Embodying HIV and AIDS Information: Experiences of Serodiscordant Couples

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Abstract

This paper aims to illuminate how serodiscordant couples were informed by their own and other's bodies in their experience of HIV/AIDS information. The lived body is the contact we have with the world. Our knowledge about others is through their bodies. In addition, illness is experienced first through the lived body. Therefore, when doctors want to learn about the illness, they extract information from the lived body. In this study, we investigated how serodiscordant couples experience HIV and AIDS information in Malawi. In-depth interviews were conducted in the homes of twenty-one serodiscordant couples and three individuals who had separated from their partners. Participants for the study were selected purposively. Data analysis was carried out using Max van Manen's phenomenological approach to generate descriptions and interpretations of the couples' experiences of HIV and AIDS information. The study found that the life-world is the overarching context of experiencing HIV and AIDS information and identified five structures of the life-world of serodiscordant couples: lived body, lived space, lived others, lived time, and spirituality. HIV and AIDS are first experienced through the lived body, and bodies were informational within the lived spaces. Thus, this research contributes to the study of HIV and AIDS information by revealing the lived body as an important source. It also identifies that the body can be an ambiguous source, since HIV and AIDS information available from the lived body may be ignored or misinterpreted by the serodiscordant couples and by those they interact with.

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Background

This paper aims to illuminate how serodiscordant couples were informed by their own and other's bodies—an important element in their experience of HIV/AIDS information. These findings emerged from a phenomenological doctoral study that investigated how serodiscordant couples experience HIV and AIDS information in Malawi. Serodiscordant couples are couples where only one partner is HIV positive. In the absence of an HIV vaccine, information has played a pivotal role in influencing behavior change (Albright 2007). The ability to design successful HIV and AIDS information campaigns is, therefore, highly dependent on knowledge of people's information behavior. Accordingly, there is a need for good understanding of the information behavior of specific groups of people affected and infected by HIV.

Although policy makers and practitioners in Malawi are aware that HIV information is an indispensable component of the fight against the HIV pandemic, their focus seems to be more on getting information to people and less on the information-related dynamics that drive behavior change. Accordingly, policy makers and practitioners ignore some information sources that are important to people living with HIV. One such ignored source is the body. As stated by Brett-Maclean (2009), the body is the central focus of people living with HIV and of physicians treating them. Brett-Maclean observes that both people living with HIV and physicians focus on monitoring viral load, body temperature, bodyweight, and other indicators of the body's response to the virus and treatment.

One of the aims of the research was to discover how information was conceptualized in the specific context being investigated: this empirical finding is presented in the discussion section of this paper. In terms of the authors' own concept of information (rather than *definition* of information, a distinction usefully drawn by Belkin [1978, 58]), information is enacted by people going about their daily activities, encoded in our environment, purposive communication in any format, and encoded in our own bodies, all which make a difference in our and others' conception and understanding of phenomena.

Brookes (1974, 149) helped construct a broader foundation for interpreting information, stating that "life is a continuous information process in which physical, genetic, sensory, and cognitive component all act together." He observes, dryly, that "the scientist's *primary* source of information is not the scientific journal, but nature itself" (142). As Bates (2006, 1037) notes, Brookes's subsequent focus for elaborating the concept of information was on what they both term *exosomatic information* (i.e., information external to the body). However, Brookes's contribution was important in setting out an argument for the insufficiency of a document-focused conception of information, and in connecting with other lines of thought, such as Jesse Shera's idea of social epistemology.

Bates (2006) explored the nature of nonexosomatic information more deeply, with embodied information a clear part of her schema. Describing neural-cultural information, Bates (2006, 1038) observes that "*embodied* information [is] identified: in experience, in actions in the world, and in communicatory expression." Buckland (1991) had also clearly identified that objects, including people, could be informative.

Both Brookes (1974) and Bates (2006) explored the meaning of information within the context of defining the discipline of information science: identifying its objects of study and what the future could be for information science research. These debates enable reflection on the nature of corporeal information within a holistic conception of information. Bates's (2006) and Brookes's (1974) perspectives are also more accommodating than (for example) a view of information as being constructed by a problem-solving individual (Savolainen 1993).

Against this background, we identify the more specialized work of Lloyd (2009, 2014, 2004, 2010) as influential on our thinking. In her study of firefighters' information literacy, information is contained in texts but, more importantly, is accessed corporeally through personal interaction, experience, and the "actioned body" (2004, 220). In her study of roadside information practices of ambulance officers, Lloyd (2009) found that sensory skills, including touch, were essential to obtaining information. Ambulance officers in Lloyd's study used textual and experiential information. Referring back to Brookes, this embraces the cognitive, physical, and sensory aspects of information, but also places it within a specific context of social practice. Drawing on this work and subsequent study of ambulance workers and renal nurses, Lloyd (2014, 95) sees the body acting as "a site of knowledge but also as a site of information for others" as it senses and interacts with people and objects.

A further dimension is added by work that delves more deeply into people's relationship with their own bodies. This is discussed further in the next section, but we mention here Mol and Law's (2004) study of people with hypoglycaemia. They explore the interaction between taking "objective" measurements (in this case, of blood sugar levels) and "inside" feelings and self-awareness of the body. The importance of the two types of information may vary depending on the individual and context. As with the example of a runner's autoethnography (reviewed in Cox, Griffin, and Hartel [2017]), an individual may draw on the quantified self, on feelings, on self-observation, and on observation of the broader world in order to draw conclusions about the state of the body.

LITERATURE REVIEW

Illness is presented in literature as an embodied experience. In our study, we found that people first experience HIV and AIDS through the lived body (Wella 2015). In addition, serodiscordant couples in our study played out their lives in social contexts within their life-worlds. Studies also have shown that discussion about HIV and AIDS in African societies is affected by the taboos associated with the sexual nature of HIV and AIDS information. Therefore, metaphors are used to make the human body, especially genitalia, open to discussion. Therefore, this review of literature will focus on how the lived-body is viewed in illness, social construction of the lived-body, and metaphors.

In phenomenology, the human body is viewed as being composed of the physiological and the psychological, as material and self-conscious. Human beings are conscious of other people occupying the same space as them (Tanaka 2015). Prereflectively, human beings understand gestures made by other people. Therefore, as Bullington (2013) observes, it is not possible to separate the biological side of the body (moving a hand to make a gesture) and the intentional side (the information the gesture aims to transmit). According to Merleau-Ponty (2015), it is not possible to separate what we call the natural part of a human being from the sociocultural, and spiritual, world because the behavior of the anatomical apparatus (the lived body) communicates meaning in the context of the world.

Turner (2013) argues that the human body should not be viewed as a mass of flesh with biological functions, but one with intentions whose actions or gestures are goal-directed and purposeful. Therefore, when doctors treat a patient, their gaze should not only be scientific; they should also talk to the patient to understand the illness in a hermeneutic way (Svenaeus 2009). Turner (2013) criticizes conceptions of the lived body that privilege the biological side and completely ignore the social and cultural side. Commenting on Merleau-Ponty's view of the lived body, Carel (2011) argues that a human being is a perceiving and experiencing organism, continually making sense of its environment through interaction with things and people within it.

The successful passage of the lived body through social spaces is both a practical problem and a skillful undertaking. This is because the lived body transmits and receives information when in social spaces. Williams and Bendelow (1998) suggest that when human beings occupy lived spaces, their bodies "scan" the scene in order to pick up the positional, gestural, and linguistic clues regarding the potential lines of action of their fellow participants in the interaction order. Within routine social interaction, bodies are constantly "giving off and receiving information" (57). The human body is structured in a way that makes it so effective in transmitting and receiving communication (Fuchs, 2005). Fuchs's examples of the means through which information is transmitted and received include gestures, facial expressions, and voices. Cox, Griffin, and Hartel (2017) observe that the body possesses knowledge and that it can be read by others.

HIV and AIDS Information Sources

Several studies have shown that the major sources of HIV and AIDS information for people living with HIV/AIDs (PLWHA) are as follows: HIV and AIDS newsletters, doctors, magazines, personal physicians, pamphlets, brochures, friends (Hogan and Palmer 2005; Huber and Cruz 2000; Veinot 2009); HIV positive counselors (Hogan and Palmer 2005); newspapers, books, television (Huber and Cruz 2000; Manda 2006); radio, family members, nongovernmental organizations (NGOs), community-based organizations (CBOs), schools (Manda 2006); and the internet.

Hogan and Palmer (2005) used a survey approach to investigate how information can assist PLWHA. In their study, respondents were asked to rank sources of HIV and AIDS information in order of preference. The five most preferred sources of HIV and AIDS information reported by the study were doctors, HIV positive counselors, magazines, brochures, and newsletters. Since the information sources were listed, one would argue that participants were influenced to select from the list and not provide their real preferences; however, it is still notable that people-sources were preferred. In her study, Veinot (2009) observes that HIV and AIDS information is better mediated through social networks. Respondents in this study mentioned doctors, family, and friends as members of networks, within which they used the internet, magazines, and other people to obtain information. The information sources reported in these studies are consistent with findings in a study conducted by Manda (2006) in Tanzania. Using in-depth interviews, focused group discussions, key-informant interviews, participant observations, and dissemination workshops, Manda investigated information flow and access in Tanzania.

All these studies have identified similar information sources, suggesting that both respondents and researchers had a common conception of what constitutes an information source. None of the studies identified the lived body as a source of HIV and AIDS information. Since some of the studies used quantitative approaches, with predetermined lists of information sources, one would argue that even the researchers did not consider the lived body as a source of HIV and AIDS information.

Lived Body in Illness

Three views of the lived body that is ill are described in the literature. First, there is the medical or scientific view; second, there is the socially constructed view; and third, there is the ill person's own experience. Svenaeus (2009) demonstrates the first two views with actions of doctors when they, in a quantifying manner, examine a patient's blood pressure or temperature. The same doctor might then look at the patient and notice that he is ashamed of his condition. In society, the patient is surrounded by healthy bodies that inform them about well-being. According to Defenbaugh (2013), the healthy bodies, having meaning that is not found in the patient's body, will help the patient construct his or her own understanding of health and illness. Studies on specific disease conditions have highlighted the subjective experience of the lived body that is experiencing illness. Ek and Ternestedt (2008) found that people living with chronic illnesses experienced physical limitations that excluded them from participating in everyday activities.

According to Svenaeus (2009), the way illness is enacted, viewed, and treated can be alienating. Alienation is felt when the lived body is turned into a biological organism that needs to be fixed by the doctor, ignoring what Defenbaugh (2013) calls the body's own narrative. Some people feel alienated when others look at their ill bodies. Kirkengen and Thornquist (2012) argue that although the psychosocial aspects of experiencing illness are increasingly being investigated, the very way in which these issues are discussed in literature demonstrates that human beings are still treated as disembodied beings. Research and professional representation of how social phenomena are experienced give the impression that the phenomena mean the same to all people.

In the health information field, the dominant discourse focuses on supporting evidence-based medicine (EBM), without an equally rigorous engagement with critique (e.g., Mykhalovskiy and Weir 2004) that identifies that an EBM approach may objectify the patient and privilege textual sources of information. With increased use of qualitative research approaches in the information behavior field, and the growth of the patient empowerment movement, more attention has been paid recently to illumination of the ill person's experience of information (e.g., Godbold 2013; Wolf and Veinot 2015). However, Wolf and Veinot (2015) identify that there is still a paucity of research into social use of a patient's information.

Social Construction of the Body

As stated earlier by Svenaeus (2009), in illness the human body is turned into a biological organism. A good example is provided by Harris (2011, 137) when describing a doctors touch: "By pressing lightly you can assess how large the vessel is and whether it will stay in place or slip and slide at the whisper of an instrument. . . . In many ways the physician's hands are considered 'tools' in their own right." This objectification of the human body fails to consider the person's world of experience and meaning. In addition, people fall ill in a society where the illness is experienced with others. Based on social constructions, some illnesses are stigmatized, some are questioned, and some are categorized as disabilities while others are not (Conrad and Barker 2010).

Meanings of the body are not inherent in the body itself but develop through interactions in society (Conrad and Barker 2010). A study of ambulance officers conducted by Lloyd (2009) found that by observing each other's bodies, the officers were able to get tacit information. Lloyd observes that, over time, ambulance officers were able to attain familiarity with their body, which provided contingent information. This contingent information was also interpreted by other ambulance officers.

Metaphors, HIV and AIDS, and the Lived Body

Metaphors used in health information, including information relating to HIV and AIDS, are widely researched. Nie et al. (2016) argue that the use of metaphors boosts the morale of patients and health personnel with respect to the treatment and healing process where the illness is life-threatening. The HIV-infected body is represented in a metaphorical sense as being wounded in war (Nie et al. 2016; Chambers 2016; Kayhan 2016). In songs, metaphors are also used to indirectly pass on warnings about the HIV infected body.

Some metaphors represent people living with HIV negatively (Chinsembu et al. 2008). According to Chinsembu et al. (2008), these metaphors are discriminatory and only push people living with HIV underground. Some of the metaphors used in Zimbabwe as reported by Mawadza (2004) labelled people living with HIV as dying bodies. People described people living with HIV as being in the departure lounge. Mawadza also reported derogatory metaphors that described the appearance of bodies of people living with HIV such as “walking stick,” and “perm hair.” These stigmatizing metaphors deny people living with HIV their basic right to a dignified life.

Among many tribes in Mozambique, terminologies used to explain how HIV infects the human body are not culturally appropriate (Kotanyi and Krings-Ney 2009). Therefore, counselors in initiation ceremonies use culturally appropriate metaphors to explain sexual transmission of HIV. Mabule (2009) suggests that translating concepts that relate to sexual organs and sexual intercourse into most African languages is a strong taboo. The translator will resort to metaphors to avoid directly mentioning concepts concerning human genitalia and sex (Mabule 2009).

METHODS

Phenomenological interviews were used to invite serodiscordant couples in Malawi to describe how they experience HIV and AIDS information. Phenomenology is a research approach that seeks to investigate the nature of the everyday world as we experience it, not as we conceptualize it (van Manen 1997). A phenomenological approach was chosen because it is rigorous enough to derive in-depth understanding of how serodiscordant couples experience HIV and AIDS information. Additionally, considering that people living with HIV are stigmatized, and that HIV concerns couples’ intimate lives, phenomenology afforded tools to achieve the level of empathy that allowed serodiscordant couples to describe their experience of HIV and AIDS information. The interviews lasted an average of 45 minutes each and were conducted in 2013. By the time of its conclusion, fieldwork had resulted in a purposive sample of twenty-one couples and three individuals who had separated from their partners because of serodiscordance. Twelve of the couples were from an urban area, and nine were from the rural districts. All three individuals were from an urban area. Table 1 summarizes the demographic characteristics of the sample.

During the interviews, serodiscordant couples were asked to describe how they experienced HIV and AIDS information. Throughout the description, couples were encouraged, using probing questions, to give specific examples of experiencing HIV and AIDS information. When these examples were given, the participants were encouraged to reflect on them and describe what the experience was like. All interviews were audio recorded and transcribed verbatim.

The interview data were analyzed using van Manen's (1997) approach to the analysis of phenomenological data to derive descriptions and interpretations of experiences. The research process involved six activities, as described below.

Activity 1: Turning to the Nature of Lived Experience

This was undertaken by identifying the phenomenon of interest (HIV and AIDS information) and formulating the research question. In addition, a purposive sample of mutually disclosed serodiscordant couples was

Table 1. Demographic characteristics of the sample

Composition	Number
HIV status	
Couples	
Male HIV positive/Female HIV negative	10
Male HIV negative/Female HIV positive	11
Individual partners	
HIV positive males	1
HIV positive females	1
HIV negative females	1
Age	
25–44	29
45–64	13
65+	3
Education	
No formal education	9
Primary school education	23
Secondary school education	12
University education	1

drawn. Serodiscordant couples were first contacted by managers of HIV and AIDS management organizations or coordinators of HIV and AIDS support groups. The researcher met only couples that agreed to participate in the interviews.

The research was granted ethical approval from University of Sheffield Ethics Committee. Additional ethical approval was obtained from University of Malawi, College of Medicine Research and Ethics Committee (COMREC).

Activity 2: Investigating Lived Experience as We Live It

This was done by conducting in-depth interviews to invite serodiscordant couples to describe how they experienced HIV and AIDS information. The interviews were conducted in Chichewa, the commonly spoken local language in Malawi. Serodiscordant couples were given freedom to choose the place, date, and time of the interview. For all couple interviews, both partners were interviewed together. This ensured that partners did not experience discomfort that their spouses were disclosing information they considered too private (Margolin et al. 2005). In addition, during the initial recruitment contact with the gatekeepers, it was clear that most couples would not commit to being interviewed for longer than 90 minutes because of work commitments. Living experiences were also investigated through recording observations in a research diary. Observations included appearances of their bodies referred to in interview conversations.

Activity 3: Reflecting on Essential Themes

The first step of this activity was to listen to all the recorded interviews. The interviews were transcribed verbatim and coded using Nvivo while in the local language (Chichewa). The interview data were coded by reading through the interview transcripts one at a time. Since the ultimate goal of the analysis was to describe how couples experience HIV and AIDS information, the codes consisted of concepts that were considered to be building blocks of the experiences described by the interviewees. During the analysis, care was taken to ensure that each concept conveyed one singular thought or idea. During the reading of the transcripts, phrases or sentences conveying a particular concept were copied in a related code. Where overlaps emerged among the codes, the codes were merged; where a significant singular thought emerged within a code, the code was broken to isolate the singular thought.

During rereadings of the transcripts, the codes were reanalyzed to confirm that concepts represented the couples' descriptions. The codes were also reanalyzed to identify relationships among the concepts. The codes were sorted according to similarities of meaning in order to derive themes. The process of developing themes was iterative. The themes were refined by back-and-forth checking with the actual descriptions provided by serodiscordant couples.

The list of themes was further refined by conducting Free Imaginative Variation. This process was carried out by picking one theme at a time and using it as a frame of reference. Specifically, we asked the question: "Is the description of the experience of HIV and AIDS information complete without this theme?" If the answer was "yes," the theme was considered incidental and deleted, and when the answer was "no," it was considered an essential theme.

The final step in activity 3 was interpretation of the themes. The interpretive process entailed constantly interrogating the themes in the context of the descriptions provided by serodiscordant couples to ensure that they were true to the experience of HIV and AIDS information. Interpretation of themes was carried out using van Manen's (1997) "structures of the life-world": lived body, lived space, lived others, and lived time.

Activities 4 & 5: Phenomenological Writing, and Maintaining a Strong and Oriented Relation to the Phenomenon

Writing was undertaken as part of the analysis of data and interpretation of the findings, and it was an ongoing process, from the design of the study, through data collection and analysis, to the end. The first phase of this process was done through proposal writing when the study was conceptualized and designed. Throughout fieldwork, notes were recorded on observations and major study events, creating a research diary. The second phase of writing commenced when analysis of the interview data started. The writing process assisted us in maintaining a strong and oriented relation with the phenomenon.

In writing, quotations from what serodiscordant couples said about their experiences of HIV and AIDS information were used. The quotations were translated into English, and a sample of the translated text was checked by a language specialist from the University of Malawi's Centre for Language Studies.

Activity 6: Balancing the Research Context by Considering Parts and Whole

This was undertaken through the process of reflexivity in order to maintain orientation to the research question. This entailed declaring the principal investigator's (PhD student) previous experience with HIV and AIDS. Throughout the study, care was taken to ensure that these previous experiences did not influence interviewing, data analysis, and interpretation.

We also were reflexive in the procedures used to recruit serodiscordant couples for the study. All potential participants were contacted by managers of HIV and AIDS support groups or managers of VCT and ART clinics. We only met serodiscordant couples that agreed to participate in the study, and never pursued those that declined.

Findings

The findings of our study identified the life-world as the overarching framework of experiencing HIV and AIDS information. As mentioned above, van Manen (1997) identifies four structures of the life-world (lived body, lived others, lived space, and lived time); however, the life-world of serodiscordant couples in Malawi was found to have one aspect that could not fit into those four life-world structures. Serodiscordant couples believed in God and described their relationship with ancestral spirits. This was identified as a fifth structure—spirituality.

This paper focuses on the lived-body. Serodiscordant couples first experienced HIV through their bodies. All couples interviewed in this study reported to have heard about HIV and AIDS before being affected and infected. All HIV and AIDS information the couples described concerned the lived body. It was about the appearance of the body of an infected person, the effect of the virus on the immune system, transmission though exchange of body fluids, and signs and symptoms of HIV infection.

Most couples described their bodies before the HIV infection, and how they took the healthy lived-body for granted. When the HIV positive partners fell ill, most couples discounted HIV as a possible illness because in everyday talk HIV was presented as an illness of people who are not married and of those engaging in sex work. Believing that HIV is sexually transmitted, serodiscordant couples could not understand how only one partner could be infected when they always had unprotected sex.

The Body as an Inhabitant of Lived Space

One of the descriptions provided by serodiscordant couples was of their presence in the life-world in bodily form. When they encountered others, they did so in bodily form. We use figure 1 to position the lived body in lived space, in sync with other structures of the life-world. At the center of the diagram are lived others, indicating that these exist in the world in bodily form. The third circle in the diagram represents lived spaces. This suggests that all people inhabit lived spaces as lived bodies. Next is the temporal dimension in which all people play out their lives. As described by van Manen (1997), this is subjective rather than clock time. The fifth existential, represented with a dotted line in figure 1, is spirituality.

When inhabiting the lived spaces, bodies of serodiscordant couples were informational. First, other people occupying the same lived spaces occupied by the serodiscordant couples were able to interpret information provided by the couples' bodies. This created an intersection with textual or graphic information about HIV and AIDS that people had seen before. As such, people were able to make lay diagnoses. Second, for serodiscordant couples themselves, the body played a central role in learning about HIV and AIDS. They learned that HIV and AIDS information (e.g., HIV status) from the two partners' bodies could be different. Physical decline

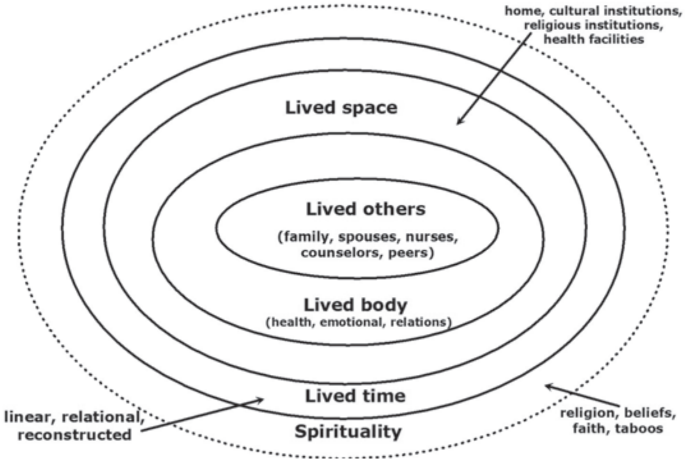

Figure 1. The lifeworld of serodiscordant couples

at the beginning of the HIV infection and regained physical health after treatment was also information from the body.

HIV and AIDS is socially constructed as an illness of people that are not married. As such, married couples believed they could not be infected. When their bodies gave out information that was consistent with HIV positive status, they did not interpret it as such. They were "just staying as husband and wife . . . thinking that HIV infects only those that are not married or work in bars" (couple #8). After diagnosis, the once-familiar body became strange, and serodiscordant couples reported that over time they learned to correctly interpret information from their bodies.

Although the description in this interview excerpt suggests that the HIV positive partner's body presented signs and symptoms of HIV infection, the couple, like many others, never suspected HIV. Some couples (8 out 21) believed that manifestations of HIV-like symptoms on the body were due to other disease conditions. For instance, couple #20 believed that the illness was the act of ancestral spirits that wanted to give the ill person healing powers. Other couples believed that the HIV positive partner was bewitched. This suggests that the couples were not able to correctly interpret HIV and AIDS that was being transmitted by their bodies.

Before diagnosis of the HIV infection, serodiscordant couples inhabited a world where life was going well. At the center of the couples' lifeworld was the home, which was jointly inhabited by the two partners. In the home, the two partners considered the bedroom as a private and secure place where they played out their married life. Since the couples had unprotected sexual contact before diagnosis, health information from one partners' body was considered applicable to the other partner as well.

> So whenever I told her to go for testing she always said; why should I waste time when you as a blood donor are tested all the time, can you see that. Even myself, I thought it was enough. However, after she was diagnosed with TB, she was constantly ill. Now when reading the NAC [National AIDS Commission] newsletters we were noticing that the signs being described are exactly what we are seeing on this person. But we were surprised because I was always testing negative. (HIV- Female partner, couple #17)

This interview excerpt suggests that, since the two partners had unprotected sexual contact and since HIV was sexually transmitted, the couples expected that HIV and AIDS information from one partner's body would be extrapolated to the other partner.

Although only the HIV positive partner was infected with HIV, the whole family was a symbol of death in their communities. This affected their participation in social life as other people discriminated against them for fear of being infected.

The Body as a Source of HIV and AIDS Information

Management of the HIV infection was a complicated undertaking that required understanding the body of the HIV positive partner. The period of living with HIV was a learning process for the serodiscordant couples. Information that was accessed from books, fliers, radio, and television was now embodied. In the interviews, most couples described the importance of knowing the viral load of the HIV positive partner. Viral load is information that is situated within the lived body. The nurses had to draw blood from each of the partners in order to access and interpret this information.

Couples were also continually monitoring other changes on the HIV positive partner's body that were indicative of opportunistic infections—changes such as sores and lesions. A female HIV negative partner said, "And the second thing—when your husband is ill bathe him. But when he has sores, when bathing him wear plastic bags . . . never bathe him without wearing plastic bags, they advised us like that" (HIV- Female partner, couple #21). Sores and lesions had a different informational value after diagnosis. Whereas before, these were interpreted as problems on the skin (the outside of the body), after diagnosis, sores and lesions were information about what was going on inside the body.

Some couples who were on antiretroviral therapy (ART) used their bodies to convince other couples to go for testing. The couples used their bodies as examples of the effectiveness of ART. In an interview conversation, the male HIV positive partner in couple #11 explained that he was an HIV and AIDS volunteer and his role was to encourage people to go for testing. He said, “I tell them that ‘this also happened to me, you may be positive, am also positive,’ and I show them my health record book . . . and tell them that am also on ART” (HIV+ Male partner, couple #11*).* This interview excerpt suggests that this respondent’s HIV positive status was not obvious from bodily appearance. During the interview, the respondent made several references to his body as being healthy and capable of carrying out chores around the home.

On the other hand, in everyday talk, people made reference to the characteristics of the HIV infected body. The HIV infected body functioned abnormally, often with signs and symptoms of well-known ailments. The body was hurting (couple #23), had sores in the genital area (couple #3), and sores all over the body (couples #7 and #21). The HIV infected body was also referred to as not being able to engage in productive work. Female HIV negative partner in couple #7 remarked, “He is a carpenter, so with the illness sometimes is able to make money and sometimes he is not.”

The body was also described as revealing or hiding the HIV and AIDS information. For most serodiscordant couples, the physical decline of the HIV positive partner represented the HIV infection. In interviews, couples also reported that some health workers used physical appearance to determine the seriousness of the illness of their patients. When the HIV positive partners were on successful ART treatment, they regained their physical stature. Their bodies looked normal and concealed the HIV infection. This is described in the following interview excerpt: “In other health centers when we go they tell me that they can’t give me food supplements because my body looks healthy, they don’t know that it’s [pointing at her husband] he looks thin yet he is HIV negative, I look fat but am positive . . . who needs food supplements, him or me?” (HIV+ Female partner, couple #3).

In addition to the body providing medical and scientific information such as body temperature and viral load, it was also subject to social, cultural, and religious interpretations. The HIV infected body was a symbol of betrayal, promiscuity, and death. One HIV positive female respondent described how betrayed she felt believing she was infected by her promiscuous husband: “My husband abandoned me when I told him that I tested positive . . . because I consider this a violent act, bringing me this disease” (HIV+ Female partner, couple #10). For some couples the HIV infected body was interrogated to find out where the virus was contracted. The interrogation was often premised on suspicion of extramarital affairs.

The Childbearing Body

Most couples who were of childbearing age viewed their bodies in terms of their potential for bearing children—the body became a source of information for its readiness to bear a child. Those that decided to have a baby went through a period of uncertainty, continually interpreting the physiological changes of the pregnant woman's body. The male HIV positive partner in couple #21 explained the types of information about their bodies that serodiscordant couples were advised to obtain to ascertain fitness for childbearing: "It is difficult to have children because we use condoms . . . the counselors advise that when we want to have a baby we should go to Lobi [Clinic] to have our CD4 count checked, and if our immunity is high we can have a baby" (HIV+ Male partner, couple #21).

After giving birth, the baby's body also became a source of information to determine the effectiveness of efforts to prevent transmission of the virus from mother to child. Any visit to the clinic was considered an opportunity to obtain and interpret information concealed within the body of the baby.

The HIV infected body was considered too weak to survive the nine-month gestation period, and serodiscordant couples, especially women, were wary of the consequences of pregnancy. Unlike in natural circumstances where the decision to become pregnant was privy to the two partners, serodiscordant couples were required to avail their bodies for scrutiny by health workers. As described by the HIV+ partner in couple #21, serodiscordant couples were advised to have their viral load checked before having a baby. Couples that had children obtained laboratory test results of their babies regularly in order to ascertain that there was no transmission of HIV from the mother. Couples monitored HIV tests, body temperature, and body weight of their babies.

The Infected and Infectious Body

Though it was invisible, serodiscordant couples were consciously aware of the virus that inhabited the HIV positive partners' bodies. They feared the virus would multiply and weaken the body. From a medical standpoint, HIV negative partners were certified free of the virus; however, most couples believed that they were both infected. As such, most HIV negative partners were conscious of their bodies as HIV infected and were confused as to why the body was concealing the virus. One female HIV negative respondent said, "I am worried with my life, because when I go for testing they, they say, I have no HIV. Now how will my illness be treated" (HIV-Female partner, couple #16).

The bodies of HIV positive partners were viewed as infectious. Being inhabited by HIV, their bodies would transmit HIV. HIV negative partners, therefore, needed information on how they could prevent themselves from being infected. One of the lingering thoughts among many HIV negative partners was evident in the following comment:

> For me, when he was found HIV positive I wanted to know how we would stay together. Sometimes I get worried; how do I continue staying with him . . . the worry comes from what we hear that an HIV negative

> person should not stay with an HIV positive person, they will infect you, like we sitting here. (HIV- Female partner, couple #10)

This narrative suggests that, out of fear of contagion, the HIV negative partners scrutinized the bodies of their spouses in search of assurance. Observation of bodies was in fact reported by serodiscordant couples as source of HIV and AIDS information. As such they seek to know the inside of their spouses' bodies from the outside. They sought assurance that they would not be infected by touching, having sexual contact, or even getting close to their spouses. The physical decline of the body was the first piece of information that prompted most couples to go for HIV testing. Additional information was then drawn from living with the virus and from engagement with health workers.

After being diagnosed, the HIV positive partners' bodies were viewed as being inhabited by the virus, and therefore infectious. Yet health workers told the couples to continue engaging in sex and have children, which contradicted public health information that warned against sexual contact with HIV positive people. The HIV and AIDS information provided by health workers was contradictory to the serodiscordant couples' experiential realities of living with HIV.

Metaphors and the HIV Infected Body

Respondents talked about metaphorical representations of the lived body in HIV and AIDS information. During an HIV counseling and testing session, a couple was shown an image of a human body being pierced by arrows. They were told that if this human body uses a shield, the arrows could not do any harm. The male partner remarked:

> In their demonstration, there were several pictures, first was a healthy person, the second was not very healthy, third's body was almost damaged, the number four was not looking okay, and getting to number five we saw that he has fallen, meaning that the immunity is no longer there. . . . And they drew a shield and an arrow meaning that we should defend ourselves . . . if we defend carelessly, we create a gap through which the arrow passes and causes a weakness in your body. (HIV- Male partner, couple #2)

The interview excerpt uses a war scenario as a metaphor to describe a sexual encounter. In the metaphor, the two partners are enemies at war, and the one who is HIV positive is firing arrows. The HIV negative partner is advised to use a shield (a condom). The use of metaphors in the context of HIV and AIDS and the lived-body is indicative of the cultural sensitivity of some information. HIV and AIDS information on the human body that is sexual in nature is enmeshed in cultural dos and don'ts. Therefore, metaphors use imagery that unmasks the information and makes it accessible.

In this study, we also identified music as an important medium that was used to transmit HIV and AIDS information. Metaphors in music were used to indirectly communicate warnings about seemingly healthy bodies that may be infected by HIV. For instance, a song by Khoza says, “It [the virus] is fattening them . . . they are injured inside.” Master Tongole’s song was found to use misogynistic representation of the female body, as evident in the following lyrics: “musanyengedwe ndi azimayi/ Akumaba moopyseza ndi mbuyo” (don’t be deceived by these women/ they steal by threatening using their buttocks). Despite being misogynistic, the use of metaphors helps the musicians to tackle culturally sensitive topics and to mention human genitalia indirectly.

Discussion

As stated by van Manen (1997), we are in the world in bodily form. When we encounter others, we do so through our bodies in conversational relationship with them. Van Manen observes that these communications occur prereflectively, which makes descriptions of the meaning of those communications inadequate.

The findings of our study suggest that the lived body has a communicative function. The serodiscordant couples drew a distinction between themselves and those they considered as normal. This view was based on the comparison they were making between their old self, before the illness, and their HIV infected bodies. Several studies have shown that illness is associated with contamination and dirtiness in the minds of others encountering an ill individual. In addition, chronic illness is experienced as losing one’s body. Our findings resonate with descriptions of living with dementia in Phinney and Chesla’s (2003) study. Participants reflected on their bodies before dementia and described the smooth flow of body processes that were taken for granted. This state of the lived body was compared to the broken-down body that was no longer habitual. In our study, the brokenness was described in terms of the requirement to take medication routinely. In Malawi, people made lay diagnoses of health statuses, including the HIV status of others, based on the appearance of the body.

The descriptions of living with HIV provided by serodiscordant couples suggest that information about the illness that was on their body was consciously experienced as rendering it transparent to the observer’s eye. People in society were able to make judgements about the type of illness the HIV positive partner was suffering from based on the information the body was transmitting. Cooley (1922) demonstrates this lived experience of the body metaphorically with a looking glass. Cooley suggests that human beings have an imagined image of how they look to the other person. Based on that imagined image, human beings have imagined judgements the other person is making about them. Viewed in the context of Cooley’s (1922) looking-glass concept, this raises a fundamental question about the effectiveness of HIV and AIDS information campaigns that ignore experiential realities of HIV positive people and the lived body as a source of information; as important are the experiential realities of HIV negative partners who are living in a serodiscordant couple. Owing to their HIV negative status, information needs of HIV negative partners in serodiscordant relationships are largely ignored. Our study findings suggest that although these HIV negative partners were not chronically ill, they appeared to go through experiences with their embodied information as if they were chronically ill.

In our study, serodiscordant couples described how, when one partner fell ill, they initially did not believe it was HIV. Although information provided by their bodies was consistent with HIV and AIDS information from books, flyers, radio, and health workers, social constructions of HIV made them believe otherwise. They believed that HIV was an illness for sex workers and not for people in stable marriage relationships. On the other hand, when diagnosed and treated, other people were not able to understand health information that was in the body of HIV positive partners. Socially, people associated slim bodies with illness and plump bodies with health. These views of their own bodies by serodiscordant couples and of bodies of serodiscordant couples by others were alienating. As argued by Svenaeus (2009), the lived body can be alien when it resists and disturbs consciousness. Cox, Griffin, and Hartel (2017) observe that the body possesses knowledge, its senses produce knowledge, and it is able to disseminate that knowledge. In the context of serodiscordant couples, the body possessed information in the form of the virus and physical decline. The body was able to disseminate this information through appearance. However, the couples were self-conscious of themselves as being married. As such, they disbelieved the information in their body.

Everyday life for serodiscordant couples entails two partners with different HIV statuses, intersubjectively inhabiting lived spaces in their communities. As described by van Manen (1997), lived space is the subjectively felt space. Sitting in one's home gives a sense of security, while walking alone on a busy street in a foreign country gives a sense of vulnerability (van Manen 1997; Wella 2015). Therefore, the home was considered safe and protective to the married partners before one of them was infected by HIV. In the descriptions provided by HIV negative partners, we were able to identify undertones of insecurity and betrayal. According to Conrad and Barker (2010), at the level of living with and experiencing illness, HIV and AIDS is socially constructed.

One respondent in our study described metaphors that are used to provide HIV and AIDS information in order to convince serodiscordant couples to use condoms. The metaphor described represented the human body as being at war in order to make HIV and AIDS messages personal and real. Studies have shown that metaphors that use war symbolisms privilege the male gender (Nie et al. 2016; Tate and Pearlman 2016; Chambers 2016). However, in our study, we found that the metaphors resonated with the sociocultural conceptions of the masculine body. Metaphors are also effective in Africa because of the oral culture that uses folktales loaded with metaphors. To be effective, we suggest that the metaphors should be validated by experiential realities of people living with HIV.

In many Malawian cultures, discussions of a sexual nature and mentioning human genitalia in public are not appropriate. This makes the human body inaccessible to HIV and AIDS information providers. Therefore, metaphors use culturally appropriate terminologies to convey sensitive messages that would otherwise be difficult to communicate in plain language. However, as argued by Mawadza (2004), metaphors are also used in everyday talk to describe the appearances of bodies of people living with HIV—metaphors that demonstrate the practice of making judgements about a person's health based on their appearance. As observed by Badura-Lotter (2012), some metaphors used among people with little or erroneous knowledge about HIV and AIDS lead to the creation of lay theories about HIV and AIDS. As a result, people fear to look, speak to, and touch persons living with HIV.

Considering that HIV is incurable, most HIV infected partners felt they had lost their bodies. Their bodies were taken over by the virus. Every day was a constant battle against the virus to prevent it from multiplying. Unlike the healthy body that is taken for granted and operates in the background (Carel 2011), the HIV infected body comes to the fore with routines of taking medication and regular medical check-ups. This brings to mind Defenbaugh's (2008) portrait of a body in a hospital room surrounded by people in white coats, and reduced to tissue, blood, and urine samples. In all this, Defenbaugh suggests, the patient's experiential voice is silenced.

Since HIV and AIDS information describes HIV as sexually transmitted, serodiscordant couples in this study believed they were both infected. Medically, only one partner was infected by the virus. As argued by Svenaeus (2009), phenomenologically, one can be considered ill even when the doctor is not able to find anything wrong. However, Svenaeus refers to the prediagnosis phase of illness. In our study, we found that the HIV negative partners also suffered imagined illness. Though imagined, we argue that this affects their consciousness of the lived body.

The findings presented in this paper demonstrate that the lived body is the medium through which HIV infection is experienced. Although the virus is hidden from the gaze of the other person, through blood-test results, body temperature, and blood pressure, the doctor is able to establish a foreign view of the inside (Svenaeus 2009). Svenaeus adds that the view of the inside can also be established by talking to the patient to understand how they experience their body in the context of the illness. From our findings, we observe that when the appearance of the body changes because of the virus that is inside, it communicates the illness to others.

Our study has demonstrated that the appearance of the body is informative about HIV and AIDS. Based on appearance, people were able to make lay judgements about being infected by HIV. We argue that this, too, constitutes HIV and AIDS information. Perceptions about HIV and AIDS emanating from everyday talk also contributed to the body of knowledge about HIV and AIDS. The following definition of information was developed from the findings in this study: information was stimuli, heard, seen, tasted, and felt, that played a role in formation of perceptions, beliefs, and attitudes about HIV and AIDS. The lived body was identified as an important source of HIV and AIDS information. HIV and AIDS information was additionally conceptualized as including the following: facts about HIV and AIDS from physical items such as brochures; facts, views, and opinions about HIV and AIDS in radio and television broadcasts, and music; talks by healthcare workers; socially constructed views and opinions about HIV and AIDS from others in the community; and actions that communicated certain aspects of HIV and AIDS. This can be contrasted with Buckland's (2017, 5–6) assertion that "in modern society, interpersonal relationships are increasingly indirect, through messages, records, and other forms of documents." The population in our study did make use of documents and radio and TV messages, but it appears that they most appreciated information emerging from direct interaction with people, encountered in bodily form.

Conclusion

HIV and AIDS is first experienced through the lived body. The body that was taken for granted no longer functions properly. During a visit to the doctor, a patient obtains information from the body to determine what is inside. When the illness advances, the physical appearance of the body changes and informs other people about the illness that is in the body. Both the gaze of the doctor and of other people occupying the same lived spaces as the serodiscordant couples are alienating.

This suggests that in illness, the lived body is information rich. The patient experiences changes in the functioning of the lived body. This brings about loss of past abilities that were once effortless, such as walking, gardening, talking. At the hospital, information is drawn from the body in the form of tissue samples or through the use of measuring instruments. Information can also be extracted by allowing the patient to describe the experiences of the lived body.

This research contributes to the study of information for people living with HIV/AIDS by revealing the importance of the body as a source information about HIV/AIDS, something that is absent in quantitative surveys of preferred information sources. Our study findings draw attention to information that is transmitted by the lived body to others in everyday interactions. The spouses of the HIV infected people experience the bodily changes that are manifested as a result of the illness. These bodily changes are indicative of viral load, nutrition, and infectiousness, among other things. Our research adds to the understanding of the social use of information generated by the patient (e.g., when using their own bodies as evidence of the efficacy of medication), an area that Wolf and Veinot (2015) identify as being underresearched.

In addition, our study found that, before diagnosis, serodiscordant couples distrusted HIV and AIDS information provided by their bodies because they perceived that the risk to them of contracting HIV was low. Other people, including some health workers, used body appearance to determine the HIV statuses of the couples—determinations that in most cases were wrong. This is a more ambiguous relationship with corporeal information than is presented by Lloyd (2014), where the body is primarily seen as a positive site of information and learning.

Our study findings have implications for practice and policy. Having identified the lived body as a source of HIV and AIDS information, we recommend that health education materials should educate people about how to decipher changes that manifest on their bodies as a result of illnesses. We have also observed that when information transmitted by the lived body is not understood correctly, it instills fear and panic in other people, resulting in discriminatory practices toward people living with HIV.

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