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## Coping opportunities and deficits displayed by People Living with HIV/AIDS (PLWHA) in Alice region, Eastern Cape, South Africa: Social work implications

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### ABSTRACT

*Indubitably, the coping capacities of people living with HIV/AIDS (PLWHA) determine the success of antiretroviral therapies (ARVS) on them or their sinking into a bottomless pit of facing a constellation of opportunistic diseases, defaulting, or even facing immature death. With thirty-eight participants subjected to interviews and focus groups facilitated using an interview guide, this study aimed at exploring the perceptions of various stakeholders on the coping opportunities and deficits displayed by the PLWHA resident in Alice town and its adjacent villages. Findings established that PLWHA bolstered their coping through the support from family members, kins and communities, assistance from faith-based organizations; and engagement in support groups; while negative coping is driven by the PLWHA states of apathy driven by poverty, stigma, and discrimination; abuse of substances, and ignorance about the disease's epidemiology and aetiology. The article has used the theory of ubuntu to explain various underpinnings of coping. Education on positive coping is critical for all the PLWHA so that they can reduce the chances of HIV/AIDS morbidity and immature death. The role of social workers in conducting educational sessions is critical.*

**KEY TERMS:** defaulting, faith-based organizations, opportunistic diseases, stigma and discrimination, support groups, ubuntu.

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## INTRODUCTION

Unequivocally, effective coping mechanisms among the PLWHA are compelling in Southern African countries with higher HIV/AIDS prevalence. Statistically, countries south of Sahara are a refuge for more than 70% of all the people living with HIV/AIDS in the globe (United Nations HIV/AIDS Programme (UNAIDS, 2017). Perhaps the need for effective coping methodologies by the PLWHA is dire in South Africa due to an HIV/AIDS Prevalence of 18.9% among 17.2 million people infected. The country finances the most expensive anti-retroviral programme in the world, and in 2017, experienced 270,000 new infections and 110,000 AIDS-related deaths (UNAIDS, 2017). Organization wise, this article discusses the coping deficits displayed by PLWHA in the Alice region of Eastern Cape of South Africa with the hope of addressing them; as well as coping opportunities and how to increase coping resilience followed by a problem statement, theoretical frame, aims and objectives, methodology, findings and discussions and a conclusion. Although the bigger research project from which this article is derived considered the socio-cultural factors and HIV/AIDS in the Alice region, this article aims to discuss the coping opportunities and coping deficits adopted by people living with HIV/AIDS resident in Alice Town in the Eastern Cape of South Africa.

## BACKGROUND

Perhaps why effective coping among the PLWHA is critical is because the journey of living with HIV/AIDS has been an arduous one due to social challenges such as stigma and poverty (Mavhunga, 2017). Coping, therefore, determines how much the PLWHA are likely to earn their lease of living or face an immature death (Nobuhle, 2017). Unequivocally, positive coping gives them a cleaner lease of life, while negative coping can lead to immature death (UNAIDS, 2017).

Incontrovertibly and opportunistically, the assistance that the PLWHA get from family members and other close kins has made the journey of living with the virus a less pernicious one (Kang'ethe, 2011). In many cases, family members have been instrumental in assuming a caregiving role and have provided a shoulder from which the PLWHA can lean on; as well as acting as a buffer stock to absorb their daily challenges such as discrimination at eclectic social settings (Liamputtong, 2013). This perhaps is due to poor operationalization and implementation of HIV/AIDS stigma laws (Kang'ethe & Nomngcoyiya, 2015).

Opportunely, strong religious faith and support from faith-based organizations, constitute critical factors that make the journey of living with HIV/AIDS a less painful one. Indeed, some of these organizations have been a mainstream of love, and hope and in some settings offer material assistance (Gyimah et al., 2010). Paradoxically, while some faith-based organizations offer the requisite psychosocial support to PLWHA, others peddle lies and even lure them to abandon taking the ARVs (Kang'ethe & Nomngcoyiya, 2015).

Opportunely, engaging and interacting with one's peers living with HIV/ADS in support groups is a very useful coping mechanism (Nobuhle, 2017). This is because PLWHA who take membership in support groups counsel one another as well as encourage one another leading to the achievement of their self-determination, and confidence to soldier on in the journey of living with HIV/AIDS. Often, support groups encourage disclosure (Kang'ethe, 2020).

On the flip side of the coin, PLWHA tends to adopt negative coping methodologies especially when they are not in good counselling hands, and in an environment bereft of knowledge of the HIV/AIDS' aetiology and epidemiology or are engulfed in a state of apathy and denialism (Kang'ethe, 2020). Denialism was driven by the Mbeki government's inadvertent and pseudoscientific disposition that doubted whether AIDS was caused by HIV/AIDS virus. Mbeki's regime suggested that HIV/AIDS was driven by poverty and that the use of vegetables such as garlic and beetroot was a better option than the use of antiretroviral drugs (Karim, 2010). This phenomenon has had hangovers that can explain the protracted denialism, stigma, and low disclosure rate of HIV/AIDS in the country (Kang'ethe, 2020).

Indubitably also, the preponderance of the use of alcohol among the PLWHA as a coping mechanism only offers a temporary solution and drives the body to higher levels of drug resistance that encourages opportunistic diseases to take a huge toll. Paradoxically, while alcohol consumption has a recreational value, albeit for a while, it ironically weakens the body opening it to opportunistic diseases such as tuberculosis (Krishnan et al., 2013).

Further, the state of ignorance of the aetiology and the epidemiology, as well as treatment modalities of the disease defies one's coping mechanism (Kang'ethe, 2015). Failure to consistently follow the drug regimen puts the body in a precarious position. A study by Kang'ethe (2012) in Botswana discovered that many PLWHA

became very weak when they abandoned the advice of biomedical practitioners for medication and concoctions prescribed by traditional healers.

### **Problem statement**

Unequivocally, the quality of coping embraced by PLWHA determines their probability to attain a satisfactory lease of life or succumbing to the jaws of morbidity or even death. Positive coping is believed to develop from an array of the following factors: Psycho-social support offered by family members, close kins, friends and communities and thereby contributing largely to positive living; assistance from faith-based organizations; and engagement and interaction with peers in support groups; while negative coping is believed to be driven by the PLWHA states of apathy usually emanating from poverty and other social challenges such as stigma and discrimination; abuse of substances, and ignorance about the disease's epidemiology and aetiology.

### **Theoretical frame - The philosophy of Ubuntu**

Historically, the philosophy of ubuntu is centred on Xhosa saying "*umuntu ngumuntu ngabantu*" which means "I am because you are, you are because I am". This symbolizes love, humanity, mutuality, reciprocity, and interdependence (Mugumbate & Chereni, 2020). For effective coping, members of the PLWHA support groups must be cordial, and mutual and display reciprocity through being there for one another. This is the spirit of being there for one another, and one offering a shoulder for the other one to lean on. The philosophy is overly applicable to this article because the findings establish that the PLWHA's coping capacities are enhanced by the love they are offered by close family members, kins, faith-based organizations and community members generally (Gyimah et al, 2010). The article hails the role of faith-based organizations for their assistance packages and offering the much-needed requisite psychosocial support such as counselling. Their ability to show compassion underpins the spirit of ubuntu (Manomano et al., 2020). Further, ubuntu is universal and places the responsibility of all to be an integral part of the society. People must hold one another with dignity, humanity, and interdependence (Mugumbate & Chereni, 2020). It is both a mutual and a reciprocal process.

### **METHODS**

This section will discuss the three aspects of methodology, research design and paradigm, methods of data collection and analysis

#### **Research design and paradigm**

The design used in the article was descriptive, exploratory, and explanative. This is because the phenomena under the study were explored and described in tandem with making explanations of the sample's nuances (Fouche et al., 2021). Moreover, the study followed an interpretative research paradigm which called for the subject matter to be subjectively described, explored through qualitative methods, which are intrusive enough to tap into the perceptions and attitudes of research subjects. The interpretative paradigm entails having the researcher closely interact with the subjects as the primary data collection instrument (Claire et al., 2018). The specific research design used was a case study. Notably, the researcher embraced the African philosophy of ubuntu by allowing the participants to use their mother tongue language. This made them happy and allowed free flow of their perspectives (Mugumbate & Chereni, 2020).

#### **Sample selection criteria, data collection and procedure**

The study used a non-probability sampling method, particularly a purposive sampling strategy (Fouche et al., 2021) to intuitively select only data-rich samples to understand the coping opportunities and deficits adopted by the PLWHA resident in Alice town and its environs. The data collection process was also cross-sectional as data was collected within a short period of time. The data collection process also respected the saturation principle where further data collection on a particular theme would be stopped when the samples appear to repeat the same idea or thought (Claire et al., 2018).

#### **Methods of data collection**

On methods of data collection, in-depth interviews, focus groups and informal discussions were used to tap the insights of thirty-eight stakeholders pertaining to the coping opportunities and deficits adopted by the PLWHA resident in Alice and its environs. Further, an interview guide with semi structured questions was used to facilitate the interviews, focus groups and informal discussions. The researcher ensured that all the participants understood the study objectives as succinctly as possible, were handled both humanely and with dignity, and were free to withdraw from the study, if they felt under any duress. Further, the narrative responses were audiotaped and

conducted in Isixhosa language and facilitated by the principal researcher's two research assistants, who were Xhosa-speaking. However, the principal researcher and his assistants also observed the participants' gestures to strengthen the thematic outcomes.

### Data analysis

Data analysis used a thematic content analysis, which entailed following a rigorous process of arranging and organising crude data into organised and consumable data that ensured a succinct guarantee to achieve the objectives of a study (Claire et al., 2018). This was achieved through coding where data that referred to the same idea or ideology was grouped or tagged/coded together. This means that data after the collection was refined and arranged into themes and subthemes that informed the answers to the research questions. Data transcription was also carried out, as the crude data was collected in Isixhosa language. This was important because of the gap in understanding Isixhosa language between the principal researcher and his research assistants. More so, jotted notes were very important in complementing the analysis. To further enrich the analysis, verbatim quotes, and analogies in tandem with the researcher's and his assistant's interpretation of the participants' temperaments were all used to inform the selection of themes.

### Ethical and legal requirements

The principal researcher sought the guidance of Fisher's assertion to ensure the study upheld the virtuous values of fairness, trustworthiness, respect for human rights, protection of individuals from harm, and confidentiality of sensitive and private information (Fisher, 2016). These qualities also reflected the principles of African ubuntu (Mugumbate & Chereni, 2020). This ethical environment also reflected the African indigenous 'Golden Rule Principle' that implores upon people to do to others what they want to be done to them. This is to manifest the principle of mutuality, love, and reciprocity (Azenabor, 2008). Importantly, the principal researcher sought informed consent from all participants before the study kick-off (Haggerty, 2016). Further, the principal researcher and his research assistants had sought a letter from their Head of Department to engage with communities surrounding Alice town and its environs. This is because the study was a community engagement endeavour (Ahmed & Palermo, 2010).

### Research domain and justification of choice

Data for this study were collected in Alice town and its neighbouring villages such as Ntselamanzi and Gaga in 2015 and parts of 2016. The choice for the research domain was influenced by several factors, including the discovery during the researcher's community engagement endeavours in the study domain that there was fear surrounding HIV/AIDS, low disclosure rate, and immense stigma (Kang'ethe, 2020). Further, the prevalence in the province was rising instead of decreasing. This justified the need to investigate the perceptions and attitudes the Alice communities held on the coping opportunities and deficits displayed by PLWHA in the Alice region.

## FINDINGS

Demographically, the study was gender skewed with women (23) overrepresented compared to their male counterparts (15). This was a notable pattern where men had apathy of engaging in many development endeavours compared to women in the study domain. Moreover, men appeared to succumb to HIV/AIDS stigma more than women (Kang'ethe, 2020). Unfortunately, the researcher ignored computing data on age, although he biasedly increased the input of the PLWHA linked to the Victoria Hospital. Therefore, close to half of the samples (15) were PLWHA. This was because the samples were intuitively selected based on the researcher's perception on their data richness. Table 1 depicts the cadre of samples that were investigated, while Table 2 connotes the themes that emerged from the study.

*Table 1: Demographic Profile of the Participants*

Method of Data Collection	Organizational affiliation	Participants		Total
		Males	Females	
In-depth Interviews	Victoria Hospital	0	1	1
In-depth Interviews	University of Fort Hare Clinic	0	1	1
In-depth Interviews	University of Fort Hare (staff)	1	0	1
In-depth Interviews	University of Fort Hare (student)	1	0	1
In-depth Interview	South African Police Services (SAPs) (Alice Station)	2	0	2
In-depth Interview	Alice Victim Support Centre	0	1	1
In-depth Interview	Community Leader	1	0	1
Focus Groups	Alice Hospice	1	3	4
Focus Groups	Lavela Old Age Centre	2	4	6
Focus Groups	PLWHA linked to Victoria Hospital	5	10	15
Focus Groups	University of Fort Hare	2	3	5
Total		15	23	38

Table 2. Thematic Findings

1	Psychosocial support from kins
2	Assistance from faith-based organizations
3	Peer support from support group structures
4	Apathy driven by poverty and stigma
5	Abuse of substances

### Psychosocial support from families and close kins

Stakeholders concurred that the assistance that the PLWHA get from kinship, friends, and communities was instrumental in strengthening their coping with the virus. The following verbatim excerpts bear testimony to the finding above. The participants verbatim reflect the group they hail from (e.g., Faith-based, PLWHA, SAPS) and their codes (1, 2...).

*Family members and communities have been shoulders for us to lean on as well as to cushion our stresses and despondency (PLWHA 1)*

*The food donations to the orphanage centres for the PLWHA children and other vulnerable groups are a testimony of community support to the PLWHA fraternity (PLWHA 2)*

Unequivocally, albeit with a few exceptions, most families, and kinships in tandem with some community members support the PLWHA and therefore heighten their opportunity to cope with the virus.

### Assistance from faith-based organizations

Although most participants, albeit with a few exceptions, praised the role of faith-based organizations in giving love, hope, counselling, and sometimes physical assistance to the PLWHA, there was an agreement among the participants that religious faith is the mainspring of love and makes the PLWHA stronger enough to ward off pangs of social challenges such as stigma and discrimination (Obermeyer et al., 2011). On the contrary, a few faith-based organizations offered a misleading faith, while some were not approving the use of condoms as preventative tools.

The following verbatim sentiments bear testimony to the finding above:

*Occasioning a faith-based organization can be a promising alternative to offer one love and hope for the future (Volunteer-Alice Hospice-participant 5)*

*Some churches go beyond giving love by giving food parcels to the PLWHA. They are contributing to the fight against HIV/AIDS by offering psychosocial support (Student-participant 30)*

*Some churches have very good counsellors to assist the PLWHA. They give assurance that living with the virus does not stop the love of God to His children, PLWHA being on the front line (Lavela old age-Participant 20)*

*But some pastors are still hell-bent on rhetoric that associates being a PLWHA with pangs of immorality. Such a phenomenon spreads stigma like bushfire instead of quenching it (Police officer- Participant 11)*

The worrisome thing is the fact that still some faith groups are still not allowing the use of condoms as preventative tools (Alice Hospice- participant 6).

Unequivocally, many faith-based organizations, albeit a few, are sources of love, hope and comfort to the PLWHA. They, therefore, offer an opportunity for positive living and therefore heighten opportunities for coping, while a few are still not very friendly to the PLWHA.

### **Peer support from support group structures**

Virtually all the participants overwhelmingly agreed that support groups of people living with HIV/AIDS, albeit with a few exemptions, were vehicles of support that strengthened the PLWHA's positive coping (Kang'ethe, 2011). However, it was not uncommon to have some support groups with a membership that was conflictual and broke other members' state of confidentiality. The following sentiments bear testimony to the finding above:

*Since I joined a support group, I have benefited from the lessons that the knowledgeable members offer to others (A PLWHA-Participant 4)*

*All the PLWHA should be members of support groups. The journey of living with the virus is a very painstaking one (A PLWHA 5)*

*But some groups are riddled with conflicts, breaking of confidentiality, and one would rather stay alone (PLWHA-Participant 6)*

Albeit a few cases, it is unequivocal that support groups are valuable vehicles of love and sharing of information among the members. They are therefore forums for increasing the PLWHA's positive coping

### **Apathy driven by poverty and stigma**

With their faces wearing despondency, the majority of the stakeholders decried the preponderance of apathy bedevilling most PLWHA (Mavhunga, 2017). This they pointed out was because of immense poverty they found themselves in and succumbing to states of stigma. The following comments bear testimony to the finding above.

*I believe HIV/AIDS is a curse just as some religious people say. This is because most PLWHAs are ever swimming in a sea of poverty (SAP- Participant 15).*

*We the PLWHA have succumbed to a bottomless pit of apathy. Poverty and stigma have been ardent drivers (A PLWHA-Participant 8).*

*We are worried about why the government cannot have an affirmative active action to prioritize the PLWHA for job opportunities (A PLWHA-Participant 10).*

Apparently, the journey of living with the virus has been a painstaking one, breeding unprecedented levels of apathy that make the PLWHA not respect aspects of positive living such as taking their ARVs according to the laid down regimen.

### **Abuse of substances**

Most of the stakeholders overwhelmingly decried the high consumption of alcohol by the PLWHA as an excuse to cope with the virus. This was contributing to higher morbidity and making the ARVs to be constantly resistant (Mavhunga, 2017). The following sentiments were echoed by stakeholders:

*The devil of HIV/AIDS appear to have broken loose, making most PLWHA to perniciously abuse alcohol. This has made them to wreak havoc their families (UFH student- Participant 19)*

*The PLWHA when defaulting because of their substance abusing behaviour should be reminded of how expensive the ARVs are and that they spend taxpayers' money (UFH lecturer- Participant 21)*

*ARVS are unfortunately not giving many PLWHA a new lease of life. This is because substance abusing behaviour is making them move to second- and third-line levels of treatment fast; and succumbing to death within a very short spell of time (Victoria Hospital Nurse- Participant 30)*

Indubitably, abuse of alcohol, albeit giving the PLWHA temporary short-lived happiness as a coping mechanism, is pernicious and detrimental to the journey towards positive living by the PLWHA. It is regrettably working against following the drug regimen and resulting in defaulting. This motivates a negative coping mechanism.

## DISCUSSION

Stakeholders hailed the assistance that the PLWHA got from their families, close kins and community members, and FBOs that largely contributed to their positive coping mechanism in their journey of living with HIV/AIDS. This finding correlates with a study by Xu et al., (2017) in China that concluded that family support contributed immensely to the quality of life among the PLWHA. Moreover, strong family support is a precursor to heightening PLWHA chances of adherence to the ARVs as well as reducing states of stigma (Kebede & Haidar, 2014). Mathivya (2017) contends that the support of family members is the most crucial aspect to be considered while planning for HAART (Highly active anti-retroviral therapy) services. It therefore determines how a PLWHA adapts to illness and therefore coping (Pereira et al., 2014). Moreover, support from family members can be useful to encourages disclosure of one's HIV status to their partners, family, and friends (Kang'ethe, 2020).

Study findings praised the role of faith-based organizations in giving hope, counselling, and sometimes physical assistance to the PLWHA (Gyimah et al., 2010). Unequivocally, religious beliefs and faith systems contribute to the interpretation and mitigation of HIV/AIDS in different contexts of different countries (Gyimah et al., 2010). The early involvement of religious leaders in coming out with programmes and intervention of combating AIDS in several African countries such as Senegal, Uganda, and Ghana, was especially important in the fight against HIV/AIDS among faith-based organizations (Gyimah et al., 2010). In Botswana, for instance, different religious groups have invested time and resources to mitigate the effects of HIV/AIDS. For example, Botswana Christian AIDS Interventions (BOCAIP) offers counselling to both the infected and their family members. This has largely contributed to the PLWHA earning positive living and thereby boosting their coping opportunities (Schoenberg, 2017).

To the contrary, some FBOs' response to HIV/AIDS prevention, care and support has been criticized for undermining overall response efforts (Casale et al., 2010). Some, such as the Roman Catholic have policies against the use of contraceptives such as condoms. This has been a bone of contention especially to the adolescents and adults who feel that they cannot abstain and engage only in sex in biologically safe days or purely for procreation (Schoenberg, 2017). To the contrary, others appear to be liberal whereas others are depicted as accepting of, and sometimes promoting, condoms (Schoenberg, 2017).

There was a unanimous agreement that support groups of people living with HIV/AIDS were vehicles of support that strengthened the PLWHA's positive coping. This is because of the psychosocial support deficit that most PLWHA experience in public services (Dageid, 2014). Usually, in many African social settings, most PLWHA face higher challenges of mental distress and disorders, physical symptoms, psychosocial challenges, poor quality of life and diminished health services. Support groups, therefore, have the potential to offer psychosocial services that the formal structures such as the clinics and VCT centres could offer. These are lacunae that support groups, through discussions, brainstorming sessions coupled with members' motivation, could attempt to address (Dageid, 2014). Support groups, therefore, are considered viable vehicles of improving coping and helping the members deal with an array of stresses they experience daily (Kang'ethe, 2011). Such includes the knowledgeable members educating others on the aetiological and epidemiological path of HIV/AIDS, ways of surmounting and diluting cultures to strengthen HIV/AIDS response, being one another's shoulder to lean on, and forming a forum for maintaining confidentiality surrounding the disease (Haffejee et al., 2014).

Most of the stakeholders decried the preponderance of apathy bedevilling most PLWHA. This is because the disease evokes many social challenges such as stigma and discrimination. This finding correlates with studies by Sinyangwe (2012) that inferred that HIV/AIDS present immense stress itself in tandem with financial burden, stigma, discrimination, and pressure from worrying about family reactions and needs. These are factors that immensely contribute to apathy and lowered quality of life to the PLWHA, making coping both an arduous and a painstaking process. Support groups can also motivate members to disclose their status. (Kang'ethe, 2020).

Study findings indicated that many of the stakeholders overwhelmingly decried the high consumption of alcohol by the PLWHA as a coping deficit with the virus. This presents a blow to adherence and opens the floodgate of opportunistic diseases. Studies by Krishnan et al., (2013) in America averred that jail detainees living with HIV/AIDS and with substance use disorders had higher chances of drug defaulting and heightened chances of morbidities. This is a recipe for poor health outcomes and therefore poor coping with the disease. Studies in Brazil by Silva et al., (2017) reflected that alcohol abuse among the PLWHA is an important public health problem that needs thorough investigation as it is associated with lower adherence to highly active antiretroviral therapy.

### **SOCIAL WORK IMPLICATIONS**

Unequivocally, the study foregrounded that PLWHA were open to various avenues of increasing their coping capacities with HIV/AIDS. Such avenues included membership with support group structures and ample support from family members and faith-based organizations and community in general. On the flipside of the coin, several activities, majorly the abuse of alcohol increased their coping deficits amid states of apathy, stigma, and discrimination. The government through the Department of Social Development should deploy as many social workers as possible to educate communities on methodologies to increase the PLWHA coping opportunities; as well as work to reduce or weaken the environment that weakens their coping deficits.

### **CONCLUSION**

Imperatively, PLWHA should be on the first line to motivate themselves to cope with the virus by dissuading themselves from practices such as alcohol abuse that increases their coping deficits. Social workers with the support of PLWHA friendly bodies such as the NGOs in cohort with the Department of Social Development and Education, should strengthen education and advocacy depicting how successful PLWHA have achieved positive living. Communities and private individuals should also take it upon themselves to support the PLWHA in their journey to achieve positive living and coping resilience and destigmatizing PLWHA.

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