
A FUTURE DIRECTION FOR HIV/AIDS COMMUNICATION: PARTICIPATION, HIV-POSITIVE CELEBRITIES AND THEIR PUBLIC SELF-EXPRESSION

Mariekie Burger*

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ABSTRACT

After almost three decades of HIV/Aids communication in South Africa, a recent HSRC report (Shisana et al. 2014) indicated that South Africans' knowledge on HIV/Aids has declined in the last few years and risky sexual behaviour amongst certain groups has increased. This shifts the thinking about HIV/Aids communication away from focusing on communication alone to issues around the uptake of HIV/Aids communication. This crisis of HIV/Aids communication suggests investigating future directions for communication about the virus in the hope that a new direction might stimulate the uptake. Instead of continuing the trajectory of strategically incorporating participatory techniques in project-based HIV/Aids communication that is conceived "outside" the target community, this article investigates participatory HIV/Aids communication that emerges from "within" society. Through a review of existing literature, this article investigates the HIV/Aids communication of HIV-positive South African celebrities, and indicates how they participate in HIV/Aids communication and how they express their life stories in public (public self-expression). Furthermore, some HIV-positive celebrities invite the public to share their life stories on a public platform – in line with the Freirean principle of participatory development communication. This form of HIV/Aids communication is also characterised by the sharing of real people's personal views regarding all aspects – not only biomedical – of the virus.

Keywords: HIV/Aids communication, celebrities' social engagement, public self-expression, participatory development communication, participatory HIV/Aids communication, future of HIV/Aids communication, health communication

* Dr Mariekie Burger (mburger@uj.ac.za) lectures in the Department of Communication and Media Studies in the School of Communication at the University of Johannesburg.

INTRODUCTION

The inherent nature of older forms of HIV/Aids communication is educational-instructional as the message is conceived “outside” the recipient community and then persuasively diffused to the recipient community in the hope that the message will result in behaviour change (Tomaselli 2011a: 8-17). This form of one-directional information transmission was modelled on the failed modernisation approach to development communication (*ibid.*). Following the successes of community-driven participatory development communication, the newer forms of HIV/Aids communication initiatives strategically incorporate selected techniques of participatory communication, such as involving the recipient community in the message production process (Tomaselli 2011a: 8-17; Tufte 2006: 691). Instead of continuing with this trajectory of refining the incorporation of participatory techniques in HIV/Aids communication, this article investigates how a truly participatory developing communication framework can form the basis of participatory HIV/Aids communication.

Thus, the focus of this article does not fall on HIV/Aids communication that is conceived “outside” of a society, but instead on HIV/Aids communication that emanates from the “inside”. More specifically, the purpose of this article is to investigate the HIV/Aids communication of a specific group of South African citizens and celebrities who communicate publicly about the virus with the aim of broadening current scholarly understandings of different forms of HIV/Aids communication in the country.

This is done through reviewing existing literature on the topic. Firstly, this article discusses the principles of participatory development communication to construct principles of participatory HIV/Aids communication. Secondly, it maps the ways in which different groups of South African celebrities communicate about the virus, differentiating between celebrities whose HIV status is not known and those who have announced publicly that they are HIV-positive. The article concludes by reading HIV-positive celebrities’ HIV/Aids communication against the foil of participatory HIV/Aids communication. In so doing, this article does not only describe participatory HIV/Aids communication, but, based on the communication of HIV-positive South African celebrities about the virus, provides a practical example of participatory HIV/Aids communication.

THE TRAJECTORY OF HIV/AIDS COMMUNICATION IN SOUTH AFRICA

Four forms of HIV/Aids communication initiatives dominate in South Africa: an early project-based form transmitting biomedical information, a newer project-based form strategically incorporating elements of participatory communication, the social movement form, and the less described, truly participatory communication form of HIV/Aids communication (Burger 2014).

Early project-based HIV/Aids communication in South Africa was based on the development communication model, whereby extension workers educated local communities in primary health care and agriculture (Chabot & Duyvendak 2011: 311-315). Based on early behaviour change models, a causal link between information transmission and adopting new practices was assumed due to a subsequent change in attitudes and beliefs (Baran & Davis 2003: 366; Obregon & Mosquera 2005: 234-237; Littlejohn & Foss 2005: 199; Tomaselli 2011a: 8-11). Primary research confirmed this assumption to be an oversimplification, as did research about the effects of communication, and research in the field of development communication (Mefalopulos 2005: 150-152; Tomaselli 2011a: 8-11; Griffin 2003: 199). Examples of this approach are found in the early Department of Health interventions, Komanani, and the early versions of loveLife (Tomaselli 2011a: 11).

Following the successes of participatory development communication in addressing social problems and bringing about sustained development, the second form of HIV/Aids communication in South Africa strategically incorporates techniques of participatory communication. On the most basic level, these communication interventions motivate the recipient community to partake in message formulation (Cambridge 2007: 191). Examples of such actions could for instance be to ask school children to design posters after a talk on HIV/Aids. On a more advanced level, the target community could be involved in activities such as *Soul City's* script writing, formative and evaluative research, and casting (Tufté 2006: 691; Usdin *et al.* 2004: 156). This refines the Erskine Childers model of “development support communication” (DSC) (Colle 2006: 495; Cambridge 2007: 191). Various models have been designed through the years to describe such community participation, but in essence they all assume that participation indicates affinity and the likelihood of adoption of messages and empowerment (Narayanasamy 2009: 6; Mefalopulos 2008: 91; Tufté & Mefalopulos 2009). This, in turn, would signify that the recipient community takes ownership of the communication initiative – conflating participation, ownership and empowerment. Another element of participation that is strategically incorporated concerns the so-called context within which the communication messages are received (cf. Obregon & Mosquera 2005: 234-237). The contextual factors are often reduced to addressing public services (such as provision of condoms, and making antiretroviral medication available), but may include a range of other factors such as cultural, language, power-political, economic, geographical, age-bound or gender-specific aspects. In this way, the work by The Soul City Institute of Development and Health Communication made great strides to ensure that contextual factors are considered (Usdin *et al.* 2004: 156; Tufté 2006: 691). Another characteristic of this form of HIV/Aids communication is to refine behaviour change models to incorporate the contextual factors, and in this way to design the social ecological model of communication, the health

behaviour (SEMCHB) model, and the AIDS risk reduction model (ARRM) (Fisher 2012: 291-294; Storey & Figueroa 2012: 75). The resultant newer form of HIV/Aids communication that emerged embeds educational messages in entertaining dramatic formats modelled on the South American telenovela (Burger 2012: 6; Storey 2006).

Both the early and the newer forms of communication about the HI virus discussed so far are project-based because the communication projects are initiated outside the target community and have the goal of changing the target group's undesirable behaviour (Tufté & Mefalopulos 2009: 10). In this way, participation is merely a strategic tool employed to persuade a target community (Chabot & Duyvendak 2011: 311-315; Narayanasamy 2009: 5-6; Jacobson 2012; Tomaselli 2011a: 8-17; Tomaselli 2011b: 25-48).

A third form of HIV/Aids communication in South Africa is social movement-based, seeking – through the work of citizens – change in the distribution of public resources (cf. Barker 2012: 176-177; Habermas 2011: 337; Zirakzadeh 2011: xxi; Huesca 2006: 754). In prompting governments to provide care for all citizens, Aids activist Zackie Achmat and the work done by the Treatment Action Campaign (TAC) directed government policy to avail ARVs to HIV-positive South Africans (Tomaselli 2011a: 8-17). The social movement form of HIV/Aids communication is linked to Freire's (1996) view of inviting communities to voice their concerns, as this helps them realise their problems and through collective action these can be addressed (cf. Thomas 2006: 476-477; Tufté & Mefalopulos 2009: 3). In contrast to the “top-down” assumption of project-based HIV/Aids communication, the community “driveness” of social movements awarded the label as “bottom-up” communication (Riaño 2006: 447-450; Thomas 2006: 476-479; White 2006: 482). However, social movement HIV/Aids communication is similar to project-based communication, which is primarily goal-oriented. Essentially, the main difference between the two forms of HIV/Aids communication lies in the citizenry reaching for the “power within” to bring about change (Nikkhah, Redzuan & Abu-Samah 2012: 41).

Based on the participatory approach to development communication, a participatory approach to HIV/Aids communication would embrace the true characteristics of participatory communication, and not cosmetically and strategically employ some characteristics in service of externally directed processes. Participatory development communication is seated in the democratic principles of celebrating diversity (multiplicity, plurality), having faith in the “power within” the community, and the Freirean ideas of verbalisation of the self; this is a step on the path to realising what the depth and breadth of social problems are (Burger 2009: 107-113; Carlsson 2005: 211-212; Erikson 2005: 36-37; Gumucio-Dagron & Tufté 2006: xx-xxx; White 2006: 482;

Habito-Cadiz 2006: 427; Nikkiah *et al.* 2012: 41). It is furthermore assumed that social developmental problems are not only material (on the level of resources), but are also non-material (on the level of respect, identity and recognition) (Al-Zoubi & Rahman 2014: 93; Burger 2009: 107-113). From this perspective, the implication is that empowerment involves affording communities the responsibility and power to engage in and monitor institutions that affect their lives (Al-Zoubi & Rahman 2014: 93). An outflow of these baseline principles is that instead of an outward orientation, faith is shown in communities to take responsibility for their current health or HIV/Aids problems and find solutions. This places the emphasis on communities to verbalise their own thoughts about the virus, the assumption being that this might point to solutions for health problems. This links with Castells' (2001: 63) view that many social actors embark on social drives to affirm their own identities whilst partaking in a social action. He argues that whilst such a social actor partakes, the person's identity is impacted, and in this way is "the locus of action".

By applying these principles of participatory communication to communicate about the virus, participatory HIV/Aids communication would involve volunteers and should not bar people who might not have expert scientific knowledge on the topic. In addition, such communication should take place in public and should also involve a range of topics that are linked to the virus, as this would imply that the virus is not only a medical condition but that it is part of life. Including more than just medical issues in HIV/Aids communication means that talks about the virus are integrated in the everyday lives of people – it is thus part of "the rest" of one's life. Not only knowledgeable people, but ordinary people, should have the opportunity to express their views. The implication of HIV/Aids communication that involves ordinary people expressing their views and talking about related aspects is that public HIV/Aids discussions may potentially involve personal expressions that might seem trivial. However, that may help destigmatise the virus and may also mean that the participatory communication involves aspects other than the material or physical aspects of the virus. In fact, including non-material aspects, such as how the virus may impact on one's self-concept or one's identity, is closely linked to self-expression. Another aspect of participatory communication is to consider aspects other than the biomedical aspect, such as how the virus is tied to sexuality, gender-based power relations, intimacy, spirituality, religion, urban legends, religion, traditions and culture.

The implication may very well be that such public self-expressions may involve the sharing of seemingly trivial and perhaps very personal views on public platforms regarding a range of issues linked to the virus. Based on this premise, this article investigates the ways (as part of the target community of HIV/Aids

communication campaigns) that South African celebrities express their personal views about the virus and the disease and how they invite the public to follow.

The reason why celebrities' HIV/Aids communication is investigated is that they influence many aspects of society, are credible agenda setters, attract media interest, have a considerable influence on society, are well-known (they are "known for being known"), and become trendsetters (Anderson 2007: 46; Cooper 2007: 11; Littler 2008: 242; Poniewozik 2005; Pillet 2009: 16; O'Shaughnessy & Stadler 2006: 396; Giles 2000: 3-4). Furthermore, celebrities' activities, expressions and whereabouts are often boasted about in the media, and media audiences seem to have an insatiable curiosity about both the public and private lives of celebrities (Turner 2004: 5). By implication, this means that it is likely that what these celebrities do or say are talking points for their fans. In fact, their fans often display a "participatory culture" by creating their own online fanzines, fan blogs and fan material (Barker 2012). Regardless of how the public "participates" in the lives of their favourite celebrities, the public displays a considerable interest in celebrities' lives.

Many celebrities support a social agenda, as showing social care is the hallmark of any good celebrity (Littler 2008: 237). In this way, many celebrities are utilising social issues to advance their careers by associating themselves with good causes, such as providing humanitarian, environment and animal aid (Stole 2006). Most of these social causes are chosen carefully to avoid running the risk of damaging the celebrity's image. For this reason, environmental causes, animals and showing care for children and war refugees are often regarded as "safe" choices. Linking the public profile of a celebrity to good causes may not only be beneficial to celebrities, but it may also benefit charity organisations. In fact, many recruited celebrities are guardians, spokespeople, the "face" of an organisation, or are simply invited to be motivational speakers at special events in favour of an organisation. In this way, non-profit organisations seemed to have joined the marketing trend of employing celebrities to advance their work and thus gain access to the already existing fan bases of celebrities to diffuse their messages and advance their work (Littler 2008: 240). However, associating a celebrity name with an illness is risky, as some diseases may be stigmatised or may be linked to social taboos. Furthermore, if there is congruence between the private life and public life of a celebrity, such as the celebrity being HIV-positive and then being involved in a social drive about the virus, the table is turned (Braunstein-Minkove, Zhang & Trail 2011: 96). In other words, not all social drives of celebrities are necessarily inauthentic and "safe" and solely employed for marketing or image building purposes. The public seem to have taken an interest in this kind of celebrity activity.

The celebrities and the causes they support constantly enjoy media attention, as celebrities and the media have a symbiotic relationship: the media needs to

provide in the needs of the public – they are dependent on media audiences – and celebrities need media attention to build their own public profiles and fan bases (O’Shaughnessy & Stadler 2006: 399). The traditional criticism against the media carrying such popular content is that it will lead to a dumbing down of society, as the media’s focus of being a watchdog for society and stimulate public debate around matters of public interest and concern for the democracy dispensation is diverted. Even though this argument is not negated, this article argues that some media attention devoted to the public causes supported by celebrities may be beneficial for society – especially if the media deals with matters of HIV/Aids.

MAPPING THE HIV/AIDS COMMUNICATION OF SOUTH AFRICAN CELEBRITIES

In South Africa, many celebrities are publicly expressing their views on HIV and Aids. Of the more than 400 South African celebrities who are involved in social development initiatives in the country, just over 100 are involved in HIV and Aids communication.

Different kinds of well-known people and celebrities were found to be involved in the communication about HIV/Aids: sports stars, television and radio personalities (including DJs), television and film actors/actresses, musicians (singers, groups, house music DJs), comedians, politicians, beauty queens, princesses, models, fashion designers, journalists, religious leaders, and even a judge. In fact, some celebrities are not only involved in publicly expressing their views about the virus (public self-expression), but they support their communication by taking action (such as riding a bicycle over a long distance to raise funds or publicly taking an HIV test to motivate others to follow suit). A number of trends of how different professional groups of celebrities are involved in HIV/Aids communication were identified.

Sports celebrities tend to be involved in once-off events, typically playing a match to raise awareness about HIV/Aids or to raise funds for an HIV/Aids charity. This is exemplified by all South African test cricket captains who sign a pledge before each test match to support the fight against HIV/Aids. Other sports celebrities often link their names to the HIV/Aids cause by endorsing a particular drive, especially whilst doing something actively in their line of expertise (for example, coaching) when they provide HIV/Aids communication (often in the form of educational and/or motivational talks). An example is J.P. Duminy who visited schools as part of the Get the Facts campaign, encouraging the youth to let their passion for cricket extend to the passion of fighting against the pandemic. Another example is found in the Sports Heroes Walk Against HIV/Aids initiative, where many celebrity sport stars such as Desiree Ellis (footballer), Wili Mtolo (marathon runner) and Baby Jake Matlala (boxer) walked their part between Johannesburg and Cape Town and

engaged with the public along the way. Furthermore, sports celebrities are often goodwill ambassadors for a sporting body's HIV/Aids initiatives, such as former cricketer Shaun Pollock's ambassadorial work for UNICEF's Unite Against Aids; soccer star Lucas Radebe being a patron for Starfish Greathearts; and soccer star Teko Modise being an ambassador for Brothers for Life. Often, and as part of these activities, they publicly take HIV tests. The only South African celebrity athlete who made her HIV-positive status publicly known, Evelina Tshabalala, was involved in setting up an HIV/Aids charity foundation.

Celebrities who have become known for their media work are often involved in once-off events involved in HIV communication. They typically appear at functions to raise awareness about HIV/Aids or to raise funds for an HIV/Aids charity; for example, the involvement of Chumani Pan (known for his role in the drama series *Montana*), Lebo Pelesane (former *Muvhango* actor and model), sports anchor Zolelwa Majeke and also Sello "Chico" Twala (musician and producer) in the Grand Unity Soccer Match at the Meadowlands Stadium (the event was organised by the SA Football Players' Union's HIV and Aids prevention project, Show Me Your Number, and by State of the Union).

Television, film or radio celebrities often link their names to the cause of HIV/Aids by endorsing a particular HIV/Aids drive, such as actress Portia Gumede's involvement in the Rand Aids Association and the Youth Against HIV/Aids and Poverty (YAHAP). Television, film or radio celebrities are often goodwill ambassadors for HIV/Aids initiatives. Many examples exist, such as Vusiwe Ngcobo being an ambassador for loveLife, Welile Tembe and Sophie Ndaba for Scrutinize!, and Terry Theto, Lee-Roy Wright and Kabonina Qubeka for Dance4Life. Some of them have publicly taken HIV tests (as did almost all the many soccer and rugby ambassadors for Brothers for Life).

Interestingly, the biggest public announcement of celebrities who are HIV-positive is seen by media celebrities Koyo Bala, Tender Mavundla, Lesego Mosepe, Jabu Sithole, the late DJ Khabzela and Criselda Kananda. Radio personalities often reveal their HIV-positive status during a radio show, after which they tend to use their show to talk about the virus and the implications thereof on one's personal life; they also invite members of the public to phone in and share their life stories with the nation. The celebrity, if he or she is HIV-positive, gives personal advice and can be a true empathetic listener due to personal experience and knowledge in this line (cf. Richley & Ponte 2008: 719). Celebrities presenting radio or television shows often use their shows to provide platforms for supportive discussions on HIV/Aids matters. In the same way, journalist Lucky Mazibuko uses his *Sowetan* column to engage with matters concerning the virus (BBC 2011).

Musicians are often involved in once-off events, partaking in HIV communication, typically appearing at concerts to raise awareness about HIV/Aids or to raise funds for HIV/Aids charities; performers include Mandoza, Pitch Black Afro, Gang of Instrumentals, Bongo Maffin, Yvonne Chaka Chaka, Mafikizolo or Ladysmith Black Mambazo performing at the Nelson Mandela Foundation's 46664 Aids concerts. The last four celebrities and a whole list of other musicians (such as Chris Chameleon, Danny K, Mduduzi Chabalala of Mandoza, Kabelo Mabelane, Jozi, Siphon Hotstix Mabuse, Johnny Clegg, Karen Zoid, Dozi and many more) are ambassadors for the 46664 Aids concerts. Many of these celebrities are also involved in other HIV/Aids initiatives; for example, Doc Shebeleza is the leader of the African Musicians against HIV/Aids (AMAHA). Many musicians, such as the internationally acclaimed group FreshlyGround, produce music with messages about HIV/Aids.

Politicians tend to establish HIV/Aids charities under their own names, and those who have lost someone who was HIV-positive tend to speak about it publicly (albeit not often). Examples are found in the work of the Nelson Mandela Foundation. It should be noted that Mandela lost a grandson who was HIV-positive, and IFP leader Mangosuthu Buthelezi lost a son and a daughter to Aids.

The only South African religious leader who is actively involved in communicating about the virus is Archbishop Desmond Tutu. He established various HIV/Aids charities under his own name, notably the Desmond Tutu HIV Centre, the Tutu HIV Foundation, and the Mobile HIV Testing Clinic.

Beauty queens, royalty and models tend to be involved in once-off charity events, often only appearing without talking about the virus. Along these lines, Miss South Africa 2011, Melinda Bam, attended the charity event for the Mohau Centre for children infected with and affected by HIV/Aids and launched campaigns in aid of the Thuthezela Aid Community Centre and the Save our Home project. Similarly, South African-born Princess Charlene of Monaco visited the Cotlands HIV/Aids Hospice, and Tansey Coetzee (Miss South Africa 2008) visited the Dudu Zwane Hospice for HIV affected and infected children on World Aids Day. Bokang Montjane (Miss South Africa 2010) partnered with the National Youth Development Agency to establish the Bokang Legacy Confidence Camp for Girls where she gives motivational talks. Comedians tend to produce shows that carry HIV/Aids messages and they are often ambassadors for HIV/Aids initiatives. Examples include Kenneth Nkosi, Pieter Dirk Uys and Desmond Dube.

However, celebrities who are HIV-positive are of great interest to this article as they are even more involved in public HIV/Aids communication than celebrities whose HIV status is not publicly made known.

The HIV/Aids communication of South African HIV-positive celebrities

Of the South African celebrities who are involved in HIV and Aids communication, the handful of celebrities who are HIV-positive tend to be more involved in HIV/Aids communication than other celebrities. Even though they do so in different ways, they tend to share their personal life stories with the public in what can be called “public self-expression” (Burger 2014).

Some HIV-positive celebrities who are involved in once-off communication on HIV and Aids are announcing publicly that they are HIV-positive and deliver a message to the public. For example, SABC2 television weatherman, Jabu Sithole, announced his HIV-positive status and advocated a change in the way people conduct their sexual lives. Popular kwaito music star, Tebogo “Zombo” Ndlovo, from the group Abashante, disclosed his HIV-positive status on the popular music show *LIVE* on national television and encouraged fans to be tested for HIV. Although these once-off HIV/Aids communications may have had an immediate impact when they took place, these messages are not sustained over a long period and will not have a lasting impression on public HIV/Aids communication in the country.

Other celebrities are more involved in HIV/Aids communication initiatives than only once-off instances and some are actively advocating the causes of HIV and Aids. The idea of sharing one’s life story with the world is found in the last group of celebrities who, to varying degrees, continue to share their life stories with the public through the work of HIV/Aids organisations which they establish. In this group, two relative simplistic examples are found where the founders are not extensively involved in public HIV/Aids communication. One example of a celebrity involved in starting up an HIV and Aids charity is marathon runner, Evelina Tshabalala. She publicly announced her HIV-positive status and is upheld as living proof that eating healthy and taking ARVs can lead to a healthy life when living with Aids. She is a founder member of Positive Heroes, an initiative claiming that people can live positively with HIV. Not long before his death, DJ Fana “Khabzela” Khaba announced his HIV-positive status in a pre-recorded message on radio during his Yfm breakfast show and urged his listeners to speak openly about sex and HIV. He received an award in recognition of his contribution to the fight against the virus. Tender Mavundla also publicly disclosed her HIV-positive status in 2007 when she appeared on the South African television programme *Idols*. She also took part in motivational talks at conferences and corporate functions, high schools and universities. Although this form of HIV/Aids communication signifies that South African celebrities have a long-term involvement, the next form of HIV/Aids communication by celebrities is sustained over longer periods of time. In this category of South African celebrities, having a longer involvement with public

HIV/Aids communication, DJ Khabzela and Tender Mavundla made a remarkable impact due to announcing publicly that they had contracted the HI virus. Another example is found in the work of celebrity actress Lesego Motsepe, who publicly disclosed her HIV-positive status on both Bob Mabena's breakfast show on the radio station Kaya FM, and on John Robbie's show on Talk Radio 702; she used these opportunities to encourage safe sexual practices. Motsepe continued her involvement in HIV/Aids communication through Afrikarize! – an HIV/Aids initiative aimed at creating new conversations about HIV/Aids and addressing the socio-economic problems of the youth. She also holds regular puppet shows to teach children about the virus (Madikwa 2011).

The third type of HIV-positive HIV/Aids communication by celebrities is linked to a long-term public commitment with issues around the virus. More so than the short-term HIV/Aids communication of HIV-positive celebrities, these celebrities share their personal life stories with the public through their HIV/Aids communication.

One example of such sustained commitment to the cause of HIV is found in the HIV/Aids work of the well-known South African Constitutional Court Justice Edwin Cameron, the first senior public official to disclose his HIV-positive status. Apart from his official position, Cameron's life story is that of seeking human rights for people living with HIV; his engagement with HIV and Aids is in the line of his legal work. He co-drafted the Charter of Rights on HIV and Aids, co-founded the Aids Consortium, and founded the Aids Law Project. Cameron's award-winning non-fiction book, *Witness to AIDS* (2006), grapples with the meaning of HIV/Aids and the threat of death. More recently, in *Justice: A personal account* (2014), he traces the justice systems in the country, punctuated with his own personal life story about how he grew up in an orphanage due to his mother not being able to support him, how he battled to make his HIV status known publicly and how antiretroviral medication saved his life.

Another example of an HIV-positive celebrity who shares his personal life story with the public in his writing, is Lucky Mazibuko. In his column in *Sowetan* (the largest daily newspaper in Africa), *Just Call Me Lucky*, he wrote his life story about living with HIV for 23 years, and he seeks to demystify the virus by sharing with the public lessons learned from it; namely, to be selfless, share experience, time, love and possessions, and to have compassion for humankind. He extended his life philosophy of helping HIV-positive people to live "through the humanity of others" by founding the Lucky Mazibuko Foundation, which offers scholarships to HIV-positive people (Lucky Mazibuko Foundation 2014). As an Aids activist, he made it public that he did not want to take ARVs himself until it was freely available to all citizens. Mazibuko has shared his life story on many national and international television and radio stations and presented a 13-part SABC2 television series known as *Positive* where he investigated the

reality of living with HIV. Due to public demand, this historic series enjoyed a re-run in 2001. Not only does he share his life story with the public, he also serves on many bodies in Africa to help those infected with the virus.

Another example of an HIV-positive celebrity who shares her personal life story with the public is Criselda Kananda (Metro FM n.d.; Parent24 n.d.; TVSA n.d.) on her radio show *Positive Talk*. Through *Positive Talk* and motivational speaking, she speaks to the public about how she contracted the virus, how she discovered that she was HIV-positive, and how she has coped with the virus for 16 years. The public can identify with her story, as it is a familiar story for many South Africans: she married a man without knowing his HIV status and upon the birth of their daughter she discovered that she was HIV-positive. Her husband left her soon after the birth of their child, and as a single mother, Kananda relied on knowledge she gained from her nursing background and went from strength to strength with her radio talk show. Today she is well-known for her HIV/Aids communication. In fact, she was acknowledged as one of the ten most influential women in the country through a *City Press/Rapport* award. Importantly, she not only shares her personal life story with the public through *Positive Talk* but, as it is a talk show, she invites the public to follow suit. Members of the public who phone in, tell their life stories and these weave together with hers to provide a platform where the public sharing of her and their personal life stories (public self-expression) forms the basis of her HIV/Aids communication.

To sum up, in contrast to South African celebrities whose HIV status is not known, HIV-positive celebrities tend to share their personal life stories with the public. Judge Cameron entered the autobiographical literary world by publishing books that were exceptionally well-received; evidenced by being translated and receiving literary awards. Cameron gave a highly personal autobiographical account of his traumatic life story about coming to terms with being in an orphanage, homosexuality, being severely ill with the virus, and finally taking antiretroviral treatment during a prominent judiciary trial. His books elicited much public discussion. Similarly, Lucky Mazibuko shares a very personal account about his experiences with regard to the virus. In his column, he emphasises humanity in his public self-expressions. Like Cameron's books, Mazibuko's life story elicited much public debate – especially through the social media platforms linked to *Sowetan LIVE*, the online version of the newspaper. Following the nature of her work, Criselda Kananda's radio talk show facilitates her continued public self-expression about HIV/Aids and she invites the public to follow her example.

The question is: How do these opportunities of public self-expression fit in with the participatory approach to development communication?

CONCLUSION

Participatory HIV/Aids communication and public self-expression

Based on the participatory approach of development communication outlined in this study, it can be argued that participatory HIV/Aids communication should provide democratic access and everyone who wishes to take part in public discussions about the virus should be able to:

- ♦ verbalise their views publicly;
- ♦ express themselves freely regarding all aspects of the virus;
- ♦ be concerned with biomedical aspects, but should also include other contextual aspects (such as how the virus impacts matters of sexuality, gender-based power relations, intimate aspects, spirituality, religion, urban legends, religion, traditions and cultural aspects); and
- ♦ engage with both the material and non-material (such as recognition, identity, and selfhood) aspects of the virus.

The HIV/Aids communication of the HIV-positive celebrities discussed in this article – especially the cases of Judge Edwin Cameron, Lucky Mazibuko and Criselda Kananda – overlaps largely with these foundational principles of participatory communication as the HIV/Aids communication of these celebrities does not only focus on the biomedical aspects of the virus, but speaks to personal experiences of identity and selfhood and also invites the public to participate in the HIV/Aids debate. The public's responses are invited by reading Cameron's books, by commenting via the Internet on Mazibuko's column, and by texting or phoning in to Kananda's talk radio show.

It can thus be said that the contribution of these South African celebrities to the existing HIV/Aids communication initiatives should be taken seriously as an important form of communication about the virus. In fact, the public self-expressions of prominent people and celebrities should not only be regarded as important – prominent people attract considerable attention – but because this form of communication about the virus is in line with the main principles of participatory communication. Furthermore, if a celebrity does not only express the self, but stimulates members of the general public to also participate in “public self-expression”, it is even more noteworthy as it may indicate a future path of HIV/Aids communication in the country. It is concluded in this article that popular public participation, by means of the public expressing their personal views and experiences with matters around the virus, is a neglected form of HIV/Aids communication in South Africa. It is thus proposed that future research should be done on the impact of personal life story telling on the broader South African population.

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