

# Self-Identity Reconstruction: Lived Experiences of Surviving HIV Positive Spouses In Relation To Their Acquired Status in Gwanda South, Zimbabwe

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## Abstract

The study aimed at exploring the nature of changes that take place in the surviving HIV positive spouses' explanatory of their acquired HIV positive status. The death of a spouse has a far-reaching effect on the surviving HIV positive partner. Central to the surviving HIV positive spouses are questions of self and identity. Narratives provided the theoretical framework for qualitative research within a dialogical self-constructivist paradigm. Homogeneous purposive sampling was used and resulted in 10 participants. Semi-structured interviews and thematic analysis were used. HIV positive status devastates the body reducing it to a 'spoiled self'. The surviving HIV positive spouses seek to develop an understanding of the self in response to the acquired status. Participants often engaged in self-deceptions and positive illusions, and this resulted in them failing to comprehend their HIV positive status as they kept blaming others.

**Keywords:** Self; Self-Identity; Self-Identity-Reconstruction; HIV; HIV Positive; Spouse

## Introduction and background to the study

The study aimed at broadly exploring the nature of changes that take place in the surviving HIV positive spouses' explanatory of their self in relation to their acquired HIV positive status. How do the surviving HIV positive spouses' make meaning of their current selves in relation to their acquired HIV positive status? This research aims to explore the process of reconstructing one's self following the death of a spouse and being HIV positive.

In their review of the psychological literature on the self, Leary and Tangney (2012) suggest that one of the stumbling blocks to linking the self to behaviour has been the view of the self-concept as stable or generalised. Their solution is to view the self-concept as a multifaceted phenomenon that is, as a set or collection of images, schemas, conceptions, prototypes, theories, goals or tasks. Self-representations are activated, according to Leary and Tangney (2012), depending on the prevailing social circumstances and the individual's motivational state; motives relating to self-enhancement, and self-consistency. Self-concepts are cognitive structures that can include content (being HIV positive), attitudes (how you feel about being HIV positive), or evaluative judgments (what you think and what others are saying about you being HIV positive) and used to make sense of the world, focus attention on one's goals, and protect

one's sense of basic worth (Oyserman & Destin, 2010). Thus, the self is the '*I*' that thinks and the '*me*' that contains those thoughts. One important part of this '*me*' involves mental concepts or ideas of who one is, was, and will become. These mental concepts are the content of self-concept and these get affected in the event of one being HIV positive.

Recoeur (1992) and Taylor (1989), both think that when referring to self-interpretations, the central question is one of the particularities of one's self-identity, and the answers are provided within culturally and socially mediated self-interpretations. This implies that the hermeneutic view of the self and narrative identity is located between an affirmation of a certain and indubitable '*I*' and a total rejection of that '*I*'. Further, it means that the person in question – the surviving HIV positive spouse – together with others, is both the interpreter and the interpreted. Recoeur (1992) holds that narrative identity mediates between two kinds of permanence in time, one based on voluntary efforts and the other on character. Narrative identity contains both concordance and discordance, both unity and plurality. The plurality in question can be both synchronous and diachronous. While Taylor (1989) focuses on the plurality and discordance on the level of strong evaluations, Recoeur (1992) deals with all kinds of discordance in the world of action.

The death of a spouse has far-reaching effects on the surviving partner. The surviving spouse must cope, not only with emotional loss, but also with a sea of changes in daily routines and future plans. While the loss of one's spouse can be one of the most traumatic events in an adult's life, Walque & Kline (2009) argue that within a year or two, the surviving spouse usually bounces back to earlier levels of physical and psychological health. As the HIV pandemic continues to wreak havoc in the Zimbabwean communities, there is a sizeable number of surviving HIV positive spouses. When a partner succumbs to an HIV related illness, the surviving spouse has to find a way to continue with life. It has been observed that the surviving HIV positive spouses often remarry and live normal lives (Matovu, 2010). In a study on the role of widows in heterosexual transmission of HIV in Zimbabwe, Lopman et al. (2009) found that owing to the need to engage in sexual activities following deaths of spouses, widows play a key role in the transmission of HIV. Mutangadura (2000) contends that life after the death of a spouse due to HIV often changes as one has to adjust to the issues involving HIV and to live without a partner. On widowhood, Ntozi (1997, p. 125) states that, "life is characterised by grief, bereavement, rituals, forced marriages, harassment, rejection, loneliness, poverty and relative mortality."

It is clear from these observations that there is a plethora of challenges faced by widows and widowers following the deaths of spouses. HIV in the marriage is usually brought in by one of the partners, hence its coming brings the issue of mistrust. Betrayal is the trust bridge that has been damaged or destroyed. This is the journey traveled by the surviving HIV positive spouses as they reconstruct their self-identity.

Central to the surviving HIV positive spouses are questions of self and identity. Concepts of the self are inextricably intertwined in our past and current experiences. As Taylor (1989) argues that what I am as a self, my identity, is essentially defined by the way things have significance for me. My self-interpretation can only be defined in relation to other people, an inter-change of speakers. I cannot be a self on my own, but only in relation to certain interlocutors who are crucial to my language of self-understanding. In this sense, the self is constituted through webs of interlocution in a defining community (Taylor, 1989). This connection between our sense of morality and sense of self means that

one of our basic aspirations to satisfy is the need to feel connected with what we see as good or of crucial importance to us and our community.

In the dialogical self theory, we have certain fundamental values which lead us to basic questions such as "... what kind of life is worth living? ... What constitutes a rich, meaningful life, as against an empty, meaningless one?" (Taylor 1989, p. 42). Hence, connections between notions of the good, understandings of the self, the kinds of stories and narratives through which we make sense of ourselves, and conceptions of society, evolve together in loose packages. The story told reconciles the story-teller's current being with his/her past being. It makes the story-teller understand both the current and the past, and, therefore, allows them to reconcile and forgive each other. Within the context of temporality, the forgiveness and reconstruction of the current and the past "being" will constitute the reconstruction of a new "being". When people lose their loved ones through death as a result of HIV, they often find themselves experiencing breakdown and disintegration, and are forced to make sense of events through the utilization of stories or narratives. Stories play a central role in the process of identity construction. As (Mair, 1989; Elliot, 2005; Pinnegar & Daynes, 2006) stated that stories are the womb of personhood and can make or break us as we construct them within ourselves. Stories can sustain us in times of trouble and encourage us towards ends we would not otherwise envision.

Marriage, amongst its many other functions, is seen as a means and a barrier to protecting men and women from sexually promiscuous behaviours associated with increased HIV risk. Marital unions, unless stated otherwise, carry the expectation of intimate and sexual exclusivity between the parties within the marriage alliance (Maphosa et al., 2017). However, this is far from reality in many marriages, especially within Sub-Saharan Africa where cultural expectations offer room and excuses for infidelity. These predispose persons within marriage to the risk of HIV infection. Persons infected by their partners often report having observed, suspected or having had evidence of infidelity of the other partner. To these couples, diagnosis of infection does not necessarily come as a shock due to reduced level of trust after observing incidences of infidelity. However, the response to diagnosis are also usually negative with respondents in a research by Magura (2015) citing feeling disappointed even though they had suspected that a similar fate would befall them. Peta (2017) states that the major reason for women staying with their husbands after being infected with HIV was that they are economically heavily reliant on them. Respondents also cited concerns over raising children from broken homes, highlighting that it was important for the future of their children that both parties continue with their marital union.

According to Magura (2015), one of these coping strategies is developing an 'us versus them' attitude and mentality. Sharing that attitude within a marital union can be very helpful in fighting the rumours associated with being HIV positive as well as providing psychosocial support for each other. HIV within the marriage union also presents a scenario where one individual within the marriage is infected and the other is not, a phenomenon referred to as HIV serostatus discordance. Reaction to serostatus discordance has been found to differ between males and females within marriage. Bunnell et al. (2007) found that women are more likely to remain with an HIV partner when they themselves are HIV negative.

Straube (2013) discusses how couples who immediately embrace the reality of their situation and adopt an alternative lifestyle that strengthens positive health outcomes have a greater chance of living fulfilling lives where they can set lifelong goals together and attain them. Self-identity among people living with

HIV was observed to have been altered and that alteration seen as a result of personal choices by most people (Kleiber, Hutchinson, & Williams, 2002). This was mostly attributed to what is perceived as bad behaviour, that is, extra-marital sexual encounters (Ekstrand, Bharat, Ramakrishna, & Heylen, 2012), injecting of drugs through needles (UNAIDS, 2013) and random and opportunistic sexual behaviours (Rhodes, Malow, & Jolly, 2010). The perception that the contraction of HIV is due to a preferred lifestyle has a significant impact on internal dialoging individuals go through.

The process of self-identity reconstruction includes conciliation, disclosing of HIV status and migration towards economic independence, hence, in the case of the surviving HIV positive spouse conciliation and economic independence were perceived as critical factors (Speakman, 2012). However, some women further acknowledged the role they had been identified as, became prostitutes and fended for their wellbeing through sexual activities in defining their reconstructed identity (Mojola, 2014). Self-identity reconstruction influenced individual behaviour through which the individual dialogues the self to acknowledge a radical shift in perspective and reorientation of personal behaviours to positive living (Parish, Laumann & Mojola, 2007). These personal behaviours include the practice of HIV treatment, seeking support from others and consistent healthy and pro-social behaviours (Kleiber et al., 2002). This process is directed towards moving from the perceived spoiled self to the reconstructed self. Building a new self-identity cannot prevent finding a place for HIV positive status within the self in the form of acknowledging and living positively with HIV.

## Methodology

In this research, narratives provided the theoretical framework for conducting qualitative research within a dialogical self—constructivist paradigm. A dialogical self—constructivist paradigm assumes the existence of multiple realities, in which the participant and researcher are co-creators of understanding in the natural world. To address the research questions within this epistemological framework, the experiences of individuals were examined in relation to their social context and the meanings the individuals themselves attach to those experiences. Smith (2008) observes that, according to narrative theory, we are born into a storied world, and we live our lives through the creation and exchange of narratives. A narrative can be defined as an organised interpretation of a sequence of events. Gardner-Neblett and Iruka (2015) identified narrative as an account with three components: a beginning, middle and an end. Freeman (1993) asserts that narratives not only bring order and meaning to our everyday life but also reflexivity; and provide structure to our very sense of selfhood. We tell stories about our lives to ourselves (dialogical self) and to others. Participants recognise themselves in the stories they tell about themselves. We can hold a variety of narrative identities, each which is connected to different social relationships. Each narrative identity not only connects us to a set of social relationships, but also provides us with a sense of localised coherence and stability.

Narrative inquiry involves making meaning out of individual experiences expressed in lived and told stories (Clandinin & Connelly, 2000). Baur and McAdams (2000) found that narrative inquiry's basic psychological needs underlie the content and structure of life stories. The purpose was to reveal or communicate an untold story, thereby giving voice to people often marginalised. Narrative researchers seek to understand and represent the meanings of experiences through stories lived and told by individuals. The researcher places emphasis on using the participants' own words and capturing their voices.

Gwanda South is found in Matabeleland South Province in Zimbabwe. It is a rural district comprising mainly of the Ndebele tribe of Zimbabwe. There are seven clinics and one District Hospital at Manama Centre. Most people in this region have a four-year secondary education and they might have failed their exit certificate, but their spoken and understanding of the English Language is good. At the District Hospital, there is a department known as Opportunistic Infectious Clinic (O.I.C) which deals with people living with HIV. This department meets with the registered HIV positive people for Gwanda South once every month for education on HIV issues and evaluation of some programmes undertaken by the members. As a member of the HIV educators' team, the researcher noted with concern that there were many widows and widowers who are registered with this O.I.C department. It is within these parameters that the research took place. This study sampled 10 surviving HIV positive spouses (5 men and 5 women) who have been widows or widowers for a year or more.

This study used homogeneous sampling. Homogeneous sampling is a purposive sampling technique that aims to achieve a sample whose participants (people or cases) share the same (or very similar) characteristics or traits (surviving HIV positive spouses). A homogeneous sample is often chosen when the research question (what is the nature of the changes that take place in individuals' explanatory of their self in relation to their acquired HIV positive status, and in relation to the roledialogical-self play in the self-identity reconstruction process?) that is being addressed is specific to the characteristics of the particular group of interest (surviving HIV positive spouses), which is subsequently examined in detail. Purposive sampling is virtually synonymous with qualitative research. The research used the semi-structured interview. This approach to interviewing has a long history in psychology and represents a trade-off between consistency and flexibility that best meets the needs of many qualitative researchers. Consistency is maintained through the use of an interview schedule consisting of a series of questions and prompts designed to elicit the maximum possible information.

Participation was voluntary and there were no monetary benefits for participating in this research. A number of measures were put in place to ensure non-maleficence and protect the autonomy of the participants. Thus, no harm was inflicted on participants directly or indirectly, intentionally or unintentionally as a result of the research. Interview transcripts and audio recorders were kept at a secure location under lock and key by arrangement with the supervisor and the local adviser. The participants used fictitious names that are pseudo names to protect their identity and those were converted into codes in the final report. Interviews were conducted in private and there was no video recording to protect the identity of the participants.

## Findings

### Participants

The demographic information of the participants is illustrated in Table 1 below.

**Table 1 Demographic information**

Participant Pseudonym	Sex	Age in years	Educational level	Number of children	Years after the death of spouse



Percy	Female	43	“O” level	Nil	4
Sharon	Female	40	“A” level	1	6
Matunzeni	Female	50	Grade 7	2	5
Matika	Female	47	“A” level	2	1
Thando	Female	38	Degree	2	2
Mafana	Male	50	Diploma	4	4
Derek	Male	45	Degree	2	2
Nhlanhla	Male	38	“O” level	2	3
Mncedisi	Male	49	Grade 7	5	2
Methembe	Male	46	Form 2	Nil	2

The participants were given pseudonyms for protection of their identities. While the interviews showed a lot of similarities within the self-identity reconstruction experience among the surviving HIV-positive spouses, each individual came with their own unique experiences of the process. Throughout, the participants would be referred to with their pseudo names given on the Table 1 for the protection of their true identities and to ensure confidentiality.

## Emerging Themes

### Self-identity track

It should be noted that I presented these themes as one possible account of the experience of participants’ self-identity with HIV. They did not cover all aspects of their experiences of self-identity with HIV and I selected them due to their relevance to the research questions. I acknowledge that they are a subjective interpretation and that other researchers may focus on different aspects of the accounts.

**Table 2 Master Themes and related superordinate themes**

Master Themes	Superordinate Themes
<b>1.0 Self-identity track</b>	1.1 The positive self and the redefinition of life 1.2 Complexities of caring for an ill spouse and dealing with death 1.3 Life without the spouse

**Self-identity track**

Self as a mental representation of one's identity is revealed through the journey travelled by an individual from early life values. The self-identity track was traced through the subthemes identified within the master theme. HIV requires lifetime changes in physical health, psychological functioning, social relations, and adoption of disease specific regimens. Self-identity is affected by one's past behaviours and what significant others are saying about an individual (Petronio, 2012). The process of self-identity reconstruction involves understanding the embarked journey, and identifying the role one played at each and every stage of that journey. The responses of individuals to life eventualities will determine their self-identity reconstruction as they journey in life of changes and adaptation.

**The positive self and the redefinition of life**

Participants found it difficult to live with the idea that they were HIV positive at the beginning of knowing their status, but gradually came to accept their status. Being shunned, gossiped about, stigmatised and discriminated against affected them a lot at the beginning. Some of the difficulties are articulated in the following excerpts:

Percy had this to say:

*At the beginning it was tough and difficult but now I am fine..... I have grown to accept what I have.....I live with my medication, it is a daily thing!! People are always looking at you with suspicion..... you do not trust anyone eish....they laugh with you now and the next time you a subject of gossip so how do you trust them.....*

Mncedisi added this:

*It's a dark patch in life when you suffer from headache you think you will die the same day.... Any illness that attacks you, you always think eish that thing has started again.....death occupies your life so much that sometimes you think like losing your head.....paranoia feelings of shame and embarrassment .....you always want to explain to people who did not ask any questions..... I am just tired ..... This thing called HIV can eat you alive.....*

Learning that one is HIV positive can be one of the most difficult experiences a person goes through in life. Embarrassment, humiliation, stigma and discrimination appear to affect the participants most as they try to figure out what it is to be HIV positive. But it is important to note that the participants were able to live happy and fulfilling lives. Ultimately, everyone's lives are different; how you cope with your diagnosis and how you move forward is dependent on how you dialogue within yourself.

Participants' backgrounds and individual and family values influenced some of the choices they made. The notion of one's values influencing how they approach life is critical in understanding the decisions they make. For example, beliefs about marriage (monogamy or polygamy), religions and other similar factors seem to have affected how the participants navigated and made choices related to intimacy and relationship in their lives. Some of these values are articulated in the excerpts below:

Derek had this

*..... I dated a lot of girls and we engaged in sexual activities and boys who never slept with girls were seen as too backward.....boys who needed no respect from others....they would also feel ashamed of themselves and promise to indulge as well for them to be part of the group....*

Nhlanhla says,

*.... As I was growing up I used to take sex very lightly. We used to have sex in the bush with girls. We had girls and enjoyed sex ..... I used to date many girls and had sex with them.....it was just a game to all of us..... eish you look back and say these are things we use to do and wonder now but by then it was the norm for most of the boys..... we will boast about the number of girls we would have slept with.....*

The use of the word “we” from the male participants above seems to imply that there was a sense of wanting to please peers so as to show how much of a man one is. In addition, sexual intimacy appears to be linked to manhood where men feel the need to show their sexual prowess by being promiscuous. On the contrary to this, a different narrative seems to apply to women, and this can be seen from the women participants’ reflections below:

Sharon quoted,

*..... As we grew up we were told that marriage was very important for any girl and my wish was to get married through a white-wedding.....I had to behave so as to be sure that I get the best man for my wedding..... What I wanted was to make sure that my parents would be happy at the end.....mmmmh I never wanted to let down my parents.....my parents were everything that I lived for.....so I tried to live a good life for my husband and always prayed to God to give me the best man as a husband.....*

The above statements show how most of the females went into marriage with hope and good intention for the future. In their early lives before marriage, they did not indulge in sexual activities as they regarded sex as sacred and was to be enjoyed only in marriage.

To participants, marriage represented commitment and the faithful love two people share. The findings highlight that for the participants marriage carries with it emotional intimacy, family, significant others, finances, communication, parenting, pregnancy, relationship, romance, sex and above all love.

Thando says:

*I got married at the age of 23 in a traditional marriage known as customary marriage. All the traditional rites and rituals were performed according to customs and values to the satisfaction of our parents. We stayed for some time with our parents before we built our own homestead just next to parents’ homestead. We were blessed with two bubbling kids and the family was a bubbling of love and happiness.....though we always missed my husband, the father of my children who was always absent as he worked in South Africa, paying us visit twice a year only due to work commitment.....*

From the research findings most of the participants married in their mid-twenties through either white wedding or customary marriage. All of their marriages had parental and community blessings, their marriages were further blessed with children and they lived happily as couples. The couples consisted of



healthy people who were never sick and according to them, there was no need for HIV testing because everyone enjoyed life and couples trusted each other. HIV was considered as a disease for urban people as they always saw and heard of those who died as people from towns coming to the rural areas only for burial. The findings indicate that marriages were all healthy up to the discovery of their HIV positive status. The coming in of HIV positive status meant the change of life and redefining it anew as the participants had to learn how to live with being HIV positive.

### **Complexities of caring for an ill spouse and dealing with death**

When one realises that s/he is HIV positive, there is tendency of projecting the blame to the next person. Most participants blamed their late partner for bringing HIV home, they even expressed their anger and this is shown in the verbatim below. Marriages are characterised by such stark gender inequalities that marriage itself is a risk factor for HIV infection. The impact of married individuals learning of their HIV positive status is too heavy to the couples. Individuals actively respond to information about their HIV positive status, invoking protective behaviour against future risk of HIV for themselves and their actual and potential sexual partners.

Matika had this to say:

*.....At first he was very angry mmmmmh ....he did not want to talk about it (HIV) with me, he thought I am the one who brought this disease at home, he couldn't face and stomach staying with me. My husband was extremely angry and it affected his health to the extent of becoming ill.....his anger culminated him falling sick and I think with a weakened immunity.....things just worsened.....*

Matunzeni says:

*Mmmmmh..... I lost trust in him, life became different and difficult, I stopped having sex even though he insisted on the use of condoms, I refused, I had a new life that was complicated to understand and felt very much embarrassed.....I always thought everyone was through what I was going through.....eish everyone is talking maybe we are the talk of the village..... HIV sure in my family it was difficult to imagine.....*

Anger appears to dominate the feelings to being diagnosed with HIV. Participants are upset about how they got the virus and angry that they did not know that they had the virus. Being embarrassed is another issue that is coming out mostly from the participants indicating that stigma and discrimination is still an issue in HIV.

Stigma and discrimination also makes people vulnerable to HIV. The participants reported being shunned by their families, peers and the wider community. Stigma and discrimination limits the people with HIV access to HIV testing, treatment and other HIV services. From the participants' views, HIV and AIDS are always associated with death, with disapproved behaviours and that HIV infection is the result of personal irresponsibility.

Derek had this to say:

*As educated people, we were respected in the community and many people looked up to us as role models. We enjoyed the esteem offered to us by the community and that made us different from others.*

*However, all this dissolved as soon as people learnt of my wife's sickness and news travel quicker if you are an important person in the community. People started shying away and shunning us and many elderly people in the community were very much disappointed in us...mmmmh ...eish... it was indeed....this thing is something in life....*

Percy had this:

*It was a double loss! I had lost my child, now it's my husband who is sick, and it's me who is also HIV positive.....what a loss.....eish God ....why me...(she sobs and I give her a piece of tissue) .....People are talking.....I have names given to me (lowanaotshisayo-the one who is hot) .....some church members also shun me.....and some are too sympathetic to the extent of making me feel too hopeless ..... This thing (HIV) is just complicated and it complicates your life.....you wonder what next.....you not sure because you like staying with death sentence at home waiting for the announcement and pronouncement of it.....stigma and discrimination will hit you so much.....*

The epidemic of fear, stigmatisation and discrimination has undermined the ability of individuals, families and societies to protect themselves and provide support and reassurance to those affected. This hinders, in no small way, efforts at stemming the epidemic. It complicates decisions about testing, disclosure of status, and ability to negotiate prevention behaviours. An unwillingness to take an HIV test means that more people are diagnosed late, when the virus may have already progressed to AIDS.

Home based care was perceived as an economically viable option available for People Living with HIV (PLHIV). The care comprised of emotional, adherence, nursing and financial support to PLHIV. Home based care was preferred over hospital base care as it ensured confidentiality and patient care without hampering routine work at home. Spouses avoided picking up any argument with their HIV positive partners. They never enquired about the source of infection and remained silent even if they were aware of their infidelity. As most of the participants were based in the rural area where the culture of collectivism is still practised, it was fairly easy to get support from family members, church members and community members.

Methembe had this to say:

*Caring for my wife was a bit difficult.....you would remember that we lost our only one child to this thing (HIV).....now my wife was sick.... I was alone I felt my gods had abandon me....why me all this....thanks to my relatives who were always there for me.....otherwise caring for this lady was going to something else I tell you.....you see as a man you need your wife and now that your wife is sick.....mmmmheish what do you do.....mmmmh do you go out... (laughs...) no it's difficult for us men eish.....*

Caring for each other is based much on how you love each other. Most of the participants reported having a difficult time seeing their spouses in pain and wasting away drifting towards death. Participants shared how they felt after their partners were ill for a long time with little help they could offer, however, they appreciated the support they got from family during this hard time.

Mafana had this to say:

*Eish.....mmmh.....eish it was very painful indeed. It was indeed painful because I never told her the truth; I thought my life had ended with the death of my wife..... I tried to seek mercy from God. My wife died for something she did not know. I have failed my wife and children.....I knew my wife was going to die but it was like I was not waiting for it..... When it eventually happened I was saddened.....like she was never sick you see death...brings those memories..... It's like you didn't do your best to prevent this death.....I am just guilty.....maybe if I had told her, she was going to understand.....now she is gone and gone forever.....*

Matika added this:

*I blame myself..... I accused myself.....I killed my husband; he was a good man full of love for his wife and children. I might not cry publicly but always cry for my husband. Down deep in my heart I know my husband loved us heartily and I really regretted why I took long to tell him about my status. If only I had told him earlier.....eish maybe things could have been different....*

The above shows that surviving spouses suffer a lot from survival guilt and search for answers for the death of their beloved spouses. The surviving spouses struggle with finding the new self as the death of their spouses also devastates the already devastated HIV positive surviving spouse.

### **Life without the spouse**

After losing a partner to HIV, surviving spouses often engage in self-blame by ascribing to themselves the responsibility for the death of their spouses. Often such are cases when the surviving spouse had engaged in infidelity which he or she suspects to have brought HIV into marriage and had, subsequently, led to the death of his or her spouse.

Mncedisi added:

*When I think of my wife I get lost in my thoughts ....eish you people you have not seen a good person if you didn't see my wife.....She was patient, loving, kind, sociable and a free person, she loved people naturally.....Oh! My Lord save me our graveyard is here at home we see these graves daily! It had been tough to live without my wife; I have many unanswered questions.....*

Matunzeni had this to say:

*My world crumbled when I lost my husband to HIV related disease. The morning that my children and I discovered his body and realised that he had passed on, is one that was forever engrained in my memory. At first, it was a memory that brought pain, grief, and sadness. And while 5 years later, his death is still difficult to face, I have come to peace with his passing and have learnt to live life well.....*

The participants were feeling the pain of losing their loved ones because they are always fighting the feelings or the reality that their loved ones are gone. Pain comes from resisting the truth that they are HIV positive and that their spouses are no longer alive. Even after a long time has passed after the spouse had died, the surviving partners said it was difficult to face the reality that their spouses were gone.

## Discussion of the findings

### Life with HIV in Self-identity track

Self-identity stems from differences that we have as individuals in the context of others; a concept that is not static, always changing to suit the demands dictated by the requirements of survival. Identity is fluid. We are each many things, a product of our past, present and future. Our identity is multifaceted and distinctly our own. The surviving HIV positive spouses were and shall always be a product of early life values, marriage life, their HIV positive status, stigma and discrimination, death of their partner and living without their spouse. Self-identity reconstruction is not a one point moment event, but a life of changes and adaptation. The identity of people living with HIV is fluid and non-linear as was observed by Moses and Tomlinson (2013). They purported that people with HIV are always sensitive to their conduct, thereby affecting the way they would behave; this they argue is because HIV is viewed as a sign of loose behaviour. Hareb (2011) alleges that people thought that people living with HIV had a spoiled self. The spoiled self emanated as the hated, disgraced, and undermined and discriminated self that individuals within the community despised.

### Marriage Life

Kposowa (2013) observed that individuals who are in a marriage alliance are at a great risk of acquiring HIV. In marriage partners are likely to relax in the comfort of faithfulness, as they both believe that their being at risk of acquiring HIV ceased on the wedding day. However, those that are involved in infidelity might fear to suggest the use of protection during sexual intercourse in fear of being suspected of infidelity. Fear of being suspected of infidelity leaves the other spouse at a high risk of being infected with HIV. Zakaras (2017) found out that there were negative attitudes towards condom use within marriage placing individuals at a great risk of HIV infection. Mafana had this to say, *‘.....we were a healthy and happy family which was an envy of many.....’* Thando added this, *‘.....we were blessed with two bubbling kids and the family was a bubbling of love and happiness.....’*

Living a life that is an envy of many creates a flawless perception of ‘purity’ and this has a huge negative effect on self-identity reconstruction for an individual who is HIV positive. The fact that married people are not supposed to be of loose morals. In their self-talk, the surviving HIV positive spouses see themselves in the eyes of their village as having been involved in extramarital sexual relations. HIV permeates the marital system easily, as the major means of prevention against HIV are not readily acceptable for married individuals. Being diagnosed HIV positive is a life shattering experience and has a great bearing in an individual’s reconstruction of self-identity. Mafana had this to say, *‘.....I was not really surprised due to my behaviour ..... but I was still a bit numbed by the results.....’* Matika added this, *‘.....at first my husband was very angry, he could not face and stomach staying with me.....’* Matunzeni also added her voice, *‘.....I lost trust in my husband, life became different and difficult, I had a new life that was complicated and felt very much embarrassed.....’* Nhlanhla angrily responded, *‘.....I was very angry with my wife .....I was working hard in South Africa, when she was busy looking for HIV back home.....’* Maphosa et al. (2017) found out that marital unions, unless stated otherwise, carry the expectation of intimate and sexual exclusivity between the parties within the marriage alliance. Hence, no one is expected to be HIV positive when he/she got

married HIV negative and any contrary reflects loose morals. Straube (2013) discusses how couples who immediately embrace the reality of their situation and adopt an alternative lifestyle that strengthens positive health outcomes have a greater chance of living fulfilling lives where they can set lifelong goals together and attain them. The participants are either angry at themselves or their late spouses. Finding out that one is HIV positive changes one's life completely as indicated by Matunzeni's sentiments. The reaction to the diagnosis of HIV positive has some lasting effects and the effects have great influence in the reconstruction of self-identity. Individuals should note that their reactions should not mark a permanent scar that would be difficult to erase in a bid to reconstruct their self-identity. However, the expectations for marriage make it difficult to easily accept being HIV positive. Being perceived as a spoiled self is a huge connotation that creates animosity between couples. When one looks at the reaction of Nhlanhla, who was working in South Africa then, shows some regret later and as a result got stuck in the process of reconstruction of self-identity. Self-identity reconstruction includes conciliation, reconciliation, disclosing and forgiving and then moving on with your life.

The process of identity transformation from spoiled self to a reconstructed self-identity happens when one is at peace in the dialogical self. This means that reconstruction of self should begin right at the diagnosis of HIV positive status.

## **Conclusions**

There are surfeits of challenges that widows and widowers encounter following the death of their spouses from HIV related illnesses. Being HIV positive brings about life values shift, the shift in terms of what we eat, in terms of what we perceive, in terms of our significant others, our physiological physique, medication and our lifestyle. The diagnosis that brings HIV positive status results devastate the body reducing it to a 'spoiled self' that is looked down upon by the self under the self-hate of being damaged and feeling of being wasted. In this crushed self, there is a need to build a strong self-identity that will propel an individual to a better future. Self-identity was tracked through dialogical self-theory propounded by Hermans (2003), which looks at what goes on in the inside and outside of the person.

The surviving HIV positive spouses seek to develop an understanding of the self in response to the acquired HIV positive status. Cohen and Sherman (2014) agree that individuals always search for evidence to know themselves better. Stanghor (2013) believes that when individuals know about themselves and have developed a positive self-concept they can modify and suit their behaviour for a better future and hold self-conversations that can lead to knowledge-based decisions that reduce cognitive dissonance. Knowledge gained of the self builds an individual's self-awareness. This current research found out that some participants often engaged in self-deceptions and positive illusions and this resulted in them failing to comprehend their HIV positive status as they kept blaming others. The blame game takes centre stage as surviving HIV positive spouses keep pushing the blame and searching for the source of HIV, and this creates a crisis between the actual self and the ideal self. In line with Pryer and Reeder (2015), the public self is highly dependent on significant others when the surviving HIV positive spouses had difficulty disclosing their statuses as seen in this current research.

Identity has been conceptualised in numerous ways. The framework used for this study centres on the dialogical self theory. From the findings in this research, it was quite clear that HIV infection has



devastating effects on self-identity of an individual. The self-identity is further flawed by the death of one's spouse after a long illness from HIV related diseases. Hareb (2011) further suggests that people living with HIV are viewed by the community as having a 'spoiled self'.

The current research concludes that early life behaviours have a great influence on self-conversations as observed by Schwarzer (2014) that self-inspection helps self-identity reconstruction through inference into their past behaviours. As stated by Goffman (2009), HIV positive people have a tendency of discriminating and stigmatising themselves. Stigma and discrimination have negative effects on self-identity reconstruction. The eventuality of death of the other spouse creates anxiety and nervousness to the surviving HIV positive spouse. Life without a partner is full of negative self-conversations which weigh heavily on the self-identity reconstruction.

## References

1. Baltazar, P. T. (2014). *Psychospiritual transformation through chronic illness: An intuitive inquiry* (Doctoral dissertation, Institute of Transpersonal Psychology).
2. Bauer, J. J., and McAdams, D. P. (2000). Competence, relatedness, and autonomy in life stories. *Psychological Inquiry*, 276-279.
3. Bunnell, R. Nassoizzi, J. Marum, E. Mubangizi, J. Malamba, S. Dillon, B. Kalule, J. Bahazi, J., Musoke, N., and Mermin, J. (2007). Living with discordance: knowledge, challenge, and prevention strategies of HIV discordant couples in Uganda. *AIDS Care*. 17(8)
4. Clandinin, D. J., and Connelly, F. M. (2000). *Narrative inquiry; Experience and story in qualitative research*. Hoboken, NJ: : Josey-Bass.
5. Cohen, G. L., and Sherman, D. K. (2014). The Psychology of Change: Self-Affirmation and Social Psychological Intervention. *Annual Review of Psychology* 65:333-371
6. Cohen, L., and Manion, L. (1994). *Research methods in Education*. 4<sup>th</sup> Ed. London: Longman.
7. De Walque, D., and Kline, R. (2009). *The Association between Remarriage and HIV Infection: Evidence from HIV Survey in Africa*. World Bank Policy Research Working Paper Series, SSRN: <http://ssrn.com> Accessed May 2016
8. Ekstrand, M. L., Bharat, S., Ramakrishna, J., and Heylen, E. (2012). Blame, symbolic stigma and HIV misconceptions are associated with support for coercive measures in urban India. *AIDS and Behaviour*, 16(3), 700-710.
9. Ekstrand, M. L., Ramakrishna, J., Bharat, S., and Heylen, E. (2013). Prevalence and drivers of HIV stigma among health providers in urban India: implications for interventions. *Journal of the International AIDS Society*, 16(3Suppl 2).
10. Elliot, A. (2013). *Concepts of the self*, 3<sup>rd</sup> Edition. London: Wiley
11. Elliot, J. (2005). *Using Narrative in Social Research*. London: Sage.
12. Freeman, M. (1993). *Rewriting the self: History, Memory, Narrative*. New York: Routledge.
13. Gardner-Neblett, N., and Ivuka, L. U. (2015). Oral narrative skills: Explaining the language-emergent literacy link by race, ethnicity and SES. *Developmental Psychology*, 51(7) 888-904
14. Goffman, E. (2009). *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.
15. Goldin, C. S. (2009). Stigmatization and AIDS: critical issues in public health. *Social Science and Medicine*, 39 (9): 1359-1366.
16. Harmon, R. (2013). *Introspection via Self Debugging*. Routledge

17. Hermans, H. (1995). Narratives Interviews. In E. v. Kardorff; H. Keupp; L. v. Rosenstiel and S. Wolff: *Handbuch Qualitative Sozialforschung*, 182-185.
18. Hermans, H. J. (2004). The dialogical self: Between exchange and power. In H. J. Hermans, & G. Dimaggio, *The dialogical self in psychotherapy* (pp. 13-28). New York, NY: Bruner-Routledge.
19. Hermans, H. J. (2013). The dialogical self in education: Introduction. *Journal of Constructivist Psychology*, 26(2), 81-89.
20. Hermans, H. J., and Hermans-Konopka, A. (2010). *Dialogical self-theory: Positioning and counter-positioning in a globalizing society*. Cambridge: Cambridge University Press.
21. Hermans, H. J., and Kempen, H. (1993). *The dialogical self: Meaning as movement*. San Diego, CA: Academic Press.
22. Hermans, H. M. (2003). The construction and reconstruction of a dialogical self. *Journal of Constructivist Psychology*, (16), 89-130.
23. Joint United Nations Programme on HIV/AIDS (UNAIDS). (2013). HIV in Asia and the Pacific. Geneva: UNAIDS
24. Joint United Nations Programme on HIV/AIDS (UNAIDS). (2014). Global report: UNAIDS report on the global AIDS epidemic 2013. Geneva: UNAIDS, 2013. *According to the UNAIDS' estimate the number of new infections in the region increased from, 21, 22-000.*
25. Kleiber, D. A., Hutchinson, S. L., and Williams, R. (2002). Leisure as a resource in transcending negative life events: Self-protection, self-restoration, and personal transformation. *Leisure Sciences*, 24(2), 219-235.
26. Kposowa, A.J. (2013). Marital Status and HIV Mortality. *International Journal of Infectious Diseases* 17(10): 868-874
27. Kübler-Ross, E. (2011). *Living with death and dying*. Simon and Schuster.
28. Kübler-Ross, E., and Kessler, D. (2014). *On grief and grieving: Finding the meaning of grief through the five stages of loss*. Simon and Schuster.
29. Leary, M. R. and Tangney, J. P. (2012). *Handbook of Self and Identity*. New York, NY: The Guilford Press.
30. Lopman, B. A., Nyamukapa, C., Hallet, T. B., Mushati, P., Spark-Du Preez, N., and Kurwa, F. (2003). Role of widows in the heterosexual transmission of HIV in Manicaland, Zimbabwe. *Sexually Transmitted Infection*, 41-48.
31. Mair, M. (1989). *Between Psychology and Psychotherapy*. London: Routledge.
32. Maphosa, S., Mutandwa, P., and Nyamayaro, A. (2017). Infidelity Appetite: Psychological Factors Influencing Women to Engage in Extra-marital Affairs. *International Journal of Innovative Research & Development* 6(1)
33. Maphosa, T. and Maphosa, C. (2014) Unmasking remarriage practices of surviving spouses in the midst of the HIV/AIDS pandemic. *Mediterranean Journal of Social Sciences*. 5(16)
34. Matovu, J. K. (2010). Preventing HIV transmission in married and cohabiting HIV-discordant couples in Sub-Saharan Africa through combination prevention. *Current HIV Research*. 8 (6): 430-440.
35. Mojola, S. A. (2014). *Love, money, and HIV: Becoming a modern African woman in the age of AIDS*. University of California Press.
36. Mojola, S. A. (2014). Providing women, kept men: Doing masculinity in the wake of the African HIV/AIDS pandemic. *Signs: Journal of Women in Culture and Society*, 39(2), 341-363.

37. Mutangadura, G. (2000). Household Welfare Impacts of Mortality of Adults Females in Zimbabwe: Implications for policy and program development. *Economic Symposium* (pp. 56-88). Durban: Iaes.
38. Ntozi, J. P. (1997). Widowhood, remarriage and migration during HIV/AIDS epidemic in Uganda. *Health Transition Review*, 125-144.
39. Oyserman, D., and Destin, M. (2010). Identity-based motivation: Implication for intervention. *Counselling Psychologists*, 38 (2): 1001-1043.
40. Parish, W. L., Laumann, E. O., and Mojola, S. A. (2007). Sexual behaviour in China: Trends and comparisons. *Population and Development Review*, 33(4), 729-756.
41. Perry, B., Oluoch, L., Taylor, J., and Corneli, A. (2014). Widow cleansing and inheritance among the Luo in Kenya: the need for addition women-centred HIV prevention options. *Journal for the International AIDS Society*. 17(1)
42. Peta, C. (2017). The 'Sacred' Institution of Marriage: The Case of Disable Women in Zimbabwe. *Sexuality and Disability* 35(1):45-58
43. Petronio, S. (2012). *Boundaries of privacy: Dialectics of disclosure*. Suny Press.
44. Pinnegar, S., and Daynes, J. G. (2007). Locating narrative inquiry historically. *Handbook of narrative inquiry*, 3-23.
45. Pryor, J. B., and Reeder, G. D. (2015). *The Social Psychology of HIV Infection*. New York: SAGE
46. Recoeur, P. (1992). *Oneself as Another*. Chicago: The University of Chicago Press.
47. Rhodes, S. D., Malow, R. M., and Jolly, C. (2010). Community-based participatory research: a new and not-so-new approach to HIV/AIDS prevention, care, and treatment. *AIDS Education and Prevention*, 22(3), 173-183.
48. Schwarzer, R. (2014). *Self-Efficacy: Thought control of action* (Revised Edition). New York: Taylor & Francis
49. Smith, J. (1993). *After the demise of empiricism: The problem of judging social and educational inquiry*. New York: Ablex.
50. Smith, J. A., and Osborn, M. (2003). Interpretive phenomenological analysis. In J. A. Smith (Ed.) *Qualitative Psychology: A practical guide to research methods*. London: Sage.
51. Smith, J. A. (2008). *Qualitative Psychology: A practical guide to research methods*. Thousand Oaks, CA: Sage.
52. Smith, J. A. (2008). Reflecting on the development of interpretive phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*. (1), pp 39-54.
53. Smith, J. A., Flowers, P., and Larkin, M. (2009). *Interpretive Phenomenological Analysis: Theory, Methods and Research*. London: Sage.
54. Speakman, S. (2012). Comparing the impact of religious discourse on HIV/AIDS in Islam and Christianity in Africa. *Vanderbilt Undergraduate Research Journal*, 8.
55. Stanghor, C. (2013). *Social Psychology Principles*. Michigan: Unnamed Publisher.
56. Taylor, C. (1989). *Sources of the self: The making of modern identity*. Cambridge: Cambridge University Press.
57. Taylor, D. M., and Osborne, E. (2010). When I know who "we" are, I can be "me": The primary role of cultural identity clarity for psychological well-being. *Transcultural psychiatry*, 47(1), 93-111.
58. UNAIDS. (2017). Ghana addressing the barrier of stigma and discrimination for women. Retrieved at [www.unaids.org/en/resources/presscentre/featurestories/2017/march/20170327\\_ghana](http://www.unaids.org/en/resources/presscentre/featurestories/2017/march/20170327_ghana)

59. UNAIDS. (2014). *Joint United Nations Program on HIV/AIDS. AIDS epidemic update*. New York: UNAIDS.
60. UNAIDS. (2013). *AIDS epidemic update*. New York: UNAIDS.
61. Wagura, A., (2015). The challenges of Sero-discordant couples. Retrieved from
62. World Health Organization.(2015). *HIV/AIDS a global epidemic*.
63. World Health Organization. (2012). Guidance on couples HIV testing and counselling including antiretroviral therapy for treatment and prevention in serodiscordant couples: recommendations for a public health approach.
64. Zakarsa J. M, Weiser, D. S, Hatcher, A. M, Weke, E, Burger, R. L, Cohen, C. R, Bukusi, E. A, andDorkwin, S. L (2017). A Qualitative Investigation of the Impact of a Livelihood Intervention on Gendered Power and Sexual Risk Behaviours among HIV Positive Adults in Rural Kenya. *Archives of Sexual Behaviour* 46 (4): 1121-1133