Walking the Talk, Talking the Walk: Embodied Health Activism in Developing Nations

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How do people with HIV/AIDS in developing nations become public spokes-models and activists who convince other consumers to adopt Positive Living, a radical consumption lifestyle? We find consumers undergo a radical self-transformation so as to qualify to become spokes-models/activists. This transformation process is characterised by a normalisation process comprising three phases: Facing the Worst which reflects from stories of denial, concealment and delayed testing. Walking the Talk includes developing lay expertise, dealing with stigma, and embodying the principles of Positive Living. Talking the Walk includes extending oneself beyond personal concerns and pursuing broad social purposes. HIV/AIDS activists must temper their radicalism and learn to deal with multiple players in a highly socio-politicised contested field.

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Walking the Talk, Talking the Walk: Embodied Health Activism in Developing Nations

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ABSTRACT

How do HIV+ consumers in developing nations become public spokes-models/activists who convince others to adopt Positive Living, a health lifestyle that clashes with local beliefs and customs? We find they undergo a radical self-transformation involving a three-phase normalization process: 1) Facing the Worst, including denial, concealment and delayed testing. 2) Walking the Talk, including developing lay expertise, dealing with stigma, and embodying the principles of Positive Living, and 3) Talking the Walk, including moving beyond personal concerns and pursuing broad social goals. As activists, HIV+ consumers must temper their radicalism and deal with multiple players in a highly socio-politically contested field.

“As my successor they crowned an individual not living with the HIV virus. When he gets around people living with HIV/ Aids, his reactions or emotions don’t mirror that of the audience, because he doesn’t seem to reflect and show the pain that they, as people living with HIV/Aids, feel.” (Mr. HIV/ Aids Positive Living 2006, Botswana)

How do HIV+ consumers in developing nations rise above a serious physical illness and its associated stigma to become public spokes-models and activists who convince other consumers to adopt Positive Living, a health lifestyle that clashes with local cultural beliefs and customs? Our respondent, Mr. HIV/Aids Positive Living 2006, gives us one clue, explaining that when his successor, who is not HIV+, gave a speech, you could tell that he was not a person “walking in our shoes.” Lay people who embody shared experiences with their audience are often perceived as more credible spokes-persons for a cause (Ignatow 2007). Also non-self interested sources are much more likely to convince other consumers to make significant changes to their behaviour (Watts and Dodds 2007).

A prominent characteristic of successful HIV/Aids social movements in the USA is that they were able to mobilize lay experts drawn from existing communities (Zoller 2005). The 1985 STOP AIDS movement in San Francisco emanated from the gay and bisexual community, and ACT UP, established in New York 1987, started as a coalition between the gay and apartheid rights movements. Such hyper-organized activist communities had already established leaders. Often these leaders were HIV+, giving them additional credibility as spokes-persons (Epstein 1995). They also had a superior capacity to generate empathetic identification by sharing with their target audience embodied illness experiences, deemed crucial to creating collective illness identities within illness movements (Brown et al. 2004).

An illness community is most likely to succeed in establishing a collective identity when the illness is widely recognized; if the illness can be linked to previous movements (e.g. the HIV/Aids link to gay communities in the USA); when the movement incorporates socio-political dimensions such as gender, race, or class; and if the movement affects a large number of the population (Brown et al. 2004). In the context of developing nations, HIV/Aids tends not be associated with particular socio-political groups, instead gaining momentum from the fact that the virus affects so many. When no established social movements exist to spin off, HIV/Aids activism must start with small groups of individuals. The situation is complicated by the fact that HIV/Aids is heavily stigmatised, often materializing in the exclusion of people living with HIV/Aids (PLWAs) from paid work and social life (Joachim and Acorn 2000). Our research draws upon an ethnographic study of The 2005 Miss HIV Stigma Free beauty pageant and 2006 Mister Positive Living contest in Botswana and in depth interviews with contestants, activist leaders, experts, and public health administrators in the period 2006-2009. The participants in these pageants are some of the very few people living with HIV/Aids to go public with their HIV+ status. To qualify contestants need to display high levels of lay-expertise about HIV/Aids and show potential to act as effective public spokes-models of Positive Living and activists on behalf of the PLWA community. The consumer behaviour in question-Positive Living-is a constellation of consumption practices that increases the likelihood PLWAs survive and not infect others. At its most basic, Positive Living involves testing to know one’s HIV status; always engaging in safe-sex regardless if one is married or single; having regular medical check-ups to check disease progression; eating a well-balanced diet; stopping smoking; and adhering to prescribed medication, and exercise. Positive Living requires a constant life long commitment to be effective.

Our study is timely for several reasons. First, HIV/Aids is a major killer on a global scale and is happening right now. No cure yet exists but people survive, often for long periods, with antiretroviral (ARV) treatment. Hence adherence to treatment, which is one principle of Positive Living, is a matter of life and death to PLWAs. Second, we observe that thirty years of massive marketing of the Western bio-medical model to the African continent has yielded very modest results in reducing HIV/Aids. A common explanation of this marketing failure is the lack of a consumer orientation needed in markedly different cultural contexts (Swidler 2006). For example the popular slogan “Avoiding Aids is as Easy as ABC: Abstinence, Be faithful, and Condomize” is not easy at all in practice. The main reason is that in African and other developing countries HIV/Aids is spread through heterosexual encounters. This situation is markedly different to Western countries where the virus is mainly confined to gay men and intravenous drug users. In developing countries the HIV/Aids virus typically affects the whole population and corrupts everyday life practices and cultural beliefs about fertility and gender relations (Liddell, Barrett, and Bydawell 2004). You cannot easily ask all people to stop having sex and stop having children.

A third reason is that HIV/Aids Positive Living movements is seen as one of the most successful health movements of all times together with the breast cancer movement (Zoller 2005). HIV/Aids activism has contributed to increased funding, greater medical recognition of alternative treatment approaches and major shifts in how clinical trials are conducted (Brown et al. 2004). Finally, HIV+ activists in a developing country represent an unrecognised and under-utilized epistemic community that operates outside established theoretical frameworks. Prominent anti-consumption factors in developing nations prevent PLWAs from adopting Positive Living with ease (Paxton 2002). Factors include elevated stigma, patriarchy, chronic poverty, alcoholism and a bifurcated political and cultural system in which traditional beliefs often ignore or reframe the disease (Liddell, Barrett, and Bydawell 2005; Physicians for Human Rights 2007).

By focussing on HIV/Aids activism in a developing African nation, we introduce a very different study context compared to the anti-business activism (Kozinets and Handelman 2004) or...
brand activism (Luedike, Thompson, and Giesler 2010) typically studied by Western consumer researchers. Our activists are not anti-consumption of certain brands or products—rather they are promoting consumption of a physical and psychologically healthy lifestyle for people infected with HIV/AIDS and uninfected people who have a high chance of infection. Very significantly physical and psychological embodiment of the disease and the Positive Living lifestyle are crucial to their effectiveness as spokes-model/activists.

In the next section we discuss the concept of Embodied Health Movement (EHM) in relation to consumer research. Then we present our study context and explain why this is a critical case that yields data of particular interest to understanding public HIV+ spokes-model/activists who promote strenuous consumption lifestyle intended to prolong life and improve its quality. Thereafter we analyse the embodied accounts of our informants and link these to theory.

**EMBODIED HEALTH MOVEMENT (EHM) ACTIVISM**

Embodied Health Movements (EHMs) have become the most widespread and empowering form of consumer activism. The term “embody” means to personify and realize in action. EHMs view their constituents as consumers and emerge from grass-roots activity (Ruzek et al. 1999). EHMs are defined by three characteristics: i) the inclusion of the body, ii) challenges to existing medical/scientific knowledge, and practice and iii) the involvement of activists collaborating with scientists and health professionals in crafting more effective treatment, prevention and research, and expanded funding (Brown et al. 2004, p.55).

Embodied illness experiences are very different from the embodied momentarily/in-situ experiences typically studied in by consumer behaviour theorists (see a review in Joy and Sherry 2004). The much cited skydiving experience (Celsi, Rose, and Leigh (1993) and river rafting (Arnould and Price 1993) studies are examples of voluntary consumer experiences that produce highly pleasurable bodily sensations. In contrast chronic illnesses are non-wanted and involve life long stressful and physically painful experiences (Joachim and Acorn 2000). Participants in EHMs not only share with others the bodily experience of living with a chronic illness but also the strenuous efforts needed to follow treatment. EHM activists typically work from both an oppositional and a collaborative position, with the existence of opponents (Brown et al. 2004; Zoller 2005). EHMs can be conceptualized as movement fields where the boundary between experts and lay people become blurred with experts, scientists and public health officials moving in and out of the field. This is a characteristic of “contested” movement fields since they challenge science, diagnosis, treatment and prevention (Brown et al 2004; Ignatow 2007). In such fields lay person expertise becomes important in setting the scientific and the socio-political illness agenda. Normally EHM health activists cannot easily exit the system or escape their opponents, as they are dependent on medical expertise and public health to treat their illness.

**RESEARCH CONTEXT AND METHOD**

In June 2001, Fetus Mogae, then President of Botswana summed up the situation: “We are threatened with extinction. People are dying in chillingly high numbers. It is a crisis of the first magnitude” (Farley 2001, A3). From 1992 to 2004 the life expectancy at birth in Botswana fell by 29 years (Stover et al. 2008) and the most recent infection numbers show that in the reproductive population age groups up to 40% are HIV positive (NACA 2009). To combat the problem Botswana became the first African country to provide free antiretroviral (ARV) treatment countrywide and since then number of people taking the drugs has grown from 150 in January 2002 to 117,045 in December 2008. In 2003, 85% of Batswana1 lived within 15 kilometres of a health care facility that offers free and confidential testing. See Exhibit 1 for a time line of HIV/Aids events in Botswana 1985 to 2015.

Data comprises in depth video-taped interviews: April 2006 in Botswana of two participants from The 2005 Miss HIV Stigma Free Beauty Contest; six participants in 2006 Mr Positive Living Contests; Mr Positive Living 2008, six HIV/AIDS experts working in the public health sector; a national leader of a PLWHA support group; a Pentecostal pastor, a volunteer youth leader and six non-infected consumers. The 2006 Mr Positive Living Contest and related workshops and events were video-taped. Subsequently we regularly collect data via email and telephone conversations and in Spring 2009, a second round of interviews was conducted with five of these respondents plus the 2008 Mr. HIV/Aids Positive Living. Since 2006 we have collected over fifty related press articles and transcribed videos produced by the BBC, Botswana TV and home videos made by informant’s families. All interviews and footage are transcribed and described in full. Materials in Setswana were translated into English by a native Setswana speaker. The two authors individually and together watched all the video footage and read the transcripts. Throughout this interactive process we structured and coded the data/quotes according to theory. A Batswana research assistant with over eight years experience in medicine, public health and HIV/AIDS in Botswana reviewed our findings for factual reliability and face validity.

**FINDINGS**

Consumers undergo a radical self-transformation to qualify to become spoke-models for HIV/AIDS Positive Living and activists of PLWA community. This transformation process is characterised by normalisation, a process whereby the chronically ill incorporate management of their condition into their everyday routines so as to live healthy more productive happy lives (Joachim and Acorn 2000). Three phases of normalization typify this process: i) Facing The Worst, ii) Walking the Talk, and iii) Talking the Walk.

**FACING THE WORST**

Facing the worst involves the first and arguably most difficult step in Positive Living, namely, taking a HIV test and learning one’s positive status. Two approaches typify this phase: concealment and acceptance.

**Concealment.** Concealment, a normalization strategy, involves people avoiding stigma and alienation by hiding attributes from others that contravene the norm (Goffman 1959; 1971). The concealment strategy involves tactics such as not admitting to the affliction, making extraordinary efforts to maintain a normal appearance, and keeping up with others in spite of suffering (Royer 1998). This reflects people’s strong need to fit in with healthy people. Clearly the testing is a critical event and the respondents remember the day they tested. “I tested for HIV in 5 April 2001; I can never forget that date, because it was another defining moment for me” (Amogelang). “The 17th of April, 1993 I took the test and the results were released on the 28th of April, 1993. That is when I learned about my positive status. I was put on medication and began to get better” (Andrew).

Consumers typically test after prolonged and highly alarming physical ailments. “I used to be young and vibrant sexually active. 1The term Batswana denotes a person who is a citizen of Botswana. 2All informant names are pseudonyms.
I was living in South Africa. I used to drink alcohol, young and vibrant. I was raped [but] I didn’t check after the rape. In 1997 I had herpes-shingles and the doctor said I should just take care of myself and use condoms. And I thought: “Why should I use condoms?” This attitude suggests that even after unusual illnesses and doctors’ advice to test, consumers continue to deny their risk.

Some consumers conceal their illness experience by explaining their motivation to test as a spiritual revelation. “I quickly dropped into the traditional doctor who threw down divination bones but to no avail. I tried several to know avail. [Then the spirit within spoke to me] “You have tried little tricks but to no avail. Don’t you recall this HIV thing?” It came to my mind and I said “Ah! I never felt sick. This must be the thing. Then I went for a HIV test” (Paul). Others deny their illness even when a close family member dies. “My brother was really sick before he went for a HIV test. It was too late” (Andrew). Both these cases were before universal access to ARV treatment was implemented. Researchers find that amongst HIV+ people, denial is a psychic numbing that protects the self from being over-whelmed by excessive amounts of anxiety (Courtney, Merriam, and Reeves 1998).

Some consumers are confronted by considerable reluctance by others to believe they are HIV+; especially if they are asymptomatic, for example they can accuse them of working for the government (Physicians for Human Rights 2007). Keneilwe, Precious’s mother explains: “When she got better from the bedridden state …They thought “No,” the government must have bought and paid her to advocate; why isn’t she looking sick, wasted and not altered in anyway?” Such views are evidence of another denial strategy, in which Batswana consumers associate the disease with negative ideas about the modern state; associations with deadly disease, bad western influences and promiscuity, thereby contravening traditional Botswana cultural norms of morality and disease causation (Heald 2006).

Acceptance. An acceptance strategy is another normalization strategy which reflects the polyphonic narratives of Ezzy’s (2000) HIV+ informants. People focus on living in the present and recognize that new treatments may not be able to help everyone. They accept the finitude of human existence…with one respondent saying: “Everyone’s dying darling” (Ezzy 2000; p.613). The HIV+ status of Magic Johnson can speed acceptance. “They showed me these tablets– ‘Combivir’ and said ‘it’s unlike before when you are positive–you can be given antiretroviral medication. You’ll be just like Magic Johnson,’ I said, ‘Okay. Well let me go have the test’” (Precious). A US study found that testing rates accelerated enormously after Magic Johnson disclosed his HIV+ status and taking of ARV (Tesoriero et al. 1995).

Some consumers are motivated to test by public health messages and media reports that raise awareness of their disease risk. “I just took the initiative to do such [to test] urged on by what I regularly heard on the radio, TV-about changing partners. When you visit health clinics they talk a lot about HIV . So considering my life style is what made me find the courage to take the plunge and test. I wasn’t exactly an innocent and careful boy, you know” (Otsile, smiling). The ability to accept one’s risky lifestyle makes a positive diagnosis less shocking (Courtney, Merriam, and Reeves 1998); although consumers know their inability to keep their positive status a secret is likely to expose them open to stigma. “I knew how naughty and careless I lived prior to this, so I kind of expected what was coming. After knowing that I’m HIV+ the first thing that came to my mind was ‘what will people say?’ because obviously I’m going to share it with somebody because I can’t really live with it alone, and somebody is going to tell the other one” (Otsile).

Female consumers may more readily test if they are not living with a male partner. “I tested for HIV in 1996, and turned out HIV negative. I used to read books and magazines published in South African magazines about people living with HIV” (Amogelang). Such actions suggest some consumers; albeit a very small group can be open testing even if testing is relatively inconvenient or very few others have tested (See Exhibit 1). However later they may delay retesting because their sexual partners are reluctant to do so.
“It really took me a long time to do the (re)test because my partner at the time kept procrastinating. It was probably, just approximating, nearly two years since I had wanted to test” (Amogelang). A Batswana HIV/AIDS expert attributes this specific behaviour to patriarchy: “Women are looked at as kind of inferior beings. The man is in control and he is so macho that he doesn’t feel the epidemic” (Itumeleng).

**WALKING THE TALK**

Walking the Talk involves efforts to incorporate the values and norms of Positive Living into everyday life for the rest of one’s life. HIV+ consumers understand the extensiveness of this behavioural modification project, admitting the process takes considerable time. “The overall change is not an easy thing. [Positive Living] is not an overnight thing. You can achieve several things within a long while” (Christopher). Walking the Talk is evident when consumers begin exerting considerable control over disease symptoms and outcomes. Mastery is the normalization strategy that typifies this stage, tactics including developing lay expertise, generating positive social comparisons (Royer 1998), and ignoring the negative aspects of their condition as much as possible (Royer 1998). A more extreme form of master includes an overconfident certainty about how long one will live and a belief that new effective treatments will always be forthcoming (Ezzy 2000).

**Coping with Stigma.** Up until recently, HIV+ positive consumers were severely stigmatised in Botswana (Physicians for Human Rights 2007). “I was at a club, a girl, she was pointing at me, “Look she’s the one; she’s the one. She’s HIV+. I think they were thinking I was not supposed to be at the club” (Amogelang). HIV+ consumers can reduce stigma by elevating themselves above other consumers who stigmatise them. A common approach is to assert that people who stigmatisate others for their HIV+ status are often people who have not had the courage to test. “If they are pointing their fingers at me, they don’t know their status” (Donald). They assert that as a result people can manifest AIDS related illnesses. “Many people who have been stigmatising to other people, I saw them to the hospital, critical sick” (Joseph). They can appeal to notions of Christian sisterly/brotherly love when condemning such uncharitable actions. “It’s very bad because Jesus loves us. God loves us. He loves everyone, whoever you are. You must accept that any human being is your brother, is your sister, is your mama, is your child” (Joseph).

HIV+ consumers can reclaim their place in humanity by rejecting a victim status. “I’m not a victim, because a victim is powerless. I’m nor a sufferer because suffering is nothing but a helpless prayer. I’m not a statistic because statistics are nothing but numbers. I’m a human being with flesh and breath.” (Precious quoted in Colours Magazine Issue 67). They can counterbalance self-stigma by highlighting the advantages of knowing their status and access to life-saving treatment. “The good part is living, knowing my status. The worst was fear and blame—I didn’t protect myself” (Andrew).

Some consumers reduce stigma by likening HIV/Aids to other serious chronic illnesses. “I realised that being HIV+ is like being infected with any other infection” (Otsile). They reduce associated self-blame by attributing the cause of their infection the forces far beyond their control. “I must accept. As much as many other illnesses are being handled that are brought by nature….This is just a condition I acquired. I couldn’t do anything because I never made an application to it. But then as fate would have it I got struck down the line” (Paul).

Sometimes consumers fight discrimination by challenging authority. “I actually said to them: ‘If someone else had cancer you would give chemo to them–now just because I have the HIV virus you won’t give me the same privilege’ (and) look I’m still alive’” (Precious). Similarly they can counteract stigma by taking the opportunity to demystify the disease in other consumers’ minds. “Yes they did try to discriminate against me but I counteracted by seizing the moment to let them know what HIV was really” (Amogelang). Other times consumers can quietly accept stigma while at the same time refusing to hide their condition. “If I go for a job and I include documents that show I am HIV+ leads to me not being accepted. It used to pain me before, but after sometime I just acknowledged and normalized in order, not to pain myself with such rejections, urging myself to just continue living life as it is and continue to advocate for living with HIV” (Tau).

PLWAs typically achieve self-acceptance through the acceptance of others, including other HIV+ consumers in support groups. “Just seeing other people who are living with HIV can relieve one off the burden they carry from receiving their results. Most of us have gone through the same stages and ordeals so we can help and encourage one another through difficult times. So we just share the experiences, I mean that’s how we help one another” (Amogelang). Talking with others is very important, facilitating the reconstruction of shattered assumptions, and reclaiming the control lost through the diagnosis (Courtney, Merriam, and Reeves 1998). “After meeting with the leader of the support group, she told me she herself is HIV positive. That she is public and open about her positive living with HIV for many years. That encouraged me to be open and tell my friends about my HIV positive status” (Otsile).

**Normalization Disease Treatment.** Consumers can have difficulty taking ARVs regularly (Weiser et al. 2003). The erratic nature of everyday life, especially for poor people in Sub Saharan Africa, means some consumers cannot predict their whereabouts on a daily basis (Physicians for Human Rights 2007). The stigma associated with HIV means they tend to prefer taking their medication out of the sight of others, for example at home. “I’ve been taking them about 4 times a day for 3 years. So that requires adequate time management…I could be held up somewhere away from home... (And) could do be forced to abandon whatever I would be doing and rush home to take the medication” (Otsile). Other consumers minimise the effort associated with taking medication. “I’m taking the ARVs. It’s more like food. You are eating food in order to live. It’s a normal thing that I take at eight o’clock” (Christopher).

The buddy system in Botswana, which comprises a network of consumer companions (Gammonley 2006), involves experienced consumers helping other consumers one-on-one to adhere to their treatment schedule. “The buddy operation is whereby you give a sick person love, care, and support. You make time to remind and to visit your client-to check how on well he or she is keeping up” (Paul). Such peer-to-peer partnerships result in benefits for both parties; less hospitalisation, improved medication adherence and higher satisfaction with life (Solomon 2004).

Not surprisingly consumers can find adjusting to safe sex difficult. “It was hard for us to change our behaviour, especially using condoms” (Boitemelo, wife of Joseph). “In the beginning I was worried she is falling in love with someone but in the end I heard what the counsellors said–what they are teaching us. I started to talk to my wife: ‘It’s better to put ourselves in a good mood, use condoms instead of using flesh to flesh because flesh to flesh is no good’” (Joseph). In patriarchal societies, such as Botswana, condom adherence may be especially difficult. A widespread saying in Botswana, derides use of male condoms: “A sweet is never eaten with the wrapper-you have to uncover the sweet and then it becomes–sweet” (Helle-Valle 1999). Other consumers sense that people blame, ARVs for promiscuity. “We have a tendance to
blame these tablets (ARVs) as the ones encouraging or appetizing you to engage in sexual intercourse. But that is not the case; it’s our minds that are polluted by dirty thoughts” (Precious). Some consumers abandon penetrative sex altogether. “I have decided not to have sex. I fear re-infection myself. I rather prefer casual love, you know, mutual masturbation” (Christopher smiles). Consumers tend to limit alcohol because they understand that they are likely to behave sexually irresponsibly if they become drunk. Joseph, an ex-soldier, explains that drunken men don’t take no for an answer. “When he is drunk, there is no control. If a girl says: ‘No, no I don’t like it’ He will force the lady to make love or to have sex with him.”

When consumers live relatively symptom free and/or follow the positive living tenets they can develop heightened feelings of control. “To me is just the most present virus and it is said you know that as smart as the virus is we have to be even smarter. (A big smile and laugh). So I believe I’m smarter than the virus now” (Paul). The control may largely illusory rather than actual. “As for my HIV it knows that I intend to be here in 2016. HIV will not kill me, only God knows how long I will live and when I shall die… It will not kill me, why, because I do all that is necessary to take control’ (Precious).

TALKING THE WALK

Talking the Walk involves volunteering for, and qualifying to, become PLWA spokes-model/activists. Three activities characterize this phase: 1) Self Transcendence, and 2) Staging Normalization, and 3) Tempered Radicalism.

Self Transcendence is the capacity to extend oneself beyond personal concerns and pursue broad social purposes and activities without devaluing the self (Coward 1990). Consumers are triggered to transcend themselves after experiencing revelations, in much the same way as Kozinets and Handelman’s (2004) activists. They link a newfound commitment to others to their spiritual beliefs. For some consumers, these transformative moments occur after failed attempts at suicide. “That was a turning point. It was like God refused to let me die. It was a turning point in my life. I started becoming the new Precious. I saw other people living with the virus and I thought, why can’t I be more like them? I got basic training in leadership and public speaking. I think it was my calling, because I wanted to share my message with the whole of society (Colours Magazine Issue 67). They explain their activities in spiritual terms. “[Precious] was passionate about starting cancer club, saying that shepherd does not have to expect anything in return.” (Precious’s sister). Other consumers can liken them to self-sacrificing spiritual figures, such as Jesus. “I was pleased because she chose to be a sacrificial lamb, a sacrifice to help teach and sensitize the community and nation at large” (Keneilwe, Precious’s mother).

Others link their revelations to more practical matters, such as the urgent need to reduce denial of the disease’s existence. “In 2003 it dawned on me that, I am a youth, and would like to be exemplary and sensitize the up and coming youth that the virus that is always being talked about is indeed out there. So I told my immediate social group that I wanted to publish my status because I want my voice to be heard, give HIV a face in the community and help them realize and see that HIV is life and amongst us” (Tau).

Some consumers appear driven by heroic patriotism. “I want to help the nation. I wanted to put men at the forefront to show not only women are infected by HIV & Aids (Andrew). “I’m a hero forever because I will live a normal life and my disclosure has saved other people” (Joseph). Significantly consumers must ultimately be driven by passion rather than hope of financial reward. “I was crowned the first Mr. Positive Living in 2006, but my aspiration and intentions went on to never be fulfilled, mainly because those people who were running the Mr Positive Living, told me that this was just a pilot project, so it does not have funds” (Tau).

Staging Normalization. Consumers understand the importance of public accountability to being effective role models of Positive Living. “Those young men (Mr Positive Living contestants), who are in the pageant, if they don’t change their behaviour, people won’t believe them. If they go back and become drunk, people won’t believe them… [They] have to be an example to people of what is supposed to be happening” (Donald, founder & director of the organization of Mr Positive Living). They also understand its reciprocal benefits for themselves. “To declare my HIV+ status publicly, to me it was a challenge because I was not living a safe life” (Precious). They become more motivated to practice what they preach. “Before [Precious] went public with her status she was a naughty girl. She used to go out to the clubs, she was young and vibrant. But now she is my lovely daughter, she obeys me, she stays at home…. before she used to be naughty and off leash” (Khumo, Precious’s mother).

PLWAs realise that drawing on their experiences helps them to connect with members of their target audiences and dispel some of the myths surrounding HIV: “What I’ll do is tell them of my experiences living with HIV AIDS and the consequences of living with HIV AIDS and tell them that HIV AIDS is not only meant for old people. Even a youth like me—I will use myself as an example—I’ve been living with it” (Tsitsi). They believe that they can appear more credible to their PLWAs than experts: “There are consequences of not adhering to medication. She or he (HIV + positive consumer) will take whatever I say, unlike the trained counsellor or the doctor that I can assure you. We are the people living with HIV/AIDS” (Precious). Consumers learn to articulate their experiences via public speaking training seminars given by COCEPWA (Coping Centre for People with Aids). They also regularly attended workshops by COCEPWA where they develop lay-expertise in the disease and its management.

Tempered Radicalism strategies recognise that chronically ill or disabled people face a dilemma (Royer 1998). Alternatively they can seek to cover up and treat their ailments so that they can participate in everyday life. However, simultaneously, they need to demand much more financial, medical and emotional support from the government compared to the “normal population.” Particularly the HIV/AIDS health movement must collaborate with authorities to secure access to ARVs (Epstein 1996/ibid). HIV+ activist s can strive to motivate PLWAs to make the best use of the resources supplied by the Botswana government. “It is sad that all the time when the national budget is announced…All our revenue goes to AIDS [and] we refuse to adhere to medication-also refusing to work for ourselves, pretending to be sick. My friends we are not sick, we live with the virus. As PLWA we have [sadly] a dependency syndrome tendency.” HIV+ spokes-model/activists are therefore different to radical anti-consumption activists who think that they must always aggressively confront their adversaries, otherwise they cannot convince non-activist consumers and the corporate elite (Kozinets and Handelman 2004). HIV+ EHM activists have a much more demanding activist role as they need to be knowledgeable of, understand, and deal with multiple players in a highly socio-politicised contested field. They cannot isolate or detach themselves from other consumers, scientists, health care providers and politicians because they depend on them to live.
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