these images, entering their

body with mine, I allowed the house where I was raised with its (now painful) memories to penetrate me.' (2018: 100)

Lock (1993) refers to the reflexive concept of "I" as being an independent aspect of the body and of nature more broadly and is the core view to understanding a post-enlightenment approach to knowledge. The enquiry of the autonomous, rational and disembodied concept of self, which has influenced anthropologists interest in the body is derived from the cultural concept of mind, body, self and emotions (Lock, 1993). Emotions are said to be representations of the manner in which the body experiences the self and its relations to the social world. These emotions are often seen within the context of our relationship within intimate social networks (Winkelman, 2009). Our personal experiences which are inherently linked to our social relations through our emotions allows us to

connect with our bodies through the self. Body mapping is a research method which allowed the participants to experience several poignant moments which created emotional empathy and brought an awareness of self- in relation to the rest of the social world. The role and value of life stories and experiences which helped shape the course of the participants lives and how they experienced their illness was further explored in a self-reflective manner. For certain participants, this was an easy task while for others, it conjured memories that were painful and emotionally hard to articulate. Some participants automatically chose to use symbols to communicate their life experiences. Sheets-Johnstone (1981) associates thinking to movement, in her essay on thinking in movement, she describes this association by outlining the parallel assumptions of the distinction between mind and body. "...to deny the possibility of thinking in movement may also be to uphold the notion that thinking is something only the mind can do, while doing or moving is something a body does" (Sheets-Johnstone, 1981: 401). This view brings us back to the critique of Cartesianism mentioned earlier in this chapter, the stillness experienced prior to the participants second shadow being traced in a manner which illustrates more movement is evidence of how the mind and the body interact congruently to form a purpose driven body in motion as illustrated in Figure 2.

When asked about her significant life stories and experiences, *Mandy*, the 32 year old participant whom we met at the beginning of this paper and who also could not read or write had drawn what at first appeared to be centipede of some sort, six squares lined up next to one another which looked like feet underneath in Figure 3 at the bottom left hand corner, with a drawing of a

woman next to it. When probed as to why she had drawn it, Mandy emotionally referred to a life changing experience, '...I wanted to throw myself under the train...I was not happy with myself and someone stopped me, I also thought of my son...'. This experience had altered the course of her life, as she came close to death she realised she needed to continue living for her son.



**Figure 3.** Mandy's body map and her life story (photo: Author, 16 February 2017).

If not probed, Mandy's drawing could easily be misinterpreted as something insignificant in nature, the true meaning yielded a much different result. Mandy had found it troublesome to communicate, if not asked to draw and paint specific life stories and experiences, she would not have been able to articulate it on her own. Mandy's experience with her illness had at this poignant moment in her life caused her enough distress which led her to want to take her own life.

Based on the outcome of several research studies using body mapping as a research method and tool, body mapping has the distinct ability to be attuned to the patient or participants emotions which in turn encourages them to remain connected to a sense of being embodied within their emotions as opposed to being more disassociated (de Jager et.al, 2016; Coetzee, Roomaney, Willis & Kagee, 2019).

## Embodied experiences: a bio-cultural approach

Judy, a 58-year-old grandmother found it highly problematic to express her emotions. When asked questions about her experience, confusion would set in and she would close herself off to going further in the process. After getting to know Judy slightly better, it was clear that a different approach was needed. The guidelines were retold to her in a simplistic manner in order for her to process it

more clearly. As the participants were asked to visualise the virus in their body, *Judy* could best refer to the virus like an animal, as a few years prior she was viciously attacked by a dog and therefore began to associate the virus to that of an animal. Judy also visualised the virus as a darkness within her, another example of the importance of symbolism in visual research. When asked if she could explain further, she felt it easier to communicate by painting how she visualised the virus. She could not articulate how to paint an animal or a dark force and instead chose to paint incoherent lines which symbolically represented what she felt the virus looked like. In Figure 4, Judy visualised the virus as chaos and confusion within her body, a chaos she felt she had little control over.



**Figure 4.** Judy's illustration of the HIV virus in her body (photo: Author, 16 February 2017).

Visualising the virus in their body for one participant unintentionally revealed the way she felt about HIV and the manner which the virus affected her physically. *Zara* saw dots as an indexical sign of HIV, as dots represented infected blood cells throughout her body and is also a physical side effect in the form of rash on one's body caused by the medication some people living with HIV at times endure (See Figure 5). She was one of the first participants to

visualise HIV in this indexical way, after seeing her illustrations, a few other participants followed suit and had mimicked her depictions by drawing dots themselves. When asked why she drew dots, Zara maintained it simplifies a complicated process in her body.



**Figure 5.** Zara's illustration of infected blood cells in her body (photo: Author, 16 February 2017).

Leatherman and Goodman, (2011) define human health and wellbeing as being bio-cultural. Human health and illness have become interwoven concepts which are considered bio-cultural in nature and are understood best within the context of humanistic and scientific perspectives. Even though biomedical views had the ability to highlight diminutive biological processes and clarifications, the field of medical anthropology had increasingly become more fixated on the socio-cultural and political aspects of health (Leatherman and Goodman, 2011). In a systemic review of body mapping, de Jager et.al (2016) outlines that body mapping has the ability to draw participants attention to their bodies by being aware of bodily or sensory elements of experiences. Research has previously neglected the awareness of the body and how it reacts and interacts with the social world. Participants had used their own cultural understandings and their

experiences with the social world to determine the ethno-physiological view what the HIV virus looked like in their bodies.

### The body politic: social injustice

When the participants were asked to personalise their body maps by making their facial features prominent, Zara started drawing what appeared to be her eyes, nose and mouth. She later decided to paint black over her face in order to hide her facial features. Elizabeth too immediately painted her face in black making no facial features visible. When asked why they chose to do this, both participants could not give a specific reason verbally. However, Elizabeth who struggled with verbal communication showed signs of previous trauma and grappled with feelings of shame and guilt. Zara was one of the participants who found it hardest to communicate her emotions in fear of feeling vulnerable. We later discovered that Zara had suffered severe trauma as a child after being raped. She was never given counselling and found it daunting to come to terms with what had happened to her. As a result, she too experienced feelings of immense shame and guilt. In a study by Simbayi et.al. (2007) on discrimination and depression among 420 HIV positive men and 643 HIV positive women living in Cape Town, South Africa, an anonymous survey indicated more than one in every three participants felt dirty, ashamed or guilty because of their HIV status. A total of 40% of participants had admitted to experiencing discrimination since testing positive for HIV. The reality of participants thus experiencing feelings of shame and guilt related to their past and their HIV positive status was made visible by the blacking out of their faces as seen below in Figure 6 and Figure 7.



**Figure 6.** Judy's illustration of her face painted in black (photo: Author, 16 February 2017).



**Figure 7.** Zara's illustration of her face painted in black (photo: Author, 16 February 2017).

These traumatic experiences points to the reality of many people of colour living in low-income areas where violence and massive social and health inequality are widespread. The history of sexual violence in South Africa, whether the perpetrator is known or unknown, perpetuates HIV transmission and is linked to social and political violence which is common in townships and inner city areas (Fassin & Schneider, 2003).

In the field of medical anthropology, the question of when illness representations are considered misinterpretations in order to serve the interest of those considered in power, poses a thought-provoking response (Farmer and Good, 1991). People in power would be referred to people considered elite in society, the medical profession, or the government. There are suffering which is grounded in social relations that could be by all definitions be illness by diagnosis and medical treatment but are in fact symptoms of disease (such as tuberculosis or diarrhoea) that are a result of systematic issues within society with severe poverty (Farmer and Good, 1991). This results in the transformation of political problems into medical issues which subdues the critical consciousness which ultimately serves the interests of hegemonic groups in society (Farmer and Good, 1991). The analysis of illness representations therefore require a critical analysis of the possible underlying issues that are

supported by authorised discourse. Health disparities has emerged as an important theme within the public health and social sciences domain as governments and nongovernmental agencies have made concerted efforts to lessen health inequalities (Leatherman & Jernigan, 2015). The causes of health inequalities has in most cases been due to the rise of capitalism, high levels of strife, malnutrition, hunger and disease. There has thus been a need to link human biology and health to social, cultural and political undercurrents (Leatherman & Jernigan, 2015). South Africa remains to be one of the most unequal societies in the world. It is the country with the largest number of people living with HIV has a tumultuous history with the epidemic that is rooted in political and social controversy (Hlabangane, 2014).

In a study concerning poverty and HIV/AIDS in South Africa, Tladi (2012) makes an empirical contribution by using South African Demographic and Health Survey (SADHS) data. The results of the study had indicated that there is an increased risk of HIV infection among the poor. This is due to poverty related issues such as low levels of formal education and low knowledge on HIV prevention. Steinert et.al. (2016) investigated the relationship between poverty and AIDS illness in South Africa by using a cross-sectional survey of 2477 households in an urban community. The results of the study indicate that there is a correlation between higher level of household poverty and a higher likelihood of being AIDS-unwell (Steinert et.al., 2016). Though these studies make a statistical correlation between poverty and HIV, it does not critically explore the root causes of the poverty and how it has impacted people living with HIV through an ethnographic in-depth enquiry.

#### **Discussion**

Body mapping as a visual research method contributes to new insights that had exemplified theorizing the body within the context of anthropology, medical anthropology and visual culture. Visual representations of the body have been one of the main points of enquiry in anthropology since the beginning, and has been prevalent in visual anthropology since it emerged as a sub-discipline in the 1940s (Farnell, 2011).

Body mapping as a visual research method not only reiterates the understanding that the body is the vehicle in which we exist within the world, but that is also contains a vast amount of layered interpretive and cultural meanings, which are key to understanding the lived experience of people from marginalised groups, and in this case, people living with HIV. The body has been politicised and racialised to segregate, to dehumanise and to uphold racial ideologies in many previous anthropological contexts. The use of body mapping within this context however, provided an alternative view, which celebrated the body as a mapping of the way the participants existed and how they interacted in the world around them.

Through a critical medical anthropology approach, it is clear that many symptoms that participants experienced regarding their illness is a direct result of the structural systematic issues they endure on a daily basis. From an emic perspective, Lambert has observed first-hand, the lack of social services and the debilitating effects of poverty on the way the participants interacted with the

world around them while making sense of their illness. All of the participants in this study considers themselves to belong to the "coloured" culture and reside in historically coloured locations in the Western Cape, South Africa that were created during the apartheid regime. It is most often within these communities that people still experience the consequences of a failed, racist regime that debilitated a nation who now struggles to overcome the obstacles apartheid had created. Poverty was not the only underlying issue which surfaced during this study. Violence is a structural, systematic issue that presented itself when in view of the sexual assault more than one of the participants had encountered.

Other similar principles that all of the visual research methods used in this study (photo-voice and photo elicitation; mobile phones and internet memes; and drawing) had in common, is the notion that images, photographs, drawings and paintings are all visual material that should be taken seriously not only in the field of visual research, visual culture or anthropology but within any field concerning the study of humanity, cultures, race, illnesses and various other fields that prioritises human relations and our interactions with the world around us. The body maps as standalone artefacts without their accompanied narratives, would certainly not have the ability to generate enough rich interpretive meanings and therefore will not be able to contribute as much to the accumulation of new knowledge. Banks (2007) argues for why (not) pictures? in Using Visual Data in Qualitative Research, by suggesting that there are two main reasons why a social researcher should include the analysis of images/ visual material into their research. Firstly, visual material have infiltrated our societies especially within the digital sphere, as our daily movements are being

reproduced through the creation of images of our daily lives. Therefore the consideration of including some form of visual representation has the ability to be used in almost any research context which involves the study of society (Banks, 2007). The second reason for why including the analysis of visual material in social research, is that a study where visual materials are incorporated in the creation or collection of data, has the potential to reveal sociological insights that may not be achieved by any other method (Banks, 2007). Whether this is true or not, it would require the same study to be conducted using methods which are non-visual in nature. Do we believe the same outcome would be achieved? No, the body maps provided an additional layer of meaning which in certain circumstances would not have been achieved without the incorporation of the body mapping method.

Body mapping as a visual research method is unique in the sense that it was the one method whereby the outcome (the body maps themselves) had created a genuine sense of agency among the participants. This I believe is due to the life-like size of the body maps, the colourful hues that were salient and highly saturated, the personal stories which invoked a list of memories emotive in nature surrounding and within their painted bodies, the accompanied text which provided further meaning to the symbols and icons etched in the paper across their bodies or the tactile experience of touching and feeling their bodies through the act of painting.

In a study on participatory visual elicitation activities, Greyson (2013) believes that participatory arts-based methods can complement traditional

elicitation techniques and has the ability to produce significant data which gives the researcher the possibility to investigate the participants experiences in a socially and culturally relevant way. It gave the participants the freedom to elicit life stories which formed critical parts of their lives. The significance of life stories in ethnography and anthropology has been recognised in several studies (see Maggio, 2014; Hertz-Lazaowitz & Shapira, 2005; Peacock & Holland, 1993; Sandelowski, 1991 and Frank, 1995). Life stories and narratives have been used as an effective method in anthropology and from the 1980s, the lived experience of individuals was considered a valid method of enquiry in academia (Frank, 1995). Allowing participants to generate their own images which better expressed various experiences in their lives was vital to the body mapping method as it added a new interpretation to illness narratives in the form of interactive images. These narratives are embedded into the body maps themselves adding yet another layer of ethnographic enquiry. A distrust which had previously emerged from the representations of people, cultures and communities had driven a response from ethnographers from critical standpoints such as feminism to recognise an account of a subject's lived experience cannot be narrowed down to an objective viewpoint but should be approached from both the etic and emic standpoint. This was found to be essential in the analysis of the body maps.

There is also a simplicity that body mapping as a visual research method contains that no other method used in this broader research study can compare to.

Little to no experience is needed from participants as participants were

encouraged to not be concerned about whether they have drawing skills or not, or whether they had little to no formal education, they are still able to participate.

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### **Disclosure statement**

There are no conflicts of interest that has influenced this research as reported by the author(s).

## **Ethical Approval**

This research study has been ethically approved by the Social Sciences and Humanities Ethical Committee of the University of Antwerp, reference: SHW\_16\_09.

#### **References:**

Almeleh, C. 2004. Mapping Workshop Manual: Finding your Way through Life,
Society and HIV. Centre for Social Science Research, University of Cape Town.
Adhikari, M. (Ed.). 2009. Burdened by Race: Coloured Identities in Southern Africa.
Cape Town, South Africa: UCT Press.

- Banks, M. <u>2007</u>. *Using Visual Data in Qualitative Research*. London: SAGE Publications Ltd. doi:10.4135/9780857020260.
- Coetzee, B., R., Roomaney N., Willis and A., Kagee 2019. "Body Mapping in Research." In *Handbook of Research Methods in Health Social Sciences*, edited by P. Liamputtong, 1237–1254. Singapore: Springer. doi:10.1007/978-981-10-5251-4\_3.
- Cornwall, A. <u>1992</u>. "Body Mapping in Health RRA/PRA." *RRA Notes* 16: 69–76.

  IIED London. Csordas, T. <u>1999</u>. "The Body's Career in Anthropology." In *Anthropological Theory Today*, edited by
- Henrietta L. Moore, 172–205. Cambridge: Polity Press.
- Douglas, M. 1970. *Natural Symbols: Explorations in Cosmology*. London, UK: Barrie
  & Rockliff. Douglas, M. <u>1970</u>. *Natural Symbols: Explorations in Cosmology*.
  New York: Pantheon, 91.
- Farmer, P., and B. J. Good. <u>1991</u>. "Illness Representations in Medical Anthropology:

  A Critical Review and a Case Study of the Representation of AIDS in Haiti."

  Mental Representation in Health and Illness, 132–162.
- Farnell, B., <u>2011</u>. Theorizing 'the Body'in Visual Culture. Made to be Seen:

  Perspectives on the History of Visual Anthropology, 136–158. Chicago: The
  University of Chicago Press.
- Fassin, D., and H. Schneider. 2003. "The Politics of AIDS in South Africa: Beyond the Controversies."
- BMJ (Clinical Research ed.) 326 (7387): 495–497. doi:10.1136/bmj.326.7387.495.

- Favero, P. <u>2009</u>. For an AnthroPoArt: engagement, Digital Technologies and Installation Aesthetics. Die Maske: Zeitschrift für Kultur-und Sozialanthropologie.
- Frank, G. <u>1995</u>. "Anthropology and Individual Lives: The Story of the Life History and the History of the Life Story." *American Anthropologist* 97 (1): 145–148. doi:10.1525/aa.1995.97.1.02a00230.
- Gastaldo, D., L. Magalhães, C. Carrasco, and C. Davy. <u>2012</u>. *Body-Map Storytelling* as Research: Methodological Considerations for Telling the Stories of Undocumented Workers through Body Mapping. Toronto: Creative Commons.
- Good, B. J. <u>1993</u>. *Medicine, Rationality and Experience: An Anthropological Perspective*. Cambridge, UK: Cambridge University Press.
- Greyson, D. <u>2013</u>. "Information World Mapping: A Participatory, Visual, Elicitation Activity for Information Practice Interviews." *Proceedings of the American Society for Information Science and Technology* 50 (1): 1–4.
- Hadolt, B. 2001. "Medical Anthropology's 'Ownership of the Body' and the Medicalisation of Social Anthropology." *AM. Rivista Della Società Italiana di Antropologia Medica* 1: 11–12. Article 11–12.

  http://www.amantropologiamedica.unipg.it/index.php/am/article/view/114.
- Hertz-Lazarowitz, R., and T. Shapira. 2005. "Muslim Women's Life Stories: Building Leadership."
- Anthropology & Education Quarterly 36 (2): 165–181. doi: 10.1525/aeq.2005.36.2.165.

- Hlabangane, N. 2014. From object to subject: Deconstructing anthropology and HIV/AIDS in South Africa. Retrieved September 3, 2020, from https://journals.sagepub.com/doi/abs/10.1177/03082 75X13519274.
- Hughes, E. G., and A. M. da Silva. 2011. *Pilot study assessing art therapy as a mental health* | *Human Reproduction* | *Oxford Academic intervention for subfertile women*. (n.d.). Retrieved *September 3*, 2020, from <a href="https://academic.oup.com/humrep/article/26/3/611/2914335">https://academic.oup.com/humrep/article/26/3/611/2914335</a>.
- Jager, A. de., A. Tewson, B. Ludlow, and K. Boydell. <u>2016</u>. "Embodied Ways of Storying the Self: A Systematic Review of Body-Mapping." *Forum Qualitative Socialforschung/Forum: Qualitative Social Research* 17 (2): 1–31. Article 2. doi:10.17169/fgs-17.2.2526.
- Joint United Nations Programme on HIV/AIDS (UNAIDS). 2018. "UNAIDS Data 2018." Geneva, Switzerland.

  https://www.unaids.org/en/resources/documents/2018/unaids-data-2018.
- Kapferer, B. <u>1988</u>. "Gramsci's Body and a Critical Medical Anthropology." *Medical Anthropology Quarterly* 2 (4): 426–432. doi:<u>10.1525/maq.1988.2.4.02a00110</u>.
- Klein, M., and R. J. Milner. 2019. "The Use of Body-Mapping in Interpretative Phenomenological Analyses: A Methodological Discussion." *International Journal of Social Research Methodology* 22 (5): 533–543. doi:10.1080/13645579.2019.1593378.
- Leatherman, T., and A. H. Goodman. 2011. "Critical Biocultural Approaches in Medical Anthropology." In *A Companion to Medical Anthropology*, 29–48. Chichester, West Sussex, UK: John Wiley & Sons, Ltd. doi:10.1002/9781444395303.ch2.

- Leatherman, T., and K. Jernigan. 2015. *Introduction: Biocultural Contributions to the Study of Health Disparities*, 171–186. ISSN: 2153-957X.
- Lock, M. <u>1993</u>. "Cultivating the Body: Anthropology and Epistemologies of Bodily Practice and Knowledge." *Annual Review of Anthropology* 22 (1): 133–155. doi:10.1146/annurev.an.22.

## <u>100193.001025</u>.

- Lys, C., D. Gesink, C. Strike, and J. Larkin. 2018. "Body Mapping as a Youth Sexual Health Intervention and Data Collection Tool." *Qualitative Health Research* 28 (7): 1185–1198. doi:10.1177/1049732317750862.
- MacCormack, C. P., and A. Draper. <u>1987</u>. "Social and Cognitive Aspects of Female Sexuality in Jamaica." *The Cultural Construction of Sexuality* 353 (143): 143–165.
- MacGregor, H., and E. Mills. 2011. "Framing Rights and Responsibilities: Accounts of Women with a History of AIDS Activism." *BMC International Health and Human Rights* 11 (S3): S7. doi:10.1186/1472-698X-11-S3-S7.
- Maggio, R. <u>2014</u>. "The Anthropology of Storytelling and the Storytelling of Anthropology." *Journal of Comparative Research in Anthropology and Sociology* 5 (2): 89.
- Martínez, R. M., C. F. Casanueva, O. González, S. M. Miranda, and K. C. Brouwer.

  2019. "Struggling Bodies at the Border: Migration, Violence and HIV

  Vulnerability in the Mexico/Guatemala Border Region." *Anthropology & Medicine* 0 (0): 1–17. doi:10.1080/13648470.2019.1676638.

- Martin, E. 1991. "The Egg and the Sperm: How Science Has Constructed a Romance Based on Stereotypical Male-Female Roles." *Signs: Journal of Women in Culture and Society* 16 (3): 485–501. doi:10.1086/494680.
- Mauss, M., <u>1985</u>. "A Category of the Human Mind: The Notion of Person; the Notion of Self." In *The Category of the Person: Anthropology, Philosophy, History*, edited by P. Carrithers, A. M. Carrithers,
- M. Collins, and S. Lukes. Cambridge, UK: Cambridge University Press.
- Meiring, Jacob, and Julian C. Muller. <u>2010</u>. "Deconstructing the Body: Body

  Theology, Embodied Pastoral Anthropology and Body Mapping." *Verbum et Ecclesia* 31 (1): 1–7. doi: <u>10.4102/ve.v31i1.367</u>. Merleau-Ponty, M., and C.

  Smith. 1962. *Phenomenology of Perception (Vol. 2012)*. London:

## Routledge.

- Merleau-Ponty, M. <u>2014</u>. *Phenomenology of Perception* (C. Smith, Trans.; New York : Humanities Press). London : Routledge & K. Paul.
- Nöstlinger, C., J. Loos, and X. Verhoest. <u>2015</u>. "Coping with HIV in a Culture of Silence: Results of a Body-Mapping Workshop." *AIDS Research and Human Retroviruses* 31 (1): 47–48. doi:10.1089/aid.2014.0316.
- Orchard, T. <u>2017</u>. *Remembering the Body: Ethical Issues in Body Mapping Research*. Cham, Switzerland: Springer International Publishing AG.
- Pauwels, L. <u>2010</u>. "Visual Sociology Reframed: An Analytical Synthesis and Discussion of Visual Methods in Social and Cultural Research." *Sociological Methods & Research* 38 (4): 545–581. doi:10.1177/0049124110366233.
- Pauwels, L. <u>2015a</u>. Reframing Visual Social Science: Towards a More Visual Sociology and Anthropology. Cambridge: Cambridge University Press, 337p.

- Pauwels, L. <u>2015b</u>. "Participatory Visual Research Revisited: A Critical-Constructive Assessment of Epistemological, Methodological and Social Activist Tenets." *Ethnography* 16 (1): 95–117. doi:10.1177/1466138113505023.
- Peacock, J. L., Holland D. C., and P. J. L. <u>1993</u>. "The Narrated Self: Life Stories in Process." *Ethos* 21 (4): 367–367. doi:10.1525/eth.1993.21.4.02a00010.
- Sandelowski, M. <u>1991</u>. "Telling Stories: Narrative Approaches in Qualitative Research." *Journal of Nursing Scholarship* 23: 3–161.
- Scheper-Hughes, N., and M. M. Lock. <u>1987</u>. "The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology." *Medical Anthropology Quarterly* 1 (1): 6–41. doi:10.1525/maq.1987. 1.1.02a00020.
- Sheets-Johnstone, M. <u>1981</u>. "Thinking in Movement." *The Journal of Aesthetics and Art Criticism* 39 (4): 399–407. doi:10.1111/1540\_6245.jaac39.4.0399.
- Simbayi, L. C., S. Kalichman, A. Strebel, A. Cloete, N. Henda, and A. Mqeketo.

  2007. "Internalized Stigma, Discrimination, and Depression among Men and
  Women Living with HIV/AIDS in Cape Town, South Africa." Social Science &

  Medicine (1982) 64 (9): 1823–1831. doi:10.1016/j. socscimed.2007.01.006.
- Singer, M., and P. I. Erickson. 2011. "As the Future Explodes into the Present:

  Emergent Issues and the Tomorrow of Medical Anthropology." In *A Companion to Medical Anthropology*, edited by Singer, M., and P. I. Erickson, 515–532.

  Chichester, West Sussex, UK: John Wiley & Sons, Ltd.

  doi:10.1002/9781444395303.ch26.
- Skop, M. <u>2016</u>. "The Art of Body Mapping: A Methodological Guide for Social Work Researchers."

- Aotearoa New Zealand Social Work 28 (4): 29–43. doi:10.11157/anzswj-vol28iss4id295.
- Solomon, J. <u>2007</u>. "Living with X." In *A Body Mapping Journey in the Time of AIDS*. Johannesburg: REPSSI.
- Steinert, J. I., L. Cluver, G. J. Melendez-Torres, and R. H. Romero. 2017.

  "Relationships between Poverty and AIDS Illness in South Africa: An

  Investigation of Urban and Rural Households in KwaZulu-Natal." *Global Public*Health 12 (9): 1183–1199. doi:10.1080/17441692.2016.1187191.
- Swain, J. <u>2003</u>. "How Young Schoolboys Become Somebody: The Role of the Body in the Construction of Masculinity." *British Journal of Sociology of Education* 24 (3): 299–314. doi: <u>10.1080/01425690301890</u>.
- Tladi, L. S. <u>2006</u>. Poverty and HIV/AIDS in South Africa: An empirical contribution.
  Print. Winkelman, M. <u>2008</u>. Culture and Health: Applying Medical
  Anthropology. San Francisco, CA, US:
- John Wiley & Sons.
- Wallace, H. J., S. McDonald, S. Belton, A. I. Miranda, E. da Costa, L. da Conceicao Matos, H. Henderson, and A. Taft. 2018. "Body Mapping to Explore Reproductive Ethno-Physiological Beliefs and Knowledge of Contraception in Timor-Leste." *Qualitative Health Research* 28 (7): 1171–1184.
  doi: 10.1177/1049732317750382.
- World Health Organization. 2020. "HIV/AIDS." HIV/AIDS Fact Sheet. November 30, 2020. https://www.who.int/news-room/fact-sheets/detail/hiv-aids