Early Adopters in the Diffusion of an HIV/AIDS Public Health Innovation in a Developing Country

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Early Adopters in the Diffusion of an HIV/AIDS Public Health Innovation in a Developing Country

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ABSTRACT

Public demonstration by early adopters of innovation benefits tends to reduce consumer resistance to HIV/AIDS public health innovations. However, elevated stigmatization, bifurcated culture, gender power relations and poverty make such public displays hard to enact in developing countries. To learn more about this difficult context for diffusion of a public health innovation, we investigate early adopters who act as public spokes-models of HIV/AIDS Positive Living in Botswana. With limited institutional support these consumers create and enact multiple roles, such as buddy, lay educator, support group member/leader and social entrepreneur. Analysis of these highly committed courageous individuals expands our understanding of the requisite personal qualities, capacities and roles of early adopters of HIV/AIDS public health innovations in developing countries.

INTRODUCTION

Early adoption is central to diffusion of innovations theory. Yet the consumer literature is remarkably silent regarding early adoption of HIV/AIDS public health innovations (PHIs) (for an exception see Rothschild 1999). We address this theoretical lacuna by investigating early adopters of HIV/AIDS Positive Living, a public health innovation in Botswana. HIV/AIDS Positive Living comprises a set of interrelated behaviours such as knowing and accepting one’s HIV status, disease management including adherence to medication regimes, caring for people living with HIV/AIDS (PLWHAs), supporting the PLWHA community and engaging in social and political outreach. Our research draws upon an ethnographic study of The 2005 Miss HIV/AIDS Stigma Free beauty pageant, The 2006 Mister HIV/AIDS Positive Living contest in Botswana and follow-up interviews in the period 2006–2009. Competitors are some of the very few people living with HIV/AIDS (PLWHAs) in Botswana to go public with their HIV+ status and to advocate positive living. We observe that these consumers attempts to influence potential adopters are severely impacted by: (1) the stigma associated with a potentially deadly sexually transmitted disease, (2) resistance to an obviously Western styled bio-medical model that fails to address negative attitudes to external intervention in post colonial countries (Swidler 2006); and (3) denial of the disease’s existence stemming from cultural beliefs about the origins illness, gender relations, fertility and sexual practices (Liddell, Barrett, and Bydawell 2004).

This paper comprises a short literature review of the diffusion of PHIs and early adopter roles in diffusion of HIV/AIDS PHIs. Findings are presented in two sections as follows: (1) the different pathways to the adoption of HIV testing, (2) the adoption of Greater Participation of PLWHAs Principles (GIPA). The discussion highlights implications for HIV/AIDS PHIs. We conclude with contributions and future directions for research.

EARLY ADOPTION OF HIV/AIDS PUBLIC HEALTH INNOVATIONS

Rothschild (1999) explains that consumers typically resist public health innovations (PHIs) for distinctive reasons. When confronted by PHIs, consumers tend to act in a self-centred manner adopting a short term perspective. They refuse to acknowledge that their individual failure to adopt could result in negative consequences for themselves and broader society. The benefits of non adoption are often immediate; while the benefits of innovation adoption are delayed and appear vague. Goldberg (1995) points out that upstream factors, such as economic, political, cultural, technological, and public sector infrastructure factors, can increase consumer resistance to PHIs (Goldberg 1995). For example, PLWHAs who are poor and have poor food security can stop taking their antiretrovirals (ARVs) because the medication increases their appetite and prevents them from experiencing a restful night’s sleep.

Who are the most effective endorsers of HIV/AIDS innovations? An extensive review of spokespersons in HIV/AIDS PHIs finds that experts, rather than HIV+ educators are most influential when they demographically and behaviourally match their target audience (Durantini, Albarracin, Mitchell, Earl, and Gillette 2006). Elaborating upon this idea, Watts and Dodds’ (2007) propose that a critical mass of “moderately influential” early adopters (the common man) are the ones who propagate widespread diffusion of innovations generally. Rossiter and Bellman (2005) suggest that the common man is well suited to public health announcements as targets typically seek to identify with the spokespersons in such messages. These ideas suggest that one way to optimize the advantage of expert credibility and consumer matching is to sufficiently increase common-man consumer expertise.

Consumers are likely to face numerous barriers when considering testing to know one’s HIV status, the essential first step in Positive Living. The primary barrier to HIV testing is the fear of learning one’s status (Valdiserri et al. 1999). High risk persons may be more worried about the result and tend to postpone HIV testing. Most HIV-infected persons remain undiagnosed until the onset of AIDS (Valdiserri et al. 1999). For consumers in developing nations such as Botswana, social stigma, lack of perceived HIV risk, and fear of having to change sexual practices also hinder testing (Weiser et al. 2006b). In developing countries with limited social security and employee rights protection, a sero-positive HIV- test tends to change a person’s one’s life radically. PLWHAs often lose most sources of emotional and economic support, namely their jobs, partners and friends.

Informed by this short review, this paper focuses on two broad research questions: (1) what propels consumers in developing nations to adopt bio-medical HIV-testing and how do they adapt to their sero-positive status?, and (2) what roles do early adopters who go public with their positive status take in the early diffusion of knowledge about living positively with HIV/AIDS? In Botswana, as in many other countries, very few PLWHAs talk about their status. Hence the testimonies of PLWHA informants who want to play a public role in diffusion of HIV/AIDS PHIs are very unique.

RESEARCH CONTEXT AND METHOD

Botswana, an economic and socially stable postcolonial Afri- can democracy, has one if the highest HIV/AIDS prevalence rates in the world (NACA 2009). Despite substantial government health campaigns since 1989 (Avert 2009), by the end of 2004, only 11.4% of Botswana’s population of 1.7 million had ever tested to know their HIV status (NACA 2009). Estimates around this time placed Botswana’s infection rate as 24% of adults (Stover et al., 2008). In 2002, Botswana was the first African country to provide free antiretroviral treatment countrywide. In 2004 Botswana introduced...
routine testing public health facilities (NACA 2009) to reduce the stigma linked to seeking testing at designated HIV/AIDS testing centres.

Data sources: Data comprises multiple types and sources. Field notes and conducted interviews were conducted at the Global Health Conference and Gender Office in November 2005 in Gaborone, Botswana. This data collection was followed by extensive video-taping of interviews in March–April 2006 in Botswana of two participants from The 2005 Miss HIV Stigma Free Beauty Contest, six participants in 2006 Mr Positive Living Contests, five HIV/AIDS experts working in the public health sector, a national leader of a PLWHA support group, a Pentecostal pastor and a volunteer youth leader. Thereafter follow-up interviews via email, phone and face were conducted in the period 2006–2009. See Appendix 1 for Informant Details.

We shot video-tape of The Mr Positive Living Contest, related workshops and events. Subsequently we regularly collected data via email, telephone conversations and follow-up interviews over a period of three years. We collected over fifty related press articles. We transcribed videos produced by the BBC, Botswana TV and home videos made by informant’s families. All interviews and footage were transcribed and described in full. Materials in Setswana1 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 guided by theory. A research assistant from Botswana with over eight years experience in medicine, public health and HIV/AIDS in Botswana reviewed our findings for factual reliability and face validity.

FINDEINDS

Informants’ reports indicate that early adoption of HIV/AIDS Positive Living involves two adoption processes: 1) initial HIV/AIDS testing, and 2) adoption of The Greater Participation of People Living with HIV (GIPA) Principles. HIV/AIDS testing involves two sub-pathways: The normative and delayed testing pathways. Figure 2 presents these early adoption pathways as flow charts. We discuss these pathways below.

1. HIV/AIDS Testing Adoption Pathways

1.1 The Normative Testing Pathway (NTP): The normative testing pathway is the mode of early adoption to HIV testing typically underlying PHI design. This pathway assumes a proactive consumer who is educated about the disease and on his/her own accord seeks testing. Three of our informants fit the definition of NTP as they clearly recall exposure to the HIV/AIDS PHI messages in the media and/or at public health facilities, which makes them aware of their high risk lifestyles. Subsequently they attend health facilities and request testing. “I just took the initiative to do such, urged by what I regularly heard on the radio, TV… So considering my life style… recollecting all that I had done…is what made me plunge the courage to go testing. I wasn’t exactly an innocent and careful boy, you know” (Otsile–smiles). Amogelang, also admitting to multiple sex partners, initially tests because she wants a baby. After testing negative, she has unprotected sex with males who reassure her of their negative status. Retesting reveals she has subsequently become infected with the virus. To outsiders, her behaviour might seem reckless, yet it is more understandable when one appreciates that in Botswana infertile individuals are socially invisible (Upton 2001). Joseph and Bontle do not openly admit to a sense of risk but test anyway: “We heard on the radio…When we went for testing, we did not suspect we were HIV+. We just went to know our status” (Bontle). Perhaps Joseph’s period in the army, in which he spent many months away from his wife, and his discharge from the army for drunkenness, is an unspoken reason for testing between husband and wife.

1.2 The Delayed Testing Pathway (DTP): This pathway suggests that consumers are in heavy denial of their HIV/AIDS risk and hence resist testing, despite suffering chronic illnesses. They provide not any, or only vague reports of exposure to HIV/AIDS PHI messages. Arguably high risk consumers attend poorly to such messages because they do not regard themselves as part of high risk groups (Raghubir and Menon 1998; Valdiserri et al. 1999). Precious, a technical college educated ex-legal secretary, with a school teacher mother, admits her to promiscuous ways. She believed that she was immune from the disease; perceiving she was not from the social-class linked to the disease, that is, poor, rural, and uneducated. She elaborates that the family of her HIV+ boyfriend’s upper middle-class family does not openly acknowledge his HIV+ status, despite the death of his previous girlfriend and their baby (a grandchild) from HIV/AIDS. After testing positive, Precious becomes very suspicious that not one of the upper level Batswana2 officials that test publicly, tests positive. These accounts add weight to the idea that Batswana, like many people worldwide, regard HIV/AIDS as the disease of a heavily stigmatised other.

DTP informants acknowledge the contribution of excess alcohol to unsafe sex. 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. “After learning of their HIV+ status, some DTP informants experience prolonged self-stigma, anger, denial, and desire to escape, including contemplating or attempting suicide. Precious explains: ‘Then they told me ‘Woman, you’re HIV positive.’ Then I just took off …I had anger, denial, blame to an extent that I even started saying I had been bewitched by my family… I thought I was a black sheep in the family (Precious).’ Precious suffers many serious illnesses before a doctor persuades her to test in 2000. Critical to her test decision, is the influence of an international PLWHA celebrity role model, and the knowledge that treatment is available. “Then they showed me these tablets–‘Combivir’ and said ‘these days it’s unlike before, when you are positive—you can be given antiretroviral medication to help you. So if they detect the virus in you, then you can take these tablets and you’ll be just like Magic Johnson.” Because I used to be a sports lady playing table tennis …because I had heard about Magic Johnson, I wanted to be just like Magic Johnson! Then I said ‘Okay. Well let me go have the test.’ (Precious).” In 2000 only .02% of Batswana had ever tested (NACA 2009) and Precious’s bravery cannot be overstated.

A comparison of the normative and delayed testing pathways points to aspects of theory. Testing by our informants suggests that they have a greater preparedness to take risks compared to the rest of the population. As stated earlier only 11.4% of Batswana had ever tested by December 2004 (NACA 2009), a time point at which all informants had tested. This finding validates the diffusion of innovation literature, which suggests that early adopters (typically first 16% of the population to adopt) are more risk-prone (Watts and Dodds 2007). However deviating from the diffusion of innovation literature, most of our informants do not have higher incomes, formal education or greater social participation compared to others. Rather they tend to come from poor backgrounds, have little formal education and confine themselves to village life.

Informants’ behaviour suggests that the degree to which a person experiences feelings of self efficacy after learning of a HIV+

1Setswana is the national and majority language of Botswana.
2Batswana are members of a Bantu people living chiefly in Botswana and western South Africa.
result influences their ability to manage the disease. Schwarzer and Renner (2000) find that a person with high self efficacy is likely to take positive steps to address HIV+ status, whereas a person with low self efficacy is likely to experience feelings of hopelessness. Contrasting Paul and Precious’s cases illustrates this point. Paul refuses to stigmatize himself and takes a matter of fact attitude towards his medication. “I sat down, and re-evaluated myself. And then came up with a thought of say ‘What is this?’ ‘This is just a condition I acquired’. And I couldn’t do anything because I never made an application to it… I have to accept. Because I don’t want to die–I don’t want to kill myself… So I must accept…I’m taking the ARVs, it’s more like food…you are eating food in order to live…it doesn’t bother me (Paul).”

At the other extreme are Precious’s mixed reactions. After testing positive, Precious falls into despair, despite strong family support. She does not take her ARVs regularly and becomes resistant to the drugs. She attempts suicide. Upon recovering, she resolves no longer to play the AIDS victim. She strictly adheres to
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a drug of last resort. She becomes an active member of the PLWHA community and goes onto become a celebrity spokes model for positive living. Despite her efforts, Precious develops a severe form of uterine cancer and receives radiation therapy to eliminate the tumour. So weakened is her health by the radiation, that she develops a deadly strain tuberculosis during a trip to a HIV/AIDS conference in Canada. After six months hospitalisation, she is flown home. Tragically Precious dies a few days later, six years after testing positive. Precious’s plight underscores the importance of testing to know one’s status. Drug therapies don’t work so well for those who have been infected for a long time (Brashers, Neidig, Cardillo, Dobbs, Russell and Hass 1999).

Implicit to the normative and delayed testing pathways are very different assumptions about the tactics that induce early adoption of HIV testing. The normative testing pathway assumes that few factors impede the motivation, opportunity and ability to test (Rothschild 1999). Consumers are motivated to test by self interest, because free life-saving ARVs are available (NACA 2009). Consumers have the opportunity to test because testing sites are conveniently located in Botswana (Steen et al. 2007). Finally, partners or family do not reduce consumer’s ability to test through social disapproval. The delayed testing pathway wrongly assumes that education is enough to motivate testing and hence fails. Unless consumers truly believe that effective and manageable treatment is available and that they are at risk, the extreme stigma associated with a deadly contagious sexually transmitted disease such as HIV/AIDS will largely prevent testing.

2. Adopting Greater Participation of PLWHAs’ (GIPA) Pathway

Informants report that adopting GIPA principles is a gradual, difficult and prolonged process. “It is not an overnight thing you can achieve” (Paul). Essential to this adoption process is participation in the PLWHA community, by initially becoming a member of a local support group.

2.1 Participating in PLWHA Community. All informants report substantial benefits from attending local support groups. First and foremost, meeting regularly with other PLWHAs and sharing stories, makes them feel less isolated, less ashamed and better able to manage their disease. “After meeting with the leader of the support group, she... told me that she herself is HIV positive, that she has been living positively with HIV for many years. That is my virus. I do not share it with no one.” These sentiments contrast markedly with Otsile’s previous stigmatisation of PLWHAS. “Before I knew my status, I didn’t want anything to do with an individual living with HIV... I hated them” (Otsile). For Precious, meeting with other PLWHAs changes her life. “That was a turning point...I saw an advert written ‘Coping Centre for People Living with HIV and AIDS-COCEPWA’, saying they were looking for a secretary–someone living with the virus...but I thought ‘let me just go to COCEPWA and hear–maybe I will have more information about HIV/AIDS’.” At COCEPWA Precious learns about the HIV virus and AIDS and trains in counselling and public speaking. She goes public about living with HIV. Her opening line in public settings becomes “My name is Precious and I am a lady living with HIV/AIDS.” Such a bold statement is very unique for a PLWHA anywhere, and should be considered a peak moment for expressed consumer voice in a developing nation.

Informants realise that going public about their sero-positive status contributes to building a consciousness of kind amongst PLWHAs in Botswana. “If I become Mr Positive Living, HIV Positive Living...I want to see the people taking action identifying themselves with me-to create or establish a common front or the onslaught of this virus (Paul).” They also realise that PLWHA community building is a means of gaining empowerment and achieving better treatment from civil society and the government. “The leaders think that as PLWHAS... we are powerless and worthless. So there is no one advocating for us, (so we do) (Precious).”

2.2 Acquiring Disease Management Skills. Being accepted by others as well as self is important for PLWHAS. Public disclosure reduces the high stress of living secretly with the disease that can erode the immune system (Holt, Court, Verdhara, Nott, Homes and Snow 1998). Some asymptomatic informants report that achieving social acceptance within their immediate social groups is difficult. People don’t believe they are infected. “After I went public about my status, some people accused me of lying... I mean even when I show them my hospital records; some of them disregard them and insist on wanting to have unprotected sex” (Amogelang). PLWHAs need to have safe sex if they wish to reduce HIV infection rates. They also need to publicly show that they are being socially responsible otherwise they will be further stigmatised. Precious states: “It’s my virus. I do not share it with no one.” PLWHAs should also seek to avoid re-infection; unprotected sex can result in cumulative re-infection as well as infection by new strains of HIV/AIDS. PLWHA couples can find conversion to safe sex difficult. “It was hard for us to change our behaviour. Especially using condoms...In the beginning I was worried she is falling in love with someone but in the end I heard what the counsellors said (Joseph).”

In strongly 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). Informants often emphasised the importance of eating nutritious meals to stave off disease progression. However observation suggests that on a daily basis PLWHA informants often had little idea of where their next meal would be coming from.

2.3 Influential Diffusion Roles. An emic account of the data suggests that early adopters who are public spokes models can adopt at least twelve roles that potentially influence adoption of Positive Living. The capacity of informants to enact such roles is a function of i) individual commitment and goals and ii) role related competencies. The latter are in part developed through participation in support group workshops in which PLWHAs are trained in lay counselling, public speaking, speaking to journalists and advocating change to politicians. We present details of these roles, in the context of four broad categories likely to associate with the diffusion of GIPA: 1) Brand Champion Roles, 2) Supplementary Service Roles, 3) Community Building Roles and 4) Social Innovation Roles.

1. Brand Champion Roles: These roles associate with being the first people to promote positive living and provide “social proof” that the disease exists through public disclosure.

(i) Pioneers: are amongst the very first people to test and to publicly admit nationally their HIV+ status. Pioneers need to be courageous, determined and visionary. As Donald explains: “Discrimination and isolation was very rife at the time... [A study in Kasane, Botswana] revealed that the majority of people said all people living with HIV/AIDS should be castrated, ostracised and quarantined. It became even more scary. The AIDS/STD Unit of Ministry of Health and Red Cross continued to give me all the necessary support and counselling...24th of November, 1993 I declared my status in public through the radio and television” (Donald).

(ii) Local Initiators: are the first to admit within a social group
to having tested HIV+. Local initiators need to be open, autonomous and qualified risk-takers. Despite the fear of stigma, they share their experiences with family and friends, admitting that the burden of their sero-positive status is too hard to bear alone. They are often very aware that the news of their positive status will spread to other locals. “I knew that telling one individual will automatically lead to a chain reaction because they would not be able to keep it between us (Otsile).”

(iii) Public Spokes Models: act as role models and public speakers about effectively living with HIV/AIDS for PLWHAS nationally. Public spokes-models need to be accountable, high self-monitors, articulate and be well versed in effective disease management. “My transformation… I used to change partners…I drank every day and big time. So by the time I went public with my status I was like I have to practice what I preach… I can’t just go to a bar and sit down with people drinking…because maybe I will get tempted and start drinking again. And what will people start thinking of me (Precious).” Public spokes-models are typically competitors from The Miss HIV Stigma Free or Mr Positive Living contests.

2. Supplementary Service Roles: These roles complement the inadequate government services needed to maintain widespread PLWHA adherence to Positive Living. Failure to achieve this goal is loaded with huge social and political significance. “The need for treatment outstrips our ability to deliver it. There is a lot of pressure on us, because if we fail people will say: ‘Botswana had everything going for it and it failed, so why should we help anyone in Africa?’” (Dr Moffat, superintendent Princess Marina clinic)”(Avert 2009).

(iv) Lay Counsellors: regularly encourage others within their social networks to test and give homespun advice about disease and lifestyle management. Lay counsellors need to be friendly, patient, giving and available to others. “You can’t go to the men and say he must go …and check their status. No. First of all you must be friendly to a person. Start to be friendly to a person be patient. Come to a person. Visit a person. If he needs your help, then help him. Until you see that your friendship gets close. That’s the time you can start to [talk to him] (Joseph).”

(v) Volunteer Carers: look after PLWHAS who are suffering from the chronic illnesses that typify HIV, often because they cannot be cared for by the public health system. Volunteer carers need to be in good health, compassionate and realise that their behaviour likely fortify norms of reciprocity amongst PLWHAS. “I go there–changing their nappies, feeding them. Because I know how it is living with HIV and AIDS. I have experience of it. Maybe one day it will be me. And somebody else will come and help me. So that’s what I am doing at the moment” (Precious).

(vi) Buddies: are experienced with ARVs and acts as guides to PLWHAs beginning the drug regime. Buddies need to be experienced and reliable. “Ah, a buddy operation is whereby you give the sick I would say…love, care, and support…to get for the medication or the doctor…medical services, health services…because when you get onto the services you get confused a bit then. Which are the better ones [What are the challenges to working on the buddy program?]… First of all you give yourself time to remind, to always frequent, visit the client. To check how on well he or she is keeping up…any side effects, and nutrition” (Paul).

3. Community Building Roles: These roles reflect the need to access the financial, personnel, and socio-political resources needed to consolidate and grow the PLWHA community nationally/internationally.

(vii) Support Group Members: As earlier discussed, support group members are essential to sharing information about disease management, providing emotional support and completing projects intended to enhance government PHIs. Support group members need to share, co-operative and committed to support group goals.

(viii) PLWHA Support Group Leaders: ensure that local support group members are motivated to complete group projects. Support group leaders need to be consumer oriented, accountable, resourceful, respected and have organisational ability. “It’s good to prioritise, even if you are busy at home with your own projects…be involved and available, for patients and people in your support group. As a chairperson, you need to lead by example, be disciplined with whatever financial support of funding you get not to abuse it. Serve the purpose of… the agreed agenda or people will lose hope, alienate and abandon the project (Joseph).”

(ix) National PLWHA Community Leaders: inspire broader society to acceptance PLWHAs by acting as a community spokesperson and advocate. They forge useful connections between PLWHAs and non-PWHAs leaders. They need to be articulate, confident, open to change and aware of the general populations attitudes to PLWHAs. Kagiso warns: “They know to be careful not to bite the hand that feeds them!”

4. Social Innovation Roles: These roles underpin the modification or creation of HIV/AIDS PHIs by PLWHAs and hence tend to reflect an improved and much needed consumer orientation.

(x) Social Entrepreneurs: initiate support groups or other community organisations likely to enhance PLWHAS physical, emotional and material wellbeing. Social entrepreneurs need to be innovative, highly passionate, determined and connected. Donald, as indicated is a pioneer. He now heads up a major national PLWHA support group founded by him. He is also a frequent critic of the Botswana governments’ inadequate support of PLWHAs. Another example is Precious’s care and counselling centre for HIV affected youth in her home village, set up posthumously by her family according to her wishes.

(xi) Advocates: fight for better treatment of infected and affected individuals of HIV/AIDS who are neglected by the government or NGOS. Advocates need to be exceedingly resourceful, independent, passionate and long term oriented. “These kids really need help…I’m advocating for them because there’s no one to advocate for them. I’m a person living with HIV and AIDS, I’m not working but I’m able. How ‘bout these kids? They don’t have anything… It’s only from my heart…It’s a long process…The government I can say…are not giving us support” (Precious).

(xii) The Politician: wants the power to create change. Not one informant was a politician but at least two of them aspired to the position: “You see I’m more politically inclined really. My challenge is to see visible changes in our country, changes for the better….I want everyone employed (Amogelang).”

Summary: An overview of the twelve roles suggests two underlying dimensions: 1) The Capacity for Positive Deviance and 2) The Capacity for Social Outreach. The former dimension asso-
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ciates with the capacity of everyday people to create beneficial solutions for themselves to social, economic and/or health problems that differ from the mainstream (Sterin et al; 1998). The latter dimension includes social domains ranging from self/family/social group, to local and national PLWHA community to broader society, nationally and internationally.

DISCUSSION AND CONCLUSIONS
This study is an early attempt to unpack the different early adopter roles to which consumers adapt in the extremely challenging context of HIV/AIDS in a developing nation. More research on this topic is needed to further theorize the roles PLWHAs can play in HIV/AIDS PHIs and their effectiveness. However our informants are living proof that PLWHAs can have strong motivation and resources to play public roles in disseminating HIV/AIDS message, educating other PLWHAs, and in modifying and expanding existing HIV/AIDS PHIs. They have negotiated and made their own way from private despair to a position where they can help others. They are the “moderately influential” early adopters who can propagate the diffusion process because they give the disease a face with which other PLWHAs easily can identify (Watts and Dodds 2007). However, PLWHAs are heavily stigmatized and are hence are a deviant minority. They lack power, status, and often competence to instigate validation processes and to exert influence. They badly need more public support, especially from powerful politicians who support the views and activities of PLWHA spokespersons.

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3Over 8 authors so due to space restrictions not stated.
4Over 8 authors so due to space restrictions not stated.
**APPENDIX**

Informant Details (all names are pseudonyms)

<table>
<thead>
<tr>
<th>PLWHAS</th>
<th>Year of diagnosis</th>
<th>Disease orientation</th>
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| Amogelang  
- 29 years old, female, single  
- Unemployed  
- Runner-up Miss HIV Stigma Free Beauty Pageant  
- Aspiring politician | 2003  
- Early presenter as no illness apparent |  
- Currently on ARVs  
- Tested negative 1996, then tried to become pregnant through unprotected sex with males who stated they were HIV negative.  
- 2005-one of less than 20 people to go public with HIV+ status |
| Andrew  
- In 30’s, male, defacto relationship with 3 children  
- Unemployed (former building contractor) | 2004  
- Late presenter (very sick at diagnosis) |  
- Currently on ARVs  
- Sexually active, uses condoms  
- 2006-went public nationally. |
| Bondle  
- 30 years old, female, Wife of Joseph, 2 children, younger child HIV+  
- Housewife | 2004  
- Early presenter as no illness apparent |  
- Currently on ARVs  
- Sexually active, uses condoms  
- 2006-went public in local community |
| Donald  
- 56 years old, male, married at least twice, three children and two grandchildren  
- Founder/Director National PLWHA Support Group – membership of 4000 (former truck driver and farmer) | 1993  
- Late presenter (very sick at diagnosis) |  
- Currently on ARVs  
- Sexually active, uses condoms  
- First person in Botswana to go public with HIV+ status. |
| Joseph  
37 years old, male, Married with 2 children, younger child HIV+ Commercial Artist (former soldier) | 2004  
- Early presenter as no illness apparent |  
- Currently on ARVs  
- Sexually active, uses condoms  
- 2006-went public nationally |
| Otisile  
27 years old, male, single, lives with parents, at least one child Un-employee, recreational football player in HIV+ team and bodybuilder. | 2004  
- Late presenter, very sick at diagnosis | Not on ARVs but on IPT (TB prevention medication)  
- Not sexually active  
- 2006 went public nationally |
| Paul  
40 years old, male, single, 6 children  
Volunteer (Local home-based-care society) and Buddy | 2004  
- Early presenter as no illness apparent |  
- Currently on ARVs  
- Not sexually active  
- 2006 went public nationally |
| Precious  
- 37 years old, female, single,  
- Part-time receptionist, volunteer advocate, spokesperson, public role model (former legal secretary)  
- Winner Miss HIV Stigma Free Beauty Pageant | 2000  
- Late presenter, very sick at diagnosis |  
- Currently on last ARV combination possible.  
- Not sexually active  
- 2005-one of less than 20 people to go public with HIV+ status. |
| Robert  
- 37 years old, male, has a girlfriend.  
- Volunteer carer, former insurance consultant/ driving school instructor, HIV/AIDS Volunteer  
- Runner Up Mr Positive Living | 2002  
- Late presenter (very sick at diagnosis) |  
- Currently on ARVs  
- Sexually active  
- 2006 went public nationally |

**Non PLWHA Consumers**

| Ruth |  
- Volunteer community organiser, local rural youth community organisation |
| Morapedi |  
- Pastor, Penta-costal Holiness Church. |
| Experts |  
- Bolokang  
- Programme assistant, National Coordinating Body, Botswana |
| Brian |  
- Project manager, National PLWHA Support Group, Botswana |
| Kagiso |  
- Masters Student of Public Health in a Western Nation, 8 yrs experience studying/working on HIV/AIDS in Botswana |
| Itumeleeng |  
- Consultant to Ministry of Health, Botswana |
| Kefliwe |  
- Officer, Gender Affairs, Botswana |