

Coping strategies for HIV and mental illness comorbidities among adult patients in south-western Uganda

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Abstract

Background

HIV and mental illness comorbidity remain one of the healthcare challenges with limited information and medical care attention. The co-existence of the two, result in poor coping thereby increasing vulnerability and poor health-related wellbeing. A number of strategies for coping with HIV and mental illness have been reported for individual states of HIV and mental illness but there is limited data on comorbidity states. In this study, we aimed at exploring coping strategies for HIV and Mental illness comorbidity among adult patients in southwestern Uganda and potential points of intervention that can mitigate challenges they encounter.

Methods

A descriptive cross-sectional qualitative study design was used. Purposive sampling was used to recruit 26 adult (≥ 18 years) patients attending health care services at one hospital and one health Centre IV in Sheema and Isingiro district respectively, in southwestern Uganda. Data was collected using in-depth interviews, was audio recorded, transcribed verbatim from the local language and translated into English. Data was managed and analyzed using ATLAS.Ti software.

Results

A wide range of coping strategies categorized as individual centered, family support, healthcare and social support were reported. Avoidance of emotional stressors like quarrels, worries and annoyance was the most common. Other strategies were; seeking medical care, abstinence from sex, attending educational trainings, health status disclosure and caring for self. In coping with the comorbidity, several challenges were encountered, but various points of intervention including financial aid and scaling up training or educating masses on the causes, dangers and preventive measures of these diseases were suggested to improve the quality of life and also to prevent new infections.

Conclusions

We found variability in coping strategies categorized as individual centered, family support, healthcare support and social support. Avoidance of emotion stressors was a common coping strategy among the respondents. Several challenges are encountered in coping but potential points of interventions to mitigate the challenges were identified. Scaling up healthcare education for all, and tailored trainings to promote coping with HIV and mental illness comorbidity, together with adopting financial aid programs directed towards poverty alleviation among these patients were recommended.

Background

The HIV still poses a great health burden worldwide with 37.7 million people living with HIV globally (1). In Uganda, the national HIV prevalence is 6.2% among persons aged 15–64 years (women, 7.6%; men, 4.7%) and varies from 3.1–8.0% across geographical regions (2) but nearly doubles to 11.3% in severe mental illness (3). However, first time admitted psychiatric patients have shown a higher prevalence of 18.4% (4) while half of HIV-infected individuals usually have symptoms of mental illnesses (5). This indicates that there is an increased risk for mentally ill patients to acquire HIV and vice-versa. Mental illnesses are health conditions involving changes in emotion, thinking or behavior (or a combination of these) (6), and may include depression, bipolar disorder, schizophrenia, psychoses, dementia, and developmental disorders including autism (7).

In southwestern Uganda, Mbarara region has a disproportionately higher prevalence of HIV of 9% for males and 13% for females, higher than the national prevalence rates at 6.1% for males and 8.2% for females (8). Also, the region has high prevalence of psychiatric disorders with 46% for any depression (9).

Since there is always a higher prevalence of HIV among people with psychiatric disorders (5), there is a likelihood of higher HIV infection and mental illness comorbidity among adult population in the region. While Isingiro district has relatively low HIV prevalence (4.8%) compared to Mbarara district, no studies have been done on the comorbidity of HIV and mental illness in the area while Mbarara has some closely related studies ongoing and is more urban compared to neighboring districts.

In Uganda, the healthcare system caters for both HIV and mental illnesses but as independent conditions. The healthcare system is stratified from health center IIs at lower levels to health center IVs and then district hospital which refer to regional referral hospitals before reaching national hospitals (10). At health center IV, there is psychiatric nurse charged with mental illnesses while ART clinic at both levels is charged with HIV management, but specialized clinical services and drugs for mental health illnesses are only provided at regional referral hospitals (10, 11). However, handling the two as comorbidities is not well integrated in the Ugandan healthcare system. Yet, people with HIV are at high risk of developing psychiatric disorders at every stage of the illness while psychiatric disorders can negatively influence the treatment adherence, induce risk behavior and influence the quality of life (12, 13). As such, more understanding and hence management of the two conditions as comorbidities is paramount.

Several studies have been done on individual states of HIV and mental illnesses, more so on coping strategies (14–16) but there is limited data on their comorbidity state, yet managing the two conditions as comorbidities could improve the quality of life of people living with HIV (PLHIV) (17). Studies on coping among PLHIV have identified a number of strategies that include; maintaining confidentiality about their seropositive condition, optimism towards treatment, search for social support, rationalization, social comparison, spirituality/religiosity, avoidance and distraction (16, 18, 19). However, it is not clear whether these coping strategies positively apply in HIV and mental illness comorbidity. To enhance coping with HIV and mental illness comorbidity, it is important to understand the prevailing coping

strategies and associated challenges in order to develop interventions that can be incorporated in the healthcare systems to improve the quality of life for patients with the two comorbidities.

Methods

Study aim

To explore coping strategies for HIV and mental illness comorbidities among adult patients in southwestern Uganda and to identify potential points of intervention that can improve quality of life.

Study setting and design

This was a descriptive cross-sectional qualitative study that was conducted at two health facilities; one health center IV and one hospital in Isingiro and Sheema districts respectively, in southwestern Uganda between February - March, 2022. The two districts are located approximately 400 Km from Kampala, the capital city of Uganda.

Study population and sample size

Adults above 18 years living with HIV and mental illness comorbidities attending healthcare services at the two health facilities Isingiro and Sheema districts in southwestern Uganda participated in the study. Data was collected until saturation was reached at 26 interviews when no more new information was being obtained from the respondents, according to Mason (20).

Sampling criteria

With help of a psychiatric nurse and an antiretroviral therapy (ART) clinic in-charge at the health facilities, we identified potential participants by their records as they came for review on their ART and psychiatric clinic days. We used purposive sampling to enroll the respondents who were adult patients with HIV and Mental illness comorbidity. Patients who had severe symptoms of mental illness or unable to give required information were excluded upon further diagnosis by the psychiatric nurse.

Data collection procedure

Data was collected by in-depth interviews using an interview guide that was *DeNovo* generated by researchers basing on the objectives of the study. The tool was first pretested on 4 respondents living with the comorbidity of HIV and mental illness at Mbarara regional referral hospital. After the pretest minor changes were made to ensure capture of required information. The data was collected by trained research assistants from Mbarara regional referral hospital with nursing and public health backgrounds respectively. They were trained by the team mentor (NK) on the use of study tools prior to data collection. Audio recorders were used to ensure capture of all the information given. Data collection was supervised by NK who gave more guidance on more probing after listening the initial audio records. Data collection was on average taking 30 minutes.

Data management and analysis

The recorded data was transcribed verbatim and translated from local language into English. The lead researcher (PK) together with NK first read all the first set of transcripts to be familiar with the data. For analysis, the data was imported into ATLAS.Ti, a qualitative data management and analysis software (21). The PK and NK used the transcripts to develop a code list in the ATLAS.Ti. To ensure intercoder reliability, the PK and NK developed the codes and code definitions independently and then harmonised the two before coding all the data. Data segments were retrieved, described and interpreted basing on recurring themes and objectives of the study.

Ethical considerations

The proposal received ethical approval from MUST REC under the number MUST-2021-285. Administrative clearance to carry out the study at the health facilities was obtained from the respective resident district commissioners, the district health officer (Isingiro district) and hospital director (Kitagata hospital). A written informed consent was obtained from each respondent prior to enrolment into the study.

Results

Socio-demographic characteristic of study respondents

A total of 26 participants were interviewed, but 5 respondents were excluded due to having severe symptoms of mental illness. Of the 21 respondents, 9 were males and 12 were females, with age range of 22–62 years (mean age of 43 years), 3 widows/widower, 7 separated while 13 either did not go to school (5) or complete elementary primary school.

Our study findings indicated that there was great variability in the patients' responses which were categorized into three themes of coping strategies, challenges encountered in coping and possible interventions.

1: Copying strategies

Most of the respondents indicated several strategies they use in order to live well with the two comorbidities. These strategies were found to fall under subcategories of; individual centered, family support, healthcare support and social support. Most of the strategies were individual centered and included; avoidance of emotional stressors such as quarrels and worries, seeking and utilization of medical care, abstinence from sex, attending educational trainings at church and health facilities, health status disclosure and caring for self.

i: Individual centered strategies

Avoidance of emotional stressors

We found that having a peace of mind by avoiding emotional stressors such as quarrels, worries and annoyance, as well as belief in self, helped many patients to cope well with HIV and mental illness

comorbidity as shown by the verbatim quotes

" ...I don't want anybody to do bad to me, I don't want anybody to disturb me, if anybody sees me in wrong, they better let me fall in that bad trap or use soft ways to rescue me from the wrong but not to force me." (Married male, 42 years).

" ...I avoid quarrels, and I don't like sitting in noisy places, you find me seated quietly. I also take my drugs well". (Married male, 52 years).

Seeking medical care: All the respondents were found to consistently seek and utilize their medications for both HIV and mental illness in time as directed by health workers which kept them healthy. For example, respondents on being asked the question: what strategies have you used to cope well with both HIV and Mental illness comorbidity, they replied:

"...when my time for taking drugs approaches, I take them, I always want to use one particular time as they told me and that makes it easier for me to take my drugs. That is how I have been doing." (Divorced female, 36 years).

"I have also not missed on picking and using my drugs on any occasion. I got a cup which I cleaned and put in my bedroom, ... at exactly 7pm daily I rush to pick my cup for water and take my drugs". (Girl, 22 years).

Abstinence from sex among unmarried respondents was another common strategy of living well with HIV and Mental illness comorbidity as seen in one of the responses:

"When my husband died, a doctor friend advised me to leave sexual engagements with men, that if I continue sleeping with them, they will be adding new viruses; I kept his word to stay alone. I have protected myself, and I have never developed any skin rushes". (Widow, 50 years).

Attending educational trainings on HIV and its associated conditions was also a common strategy among respondents with both HIV and mental illnesses as shown by the quote below:

"I take my drugs very well, and also I have allowed myself to be educated about HIV and other conditions that are always associated with it". (Widow, 45 years).

Health status disclosure. Most of the respondents showed that they disclose their status of HIV and mental illnesses without any problem, and this gives them freedom to live with others without worries.

"...I tell people that I am infected and on drugs so that in case they find me dead they don't wonder what killed him". (Married man, 52 years).

"With mental problem you can't hide from them, because they also see, so I tell them". (Divorced male, 36 years).

However, a few respondents find concealment of their illnesses as their coping strategy while others find it is easy to disclose HIV status but not mental illness. These observations are shown by the quotes below;

"...now waking up and you start announcing yourself before someone that you are sick of this and that, what does it mean? It is difficult. Instead, you keep quiet until the time comes for death to take you... that is it. ... but not announcing yourself". (Married man, 44 years).

"...for HIV, I disclose it to people but for mental problem, people discover it themselves, when they see how I am dancing or talking". (Married male, 43 years).

ii: Family support

With a few exceptions who reported abuse and harassment from family members, most of the respondents recognized family care/support from close relatives as a key coping tool in living with HIV and mental illness comorbidity as in the verbatim quote:

"I have a wife who took the initiative to understand my two conditions and she understands together with my children how my attack of mental problem begins and so do what they can to help me". (Married male, 42 years).

"My wife asks me some questions and how I have responded to them, she judges my mental condition. I and my wife, we agreed that no one breaks the other because we know our conditions". (Married man, 44 years).

iii: Healthcare support

Respondents expressed the importance of the health care system towards people living with HIV and Mental illness comorbidity; mainly involving counselling services from the health facilities, trainings regarding HIV and its comorbidities and follow ups from the health workers. This was so motivational to the respondents as most of these services were offered free of charge at the facilities, and out of personal willingness and expenses by the health workers to meet some costs like mental illness drugs.

"...., my counselor is always there for me, and if anything disturbs me, it is where I rush to. And at times they follow us to our homes to ask why we are not picking our drugs". (Divorced male, 36 years).

"I was started on both ART and mental illness drugs, teaching me all the directions to follow and I really follow them well. They usually teach us that sometimes mental illness is as a result of HIV, so they advise us to always take HIV drugs promptly". (Divorced female, 38 years).

iv: Social support

Most of the respondents commended social interactions including church activities, community social events and individual interactions with community members to play a big role on their wellbeing. When asked on how the church has helped them to cope with the two comorbidities, most of the respondents

acknowledged the role of prayer and some talks/ trainings on healthcare for their emotional stability. Some of these observations are shown in the quotes below:

"...they teach us a lot when they call us for trainings at the church, and they also pray for us". (Widow, 45 years).

"They (meaning church) know my HIV status because I revealed to them how I got it. So, whenever I am mentally ill, they come and pray for me and mental become ok although it keeps coming back" (Divorced male, 36 years).

Social support from community members through gatherings and individual interactions were found to reduce stigmatization, and the patients felt they were being cared for as shown in quotes below:

"I fear going to the public when I have a wound, fearing to infect them with my blood but when I don't have wounds I interact with the people freely, I converse with them and I forget about the conditions I have. I can't live without other people". (Girl, 22 years).

"You see with HIV and mental problem, if you can get your drugs, food and friends to socialize with and you have not taken alcohol, you can live a better life". (Married male, 42 years).

However, a few respondents found use of negative coping strategy of avoiding such gatherings would give them peace of mind as shown in the quote below:

"You are there thinking of how you are going to struggle with your diseases especially HIV and such people start other discussions. So, me I find it not easy to join them". (Divorced male, 36 years).

2: Challenges encountered

Patients with HIV and mental illnesses comorbidities adjust to cope and live well with these conditions but encounter various challenges along the way. Financial challenge was the most common, with respondents claiming lack of money to take care of themselves. For example, when asked the challenges they meet while coping with HIV and mental illness comorbidity, some of the respondents reported that;

"... I always lack money for up keep, it's the major problem I have, but my brother dresses me" (respondents cries)". (Widower, 50 years).

"...getting worried, because I don't have my own house, also I can't have money to buy a mattress or buy a plot and build it. I also work too much like digging for others in order to get some money to survive on, and this has led to my poor health". (Divorced female, 38 years).

Because of their health status, some of the respondents have been left isolated while others no longer have close friends. A widow aged 48 years narrated that:

"... yes, I meet challenges. After they (meaning friends) have discovered that you are sick, they run away from you. For example, where I stay, I am isolated, I care for myself and I have discovered that my

neighbors are now my enemies, me I am alone with my God” (widow, 48 years).

To some respondents, mental illness re-occurrence, bad dreams and hallucinations were quite disturbing while mental illness itself has been implicated in aggravating health conditions of the respondents especially causing intake of wrong drugs or forgetfulness altogether. These observations are shown by the verbatim quotes below:

“... for sure because I take my drugs, it’s as if I am not infected with HIV because I have no signs of it but mentally, I still have a problem... I see some pictures that appear like Jesus, you really see Jesus, I am really disturbed by this Jesus. My eyes see different things, that appear like snakes, ghosts, dead people”. (Married male, 44 years).

“... when my head is upset and tells me to go, there I go and leave my drugs behind. You find when I have reached like in Mubende (a district 120 km away), but after I have settled mentally, I remember the drugs. There is a time I moved away with a wrong drug and got skin rash when I took it”. (Divorced male, 36 years).

While community and family support are instrumental in coping with HIV and mental illness comorbidity, to some respondents they are the source of stigmatization causing them to lose hope. Some self-proclaimed spiritual healers (prayer warriors) have taken advantage of patients’ health status and abused them sexually, which in some patients was the cause of HIV infection. This was revealed by a respondent who got it from a prayer warrior who had committed himself to taking care and praying for her at his home.

“My parents usually abuse me and I lose hope” (the respondent cries). Even people around talk about us that we are sick of HIV and this really annoys me”. (Divorced female, 38 years).

“...I got from a pastor (prayer warrior) who asked my parents and took me to his home to keep praying for me, but he died” (Respondent cries). (Girl, 22 years).

3: Potential interventions

Training or educating masses

Potential points of intervention have been suggested by the respondents to mitigate the challenges they encounter while coping, and possibly reduce spread of the HIV. It was reported that there has been laxity on educating all people on the causes and dangers of these diseases especially HIV, calling for government or religious institutions to embark on training or educating masses on the causes, dangers and preventive measures of these diseases. This would prevent new infections or at-least help those infected to take care of themselves very well. These observations are indicated in the quotes below

“Government and the church should provide trainings/ education to all the people on the causes of these diseases and how to prevent them”. How do you think this can help? *“May be people can be careful not to get the disease”.* (Widow, 45 years).

Status disclosure: To enhance coping with HIV and mental illness comorbidity, most of the respondents re-affirmed that status disclosure to other people is one way to become free and get necessary assistance. For example, in response to the question: In your own view, what can be done for people living with HIV and mental illness to cope well and live a good life, one respondent indicated that;

“...people should always disclose their status to community members to be helped and people in community should also help their fellow sick members. And again, you live a very free life”. (Widow, 50 years).

Financial assistance

Financial aid to the sick or setting up income generating projects for these patients or getting them employed in such projects to enable them take care of themselves has been noted as one possible intervention that can address the financial challenges. Most of the respondents reported poverty as their main problem, and end up doing strenuous activities like full day digging for survival which weakens their bodies. These observations are indicated in the quotes below

“...the rich people or government should help the sick by giving them some money to keep them surviving as they do for the elderly. I wish they could give every sick person at least some money to help them live a better life”. (Married man, 44 years).

“...government or some organizations should start income generating projects for such people to eliminate poverty so that when they get sick, they get good care. It should also build homes for these patients to live in so that they can feel at home”. (Widow, 45 years).

Respondent (Widower, 50 years) summarized his feelings on what can be done to improve coping with HIV and mental illness comorbidities. His narration indicates that avoiding sex, good nutrition, treatment adherence as well as prayers and counselling can help people with the comorbidity to live a better life.

“...stop moving around with men/women though already infected, they should eat and drink enough, let all people test themselves because once you find that you are sick, you get medical advice and take drugs very well, and you can always move with your drugs so as to take them on time and you don't miss. Those who are mentally ill should always go to hospital for drugs and should take a lot of water. Church should always come to pray for those people and counsel them”.

Discussion

Our study was set to explore the coping strategies for HIV and mental illness comorbidity among adult patients, and to identify potential points of interventions that can enhance their quality of life. We found a wide range of coping strategies categorized as individual centered, family support, healthcare support and social support. A number of challenges encountered in trying to cope with the comorbidity were reported but respondents suggested possible interventions that can mitigate these challenges and improve the quality of life.

We found that avoidance of emotional stressors such as quarrels, worries and annoyance was a commonly coping strategy. This has not been previously reported in HIV and mental illness comorbidity but also in individual states. The respondents revealed that it gives them peace of mind, which is key in improving the quality of life for mentally ill patients (6). Other findings like status disclosure and seeking medical care were common coping strategies and seem to play a big role in medical adherence and hence improved quality of life. This is supported by Muntumba et al., (14) who found status disclosure a critical predictor of ART adherence among people living with HIV, just like Medley et al., (19) who found 80% of women in Uganda disclosing their HIV status, with most reporting positive outcomes. Muntumba et al., (14) reported that lack of disclosure affects medical seeking behavior and hence creating a big obstacle to medication adherence. Equally, the observed social support has been regarded as a potential mediator in explaining the effect of disclosure on treatment adherence (22), which has been shown to be the main determinant of clinical and biological outcome measures as well as mortality and hospitalization in HIV patients (23–25). Moreover, non-adherence to ART was reported as a determinant factor for depressive symptoms (26).

Belief in spiritual healing as a coping strategy is not unique here. It has been reported to influence medical care seeking behaviors and is a common coping mechanism among most patients in the area (27). Participation in educational training on HIV and mental health care, abstinence from sexual engagements, good nutrition, seeking medical care, and family support were other common coping strategies used in patients with HIV and mental illness comorbidity. Most of these coping strategies have been reported to be used in individual states of HIV and mental illnesses (7, 18), and our findings indicate that they are also applicable in comorbidity states.

While coping with the comorbidity, the respondents reported a number of challenges they encounter ranging from financial crisis, neglect, sexual abuse, hallucinations to mistakes and forgetfulness in drug uptake, the last four being linked to mental illness according to the respondents. The financial crisis was the major challenge because majority of the respondents were of low class (poor background) with low literacy, and struggle to take care of themselves. Moreover, more than half of the respondents constituted of widowed or divorced individuals, with little or no income at all.

When respondents were asked to suggest possible interventions that can mitigate the observed challenges, most of them indicated financial support as key possibly because of the high poverty levels among respondents. Moreover, HIV itself is a cause of poverty for those infected with it, and evidence to this regard is plentiful (28). Adopting financial aid programs directed towards poverty alleviation among patients with HIV has previously been noted as a potential intervention that can reduce prevalence and improved quality of life in these individuals (29). Also, scaling-up educating programs for the masses on causes, preventive measures and dangers of HIV and its comorbidities by government or religious institutions would help all people to avoid acquiring the diseases or at least help those with the conditions to take good care of themselves.

Strengths & limitations

Our study has revealed common coping strategy of avoiding emotional stressors in HIV and mental illness comorbidity which has not been previously reported. Other observed coping strategies have been reported in individual states of HIV and mental illness but our study reveals that they are still applicable in comorbidity state. While we were unable to perform HIV and mental illness diagnosis, we relied on medical records to carry out purposive sampling to get the right respondents. Also, while different levels of health facilities (health center and hospital) may get different categories of HIV and mental health patients in terms of literacy levels and backgrounds, we used both health center and hospital to mitigate that variability.

Conclusion And Recommendations

We found variability in coping strategies used by people living with HIV and Mental illness comorbidity categorized as individual centered, family support, healthcare and social support. While avoidance of emotional stressors was a new finding in patients with HIV and mental illness comorbidity, we observed that most of the coping strategies used in individual states of HIV and mental illness are also applicable in comorbidity states. Scaling up healthcare education and trainings to promote the positive coping strategies, and adopting aid programs directed towards poverty alleviation among patients are recommended. This study therefore, serves to build a foundation for novel public health interventions that can improve care for people living with HIV and mental illness comorbidity in Sub-Saharan Africa.

Abbreviations

PLHIV - People living with HIV

ART - Anti-retroviral therapy

MUST REC - Mbarara University of Science and Technology Research Ethics Committee

Declarations

Ethics approval and consent to participate

This study was approved by the Mbarara University of Science and Technology Research Ethics Committee (Approval no. MUST-2021-285). Further permissions and clearances were obtained from the hospital director, district health officer and respective resident district commissioners. Written consent in local language was obtained from all study participants. All methods were performed in accordance with the Declaration of Helsinki to ensure respect for all the respondents, protecting their privacy, health and rights, carefully reducing risks and burdens to these individuals.

Consent for publication

Not applicable.

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contribution

All authors contributed to either design of the study, data analysis and/ or writing of the manuscript. The first author (PK) and the corresponding author (NK) did the data analysis and wrote the first draft of the manuscript while the other authors (JBN, ON, TJM, RN, EW and OC) contributed significantly to the revision of the draft. CO was the senior researcher on the team for providing overall guidance right from protocol development to the final manuscript. All authors have read and approved the final manuscript.

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