Literature Review Report:
Communication sharing practices and needs of people living with HIV: A case of Nkangala in Mpumalanga and Ekurhuleni in Gauteng

TITLE

Literature Review Report: Communication sharing practices and needs of people living with HIV: A case of Nkangala in Mpumalanga and Ekurhuleni in Gauteng

A LITERATURE REVIEW REPORT PREPARED FOR

Centre for Communications Impact

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This report was prepared for the Centre for Communication Impact by the Research Use and Impact assessment (RIA) unit of the Human Sciences Research Council (HSRC)

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This research was supported by Cooperative Agreement Number GH001932-01 from the US Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the US Centers for Disease Control and Prevention, the Department of Health and Human Services, or the U.S. government

Acknowledgements

The Centre for Communication Impact (CCI) literature review report was undertaken by the Human Sciences Research Council (HSRC). We wish to thank all healthcare workers in all the districts where the study was conducted, for providing insights into the state of HIV and adherence in the respective healthcare facilities.

We would like to thank Dr Konosoang Sobane, Dr Sarah Chiumbu, Dr Cyril Adonis and Ms Ragi Bashonga for their dedicated and tireless effort in producing this report. Your efforts are highly appreciated

We also sincerely thank the fieldwork team, under the committed supervision of Ms Zuziwe Khuzwayo whose devoted efforts and time made the survey a success. The team also highly appreciates the administrative and support staff of RIA for their commitment into ensuring the successful completion of the project. The support offered by the CCI office prior and during the survey is also highly appreciated.

Table of Contents

List of Abbreviations and Acronyms

AIDS	-	Acquired immunodeficiency syndrome
ART	–	Antiretroviral treatment
BCC	-	Behavioural change communication
CCI	-	Centre for Communication Impact
CHWs	-	Community health-workers
HIV	-	Human immunodeficiency virus
IEC	-	Information, Education and Communication
LTFU	-	Loss to follow up
NGO	-	Non-Governmental organisation
PLHIV	-	People living with HIV
SABC	-	South African Broadcasting Corporation
SADC	-	Southern African Development Community
SBCC	-	Social and behavioural change communication
TPB	-	Theory of planned behaviour
TRA	-	Theory of reasoned action
VCT	-	Voluntary counselling and testing

Executive Summary

Communication efforts and strategies for HIV and ART adherence are increasingly being considered as a way of supporting people living with HIV (PLHIV) in South Africa and elsewhere. In HIV care and treatment non-adherence is a threat towards achieving positive health outcomes for PLHIV, since it compromises viral suppression, and ultimately their well-being. Previous research has identified a range of barriers to adherence that fall in the categories of psycho-social, economic and structural barriers. Among the many interventions explored to improve adherence, a communication strategy has been identified as essential. In cognisance of that the Centre for Communication Impact (CCI) has undertaken to develop a communication strategy that is aimed at improving adherence to Anti-retroviral treatment (ART). In order to inform that strategy there is need to learn from other communication initiatives that have been handled in other programmes in developing countries. This literature review provides these insights, together with pertinent theoretical frameworks that can be drawn on in developing the envisaged programme and strategy.

The literature reviewed initiatives of health communication in general, and adherence communication specifically in other developing countries, looking particularly at factors that accounted for their success or lack of it. Based on a common understanding that a good communication strategy should be grounded on sound theory, the initial discussion in this review points to some of the pertinent theoretical frameworks that can use used to develop an adherence communication strategy and shows how they can be applied to that strategy. The review then goes on to identify some of the important characteristics of a communication model, in order to inform an effective communication framework. It further discusses some of the successful health communication and adherence programmes, resources and information sharing practices that have been used in other developing countries. The strength and weaknesses of programmes that were implemented in several countries across Africa and beyond are dealt with in detail, as they become lessons for the envisaged CCI strategy.
This was meant to identify growing concerns about the problem of treatment initiation and non-adherence to ART and lessons learnt. The review then delves into specific tools and resources that have been used in other countries and highlights some of the features that made the tools useful. The concluding remarks argues for the development of an evidence

based strategy, that employs the tenets of multimodality, contextualises messages and capitalises on resources already available for communication and that targeted users are already familiar with.

1. Introduction and background

South Africa has done considerably well in the roll-out of HIV treatment, however there are growing concerns about treatment initiation and non-adherence to ART. The HIV prevalence and incidence statistics sourced from the SANAC website[1] show that during the period of 2009 – 2016, of the 7,053,987 people living with HIV (PLHIV) between the ages of 15-49 years only 48.5% were on antiretroviral treatment (ART). In a survey conducted by Van Dyk in 2009/2010 to look at adherence levels in a post-rollout South Africa among 450 PLHIV on ART (Van Dyk 2012), 40.1% of the ARV users reported adherence levels of more than 90%, 49% reporting adherence levels of between 70% and 90%, and 10.9% reported adherence levels below 70%. Although this survey had limited scope, it provides insight into the extent of the problem of adherence. The South African Department of Health indicates that the most common cause of death in AIDS patients in South Africa is related to non-adherence to ART[2].

Other studies have described HIV treatment non-adherence by examining demographic characteristics of PLHIV who are lost to follow up (LTFU). Evans et al. (2013) define LTFU as missing a scheduled appointment by more than three months (~90 days). The Gauteng multi-sector AIDS council report of 2011/2012-2013/2014 notes that an estimated 30% of patients were LTFU on ART in the period under review. Studies conducted in some clinics in in the North West and Gauteng provinces of South Africa show some demographic characteristics of PLHIV who are LTFU. For example, Wang et al. (2011), conducted a study to identify patient characteristics associated with LTFU 6 months after starting ART among adult patients in the Southern African Catholic Bishops' Conference (SACBC) and the Catholic Relief Services (CRS) clinics in Tapologo, Rustenburg. They established that younger age and pregnancy among women was positively associated with LTFU. In this study 6% of the women were LTFU after 6 months of treatment initiation, and the same study reported that older adolescents and young adults were more likely to be LTFU after ART initiation. In another study examining LTFU during pre- and post-delivery following up pregnant women who had just been newly diagnosed with HIV in a Johannesburg clinic, Clouse et al. (2013) reported that 57.5% of the

[1] http://ivizard.org/sanac/ accessed on 16 November 2017.
[2] Department of Health. HIV/AIDS and STI Strategic Plan for South Africa 2007–2011. Pretoria: Government Press; 2009

women were LTFU between HIV testing and six months postpartum. The two studies associate LTFU after delivery to the likelihood that women studied in Rustenburg and in Johannesburg are probably migrant workers, who return to their respective countries or to the rural areas prior to delivery, without a formal transfer from their clinics. Clouse et al. (2013) also suggests that in some cases, LTFU after delivery may be caused by lack of financial resources to continue with care, given the added burden of financially caring for a new-born. Wang et al (2011) therefore recommends improved linkages with other ARV centres and maternal services via data sharing to systematically monitor patients wherever they go.

Poor ART adherence rates (taking less than 95% of medications as prescribed) have been shown to result in poor health outcomes such as treatment failure and the development of drug resistance as noted in Anzia et al. (2016). Van Dyk (2012) notes that drug resistance arises as a result of the high genetic variability of HIV (or its ability to mutate rapidly) and can lead to cross resistance to other drugs that are in the same class as ARVs. He also notes that poor adherence results in compromised viral suppression, which means that patients end up with high viral loads, resulting in low quality of life and possible death among PLHIV as also noted in Bangsberg (2008). Uncontrolled HIV viral load is a risk factor for onward transmission of HIV. This includes transmission of drug resistant HIV strains as well (Van Dyk, 2012).

Several studies have noted an array of barriers to ART adherence, which range from psycho-social to structural barriers (Chop et al, 2017) as discussed in detail in *section 2.3* below. Besides these barriers, an additional problem has been identified as that of the effectiveness of communication between the medical profession and patients, in particular in communicating issues around HIV, ART and adherence. HIV-related communication is done through several channels such as healthcare provider-patient communication (Anthonissen and Meyer, 2008; Zachariah et al, 2006); messaging through behavioural change communication BCC programmes that use multi-modal messaging (Sobane, 2012) and other multimedia-messaging such as SMS (Mukund et al. 2010), TV and radio campaigns. When communication is not effective, patients' understanding of the condition, and the value of adherence to treatment thereof is compromised (Barford et al., 2006; Bharath-Kumarr et al., 2009).

Since effective communication is seen as a hallmark of the successful treatment and care of HIV and AIDS (Lucoshek et al. 2003; Airhihenbuwa 2000, Anthonissen and Meyer, 2008) there is a demand for a communication process that is effective in delivering HIV messages in order to facilitate adequate understanding that could in turn result in treatment adherence. Although there are no specific examples of effective communication ART adherence programmes, there is a consensus among communication researchers that BCC programmes for HIV and AIDS, such as the ones discussed in *Section 5. 2* below present some useful examples of integration between the communication processes and the overall programme of care. In such cases the communication process is meant to develop positive behaviours; promote and sustain individual, community and societal behaviour change; and maintain appropriate behaviours. The implication of the above is that individuals and communities can reduce their level of risk or change their behaviours when they understand basic facts about HIV and AIDS, and perhaps also improve their potential for adherence. (Lucoshek et al. 2003; Airhihenbuwa 2000, Anthonissen and Meyer, 2008; Sobane 2013).

There is consensus among health communication researchers that there is a need to carry out periodic critical evaluations of communication approaches and strategies about adherence to ART. Chesney (2006) states that the most reliable indicator of adherence is viral load suppression. Periodic clinical assessments of patients initiating ART can provide data on viral load suppression within 24 weeks of treatment (Chesney, 2006). Along with these clinical assessments, there is also a need for periodic critical evaluations of communication approaches and strategies about adherence to ART as showed by Anthonissen and Meyer (2008). They show that in HIV and AIDS care, as is the case with other non-communicable diseases (NCDs), communication is required to improve patients' understanding of the disease and their ability to adhere to a rigid treatment protocol. It is against this background of issues around adherence, and the significance of effective communications and messaging, that the Centre for Communication Impact (CCI) seeks to develop an adherence communication strategy for PLHIV to be piloted in Nkangala, Mpumalanga and Ekurhuleni, Gauteng, with the intention to upscale to other districts at a later stage.

This literature review examines initiatives of adherence communication in other developing countries, looking particularly at factors that accounted for their success or lack of it. Specifically the literature review discusses some of the pertinent theoretical frameworks that can be drawn on in developing effective communication strategies to improve HIV adherence programmes. This review shall provide lessons learnt and insights from national and international ART adherence communication initiatives to inform the development of the Centre for Communication Impact's ART adherence communication strategy / programme.

2. Theoretical frameworks and approaches to healthcare communication

According to Airhihenbuwa and Obregon (2000), effective communication strategies should be grounded in sound theory. There is a wide range of health communication theories, especially from disciplines such as social psychology and communication science that help in predicting the relationship between interventions, including other factors/variables and HIV outcomes. These help in understanding how, when and why people change their behaviour and thus help inform at what point of intervention it is best to target a message. They also enable the identification of actions needed to influence behaviour change and the factors that hinder or promote these changes. These theories therefore help to shape the conceptualisation of effective communication intervention activities. This section discusses the communicative ecologies theory as a framework that looks at the range of communication tools available in a given community. It then discusses the meta-theory of health communication which shows how a communicative strategy can influence adherence by having an effect on a set of ideational factors. The section also considers the social and behavioural change communication which looks at how communication can influence a change in behavioural patterns, and in turn adherence. Lastly, the section looks into cognitive and stage step theories which explain how people's beliefs can influence certain changes in behaviour.

2.1 Communicative ecologies

An effective communication strategy needs to be based on evidence of available information resources and practices in a community for which it is intended. The design of a communication strategy can be informed by conducting a communication ecology assessment of the targeted community, or one that is similar to it. The concept of communicative ecology defines a number of mediated and unmediated forms of communication existing in a community (Tacchi et al. 2003). Foth and Hearn (2007) conceive communicative ecology as having three layers – a technological layer which consists of technologies and connecting media that enable communication and interaction, a discursive layer which is the content of communication available in the community, and finally a social layer which consists of people and social modes of organizing those people. These three layers converge in distinct and localized 'communicative ecologies' (Foth and Hearn 2007). The communicative ecology does not ignore the context of the community in terms of who has access to certain resources, power relations and the local economy. These are all important factors when one wants to understand why certain mediums are used in specific spaces and the personal role that the media come to play in people's lives (Tacchi et al, 2007).

- **The technological layer of communication**

In the South African context, the technological layer of communication denotes the mass media (print and broadcast media) and new media technologies (Internet and mobile phones) available in communities. The mass media in South Africa, as a commercial enterprise, is generally focussed on being highly corporate and commercialized. However for communities where television broadcast is not accessible, community radio plays an important role as an alternative source of information. In rural resource-limited areas community radio is less costly and enables isolated communities to voice their own concerns, while they also get informed. For example, the *Africa Renewal Magazine, July 2005* shows that on air, ordinary citizens discuss issues that are central to them, such as gender relations and combatting HIV/AIDS, and hence are informative to listeners[3]. In terms of new media Mukund et al (2010) shows that South Africa has one of the largest cell-phone coverages in the world, and people use cell-phones as a daily communicative tool. In addition to personal mobiles, cell phone

[3] http://www.un.org/africarenewal/magazine/july-2005/community-radio-voice-poor

containers operated in spaza shops and individual homes are widespread across many townships and rural areas (see Skuse and Cousins 2005, 2008). Because of their accessibility, they are an ideal resource for health communication, and can also be relevant for ART adherence communication. Statistics from Africa Renewal Magazine show that South Africa has 128% of mobile penetration (active connections to population), with a total of 66.1 million mobile connections (active sim cards)[4]. Because of their (cell-phones) accessibility, they are an ideal resource for health communication, and present an opportunity for a wider reach for ART adherence communication programmes that use cell phones as a communication tool.

- **The social layer of communication**

The social layer of the communicative ecology consisting of community organizations, rallies, community meetings, social clubs (stokvels) and churches provides useful and alternative communicative spaces where social networks are forged and strengthened. These forms of unmediated communication (face to face/interpersonal communication not done through any channel of media, as opposed to mediated communication which is done through different form of media) play important roles in broader community struggles for social and economic development (Chiumbu, 2010; Wilkinson, 2013). These kinds of social networks that are already available in most South African grass-root communities can be tapped into ~~on~~ as platforms for communicating HIV treatment adherence messages. Their value is that they already have strong roots in the community and have insider perspectives of adherence issues in their locality. Such community networks have already been used successfully in other countries such as Malawi, as noted in Zachariah et al (2006) and South Africa (Wilkinson, 2013). Details of these studies are discussed in *Section 4* below.

- **Meta-Theory of Healthcare Communication**

Another theory that is useful in conceptualising an adherence communication model is the Meta-Theory as depicted in Figure 1

[4] http://www.un.org/africarenewal/magazine/july-2005/community-radio-voice-poor

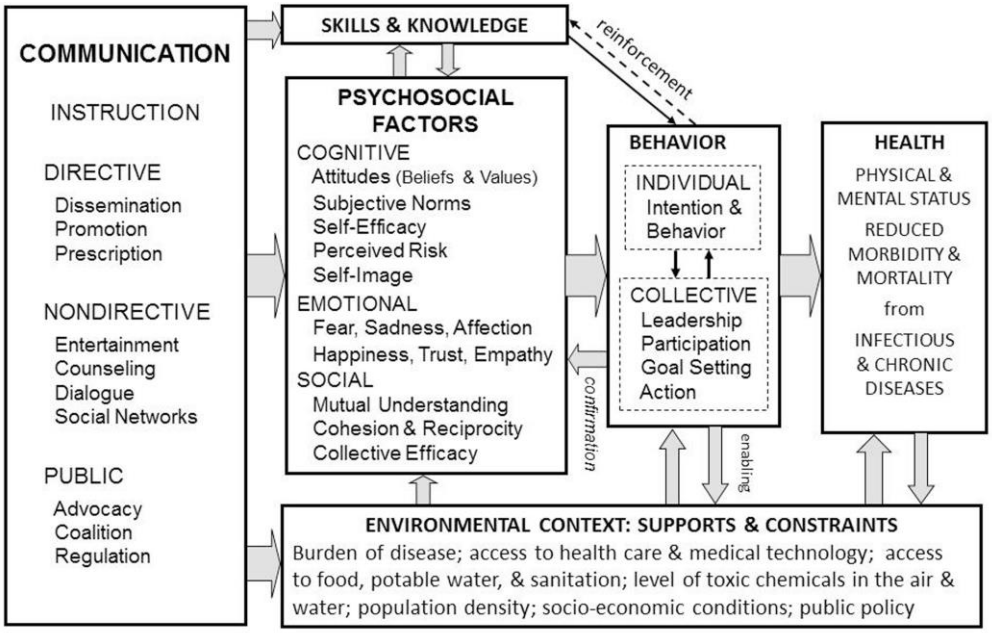

Figure 1: Meta-Theory of Health Communication (Kincaid et al., 2012).

According to the multi-theoretical framework above, an adherence communication strategy that incorporates resources such as promotion, dialogue, and advocacy among others, can influence adherence behaviour through its effect on a set of ideational (psychosocial) factors such as cognitive elements (e.g. beliefs), emotional factors like self-efficacy, and social elements, e.g. interpersonal communication. Self-efficacy and social elements are key theoretical constructs in behavioural sciences and are thought to influence all aspects of human behaviour, including health-related behaviour (Bandura, 2006). When ideational factors that are relevant to understanding HIV disease including the need for adherence to ART are addressed, HIV communication programmes are more likely to have a positive impact on health behaviours and ultimately on positive outcomes for ART.

The Metatheory subsumes an incorporation of social and behavioural change communication (SBCC) in an adherence strategy. According to Sawers and Stillwaggon (2010) some of the HIV prevention programmes in the Southern Africa Development Community (SADC) have been successful in positively influencing behaviours such as condom use and HIV testing at

population level, because BCC was a key component in these programmes (also see Kincad 2012; Sobane 2013).

2.2 Social and behaviour change communication

Social and behaviour change communication (SBCC), is an approach that has been used in healthcare communication which involves the study and application of communication strategies for promoting positive health outcomes (Kreps & Maibach, 2008). SBCC is concerned with communication that takes cognisant of social determinants such as knowledge, attitudes, norms and cultural practices. The approach thus uses mass media, community-level activities, interpersonal communication, information and communication technologies, and new media. In other words, SBCC adopts the communicative ecology paradigm discussed above.

The SBCC approach evolved from the Information, Education and Communication (IEC) to Behaviour Change Communication (BCC) to SBCC. IEC, a term used to describe "the strategic and theoretically informed process of developing educational messages using a range of media platforms to facilitate a desired behavioral or social change" (Govender 2013: 1), was developed in the early 1970s, when the use of mass media (most specifically radio drama) was seen as a useful tool in disseminating health information. The use of mass media for health communication or development communication more broadly, was based on the modernisation approach that overlooked the complexities of culture and social relations that were the fundamental cause of underdevelopment (Melkote and Steeves, 2001). The early thinking on the use of mass media saw media as having direct, immediate and powerful effects on behaviour change. This was premised on the belief that the mass media could influence a very large group of people directly and uniformly by 'shooting' or 'injecting' them with appropriate messages designed to trigger a desired response (McQuail and Windahl, 1993).

The IEC approach assumes that people will follow health advice and adopt healthy behaviours when they are provided with the "right" information. Its main weakness was that audience were seen as 'passive recipients' of information. BCC went beyond just providing information,

but focused on developing communication strategies which are appropriate to people's social-cultural settings.

This approach views audience input and feedback necessary for the design of campaigns. BCC efforts, however, have focused on individual behaviour change (Story and Figueroa 2012). SBCC expands BCC, recognizing the importance of acknowledging that change at the individual level occurs within particular socio-ecological contexts. The communicative ecology approach would then strengthen SBCC efforts as it allows for understanding of communication as it interacts with structures that are mediated, informational, situational and contextual in their respective environments (see Matthias 2011: 31). It is currently accepted that successful behaviour change interventions are built on an understanding of the complex social, cultural and economic factors that make up the multiple levels of causes of health and health behaviour. In addition, Ganesh (2004) notes that good communication strategies use concepts that range from psycho-social learning theories of role modelling communicated via the mass media to the use of advocacy and social mobilisation. He further elaborated that dialogue with, and active participation of individuals are essential elements in communication for behaviour and social change. The SBCC approach places the emphasis on participatory approaches, community engagement in defining issues and identifying options for action. Due to the many phases through which it has evolved, and the lessons learnt from each phase, SBCC is a valuable resource in informing the development of new communication strategies. Its potential to facilitate participation of the targeted population, and a consideration of social factors makes it an important tool to draw on in developing an adherence communication programme.

Adherence communication draws a lot from SBCC because the aim is the same, which is, to improve health outcomes. Literature explains adherence as the extent to which patients follow medical instructions (WHO, 2003). The term "adherence" is more preferred in health communication literature than "compliance" as it conceptualises a patient as participatory in the decision-making process about treatment, as opposed to passively following the orders of healthcare providers (Haskard-Zolnierek and Thompson, 2016). This subsumed patient participation also embeds the visibility of the patient voice in the care process as noted in Sobane and Magampa (2016), and therefore an aspect of communication.

One of the significant predictors of adherence is effective communication because it contributes to patients' understanding of their illness and the risks and benefits of their treatment (Di Matteo, 2009:1). Within the sphere of HIV and AIDS, good unmediated communication between providers and patients has been found to improve adherence to ART because it allows the provider to tailor the advice on issues such as: i) medication taking time, and ii) appropriate lifestyle changes to the patient's needs (Malta et al, 2005). Also, patients who participate in decision-making regarding treatment often take some of the responsibility and accountability for recovery, and hence of adherence (Bishop and Yardley, 2004; Schoenthaler, 2009; Robertson et al. 2011). Patient participation in decision-making refers to the presence of their voice in certain aspects of decisions about treatment, even though they cannot make expert decisions, as noted in Sobane and Magampa (2016). It is evident from this literature that a good adherence programme should illuminate patient participation in its strategies.

2.3 Cognitive and Stage-Step theories

A number of social psychological theories have been at the forefront of research into predicting and explaining health behaviours, including ART adherence. These theories can be divided into two types, namely cognitive theories and stage-step theories. According to Rutter and Quine (2002), cognitive theories are based on the assumption that a certain set of perceptions or beliefs will predict behaviour and therefore provide continuum accounts of behaviours (examples of such theories are discussed in detail below). Step theories, on the other hand, assume that the individual is not on a continuum but at a 'step' or 'stage' with each step representing a move forward towards achieving a desired behavioural outcome (Rutter & Quine, 2002). Examples of cognitive theories are the Theory of Planned Behaviour (Ajzen, 1980) and Health Belief Model (Becker 1974), while Stages of Change Model (Prochaska & Diclemente 1983), constitutes an example of stage-step theories. All of these theories are based on notion of social cognition, the central tenet of which is that people's social behaviour is best understood by examining their beliefs about their behaviour in a social context (Rutter & Quine, 2002). In light of the importance of beliefs and perceptions in predicting behaviour, it can be deduced that PLHIV's beliefs and perceptions about HIV, AIDS and ART will predict their adherence to treatment.

It there becomes imperative that prior to developing a communication strategy, an attempt is made to establish people's beliefs and perceptions about HIV and its treatment, in order to be informed about what the likely behaviours that may arise are.

Drawing from these theories will therefore provide a theoretical basis to inform the development of an inclusive communication programme that will provide information and knowledge about adherence. It will also facilitate narrative change that will foster belief in treatment and motivation to adhere, and helping patients to overcome barriers. This is in line with O'Carroll et al. (2011) statement that interventions to improve adherence should target patients' beliefs about medication. In addition, the theories highlight the need for interventions to be multifaceted in order to address issues related to treatment beliefs, perceived barriers, and social support.

- **The Theory of Planned Behaviour (TPB)**

This is a modified version of the Theory of Reasoned Action (TRA) (Ajzen & Fishbein, 1980). The TRA originally proposed that any intervention attempting to change behaviour should focus on beliefs, as these influence attitudes and expectations and in turn influence intentions and behaviours. It was then proposed that behaviours are not under 'volitional control' and the model was re-visited and expanded to include 'perceived behaviour control' (Rutter & Quine, 2002). The TPB follows the same reasoning as the TRA with the addition of 'behavioural control' as a determinant of behavioural intention and behavioural change. According to the TPB, the main determinant of behaviour is based on the person's intention to perform that behaviour, and intention is determined by three factors:

- Attitude to the behaviour: the balancing of the pros and cons of performing the behaviour or the risks and rewards they associate with that choice. Horne et al. (2001) reported that a lot of patients do not adhere to treatment because of a certain attitude towards the medication, or the duration of the disease. However, if a patient is educated about their disease as well as the treatment procedure, they will more likely adhere to the instructions (Horne et al., 2001).

- Subjective norm: social pressure from significant others, for example peers, media or family. Perceived subjective norms, on the other hand, are a person's evaluation of others'

expectations of a specific behaviour (O'Boyle et al., 2001). Social pressure encourages people to act in a socially desirable way which motivates them to comply with these social expectations (Ogden, 2000).

- Perceived behavioural control: the perception that person has about their ability to perform the behaviour (Ajzen, 1980). Perceived behavioural control refers to an individual's belief that he or she can engage in a specific behaviour and takes into account both internal and external factors. Internal factors are the abilities, skills or information that he or she possesses, whereas external factors are the opportunities or barriers that he or she may experience (Ajzen & Fishbein, 1980).

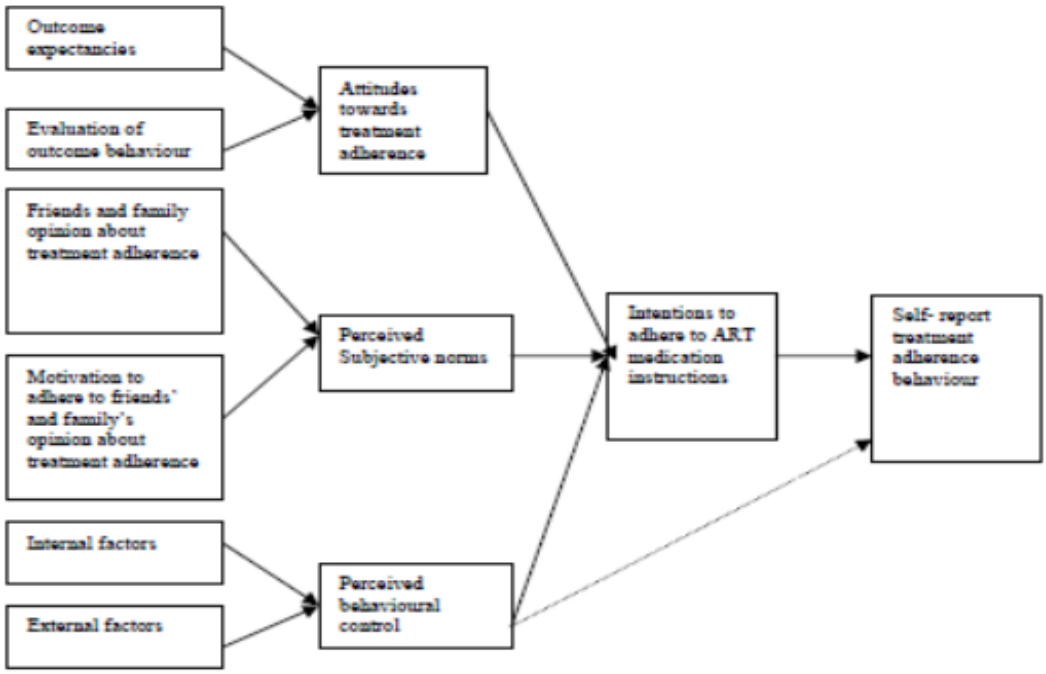

Figure 2: The theory of planned behaviour as applied in the context of ART adherence

In relation to adherence, attitudes towards behaviour include an individual's beliefs about the outcome of the behaviour and also evaluations of these outcomes (Saal, 2011). Attitudes towards ART adherence, on the other hand, refer to an individual's evaluative opinions, which can be either negative or positive, of the outcome of behaviour (Ogden, 2000). According to Horne et al. (2001), a positive attitude towards behaviour is related to its practice, whereas a negative attitude is not. For instance, it was found that negative attitudes toward ART are related to non-adherence among HIV positive patients in the United States (Viswanathan,

Anderson, & Thomas, 2005). Similarly, Horne et al. (2001) reported that a lot of patients do not adhere to treatment because of a certain attitude towards the medication, or the duration of the disease. However, if a patient is educated about their disease as well as the treatment procedure, they will more likely adhere to the instructions (Horne et al., 2001). Perceived subjective norms, on the other hand, are a person's evaluation of others' expectations of a specific behaviour (O'Boyle et al., 2001). Social pressure encourages people to act in a socially desirable way which motivates them to comply with these social expectations (Ogden, 2000). Perceived behavioural control refers to an individual's belief that he or she can engage in a specific behaviour and takes into account both internal and external factors. Internal factors are the abilities, skills or information that he or she possesses, whereas external factors are the opportunities or barriers that he or she may experience (Ajzen & Fishbein, 1980).

- **Health Belief Model (HBM)**

This theory proposes that a person's behaviour can be predicted based on how vulnerable the individual considers themselves to be. 'Vulnerability' is expressed through risk (perceived susceptibility) and the seriousness of consequences (severity), which need to be considered before a decision can take place. In addition to this, self-efficacy, defined as a person's perceived confidence of their ability to perform that behaviour, is also a predictor of behaviour. Underlying all of this are four factors that need to take place for behaviour change to occur. These are demographical, sociological, psychological, and structural factors. This model, and elements from it – particularly 'perceived barriers' and 'perceived susceptibility' – has been used to predict preventive health behaviours (Naidoo & Wills, 2000) and sick role behaviours (Janz & Becker, 1984). In developing the CCI communications programme these elements can be drawn on to provide a framework of factors that pre-determine the potential for non-adherence, so that such factors can be addressed in the communications programme.

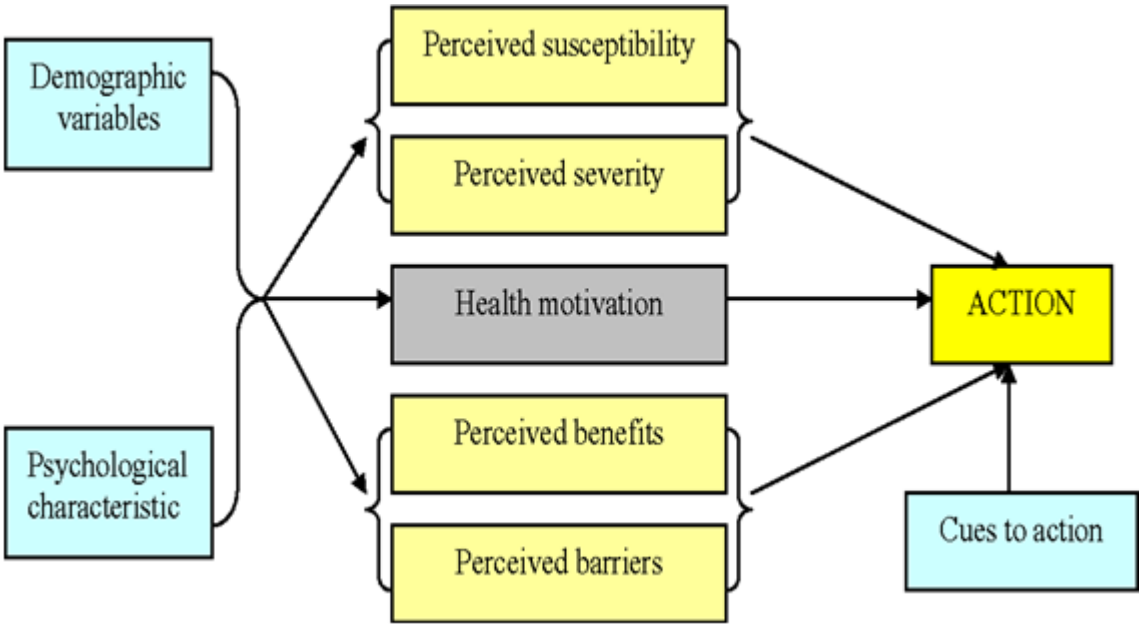

Figure 3: The Health Belief Model (HBM)

Source: Hausmann-Muela, Muela, Nyamongo, and Mills, 2003

Afe, Motunrayo, and Ogungbade (2017) conducted a cross-sectional study to explain the dynamics of HAART adherence among Nigerians living with HIV/AIDS using the Health Belief Model (HBM). They found that the Health Belief Model (HBM) components such as the belief that i) adherence to Highly Active Antiretroviral Therapy (HAART) improves a HIV patent's health condition, ii) adherence to HIV medication is feasible in the Nigerian context, iii) refusal to adhere to HAART is a serious health risk for the HIV patient, iv) non-adherence to HAART is life threatening for the HIV patient, v) non-adherence to HAART can lead to AIDS faster), vi) the consequences of non-adherence to HAART are severe , all show significant statistical association with HAART adherence.

Based on this, they concluded that the Health Belief Model was most suited to explaining or predicting patterns of HAART adherence behaviour among Nigerian PLHIV. In terms of the HBM therefore, ART adherence behaviour is informed by the subjective belief that HIV poses a threat to the person's well-being, and that adherence to ART would be effective in mitigating that threat. Put differently, the belief in the personal threat of HIV combined with the belief that adherence to ART will be effective in combating that threat, is likely to promote ART adherence.

A communications programme for adherence should therefore strengthen these beliefs in order for PLHIV to understand their vulnerability, and be motivated to take action by adhering to medication, so that they can reap the perceived health benefits. The theme of vulnerability and the need for action should therefore be clearly articulated in the messaging. For a schematic representation of this, see figure 2.

- **Stages of Change Model**

This is a cyclic model that suggests that people change their behaviour at certain stages in life, rather than making one major change (Prochaska & Diclemente, (1983). It is based on the assumption that people are at different levels of readiness to change, and during the change process they move through a series of stages. People move from pre-contemplation; (not ready to change), to contemplation; (thinking of change), to preparation; (getting ready to change), to action; (performing the change), to maintenance; (continuing the change), to relapse; (abandoning changes and reverting to former behaviours) (Prochaska and Diclemente, 1983).

Figure 4: The stages of change model (adapted from Prochaska & Diclemente, 1983)

In order to assess the degree of readiness for HIV infected patients that were on treatment and evaluate factors potentially influencing readiness, Södergård et al. (2016) administered The Wiley's 2-item readiness assessment, which categorises patients in either of the five stages of change. Patients who were catogorised as in the action or maintenance stage were found to be most ready to adhere to medicines compared to those who were in the other stages. This suggests that while the initiation of ART is extremely important, follow-up and motivation throughout treatment is also important to ensure good treatment results (Södergård et al, 2016).

Measures of the stages of change have been validated among patients who were newly initiated on ART (Willey, Redding, Stafford, et al (2000); and have also shown to predict viral load in a small prospectively followed sample of HIV positive women (Highstein, Willey, & Mundy, 2006). In addition to this, the stages of change model may function as a screening tool for clinicians to discover patients at-risk of lower adherence (Genberg, Lee, Rogers, Willey, & Wilson, 2013).

The frameworks and approaches presented above point to a need to first understand the context specific aspects of a particular community or population group, before one designs a communication strategy. They also provide inclusive frameworks that will ensure ownership of a communications programme by targeted users. This seemingly bottom-up approach to communication is more likely to be received positively by the users than a top-down approach.

3. Communication and Barriers

3.1 Characteristics of an effective communication strategy

In developing a communication strategy it should be taken into account that such a strategy usually has two main aspects namely, formal aspects and content. Formal aspects of communication are concepts such as message framing by the designers or developers of the messages, and the language used in developing these messages. According to Garcia-Retamero and Cokely (2011) message framing in health information can adopt a gain frame in which messages are designed in a way that they emphasise the benefits afforded by adopting particular health behaviours, or a loss frame in which messages are designed in a way that emphasises the costs associated with failing to adopt health behaviours. In a study done by Zhao et al (2012 to investigate the effect of message framing in adherence-promoting communication targeting patients with chronic diseases, it was found that messages that have been designed with a gain frame, emphasising the benefits of treatment taking and adherence, were more easily accepted than those with a loss frame. With regards to language use, it is important that the strategy uses jargon-free language, and explain instructions to its beneficiaries in a simple manner (Brincat, 2012).

Brincat (2012) notes that message content is very important in communicating with patients both during provider-patient engagements and in other forms of healthcare communication. One of the issues to be considered when communicating about health issues is that information content should preferably be “discussed”, and not be “ just presented or given”, and it should take patients’ beliefs and culture into account (Brincat, 2012; Malta et al, 2005). Secondly, in order to modify behaviour, healthcare providers and other health communicators should refrain from taking on a “business-like” persona, and take a more friendly and invested approach in communicating with those whose health behaviour they seek to influence (Brincat, 2012). Service providers should use simple language to ensure that patients understand instructions clearly and correctly. As demonstrate by Brincat (2012), encouraging patients to ask questions resulted in greater patient satisfaction (Brincat, 2012).

A good communication strategy acknowledges the need for different communication messaging and strategies for different patient populations and conditions. This means communication tools and resources should be designed according to disaggregation based on specificities of socio-demographics of targeted population groups particularly age and gender (Dodds et al, 2003, Brincat 2012, Zhao 2012). In a study conducted by Dodds et al. (2003) among adolescent women who receive HIV treatment and care at the University of Miami, Jackson Memorial Medical Center, it was shown that the youth had unique complex factors that are gender specific and that this determined retention in care and adherence to treatment. In this study some of the gender specific barriers to adherence were found to be pregnancy and having to take care of one or two children. The economic burden of having to take care of children sometimes impeded their access to care.

This is consistent with the findings from Bernays et al. (2016) who conducted a multi-country study that included the UK, Ireland, Uganda and the USA in 2011, as well as a study done by Ankrah et al (2016) in Ghana that all showed that adherence barriers to treatment were unique and had to be addressed through an approach that targets their age. Bernays et al (2016) established that young people's adherence to treatment was impeded by clinicians' lack of empathy; lack of clinicians' acknowledgement that adherence can be affected by factors beyond an individual's control and scolding for being irresponsible. Ankrah et al. (2016) identified general anxiety characterised by fear of disclosure and of taking treatment at home by the youth, as a barrier. Bernays et al. (2016) recommends a solution of improving clinical communication by introducing adherence communication that appreciates the wider implications of being on ART, and which acknowledges that adherence in the youth's case can be affected by periods of transition, schooling and changes in household composition due to family problems or additions. In addition to clinical communication Ankrah et al. (2016) recommend encouragement of support from parents (both financial and social) by reinforcing family closeness, cohesiveness, and problem-solving skills with adolescents.

Gender equity plays an important role in the success of SBCC programmes, therefore interventions or programmes that are gender blind may be ineffective or fail. As an example of a gender sensitive initiative, the Health Communication Capacity Collaborative (HC3)[5], a

[5]https://healthcommcapacity.org/technical-areas/family-planning/gender/

global project funded by USAID and led by Johns Hopkins Center for Communication Programs developed gender transformative tools that integrate gender and gender constructs into SBCC. The Gender Guide for Health Communication Programs[6] developed by this project shows that to develop a gender sensitive health communication programme, there is a need to conduct an in-depth study of the health concerns of men and women, their communicative practices and tools they have access to, prior to developing the programme. This then informs the development of messages that target concerns of each gender. It should be noted however that integrating gender into an SBCC health programme is not always easy, especially if the programme is not designed to specifically address gender equality and transformation (Martin 2016), which may be the case with a number of HIV adherence programmes. Gender dynamics affect adherence to ART in different ways for women and men. For example, women may have heavy household workloads that make it more difficult for them to take their medications on time. In other instances, women, for fear of violence, might not disclose their HIV status to their spouses, thus making adherence difficult. In a study in Njombe District of Njombe Region, Tanzania conducted in 2015 on how gender affects adherence to ART, Kahamba et al (2017) found that women were less likely than men to consult their spouse/partners before getting tested. In addition, women, especially married ones, were more likely to face social problems, including stigma, when disclosing their HIV status to their partners. These dynamics affected women's next phase of living with HIV and had a negative impact on ART access and adherence to services (Kahamba et al 2017).

Beyond youth and gender-based approaches, intersectional approaches are slowly gaining popularity in health communication initiatives. The term "intersectionality" was coined by Kimberlé Crenshaw in 1989 to denote approaches that move beyond single categories of analysis (e.g., sex, gender, race, and class) to consider simultaneous interactions between different aspects of social identity (e.g., race, gender, class, ethnicity, sexuality) as well as the impact of systems and processes of oppression and domination (Hankivsky et al 2009). For example, in the USA, in health interventions among African American women, intersectionality is increasingly being adopted as a new paradigm "which seeks to counteract one and two-dimensional approaches by bringing to the fore the complexity of social

[6] https://www.thehealthcompass.org/sbcc-tools/gender-guide-health-communication-programs accessed on 03/12/2017

locations and experiences for understanding differences in health needs and outcomes" (Hankivsky et al 2009). This approach is relevant in the South African context, where there is a history of deep-seated divisions and inequalities based on race, class, culture, income, education, age, ability, sexual orientation and ethnicity. In designing SBCC in health interventions and communication strategies such as adherence communications in South Africa, there is therefore ideally a need to consider all these factors. It should however be noted that such initiatives require an investment of ample resources that are often not available in developing countries such as South Africa, but the costs certainly outweigh the benefits of this approach.

Adherence campaigns targeted at specific populations are also supported by Nieuwlaat et al (2014) who suggests that the most effective intervention are those tailored towards contextualising the intervention to a specific patient. A qualitative study done by Rochon et al (2011) came across five constructs in HIV patients' adherence communication: cultural beliefs and language stigma, cues to action, self-efficacy, and mood state. Based on their findings, they are developing an adherence-related social marketing campaign. Blake et al (2010) suggests that "tailoring" is the most effective tool in adherence communication and has developed an automated telephone call reminder tailored to each patient's medication, serving those patients with lower literacy levels. The correlation between adherence and literacy has been established in previous studies such as Kalichman et al. (2008) who observed that participants with lower-health literacy also demonstrate poorer adherence compared to participants with higher literacy. A distinction is made between general literacy which refers to the ability to read and write, and health literacy which is defined by Sørensen et al. (2012) as the ability to:

i) place one's own health and that of one's family and community into context,
ii) understand which factors influence health,
iii) know how to address such factors,
iv) being able to take responsibility for one's own health as well as one's family health and community health.

According to Pignone et al. (2006) adherence involves optimal self-care and low general literacy limits the ability of the patient to acquire optimal self-care knowledge and skills, because acquiring such skills may require processing a great deal of sometimes complex information. Such information is often not provided in easy-to-understand formats. Kalichman et al. (1999) shows that inadequate health literacy in particular compromises a patient's ability to fully understand the health condition and the value of adhering to treatment. In order to assist low general literacy patients to understand health communication some communication programs have used pictographs, which are pictures/graphs that are used to simplify jargon-laden medical terms. (Finocchario-Kessler, 2012). This facilitates health literacy and thus adherence.

3.2 Barriers to effective communication

Barriers to non-mediated healthcare communication can be between providers and patients, and since part of the CCI mentorship programme uses this kind of communication between mentors and mentees, it is not necessarily an exception. A study done in Rio de Janeiro (Malta et al, 2005) explored the barriers to effective communication between healthcare providers and HIV positive patients from the perspective of the providers. Some of the barriers that were identified in this study were:

- Heavy workloads resulting on insufficient time to discuss HIV and adherence with patients

- Doctors found it difficult to discuss treatment adherence with patients because they lacked counselling skills and they also felt that they were invading patients' privacy by asking too many questions about adherence, and they felt they had poor communication skills, sometimes adopting judgmental tones with patients. They thus avoided discussing adherence with patients and instead referred patients to other health professionals such as nurses and counsellors. This observation has been made in other countries like Lesotho (Sobane, 2013) and South Africa (Deumert, 2010). This is a useful approach when such counsellors and nurses have been trained and equipped with communication skills to do proper patient counselling. As noted in

Zachariah et al (2006) it becomes very useful to use community counsellors in cases like this because they know and understand contextual factors that are likely to impact adherence in that specific community. As an additional solution, Malta et al. (2005) suggest that doctors should be communication trained in order to improve their communication skills as part of their medical training.

- Doctors did not freely discuss the adverse effects of the medication because they did not want to "scare" their patients
- In this study, doctors acknowledged that not understanding the patient's lifestyle, beliefs and conceptions about the severity of their disease were potential barriers to adherence. Ludwick and Silva (2000) recommend learning as much as one can about the language, customs, beliefs and values of their patient populations.

They further recommended understanding of non-verbal communication for all healthcare service providers and communication agencies that are involved in health communication. This is not different from what has been acknowledged by doctors in the South African context (for example in Deumert 2010). The extent of cultural and linguistic diversity in South Africa makes it more critical to incorporate intercultural communication training in the curriculum in medical schools to improve communication with patient. As another way of facilitating intercultural healthcare communication interpreters are in some cases used. Research on medical interpreting, for example, Rosenberg et al. (2007) and Bezuidenhout (2008) is coherent in acknowledging the value of interpreters in enhancing communication between healthcare providers and patients in linguistically diverse contexts (Meeuwesen et al., 2009). In some cases interpreting is done by informal interpreters who are not a formalised part of health care institution, but perform their role on the basis of need such as family members who have accompanied the patient, cleaners at the healthcare facility and nursing staff (Meeuwesen et al. 2009; Poscḧhaker, 2000, Killian et al. 2014). These interpreters are useful as cultural communicators and brokers.

A multi-country qualitative study on young people living with HIV and AIDS conducted in the UK, Ireland, Uganda and the USA in 2011, as reported in Bernays et al. (2016) presented data regarding disclosure and information about HIV by young HIV patients. According to this study, young people were reluctant to voice their adherence difficulties in the context of their relationships with clinical care teams. The main reason put forward was that there were reports of being previously scolded by health care staff and carers when they did not take their pills. The overall tone of reproach, and the blame for their individual failure to adhere was a common feature of the narratives of these participants. Also prevalent in ~~In~~ Zimbabwe and Uganda, was pressure on young people to maximise benefits of available ART. This was done by emphasising their need to be grateful for the care they receive, but also to be mindful of the many peers who lack access to the same life-saving drugs, by the clinical staff. This raises pertinent issues about the need to establish and maintain good relationships between healthcare providers and PLHIV. This is also relevant and significant for the CCI mentorship programme which is based on the relationship between mentors and mentees. Some studies have suggested disclosure to peers, support groups or lay health workers in such cases as discussed in detail in section 5.1 below (Zachariah et al. 2006; Gusdal et al. 2011).

3.3 Barriers to ART adherence

To develop an effective adherence communication strategy, there is a need to first understand some barriers that have been identified in the literature. Past literature has identified and grouped economic, psycho-social and physical factors as some of the barriers to treatment adherence.

Among the economic factors, unemployment has been cited as one barrier to treatment adherence. Patients who do not have money for transport to go and collect their medication from health care facilities may end up missing on their prescribed medication because their medical stock had run out (Loeliger et al. 2016). Unemployed patients may not have enough money to buy appropriate nutritious food that should go hand in hand with treatment including HIV treatment. In a study done in the USA, respondents who were food insecure did not adhere to treatment guidelines because they lacked food which was required when taking the medication (Kalichman et al, 2016).

The same barrier has been identified in South Africa case as food security has been highlighted as a challenge in PLHIV adhering to treatment (Hodgson et al., 2014). According to Heise et al. (2013) cash transfers, which refers to providing cash to vulnerable groups, can offset the effects of unemployment and serve as a resource to facilitate adherence. A technical note prepared by the Livelihoods & Food Security Technical Assistance (LIFT II)[7] also notes that linking cash transfers to adherence to antiretroviral therapy (ART) and retention in care provides an opportunity to reach those that are mostly in financial need and whose economic situation compromises adherence.

Stern et al.'s (2017) study conducted in Khayelitsha reported that substance abuse was a psycho-social barrier to ART treatment. PLHIV who abuse alcohol and drugs did not always follow treatment as instructed. These results are consistent with the findings of Merlin et al. (2012) who reported that patients who engaged in substance abuse have twice the chance of poor adherence to ART than those who did not engage in it. According to Loeliger et al. (2016) and Michel et al. (2013) since substance abuse can be a form of "escapism" from the reality of one's HIV status, HIV/ART interventions must be modified to better address substance abuse, mental health, and other medical co-morbidities.

The fear of social stigma associated with disclosing one's HIV status was another factor that hinders treatment initiation and adherence. This observation is consistent with one made by Zachariah et al. (2006) who established that stigma and discrimination towards PLHIV was still common. In a study conducted by Masquillier et al. (2016) in Mitchell's Plain/Klipfontein Township which they describe as an "impoverished and densely populated area on the periphery of Cape Town", it was reported that stigma creates a certain level of silence about the disease from households with PLHIV. As a result it made it difficult for PLHIV to get support from their families and to initiate or adhere to treatment. Zachariah et al. (2006) also notes that stigma made it difficult for interventions to be implemented because it compromised people's willingness to be associated with HIV related interventions. Brown et al. (2003) report on educational intervention to offset stigma, composed of:

[7] LIFT II is a PEPFAR-funded Associate Award under the FIELD-Support LWA, a cooperative agreement between USAID's Microenterprise and Private Enterprise Promotion Office and FHI 360 and its consortium of 24 development partners

i) Information-based approaches in which the information is delivered through a variety of channels including advertisement, leaflets, information packs, videos or presentation in a class or lecture. The content generally includes factual description of HIV/AIDS and emphasise that PLHA are not to blame for being infected and that they should be accepted into the community.
ii) Skills-building approach aimed to teach participants skills for diffusing conflicting situations when confronted with a situation where they have to mitigate conflict around stigmatizing PLHIV.

Brown et al. (2003) shows that a small group of university psychology students in the United States, who had been exposed to these kind of interventions showed an increase in tolerance toward PLHIV and a reduction in stigmatizing attitudes. This is because the intervention provided information coupled with practical skills that facilitated non-stigmatising behaviour.

Other barriers to adherence are of a structural and systemic nature and are related to lack of resources in healthcare facilities. In a study conducted by Loelinger et al. (2016) among Community Healthcare Workers (CHWs) and PLHIV, it was established that the shortage of human resources resulting in high workloads, and in some cases, inadequate infrastructure in the public healthcare facilities resulted in long queues that deterred PLHIV from adhering to treatment. Similar findings were reported by Coetzee (2011) who observed that over-crowding in public clinics and hospitals had a negative impact on retention on treatment. Research conducted by Stern et al. (2017) in Khayelitsha highlighted the lack of resources in clinics and hospitals as a barrier to adherence. Patients complained about instances of stock running out in rural clinics which compromises their adherence to treatment.

In another study conducted in the rural areas of Bushbuckridge, CHWs reportedly experienced lack of, or limited access to formal training and education needed to assist PLHIV (Zulliger et al, 2014). While some CHWs had improved their communication skills because they had prior experience gained in previous jobs, others lacked these skills because they had limited or no training on skills to provide ART support (Zulliger et al, 2014).

This compromises the extent to which they can be efficient in helping patients to understand the need to adhere to treatment.

Initiatives to address these problems should ~~also~~ take into account the value of an inclusive and effective communicative strategy that will facilitate improved adherence outcomes. Such a communication strategy should be conceptualised with a clear understanding of the complex nature of barriers, and acknowledgement that communication is only one factor that can improve adherence trends, amidst a range of other possible solutions. An important step in such initiatives is to learn from the successes and failures of past initiatives, therefore in the next section the literature reviews some of the HIV communication related resources and programs that the CCI could draw from.

4. Successful adherence programmes, ART resources and information sharing practices and communication tools

4.1 Adherence programmes in the Global South

While the benefits of HIV Antiretroviral Therapy (ART) are well established, its success and long-term effectiveness require high levels of adherence, which is often challenging, and not accomplished by some patients (Paterson et al, 2000). Encouraging all patients to adhere to treatment and making sure that they are retained in treatment requires ample collective interventions including effective communication.

Most of the communication campaigns around HIV have focused on the BCC emphasis on curbing new HIV infections. Campaigns around adherence have often taken an approach of using community based approaches, however Ancheta et al. (2016) shows that very little is known about the effect of community versus health facility-based interventions in improving and sustaining antiretroviral therapy (ART) adherence.

In a systematic review comparing community interventions and health facility-based interventions, Nachega et al. (2016) established that participants assigned to community-based interventions had statistically significantly higher rates of treatment engagement.

Community-based ART delivery models were also found to be cheaper and cost-effective, and also more accessible compared to facility based ones. Nachega et al. (2016) concludes that community- versus facility-based models of ART delivery resulted in at least comparable outcomes for clinically stable HIV-infected patients on treatment in LMICs and are likely to be cost-effective.

The successes of community based interventions in reducing HIV infection rates, and facilitating adherence have also been reported in countries such as Thailand (see Nelson, et al. 1996), Ethiopia and Uganda (Gusdal et al, 2011). In Uganda and Ethiopia an adherence to ART community based programme was implemented in both countries for a cohort of HIV-infected people. The programme in both countries involved home-based care in which HIV and AIDS care, prevention, and support services were provided to enhance adherence in rural vulnerable communities. Eligible PLHIV were those with advanced HIV or a CD4-cell count of less than 250 cells per µL. Adherence interventions in particular included group education, personal adherence plans developed with trained counsellors, a medicine companion, and weekly home delivery of antiretroviral therapy by trained lay field officers. The positive results of this programme demonstrated that good adherence and response to antiretroviral therapy was achievable through a home-based AIDS care programme in a resource-limited rural African setting. The particular strength of this approach was that it reduced the burden of travel for PLHIV and it provided a peer-supporter, which is a useful resource in encouraging adherence.

In the same programme peer counsellors who were facilitators of adherence, played an important role by acting as role models, raising awareness, and being visible in the community. These acted as a bridge between the health care system and patients. Peer counsellors from the local community provided patients with an opportunity to individually talk to someone who was also living with HIV, who had a positive and life-affirming attitude about their situation, and were willing to share personal stories of hope when educating and counselling their patients.

In retrospect, peer counsellors in both Uganda and Ethiopia also found reward in helping others while at the same time acknowledging their limitations and need of support and remuneration. The main challenge was that their role and function were not clearly defined

within the health care system hence they received negligible financial and organizational support. Another challenge with this approach was that while it reduced costs for PLHIV, costs and logistical support needs were transferred to the implementers, implying that the cost would be incurred at to the national level if the programme was rolled out nationally.

Another successful programme was implemented in rural Malawi (Zachariah et al. 2006). In this programme community involvement was initiated to assist in the fight against HIV/AIDS and tuberculosis (TB) in a rural district in Malawi in 2003. Local community members provided voluntary counselling and HIV testing (VCT) as lay community counsellors. These community members provided care and support to 5106 HIV-positive individuals, and the programme significantly improved trends in testing and adherence. The successes of these programmes were attributed to the fact that these community volunteers were able to play an important role in reducing community stigma associated with HIV/AIDS and TB. Because of their insider perspective, they were able to effectively interact frequently with household members as well as religious and traditional leaders, and they invariably increased community awareness. Through their activities, and particularly by providing care within homes, they were able to positively solicit family support for individuals under their care.

Another approach bringing services to the clients was the US Center for Disease Control and Prevention (CDC) and AIDS Support Organization (TASO) led programmes in rural Uganda which had success in the treatment of hundreds of HIV-infected individuals, largely in their own homes (Apondi et al. 2007). Called the Home-Based AIDS Care Project (HBAC), it included a weekly home visit by a medical field officer and a basic package of medical services for affected individuals' families. At the weekly visits, the field officer would deliver antiretroviral treatment, perform a pill count, provide adherence support, administer a questionnaire to assess drug failure or toxicity, and collect necessary specimens and measurements. In addition to this, adherence was supported by a volunteer "medicine companion" and support groups. Anecdotal evidence suggested a dramatic improvement in the health of the participants involved in the programme and a significant reduction in AIDS-related deaths in the rural community in which they lived (Apondi et al. (2007).

In South Africa Peltzer et al. (2012) assessed the effectiveness of an ART adherence intervention programme implemented in a hospital in Kwazulu-Natal. The intervention was comprised of three information-sharing group sessions facilitated by a trained lay health worker from the local community in the Ladysmith hospital in Kwa-Zulu Natal. The aim of this intervention programme was to improve adherence to antiretroviral therapy (ART) in a cohort of HIV-infected adults. They discovered that there was a significant improvement in ART adherence and CD4 count among people involved in the programme. They therefore concluded that lay health workers may be a useful resource to enhance adherence in resource-constrained setting.

The ART-adherence club model (Wilkinson, 2013) provides patient-friendly access to antiretroviral therapy (ART) for clinically stable patients to reduce waiting times experienced at most health facilities. In this program ran in Khayelitsha, patients were allocated to an ART club, and club members met as a group either at a facility or a community venue for less than an hour every two months. Group meetings were facilitated by a local lay club facilitator who provided a quick clinical assessment, provided referral where necessary, and dispensed pre-packed ART. The programme resulted in increasing clinical human resources for new patients and those who were clinically unstable thus reducing the burden on healthcare facilities.
It also encouraged retention in treatment since these patients did not have to wait in long queues. In another study which looked into the effectiveness of the adherence in Khayelitsha, Luque-Fernandez et al. (2013) found that participation in adherence clubs was associated with viral suppression and increased CD4 count. These findings are corroborated by Grimsrud et al. (2015) who found that after 12 months of implementation, only 6% of patients were lost to follow-up (LTFU) and fewer than 2% of patients experienced viral rebound. The success of the clubs is attributed to peer counselling and the value of talking to someone who is in the same position as PLHIV.

Apart from community based care programmes, there have been programmes that focus on multimodal communication and information dissemination. According to Kress (2009) multimodality is an approach that uses different modes to communicate. A specific regional example is found in the work of Sobane (2012) who reported on the activities of Phela Health and Development Communications (PHDC), an NGO which distributes BCC information on HIV

and AIDS in Lesotho. The program adopted multimodality in its community campaign. PHDC produced a combination of print, radio and television materials that are targeted at Lesotho citizens above 18 years of age. This approach became successful because of two factors. Firstly it used multi-media to make sure that information is accessible to all, and secondly because the information did not assume a blanket approach but disaggregated messaging by age groups and was thus age appropriate. An important lesson about the PHDC is the use of different modes of communication because it makes it possible for the programme to be inclusive and cater for the needs and preferences of a wider range of people. For example, for some people messages in the audio-visual mode are appealing while for others literary texts are more appealing. Another lesson is the use of age specific messaging in developing a programme. This ensures that messages are commensurate with the targeted age groups and are understood by them.

This section has discussed a range of adherence programmes detailing some of the success factors and lessons that can be learnt from them. One of the lessons to be learnt in these programmes is that there is value in adopting an approach that uses the local community as a resource. With adequate training community health-workers become useful in unpacking the complexities of the treatment using lay language and with the added benefit that they are likely to have cultural sensitivity. They are also able to contextualise treatment issues in a way that can be understood and accepted by those they serve. The studies also reflect the importance of targeting information to specific groups and of being innovative in communication to ensure that the model is inclusive.

4.2 HIV related communication resources and tools

Communication about HIV is viewed as complex by many scholars (see for example, Ajoulat, 2002; Ijadunola et al. 2007; Anthonissen and Meyer, 2008; Sobane, 2015). One of the reasons for this is that it entails topics that people are often reluctant to talk about, and that are in some cases culturally sensitive. Some of these topics are issues of sexuality, sexual health and practices (Helleve et al. 2009); and the prospect of death since some people still associate HIV with a possible near-future death (Ajoulat, 2002; Ijadunola et al. 2009). This complexity is to be taken into account in developing communication initiatives meant to improve initiation of and adherence to ART.

Health communication in countries of the Global South, following changing patterns in development communication, has shifted from mass media to participatory, dialogical processes of communication. There has been a transition from targeting individual behaviour change to social change (Govender 2010). Across the globe, communication initiatives in health behavioural change interventions recognise the need for systematic and socio-ecological thinking which recognise the fact that "individuals and their immediate social relationships are dependent on the larger structural and environmental systems: gender, power, culture, community, organization, political and economic environments" (The Manoff Group 2012: 4). Novel interventions to improve engagement are therefore necessary to ensure medical adherence, improve long-term outcomes, and reduce HIV transmission. There are a number of innovative communication strategies that have been successfully employed, especially in developing countries, to improve adherence to HIV treatment.

- **Narrative approaches**

Narrative approaches to health communication are interested in the role of story-telling in conveying health information and promoting health behaviours. Narrative communication is context-dependent because it derives meaning from the surrounding situation and provides situation-based stories that are a pathway to processing story content (Lee, Fawcett & De Marco 2016). These approaches are emerging as a promising set of tools for motivating and supporting health behavioural change. Narratives are intrinsically persuasive, which offers health communicators tactics for persuading otherwise resistant audiences (Dahlstrom 2014). Their importance lies in the fact that narrative communication is the basic mode of human interaction. We use it in our day-to-day lives, in policy or political communication and in journalism. Narrative forms of communication include use of entertainment-education, story-telling and testimonials. The most dominant form of narrative used in health communication in the Global South is the Entertainment-Education (EE), an intervention that uses entertainment and popular culture to promote behavioural change. EE has been defined as "the process of purposely designing and implementing a media message to both entertain and educate, in order to increase knowledge about an issue, create favourable attitudes and change overt behaviour (Singhal and Rogers 1999, cited in Govender 2013: 1). This form of

health communication has over the years moved from the didactic radio or TV drama such as Soul City, to gripping popular media texts such as Shuga (Nigeria, Kenya and South Africa) and Intersexions (South Africa). Shuga, a form of EE, used a multi-media approach and the message of the drama series is repurposed in other communication platforms such as social media, internet, radio and TV talk shows. The funders and producers of Shuga state that they seek to strike a chord with young people and provoke a significant "shift in their attitudes and behaviour towards sexual health and associated public health issues. Combining these messages with stylish production, poignant storylines, believable characters and world class acting allows Shuga to sweeten the pill and make an impact where other campaigns may have failed to resonate in the past".

Successful health communication campaigns that have used the narrative approach employ culturally tailored narratives to depict experiences of individuals modelling health risk reduction behaviours.

The use of role model stories is increasingly becoming appropriate for adaptation in the development of health communication interventions. This approach is primarily based on social learning-cognitive theory (Bandura, 1986) wherein role model stories combine experiences of a "model" individual in a narrative format that incorporates cultural values, language, and local relevancy for targeted communities. Role model stories share information in "a non-threatening manner by fostering identification with story characters and experiences, engaging recipients with storyline messages, appealing to personal values and interests, reducing counterarguments against key messages, and improving information retention" (Hinyard & Kreuter, 2006, cited in Berkley-Patton 2009: 2-3).

- **MHealth Interventions**

Over the years mobile phones have been used in health intervention programmes. The use of mobile phones for health awareness is called mHealth. The World Health Organisation in its report *"mHealth New horizons for health through mobile technologies"* (2011) identifies several categories of mHealth such as health call centres, mobile telemedicine, appointment reminders, community mobilization and health promotion, mobile patient records, information access, patient monitoring, health surveys and data collection, surveillance,

health awareness raising, and decision support systems. mHealth especially in the area of HIV and AIDS is growing in Africa. According to Klasnja and Pratt (2012), mobile technology is a particularly attractive tool for delivering health interventions, due to: (1) its widespread adoption and potential for powerful technical capabilities; (2) the tendency to carry mobile phones everywhere; (3) people's emotional attachment to phones; and (4) the context-awareness features of mobile phones that allow for personalisation (p. 185). In particular, texting is an effective way to educate and support underserved and diverse populations due to its mass reach and relatively low cost (Fjeldsoe, Marshall, & Miller, 2009). For health purposes, texting can be used to (1) enhance health service provision (i.e., appointment reminders, vaccination reminders); (2) distribute mass health education messages (i.e., disease outbreaks); (3) encourage better disease self-management practices; and (4) deliver personalised health promotion interventions (Fjeldsoe, Miller & Marshall, 2012, p. 168). Studies elsewhere have also found that mobile phones have advantages when used in health programmes for youth, as youth in general are responsive to and excited about using new technologies.

A growing number of studies in the United States, for instance, have evaluated the impact of mobile text messaging on health outcomes, such as smoking cessation and physical activity (e.g., Rodgers et al., 2005, Fjeldsoe, Marshall, & Miller, 2009).

The recent explosion of mHealth applications in the area of HIV care has led to the development of mHealth interventions to support antiretroviral treatment adherence in South Africa, Kenya and Uganda. MHealth strategies including cell-phone and text messaging have shown success in the Global South for medicine adherence. In South Africa, organisations such as CellLife and Strengthening South Africa's Response to HIV and Health (SSARHH) have successfully used mobile phones in the prevention, treatment and care of HIV and AIDS, and to support the HIV sector in general. Uganda has also seen successful use of mHealth in HIV treatment campaigns. As compared to the traditional peer health worker intervention, clinical staff in rural Uganda believed that the peer health-worker & mobile phone intervention had improved the delivery of HIV treatment services & overall mHealth of HIV patients (Chang 2008).

In another Uganda study on the use of mobile phones for patient appointment reminders among a cohort of patients receiving ART, most patients who had missed appointments presented for treatment within a few days after mobile phone recalls (Kunutsor 2010). In a study in rural Kenya, it was found that patients who received SMS support had significantly improved ART adherence and rates of viral suppression than those who did not (Lester 2010).

MHealth in ART adherence to treatment campaigns has mainly used mobile to remind people to take their medication. In their systematic literature review, Mukund et al. (2010) found evidence that SMS can improve service delivery through appointment reminders and improve communication and is a useful tool to monitor and support adherence to medication.

One of the programmes that successfully used SMS messages is the Kenya Weltel programme implemented in 2007-2009 to improve adherence to ART (Van de Kop et al. 2012). The intervention involved sending weekly messages to patients inquiring how they were doing and participants were required to respond either that they were well or that there was a problem.

In a randomised controlled trial (RCT), Van de Kop et al. (2012) show that weekly text messages led to improved ART adherence and viral load suppression among those initiating ART. The intervention enabled frequent communication between clinicians and patients and many patients valued the service for the support it provided.

- **Social Media**

Beyond mobile phones and text messages, the use of social media in health communication interventions is being adopted, although the current body of knowledge on this is limited. Social media is increasingly being considered as an innovative tool in SBCC because of its capacity to target and reach diverse audiences since it is not limited by space or time. Social media is an inexpensive, effective method for delivering public health messages. Based on the understanding that SBCC is not merely the transmission of health information to passive audience, the multi-way interactivity in social media offers an unmatched advantage (Adams, 2010; Taylor, 2012). Not only is social media being used in searching for health information, clients now get involved directly in managing their health conditions through the use of social

media (Campbell & Craig, 2014, cited in Adewuyi & Adefemi 2016:111). Although in most countries in the Global North, social media is being increasingly used by public health departments, it is not yet clear how best to capitalize on social media for raising awareness and, ultimately, triggering behavioural change (Gough et al. 2017). In Africa, the use of social media in health communication campaigns is still very low. There is room for expansion despite digital inequality or divide, to creatively use social media for communication campaigns in the HIV sector. Research shows that mobile social media use in Africa is increasing year by year (Gough et al. 2017).

- **Pictographs**

In another intervention Finocchario-Kessler et al. (2008) developed, piloted, and evaluated pictorial images to communicate the importance of consistent dose timing and the concept of drug resistance to participants enrolled on the Motiv8 adherence project. The image messaging package consisted of pictures to explain concepts such as viral suppression, viral mutation and drug resistance, since these concepts are difficult to explain verbally for both low and high literacy participants.

They give an example of an image of a brick wall which was used to represent how ART medication, when properly taken, creates a barrier that blocks HIV from copying itself. They reported that the tools were well-received, and 80% of participants felt that they helped them to adhere to their medications.

The array of communication resources and tools that have been presented in this section highlight the need to be innovative and to capitalise on new and accessible technologies when developing a communication strategy. This implies that there is a need to conduct an in-depth needs assessment prior to developing a strategy, to gain insight into what resources are already available and how they can be harnessed for use in the envisaged strategy.

5. Conclusion

This literature review reflects the fact that adherence is a complex process that has to be thought through carefully before designing a communication strategy. According to Machtinger and Bangsberg (2017), improving adherence requires a combination of methods appropriate to the patient and clinical setting. They further suggest that alterable factors that are known to impact adherence should be addressed in a proactive and ongoing manner, and that adherence interventions should include dedicated educational and collaborative time with every patient to plan for medication adherence and to maintain necessary support and collaboration throughout the course of treatment. There is need to consider the plethora of psycho-social and socio-economic factors that have an impact on adherence, and also the inequalities that are associated with information access. It also points to the fact that there is a need to think broadly about delineating messages by age group in order to ensure that message content is suitable for the target group while it maintains a general consensus on the value of effective communication in adherence improvement. Notwithstanding all of this, what is ultimately required is a commitment to ask about and support medication adherence regularly in an open, non-judgmental, and collaborative manner (Machtinger & Bangsberg (2017).

From the literature review, key messages that come out and that are important for consideration in communication strategies include:

1. Targeted messaging with special emphasis on age and sex. Use appropriate communication methods including social media.
2. Stigma might still be a big issue, thus it needs to explored further, and how this can be addressed using appropriate communication methods.
3. Training of health care service providers on effective communication. This should include providing clinical information in understandable ways, taking time to understand patients' challenges and cultural, social, religious sensitivities.
4. The use of volunteers and/or lay health care workers is valuable in that it unburdens the health system. The transition from health facility base to community based support is suggested.
5. Exploring the role of communities in communication of health promotion.

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