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HIV, MENTAL ILLNESS AND SUBSTANCE ABUSE: THE EXPERIENCES OF PERSONS DIAGNOSED WITH TRIPLE DIAGNOSIS AT CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL OUTPATIENT CLINIC

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Medicine in the branch of Psychiatry.

Johannesburg, 2021

DECLARATION

I, Sibulele Zuma, declare that this research report is my own work. It is being submitted for the degree of Master of Medicine in the branch of Psychiatry to the University of the Witwatersrand, Johannesburg. It has not been previously submitted for any degree or examination at this or any other University.

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2nd day of June, 2021

ABSTRACT

INTRODUCTION:

The term triple diagnosis is used to refer to patients with mental illness, substance use disorder as well as HIV infection. Not only is this group clinically complex to manage optimally, but it is also faced with unique challenges that have both predisposed them to having this condition as well as those that are the sequalae of living with multiple co-morbidities.

The purpose of this study is to look at the subjective experiences of those individuals who are living with and being managed for a triple diagnosis.

METHODS:

This is a descriptive qualitative study using the convenience sampling method. Semi-structured in-depth interviews with 12 open ended questions were conducted with 10 participants from the '3D' Triple Diagnosis clinic at Chris Hani Baragwanath Hospital in Soweto, South Africa. This was done between July and December 2018. The participants were questioned about awareness of their condition, the experience of the clinic where they receive health care, the experience of disclosing their diagnoses, their general life challenges and their perception of the level of difficulty that the triple diagnosis may or may not pose in their lives.

RESULTS:

It was found that the triply diagnosed individuals are most knowledgeable about their HIV diagnosis and seek health care primarily for it. Many are aware of their psychiatric diagnoses and most are aware of their substance use disorders but are less forthcoming due to feelings of guilt and shame on a background of minimal support from those in their lives. This is compared to more support felt for HIV and mental illness diagnoses, with a few exceptions.

The areas of greatest difficulty in general included financial difficulties with unemployment, the burden of being stigmatised for having HIV and poor social support with poor interpersonal relations, as well as having to cope with past childhood stressors that preceded the triple diagnosis.

Many participants noted that the burden of living with three chronic conditions, as opposed to one like other people, was difficult. They experienced the clinic as a supportive base to help with the challenges the three diagnoses pose. However, the overriding stance was that whilst being triply diagnosed poses a unique set of difficulties, there are conditions that are more difficult to have.

CONCLUSIONS:

Attending a specialised multidisciplinary clinic that is specifically geared at managing triple diagnosis is beneficial for the physical and mental health of this population. Providing a space where they are seen and heard helps these persons cope with their multiple hardships. This also helps with the reduction of some of the harmful coping strategies previously used by this group.

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1. INTRODUCTION

1.1 Background

Triple diagnosis refers to co-morbid psychiatric illness, substance use disorder and HIV infection in the same individual (1). As is seen in the United States of America (USA), there is generally an increase in the prevalence of mental illness in the population of patients living with HIV. Research reveals that over 40 percent of people living with HIV have a diagnosable mental disorder. Mental disorders are highly prevalent among people living with HIV/AIDS, with major depressive disorder occurring almost twice as frequently amongst this group than in the general population (2).

In the same vein there is also a scarcity in the literature when it comes to the triply diagnosed. The available literature on this group has been done mainly in the USA and Eastern countries. In terms of research, two percent (78/ 3374) of all health publications in South Africa were on mental health topics during the last five years (3). In the literature that does exist, the content is primarily on the tri-directional, cyclic relationship between using substances, developing mental illness and contracting HIV infection and subsequently managing it. Whilst this is important to examine in the pursuit of providing optimum treatment for these individuals, it does not examine the experiences of living with this challenging diagnosis.

To provide holistic and adequate care that addresses all the needs of triple diagnosis patients it is important to really understand what it is that they encounter with their burden of disease.

Despite this, there are few centres that are dedicated to providing outpatient care for those with co-morbid mental illness, HIV and substance use disorders. This informed the aim of this study which is to describe the subjective experiences of individuals diagnosed with HIV, mental illness and substance use disorders, who are receiving care and treatment at a clinic dedicated to the triply diagnosed.

1. Aim And Objectives

The study aims to provide qualitative data that explores the experiences of those who are triply diagnosed in a South African setting. The subjective experience described by participants is a proxy of their lived experience.

Through semi-structured interviews, the objectives are to:

1. Describe the day to day experiences and challenges that these patients encounter, which may potentially affect their quality of life, as a result of being triply diagnosed.
2. Evaluate various themes pertaining to factors that may impact these persons lived experiences.
3. Further explore their awareness of their diagnoses and their feelings about the care they receive at a clinic that is dedicated specifically to their conditions.

2. LITERATURE REVIEW

The term “triple diagnosis” was created to describe a new group of individuals with complex medical and other social care needs who required specialised health care services (4).

There is an increase in the prevalence of psychiatric disorders in individuals who are diagnosed with HIV as opposed to the general population in the USA (2). This is the same in our setting with mental disorders being found to be highly prevalent in a South African cART (combined antiretroviral therapy) clinic, with a 34.9 percent prevalence of major depression, 14.8 percent prevalence of post-traumatic stress disorder and a 10.1 percent prevalence of alcohol abuse (5).

A Complex Group of Patients with Unique Management Needs

These patients are complex, often requiring difficult clinical management solutions (6). Patients with a “triple diagnosis” pose a new set of dilemmas to clinicians engaged in psychiatric, medical and substance abuse treatment. The interdisciplinary management challenges include promoting abstinence from substance use, the provision of adequate access to psychiatric care and the management of the HIV. Their needs challenge the resources of these separate treatment systems and require the creation of new systems of care that cross the boundaries of these disciplines (7). This group is clinically complex because HIV disease progression is affected by substance use as well as psychiatric illness burden due to both direct as well as indirect factors (6). Continuing substance abuse with poor treatment adherence coexists with psychiatric disorders leading to increased morbidity and mortality (6). While there is greater need for holistic care for this group of patients, there are few centres that are

dedicated to providing outpatient care for those with co-morbid mental illness, HIV and substance use disorders.

Determinants of the Course of Illness in this Group of Patients

Both loss to treatment follow up and late treatment initiation, among other factors, are responsible for the morbidity and mortality that is seen in triple diagnosis as is seen in patients with only psychiatric disorders (6). Clinical, diagnostic and demographic factors are determinants of treatment initiation in individuals with dual HIV infection and substance use or psychiatric disorders (8). Among patients with dual psychiatric diagnosis and co-morbid HIV infection significant predictors of visiting a psychiatric clinic included not having an AIDS/ stage four HIV diagnosis as opposed to being clinically more ill as well as having a diagnosis of major depression or bipolar disorder as opposed to other psychiatric conditions (8).

The Prevalence of Comorbid Mental Illness and Substance Use Disorders in HIV Infection

It is known that there is a high prevalence of psychiatric and substance use disorders among HIV infected individuals. Existing research suggests that the exact rates of psychiatric and substance disorders among these individuals varies depending on the population studied as well as comparison groups used (9). However, the prevalence of major depression has been found to persistently range from 22 to 32 percent in HIV infected persons which is two to three times higher than the prevalence of depression in general community populations (9). The exact prevalence of other psychiatric disorders that are known to be common in this population, particularly anxiety disorders, remains uncertain, with variability across various studies. A

study done in Cape Town at an HIV clinic looked at the persistence of psychiatric disorders in HIV patients, where the prevalence of PTSD was found to be 14.8 percent. This was second to depressive disorders which had a prevalence of 34.9 percent (10).

Similarly, substance use is also known to be common in the HIV reactive population, but exact prevalence rates remain varied across different populations and studies. A Zambian study looking at the engagement in care as well as substance use and use disorders in persons living with HIV found that there was an escalation in pre-existing substance use at the time of being diagnosed with HIV (11). The study also found that after diagnosis a common factor leading to a loss to treatment follow up was substance use, with the prioritization of using substances over taking cART being reported by some participants (11).

Illicit substance and alcohol use disorders are frequently co-morbid with depression, anxiety and severe mental illness. Not only do these disorders increase the risk of contracting HIV, they have also been associated with decreased cART use, poor adherence and subsequent poor virological suppression (12). The literature that has evaluated the relationship between substance use disorders and HIV outcomes has primarily focused on injection drug users. Similarly, the literature that has evaluated the relationship between mental illness and HIV has focused mainly on depression with a lesser focus on severe mental illness. To date, there is minimal literature evaluating the association between co-occurring HIV, substance use disorders and mental illness on cART uptake, adherence and virological suppression (12). Zahari et al does however suggest that a multidisciplinary intervention to address HIV, substance use and psychiatric disorders in the community setting is urgently needed to provide adequate care for individual patients as well as to curb the development and transmission of

drug resistant HIV (13). Given the associations among HIV risk behaviours, psychological dysfunction and substance use disorder, the advantages of integrating prevention and treatment services for HIV/AIDS, mental health and substance use disorders are clear (14). This is reiterated by Mellins et al whose data shows that both mental illness and substance use must be addressed in HIV infected adults living with these co-morbid illnesses to improve adherence to antiretroviral treatment (15), therefore decreasing the morbidity and mortality that is known to be higher in the triply diagnosed population in comparison to those who only have HIV infection without substance use or mental illness. Similarly, Whetten et al found that there is increased effectiveness in integrating mental health and substance use disorder treatment models for triply diagnosed individuals seeking HIV treatment. There is resultant improvement in critical behavioural health and health care utilisation outcomes in this group (16).

A Paucity in Literature on Triply Diagnosed Patients in the African Setting

Most of the literature that looks at the triple diagnosis population has been done in the USA and a few in Eastern countries (2). Very few of the studies on this population were undertaken in our setting or in any of the other African countries. The studies that were done in the USA and in Eastern countries looked at the tri-directional relationship between the three conditions as well as the various risk factors that increase their co-existence (12) or they looked at the best management approach for optimal clinical outcomes in the triply diagnosed population (16). Whilst ideal management was explored in some of the studies on this population, none of them looked at the actual experiences of those who were being managed. Their day to day difficulties and stressors that are as a result of being triply diagnosed are not addressed in any of the literature. This is important to explore in the study as it will provide insight on the factors that both diminish and enhance their quality of life. This would enable the application of targeted,

holistic and specialised care that adequately addresses the mental and physical health needs of this group in our setting.

The pattern and prevalence of substance use in our setting has a number of differences in comparison to the USA. There is a lower prevalence of intravenous substance injection with less use of more expensive illicit substances such as heroin. Lower priced substances such as cannabis have a greater prevalence of use in the South African context (17). Also, despite government led efforts against tobacco use through public use restrictions since the late 1990s, there remains a high prevalence of cigarette smoking and tobacco (colloquially termed snuff) inhalation across gender and race groups (17). Along with the high tobacco consumption is alcohol use which continues to rise with both direct and indirect health effects on the general South African population (17). Beyond the direct effects of alcohol and other substances on brain function, substance use disorders tend to be associated with other health behaviours that increase the risk of brain injury, including head trauma, poor health care utilisation and nutritional problems (18). Furthermore, those with daily substance use have poorer adherence than those using less than four times a week and those patients with poly-substance use disorder have the poorest adherence to highly active antiretroviral treatment (HAART) (18). There are also known psycho-social sequalae of substance use disorder in this population, such as impaired interpersonal relations which affects the quality of life of these individuals. These factors were explored in greater depth in this study.

3. METHODOLOGY

3.1 Study Design

This was a qualitative study done using convenience sampling. A qualitative, explorative method was chosen due to the lack of information available in current research around the experiences of people who have been diagnosed with HIV, mental illness and substance use disorders in current research. It aims to provide insights into a problem area that is poorly understood.

The chosen study design was one that allows for the participants' interpretation of their lived experiences to be expressed as opposed to just the facts of their circumstances. This was utilised in order to fulfill the aim of the study. Their lived experiences are impacted on by their perception, awareness and knowledge.

3.2 Study Site

The research took place at Chris Hani Baragwanath Academic Hospital in Soweto, in the south of Johannesburg, South Africa. As an academic institution Chris Hani Baragwanath Academic Hospital is associated with the University of the Witwatersrand's medical school. It is a state funded tertiary hospital which is also the largest hospital in Southern Africa with approximately 3200 beds, structurally occupying around 173 acres.

The study was conducted at the Triple Diagnosis (three D) Clinic. The clinic began in 2016 and consists of patients that are referrals from the Zamani Substance use disorders and Luthando Neuropsychiatric clinics. Both clinics are dual diagnosis centres at Chris Hani

Baragwanath Academic; Luthando offering HIV and mental health care service while Zamani offers substance related and mental health care services. The clinic was started in response to doctors from both clinics observing large numbers of overlapping patients, their triple diagnoses inhibiting optimum management. It was also an attempt to minimise the financial and time outlay for patients attending two monthly clinics on different days.

The motive for initiating the clinic was to provide comprehensive, holistic care for individuals with co-morbid HIV infection, mental illness as well as substance use disorder. To date it caters for more than 150 triply diagnosed individuals; males and females, all above the age of 18. The patients are managed for HIV infection, psychiatric diagnoses, and their substance use disorder. On a triple diagnosis clinic day, patients consult with the senior medical officer from Luthando Clinic, as well as a psychiatrist from Zamani, the substance dual diagnosis clinic. Motivational interviewing is provided, as well as continuity of care from a named doctor. The doctors communicate with each other regularly about patient matters. Substance use counselling groups facilitated by the psychology and occupational therapy members of the multidisciplinary team are run weekly at the clinic. These groups are also used to address other health issues pertaining to these persons such as treatment adherence. Individual psychological services are made available upon referral by the clinicians managing the patients. Occupational therapy assessments and rehabilitative work is also available, again upon referral by the managing clinician.

3.3 Study Population

The study participants consisted of adult patients who attended the triple diagnosis clinic exclusively and had been receiving care for all three conditions there for at least the past twelve months.

All participants in the study are living with HIV, a substance use disorder and a psychiatric diagnosis according to DSM-IV diagnostic criteria who are receiving care from the 3D clinic for the above.

Those who were considered to participate were individuals who were able to consent to being part of the research and were assessed as psychiatrically stable enough to do so by an external psychiatrist. Patients with a score of less than 10 on the International HIV Dementia Scale (IHDS) were excluded.

Permission to conduct the study was obtained from the Chief Executive Officer of Chris Hani Baragwanath Academic Hospital. Clearance was also granted from the Human Research Ethics Committee of the University of the Witswatersrand with clearance certificate number M180356.

3.4 Sample Size

A sample size of 10 individuals that attended the clinic at Chris Hani Baragwanath Academic Hospital between July and December of 2018, was randomly selected in order to obtain

information on a range of experiences. However, this could have been increased to 15 if new experiences had emerged during the course of the interviews. However thematic saturation in the content of the interview answers was reached after the initial sample of 10 interviews was completed.

The number 10 was chosen because qualitative studies require significantly smaller sample sizes than those that are needed for validity of results in quantitative research. Qualitative studies should be large enough to attain saturation where adding more participants would not result in acquiring additional information. For qualitative phenomenogical studies Creswell (1998) recommends five to 25 participants. There are however no specific rules when determining an appropriate sample size in these studies.

3.5 Material

Semi-structured in-depth open-ended clinical interviews with twelve questions were conducted with each participant. The list of questions is included in the appendix.

Data was collected using open ended clinical interviews. The interviews were conducted by the principal researcher in either English, Zulu or Xhosa, depending on the individual's language of preference.

The focus of the interviews was on the individual experiences and perceptions of participants regarding their psychiatric diagnosis, substance use disorder(s) and HIV status, including the hardships that accompany all three diagnoses. Each patient was interviewed once. The

questioning explored factors that have posed as difficulties as well as factors that have helped with the coping of these difficulties for these persons.

This form of interviewing optimises the level at which participants express themselves. It gives the interviewee an opportunity to fully express their experiences in an unrestricted manner.

Each question asked in the interview served to explore specific content with regard to the participants' experiences:

Question 1: Explored the participants' basic knowledge of having the various diagnoses.

Question 2: Explored the participants' awareness of their triple diagnosis and the fact that there is a specialised clinic for their condition with its specific needs.

Question 3: Explored their experience of the quality of care that they were being provided with at the triple diagnosis clinic.

Question 4: Explored their knowledge of their various diagnoses.

Question 5: Looked at their exposure to the concept of triple diagnosis.

Question 6: Explored their knowledge of their diagnosis of HIV and their experience at being diagnosed with the illness.

Question 7: Explored the participants' knowledge about having a psychiatric illness and their experience of being diagnosed with mental illness.

Question 8: Explored the participants' knowledge of having a substance use disorder and their experience of having this knowledge.

Question 9: Explored what the individuals perceived as most of a struggle with regards to their lives in general.

Question 10: Looked at their cognisance of the interplay between their health conditions.

Question 11: Explored the experience of disclosure of the various conditions they are diagnosed with and the quality of their support structures upon disclosure. This question also explores the participants' ideas that may inform them electing not to disclose.

Question 12: Explores the participants' perceptions of the level of difficulty it poses to live with triple diagnosis beyond the point of being diagnosed.

3.6 Data Collection and Analysis

After obtaining consent, the interviews were conducted and recorded. The recordings were stored on one dictaphone which only the principal researcher had access to. Thereafter each interview recording was transcribed by the principal researcher. From those transcriptions themes were extracted manually.

The data was analysed separately by each of us; the principal researcher and all supervisors, namely; Dr G Jonsson; a neuropsychiatrist and Dr L Paruk; a general psychiatrist. Once we had all manually analysed the data, common and contrasting themes were discussed and reconciled. This contributed towards inter-rater reliability of the findings.

Each of us utilised phenomenological data analysis. We each started by going through the interview transcriptions and highlighting "significant statements" that provided an

understanding of how the participants experienced the phenomenon (20). This step is called horizontalization. Clusters of meaning were then made from grouping significant statements into themes (21). Once clusters of meaning had been formed, textual descriptions were constructed. Textual descriptions were constructed by utilising the themes and statements derived from the clustering of meanings. Creswell explains that "the statements and themes are also used to write a description of the context or setting that influenced how the participants experienced the phenomenon, called structural description (21)." From the structural and textual descriptions, the researcher will then write a description that presents the essential, invariant structure (22). The focus of the essential, invariant structure is to describe the common experiences of the participants. The researchers then discussed the themes that had been individually identified. Common and contrasting themes were discussed and reconciled.

When the themes that had been extrapolated from the 10 participants were reviewed, and no new statements that were deemed as significant to fulfilling the study aims emerged, it was concluded that saturation had been reached. An important aspect of qualitative research is reaching saturation. It is reached when further observation and analysis reveal no new themes. Despite its importance there is no validated means of objectively establishing it.

3.7 Ethics

The study received ethics approval on the 29th August 2018 from the Human Research Ethics Committee of the University of Witwatersrand.

Upholding all ethical considerations was core, particularly when working with vulnerable population groups such as those living with mental illness. It was also important that ethics were upheld as the nature of the interview content was sensitive.

Maintaining patient confidentiality was an important consideration throughout the research. The participant's details including their names and hospital file numbers has not been mentioned in the data to maintain anonymity.

Informed consent was obtained from all the participants prior to data collection. They were informed on the purpose of the study, how the information obtained from them would be anonymously presented as well as their right to decline participation in the study at any point even if they had initially agreed. They were informed that electing to not participate in the study would not in any way be used against them during their continued care at the clinic. All this information was communicated to them in the form of an information leaflet as well as verbally prior to commencing all interviews. This information sheet also included an explanation of what the study entails, unforeseen risks and potential benefits of participating in the study, their rights as potential participants, who the research team includes as well as the principal researcher's contact details which were provided should they have required any additional information in relation to the study. This was to ensure that those who decided to participate in the study were adequately informed. Study participants were also required to give informed consent for the interviews to be recorded and for those audio recordings to be transcribed. They were given an information sheet. This leaflet included information about the recording and transcribing procedures. They were informed about how their anonymity would be upheld in the handling of the recordings that were only accessed by the research team until they got deleted. The leaflet included their right to withdraw their consent to being recorded as well as having their transcriptions being used in the study. They were also made aware that should they decide to consent to participate they would be doing so despite there being no monetary gain in part taking in the study.

There was a distress protocol in place which was necessary because of the nature of the study, where personal information, which was potentially distressing, was being disclosed by the participants. The protocol was put in place as a means of preparation should a participant have become emotionally distressed during the interview phase of this study. It was there to ensure that participants who experience emotional distress as a result of the interview would be readily identified and supported appropriately to ensure that no harm would be caused. There were specific strategies that were in place during the interview process to assist the participants should they have experienced discomfort or distress. Distressed participants would be reminded that it is appropriate to terminate the interview as soon as the distress became apparent. Time would also be spent with the interviewer providing assistance, discussing their concerns and informing them about the psychological support services that would be available to them at Chris Hani Baragwanath Hospital as well as in their community. Referral to these support services was to be done by the interviewer when required. Additionally to ensure that the emotional state would have resolved, a follow up call would be made by the interviewer a day after the interview to check in on the participant as well as to remind them of the support services that could be made available to them. In the end none of the participants used the distress protocol. They all understood that it was available to them but reported existing psychological services at the triple diagnosis clinic being the reason they felt they did not need access to the protocol. Similarly, none of them required a follow up phone call the day after the interview.

3.8 Budget

The budget for the study was funded by the principal researcher and was as follows:

- Travel and petrol: R1000
- Printing and stationery: R500
- Other costs: R500 Total: R2000

4. RESULTS

The sample participants included five males and five females aged between 23 and 45. Nine of them were African and one was of mixed racial origin.

The various themes that were extrapolated from the 12 interview areas that were noted in the methodology will be reported on below. Each interview area will be noted with the themes identified in order of frequency until saturation was reached, as well as some accompanying quotes from where these themes emerged.

PERCEPTIONS OF REASONS THEY SEEK HEALTH CARE

What the participants understand as the reason they seek care from the triple diagnosis clinic:

Themes:

Attending the clinic for a specific condition within the triple diagnosis

1. Seeking health care for HIV infection

2. Seeking health care for psychiatric diagnosis or symptoms

3. Seeking health care for substance use

Attending the clinic for more general reasons

4. Seeking health care to help with being able to cope with life stressors

5. Seeking health care for other general medical conditions

6. Seeking health care for good health in general

The participants either showed specific knowledge of their reasons for being recipients of care at the three D clinic or they perceived the clinic as a place where they receive general health

care, including even receiving help with coping with general life stressors. A single participant revealed a paucity of knowledge regarding reasons for their attendance. The following particular themes were identified upon analysis of the interview content:

1. Seeking health care for HIV infection

Most of the participants perceived their HIV infection as the principal reason they attend the clinic. Accessing their cART was deemed a priority as was expressed by:

’’I come for the illness in my body;...the sickness HIV...” (MM)

”I come here because I have a status problem; I am HIV positive.” (MN)

”I attend the clinic Luthando because I was diagnosed HIV positive” (VCN)

2. Seeking health care for psychiatric diagnosis or symptoms

Some of the interviewees identified mental illness as the main reason they attend the clinic , in addition to the HIV infection. They showed varying degrees of knowledge regarding their mental health diagnoses, ranging from being able to describe the symptomatology of their illnesses, to knowing their actual diagnoses:

“I have a sleeping problem and I hear voices and see things.” (MN2)

“I attend the clinic because of schizophrenia…” (TK)

“I come to the clinic for depression…” (TA)

“…the depression is also attended to here…” (JA)

“…and I also have schizophrenia.” (JN)

“…and I committed suicide 3 times and was admitted in the psychiatry ward.” (CM)

3. Seeking health care for substance use

Seeking help additionally for a substance use disorder was reported by only two of the interviewees. It impressed as less important, in relation to the other two themes:

”... because I was found to have substance abuse.” (VCN)

”...I was then also drinking too much alcohol so I was referred to this clinic from there.” (CM)

4. Healthcare seeking to cope with life stressors

"... after my first born died, she committed suicide in 2010. She drank my pills and killed herself with them." (TA)

"... I was living with my children's father and he became emotionally and physically abusive and...so I was referred to this clinic from there. I attend this clinic so I can be alright and cope in life..." (CM)

5. Health-seeking for other general medical conditions:

Some participants noted another medical condition; specifically epilepsy management as a condition they seek help for:

"I come for the illness in my body: epilepsy..." (MM)

"I attend the clinic because of ...I have epilepsy..." (JN)

6. Seeking health care for general good health

Another interviewee expressed general health care as the reason for clinic attendance:

"...I come for good health..." (MM)

THE EXPERIENCE OF THE QUALITY OF CARE PROVIDED AT THE TRIPLE DIAGNOSIS, AS OPPOSED TO A GENERAL CLINIC

Here the thoughts of the participants on the standard and efficacy of care they received at this specialised clinic were explored:

Themes:

1. Better quality of care

2. Same quality of care

1. Better quality of care

Most of the participants felt that the triple diagnosis clinic provided them with a superior quality of care. This was with regards to time spent waiting to be seen, attention given to their stressors, advice given to them to promote health, time given to them to express concerns about medication, clinician attitude towards them, access to more medication and thorough examination at visits. This is evidenced by the following quotes:

”Its good because when I arrive here no time is wasted waiting.” (MN1)

”...but better than any other hospital. They take care of me and give me lots of advice and give me a lot of attention with what I am going through right now.” (MN2)

”This one I get the time to explain my problems about my illness and other things to the doctor.

”I get a chance to speak about difficulties with the medication like side effects and problems with adherence to the medication and hardships with withdrawal from having to stop alcohol... So, they help with the problems with how to control myself and stress management...” (VCN)

” The pills I get here help me. My doctor is also alright.” (TA)

“I find the service better because you have access to a lot of things like pills and the level of care. They make sure you are properly checked up on and not just given medication.” (JA)

“…the doctors are able to listen to your problems as a patient and help you.” (CM)

“they tell the dates of when to get my medication and to talk to the doctors about how I feel and how things are going.” (FP)

2. Same quality of care

Some interviewees experienced the standard of care to be no different from past contact they had had with community health care services:

”No its not different.” (MM)

” It’s the same; you see a doctor then collect medication and then you leave.” (TK)

AWARENESS OF THEIR TRIPLE DIAGNOSIS AND THE EXISTENCE OF A SPECIALISED CLINIC

The participants knowledge of their various diagnoses was explored, based on information they had been given in the past.

Themes:

1. Awareness of HIV diagnosis and mental illness

2. Awareness of a triple diagnosis

3. Awareness of HIV diagnosis and another medical condition

1. Awareness of HIV diagnosis and mental illness

Most of the interviewees were well aware of being dually diagnosed with HIV infection as well as with a mental illness. Many could recall when or where they were initially diagnosed:

" I have bipolar and high blood as well as HIV." (MN1)

"Mental problem and my HIV status are the only 2 that I know of..."(MN2)

" I have been told I have schizophrenia which is a mental illness and HIV which is a virus." (TK)

"HIV positive and bipolar mood disorder…" (TA)

"I was diagnosed with HIV and major depression." (JA)

"...HIV I got along the way as I am back from prison...The schizophrenia I am not sure of how it came about." (JN)

" I have been told I have major depression, I am HIV positive..." (CM)

" I am HIV positive and I don't know the other sickness, but I get medication for an illness of the mind." (FP)

2. Awareness of triple diagnosis

Many of the participants admitted to substance use with some reporting perceiving the use as a problem. However, a single participant viewed their use of substance(s) as a diagnosed condition or ailment additional to their other two illnesses, reporting that:

” The doctors told me I have a mood disorder and substance abuse; alcohol and dagga but mostly dagga because I don’t use alcohol a lot... I also have HIV.” (VCN)

3. Awareness of HIV diagnosis and another medical condition

A single interviewee did not show an awareness of having a psychiatric diagnosis. They rather perceived having epilepsy in addition to HIV being their only known diagnoses:

” ...epilepsy and HIV illness” (MM)

KNOWLEDGE OF WHAT THEY RECEIVE CARE FOR

What the participants understand as the issues they receive help with at the clinic

Themes:

Treatment for the various triple diagnosis conditions

1. Wellness and treatment adherence in HIV infection

2. Psychiatric symptoms

3. Counselling for substance use

Treatment for psychosocial factors

4. Psychological hardships

5. Social problems

1. Wellness and treatment adherence in HIV infection

Most of the participants expressed that they felt they received the most assistance by getting access to their cART as well as support with improving their adherence to it. They perceived this as a positive contribution to their general well being beyond just the HIV infection:

” All problems that I encounter which are health related. If I encounter a problem, they help me.” (TA)

"... They also helped me with taking my ARVs, I no longer skip days and take them at the right time." (CM)

" They give me treatment to drink and it treats me well." (MM)

" help me by giving me medication." (MN1)

"help me with taking care of myself and taking care of my status and staying good." (MN2)

"They give me medication and even check me. They check for diseases…" (FP)

2. Psychiatric symptoms

A few interviewees noted the promotion and preservation of their mental health functioning as benefit from the care they get at the clinic. They also reported the specific symptoms they sought help for:

"… help me with being able to cope, sleep and eat well. To cope in the sense that when I drink my pills, I am able to concentrate." (TK)

3. Counselling on substance use

A single participant reported that they received help in order for their use of substances to remit. They admitted to having failed to do so prior to having contact with the clinic:

"... My excessive drinking, they counselled me on…So, I tried to stop alcohol and I no longer drink now. That's how they helped me." (CM)

4. Psychological problems

More participants viewed the clinic as a place where they were equipped with the tools to cope with psychological stressors that they were previously overwhelmed by. They made statements that alluded to the fact that the psychological services offered at the clinic were seen as a source of refuge for them when they found themselves in crisis or with feelings of loss of control:

" There are usually group discussions I go to. The last doctor appointment the doctor suggested I should see a therapist or psychologist, so I am able to speak with them about most things." (VCN)

"... If I have a problem, I have someone outside of home that I can trust to speak to. I am also able to phone the clinic if I have a problem and the doctor will tell me if I need to come into hospital for it. Also, if I feel like I am not coping and feel I want to commit suicide again I can phone the clinic then come so they can help me." (CM)

"…staying good and not thinking too much. Sometimes it gets a lot in my head and I can't even control" (MN2)

5. Social problems with the provision of a disability grant

The theme of struggles with social difficulties came up frequently. This occurred repeatedly throughout the interview process. It was therefore not surprising when some of the interviewees reported that assistance with their poor socio-economic situation was a benefit they appreciated as an additional clinic service.

".. help me get grant money here at the clinic, so it has helped me to be able to stand on my own feet. I don't have a father, he died when I was 6 months old. He died painfully after burning himself with petrol, paraffin, diesel and no one knows why he did that. We were raised by our mother only. I got arrested and went to prison and came back as an adult which means I have to try and support myself without going back to crime. The grant money they give me here protects me from involving myself in many wrong things. I eat well." (JN)

EXPOSURE TO THE CONCEPT OF TRIPLE DIAGNOSIS

Knowledge of the term "triple diagnosis" was questioned here. Probing on what the term meant and then if they realised that they were triply diagnosed, was conducted.

Themes:

1. Lack of exposure to the term triple diagnosis

2. Poor understanding of the meaning of triple diagnosis

3. Inferring that the concept could apply to them but no real understanding of how

1. Lack of exposure to the term triple diagnosis

All except one had not heard of the term. This remained even when translated into vernacular languages such as Zulu, to ensure that this was not due to a language barrier. The interviewees had simply never been exposed to the term. Some seemed objectively concerned about not knowing what it meant, those patients were reassured appropriately. This theme indicated that when clinicians have interacted with these patients regarding their illnesses this term had never been used:

”No, never heard of the term.” (MM)

”No, it’s the first time I hear of it... I don’t even know what it is.” (M N)

”No, never heard of the term.” (MN)

”No, never heard of the term.” (VCN)

”No, never heard of the term.” (TK)

2. Poor understanding of the meaning of triple diagnosis

It was therefore not surprising that none of them knew what the term meant or stood for. This also included the one interviewee who had heard the term.

”...I don’t know what it means.” (MN)

”Don’t know what it means.” (VCN)

”I don’t know.” (TA)

”I don’t know.” (CM)

3. Inference that the concept applied to them but no real understanding of how

Interestingly despite having no contact or knowledge of the term many of the participants assumed that the term applied to them. Most of those that made the assumption reasoned that they had already been used to receiving various serious diagnoses in the past. This showed that they perceived themselves high risk to medical conditions.

”Not sure, it might be because I am a patient.” (VCN)

”It could, but I am not sure.” (TK)

”Not sure because I am often sick so I would not be surprised if another thing came up.” (JA)

“Yes, I have to live with the condition. It is well; what is done is done, I cannot rewind the time, I just have to cope... Most people do not know that I have HIV. A few know that I have schizophrenia because they think that is why I get the grant. They do not know that I also have epilepsy.” (JN)

AWARENESS OF HIV DIAGNOSIS AND THE EXPERIENCE OF THE DIAGNOSIS

Questioning the participants about this particular topic had two main revelations. The first was that all of the patients were cognisant of their HIV statuses. Secondly, it revealed that memories of the day when they learned that they had HIV, were filled predominantly with negative emotional experiences. Whilst the interviewees interestingly spoke with ease and candor about these memories, the content revealed the emotional anguish that came with the diagnosis of HIV.

Themes:

1. Knowledge of HIV diagnosis

Initial negative feelings about the diagnosis

2. Devastation and emotional pain

3. Fear of having HIV

4. Disbelief at the diagnosis of HIV

5. Denial about HIV infection

6. Shame about facing loved ones and potential rejection

7. Immediate acceptance with self blame for actions that predisposed to infection

Positive perceptions on diagnosis

8. Realisation that life-saving medication is available

9. Determination to live for children despite diagnosis

1. Knowledge of HIV diagnosis by all

All participants knew that they had HIV and reported that the diagnosis was given by a health care provider.

”Yes, I have been told I have HIV...” (MM)

”Yes, I was told at the clinic.” (MN)

”Yes, I was told during a 3 month hospital admission...” (JN)

This disclosure was subsequently followed by a range of negative perceptions:

2. Devastation and emotional pain

” I felt bad…” (MM)

“…it was devastating, heart breaking because I don’t take kindly to bad news. It destroyed me to be frank…” (MN2)

“…it was very painful, and I hated my partner because I got it from him. I was married before then after my divorce I had this boyfriend and he didn’t tell me he was HIV positive. He was hiding his tablets and would drink them from behind the cupboard and never disclosed.” (TA)

3. Fear of having HIV

”It was scary and...” (MN1)

4. Disbelief at the disgnosis of HIV

”...and unbelievable.” (MN1)

5. Denial about having HIV

”...I couldn’t accept it so much that I had to first be admitted at the psychiatry ward...I also had to have counsellors come to my home and help me” (VCM)

” At first I didn’t accept that I had it then later I tried to understand.” (FM)

6. Shame about facing loved ones and rejection

”It was difficult because I did not want to tell anyone. So I kept it to myself for a long time.” (TK)

” first I was scared as to how I would face the people who had been caring for me whilst I was in hospital…For me, it was a shock…I was shocked first and didn’t know how I am going to tell them. I wondered if they would still look at me in the same way or maybe look at me another

way.” (TA)

7. Immediate acceptance with self blame for actions that predisposed to infection

Even when one participant reported acceptance of the diagnosis upon being told it was still associated with negative emotions towards themselves:

”...it was fine honestly. There is a reason for everything in life. There is a reason I got HIV, its because I did not think for myself.”(JN)

8. Realisation that life saving medication is available

Being informed about the efficacy of cART prior to their own diagnosis, and being in contact with others who had been adherent to cART and thereafter led normal, healthy lives resulted in positive reactions after diagnosis.

” but later realised I just need to follow the clinic rules and take medication well so that I can be like all other people.” (MM)

“I knew when I was diagnosed that HIV in 2001 that is not a death sentence if you eat well and take your treatment. I had liked reading up on it and watching TV programs on it, so I knew.” (CM)

9. Staying alive for offspring

An interviewee described needing to maintain a positive outlook despite the diagnosis because of her parental responsibilities. She was driven to live beyond the bad news for altruistic reasons:

”I was shocked but told myself I won’t not attend the clinic because I will take treatment for my children’s sake. I wanted to see them grow until they finish school. Their father died and he never told me he was positive...” (CM)

KNOWLEDGE AROUND PSYCHIATRIC ILLNESS AND THE EXPERIENCE OF BEING DIAGNOSED

Nearly all of the patients were cognisant of having a mental illness. It was also noted that these diagnoses were met with a lot of self judgement and fear of stigmatisation by others, secondary to their own negative ideas.

Themes:

1. Knowledge of having mental illness by most but not the exact diagnosis by name

2. Another medical condition affecting the brain acknowledged but not psychiatric illness

Initial negative feelings about the diagnosis

3. Having a disturbed mind

4. Confusion about getting a diagnosis that was unknown and foreign

5. Disbelief and shock

6. Inferiority in the eyes of others

7. Sadness about having mental illness

Positive feelings about the diagnosis

8. Relief about the explanation of past symptoms

1. Knowledge of having mental illness by most but not the exact diagnosis by name

”Yes, I was first told at a private clinic in town by a doctor...” (MN)

”I was told I have depression...” (VCN)

”Yes, I was told I have mental illness...” (TK)

”Yes, first the name confused me and I was anxious wondering what it meant.” (JN)

2. Another medical condition affecting the brain acknowledged but not psychiatric illness

Only one participant was not aware of having a psychiatric diagnosis, rather reporting having epilepsy. Interestingly, despite not acknowledging the presence of mental illness she still received the diagnosis in a negative manner as it resulted in perceptual and cognitive disturbances much like mental illness:

”No, I have seizures not mental illness. I felt bad when I was told I have epilepsy and that my mind gets disturbed sometimes...That didn’t feel good because I never knew I could get such an illness” (MM)

3. Having a disturbed mind

Most of the participants encountered the diagnosis with difficulty as is evidenced by the array of negative ideas they had about mental illness:

” …it becomes like you are mentally lost. It breaks you as a person when they tell you that everything in your mind is complicated…” (MN2)

“…I was losing my mind… and couldn’t understand what was going on with my life.” (TA)

4. Confusion about a diagnosis that was unknown and foreign

” …I didn’t even know the term depression…” (MN2)

“at first I didn’t understand what bipolar…” (TA)

“My daughter would Google it and tell me that it is not a bad disease, I must just take my medication. I thought it was a white person’s disease because I had never heard of it before I was told I had it.” (TA)

”...first the name confused me and I was anxious wondering what it meant.” (JA)

5. Disbelief and shock

” It was unbelievable when they first told me…” (MN1)

“I didn’t believe them when they told me because they kept changing the diagnoses.” (TK)

“I thought it’s just maybe because I don’t want to let go of things that have happened in my past like being abused, harassed, living on the streets and all of those things. My cousin sexually abused…I was surprised when they told me it was a mental illness that I had.” (JA)

“…it shocked me. I was just not coping at the time…” (CM)

6. Inferiority in the eyes of others

“… and you talk to people and they don’t believe what you say or listen to what you say because all they think is that this guy is delusional he is saying nothing that is good.” (MN2)”

“At home they thought I had been bewitched or I am crazy in the head.” (TA)

7. Sadness

”I felt sad because now there was something else that I didn’t know that was being added to the HIV.” (TA)

8. Relief about explanation of past symptoms

A few, surprisingly found some solace in getting formally diagnosed as it better explained their past inappropriate behaviours and emotions to themselves and those in their lives.

” … it explained my behaviour. I could see my behaviour was different to other people’s and I was short tempered too.” (MN1)

“…it gave me closure about the way my behaviour was the way it was.” (VCN)

KNOWLEDGE OF HAVING A SUBSTANCE USE DISORDER AND THE EXPERIENCE OF IT

Nearly all of the participants, knew that they abused one or more substances at some point. The experience of a formal diagnosis at the clinic, and the help offered by the clinic, are detailed:

Themes:

Negative feelings at being told about substance use disorder

1. Sadness about having to stop use

2. Feelings of being misunderstood

3. Shame and guilt

Positive perceptions upon diagnosis

4. Acceptance due to self awareness about the problem

Despite the participants pre-existing knowledge about having a substance use disorder, receiving the news as an official diagnosis by a health care provider was still met with primarily negative feelings by half of the interviewees. One got the impression during the interviewing process that having an objective source confirm what they had already known left them with feelings of humiliation at being found out and also mourning having to stop using what for many of them had been a tool to cope with past traumas and daily stressors:

1. Sadness about having to stop use

" I felt bad because I was told that I have to just stop alcohol..." (MM)

2. Feelings of being misunderstood

"…but deep down in my heart I wish they could be in my shoes right now and understand the road that I am going through that sometimes it's hard it is to keep away from alcohol

because sometimes I just need to sleep, to break away from this problem, just be me, just have a good night of rest."(MN2)

"I would always tell him I am just de-stressing and smoking a bit, but it was actually a lot. I felt like maybe he was trying to control me or something, but he meant well." (JA)

3. Shame and guilt

"it's a bit embarrassing because it causes a sort of low self esteem to know that I am dependent on a substance in order to overcome something or for relaxation; getting high to become sedated." (VCN)

"It made me feel bad when I was told that my use is a problem because everyone doesn't like cannabis so I feel as though I am doing something that hurts people's feelings. I really love it..."(JN)

The other half of the interviewees were expectant and accepting of the diagnosis because of their self awareness or the awareness of those in their lives about the substance use problem:

4. Acceptance due to self awareness of the problem

" … everyone in my life has told me that I have a problem and I know I have a problem and it is alcohol and I smoke too much cigarettes. "(MN2)

"… I believed them and found myself accepting it because it was the truth. I also already knew it was a problem." (TK)

"I knew I had a problem and people in the township were judging me saying this one is crazy; she is not alright in the head and didn't take me seriously. That also drove me to isolate myself and drink more." (TA)

"I saw myself because I was a person who drinks a lot whenever they have money. I would drink a lot over month end. I would drink daily to forget but in the morning it would all come

back. I was now forgetting to drink the pills (ARVs) and was not eating. I knew it was a problem." (CM)

AREAS OF GREATEST DIFFICULTY IN LIFE

Here the participants were questioned about which problems they found to be the most challenging in their lives in general. It was expected that the nature of the experiences they shared may have elicited distressing emotional responses. However, the interviewer found that despite the sensitive nature of the shared content, because rapport had been established by this stage of the interview, the sharing of this information was done with relative ease and candor. None of the participants became overwhelmed or uncontained. Some even reported finding solace by sharing in a safe space.

Themes:

1. **Past trauma: abuse, parental neglect and loss**

2. Financial difficulties

3. Unemployment due to mental illness

4. **Burden of having HIV and being stigmatised**

5. Social isolation and break down of interpersonal relationships

6. **Poor social support**

7. Academic difficulties due to psychotropic treatment

Living in low socio-economic circumstances, and the difficulties that come with that, was the most common theme. These circumstances were noted to have been present both prior to the participants being triply diagnosed, as well as a result of the consequences of having triple diagnosis. Those that were the sequelae of being triply diagnosed were either directly

due to poor health and the inability to maintain occupational functioning, or indirectly due to the stigma of these diagnoses resulting in significant social isolation.

1. Past trauma: abuse, parental neglect and loss

Various forms of complex trauma from early life to recent years, including being triply diagnosed, was an exceedingly common thread among many of the participants. This theme came up at various points during the interview but was fleshed out in detail by the interviewees at this point:

"...Of my mother's children I grew up alone with my uncle and his wife in Port Elizabeth where I got abused." (JA)

"…because I don't want to let go of things that have happened in my past like being abused, harassed, living on the streets and all of those things. My cousin sexually abused me and another family friend…I did not have a mother or a father." (JA)

"My child and I... I am the only one who can help him, his father died." (MN)

"The depression I got after my first born died, she committed suicide in 2010. She drank my pills and killed herself with them." (TA)

"My problem is that when I was growing my mother died when I was 17. She left me with my younger siblings, the oldest was age 9. So, from my youth I had to become a mother, it was tough. From there I got married at age 21 with a husband who toyed with me. Then I got a boyfriend who had HIV and there my child dies at age 15. All of these things happened one after the other." (TA)

"I don't have a father, he died when I was 6 months old. He died painfully after burning himself with petrol, paraffin, diesel and no one knows why he did that." (JN)

"I was living with my children's father and he became emotionally and physically abusive…" (CM)

“Thereafter he would forcefully sleep with me without a condom and that is how I got infected. He was very abusive; hitting me, swearing, physically and emotionally he abused me.” (CM)

“my mother …she is someone who is not supportive towards me…She never cared for me; my grandmother raised me. My 2 siblings who are younger than me were taken by their father, I don’t know who my father is…Not knowing my father still hurts…” (CM)

2. Financial difficulties

” … have a temporary 6-month grant, money is difficult to come by. My child and I don’t live well, I can’t do all things for him; can’t buy him clothes and food. He is 7 years old. I am the only one who can help him, his father died.” (MM)

“Financial problems…” (VCN)

“Money is a problem. I also get the temporary disability grant which is R1700. When it is stopped it, all goes backwards and my child struggles.” (TA)

3. Unemployment due to mental illness

” Financial problems, struggling to be employed. The last time I was employed I still heard voices so things were not alright at work so I had to quit, in fact I had to resign in 2016.” (VCN)

” The problem is that I am at home not working, sending my cv here, there and everywhere. I was used to working before all these sicknesses. I was a cashier, working with money then I started getting sick at work in 2009. My boss said I am not alright to be working under that job description, I should be a cleaner and he was demoting me” (TA)

” What stresses me most now is that I can’t find a proper job. I don’t have a stable home...” (JA)

4. **Burden of living with HIV and stigma**

” The HIV has been the most challenging. At my maternal family side one of my uncle’s heard that I have HIV they no longer liked me that much. My sister’s child then got sick with HIV and they said I am the one who has made the whole family sick.” (CM)

” The most challenging thing is that I am now sick with HIV because in future I cannot have a baby.” (FP)

5. Social isolation and break down of interpersonal relationships

” …It ends up making me not trust myself around people. I am scared I might swear at that person and they may think I mean it and then do something to me.” (MN2)

“…that I can no longer hang out with my friends, little time is spent with them. I don’t want to sit with them for long because I know I have to focus on my treatment.” (TK)

“…my husband has forgiven me, but he has not yet moved back home. He has forgiven me for the way I treated him before he left. I was moody, I made a big deal out of small things, I was constantly aggressive and always blamed someone for my stuff. It’s like I was abusing him in a way…” (JA)

6. **Poor social support**

” My family I don’t really have a relationship with them. My only real family is my husband and his child. Even as brothers and sisters we never see eye to eye, we were never that family where you could go to each other when you have a problem. We all live separate lives...So, I never had someone who I could share my problems with.” (JA)

” I am burdened with 3 conditions on my own, having to maintain drinking all the pills on my own. Sometimes I get confused and end up forgetting if I have taken the pills or not, no one is supervising me. I am alone at home...” (JN)

7. Academic difficulties due to psychotropic treatment

One participant reported impairment in their capacity to succeed scholastically, due to cognitive deficits which he attributed to psychotropic medication. This statement was initially worrisome as it suggested that his negative experience with his medication may impair treatment adherence in the future. This concern was allayed when the interviewee subsequently reported that he was now on different management which he preferred.

" School is the most difficult thing as I am studying electrical engineering. The bipolar medication I was on before made me forgetful...last block I didn't qualify for the exam because I got low marks." (MN1)

COGNISANCE OF THE INTERPLAY BETWEEN THE HEALTH CONDITIONS WITHIN THE TRIPLE DIAGNOSIS

The participants were questioned about whether they thought that the health problems within the triple diagnosis interacted with one another.

Themes:

1. No correlation known

2. Substance use negatively affecting treatment adherence

3. Alcohol contraindicated with taking medication

4. **HIV can cause mental illness or worsen it**

1. No correlation known

Half of the participants were not aware of a correlation between the three health conditions. Some went on to attributing this paucity in their awareness to a lack of knowledge on the causes of the various conditions:

"No they are not related." (MN)

”I can’t say precisely if they interact because I don’t know what the cause is...” (MN)

”I don’t think they interact.” (TK)

”No I don’t understand how they interact but a doctor once told me they go hand in hand.” (JA)

”I don’t think so.” (CM)

The other half who postulated that there was a correlation, had various ideas of how they actually correlated. The commonest two ideas were around substances being contra-indicated with treatment, or hindering compliance to it, and HIV contributing to the development of mental illness:

2. Substance use negatively affecting treatment adherence

” They do interact. You must just take treatment well and not drink.” (TA)

3. Alcohol contraindicated with taking medication

“my illness needs treatment and the treatment doesn’t go with alcohol.” (MM)

4. HIV can cause mental illness or worsen it

” other people become depressed when they find out they have HIV and others have it naturally. I also had that kind of problem where I felt alienated and isolated when I found out I had HIV in 2010, it made the depression worse.” (VCN)

”The reason I became mentally ill was because of the HIV.” (FP)

THE EXPERIENCE OF HIV DISCLOSURE: THE REACTION OF THOSE DISCLOSED TO AND WHAT INFORMED THE DECISION NOT TO DISCLOSE

The participants were asked whether they had disclosed their HIV statuses to anyone, as well as the nature of the response received.

All except one participant had disclosed their diagnosis to at least one family member, closest friend or romantic partner. Whilst the disclosure rate was high, it was noted by most of the

interviewees that it had been done with difficulty, after deliberation, and only to those they felt they could trust.

The themes were analysed in two groups: the nature of reactions and the factors that informed the decision around disclosure.

Themes:

Reactions of those disclosed to

1. Support and kindness

2. Encouragement to take cART well

3. Ill-treatment and shaming

Ideas that affect disclosure

4. Fear of being perceived as ill and infective

5. Fear of rejection

6. Fear of dying and leaving dependents uncared for

Despite their fears about disclosure, most of the participants reported positive reactions from those they disclosed to. Disclosure was mostly met with sensitivity, encouragement to adhere to treatment for continued health, and offers of support.

1. Support and kindness

"They did not react badly." (MM)

"She reacted well because she still treats me the same way she did before she knew…and she doesn't disclose my status to other people." (MN1)

"They were so kind. They just gave me a lot of hope and strength to just accept it and move and live life." (MN2)

"She encouraged me; she did not have a problem." (TK)

“They accepted it and were so supportive.” (JA)

“She told me all would be well, and it happens to anyone, but I was embarrassed…my family reacted well.” (JN)

“I told my uncle who then told my aunt and were supportive. My uncle and my aunt were not shocked. They just told me to take care of myself and to stop drinking alcohol…My uncle refused for me to tell my mother because she is someone who is not supportive towards me, she never cared for me…” (CM)

2. Encouragement to take cART well

” They told me to go to the clinic and get medication and take it well so that I can be alright.” (MM)

” She is the one who encourages me at night to drink my pills ad reminds me of the time.” (MN1)

” After I was discharged from hospital they would make me food, ask me if I have taken my pills and if I am alright...” (JA)

A few patients did however report negative reactions from those close to them. These included being embarrassed about the status in front of others, and being ostracized as well as stigmatised by family members. These reactions seemed to re-enforce the concerns these participants held about disclosing in the first place. It also brought more emotional distress in addition to receiving the actual diagnosis:

3. Ill treatment and shaming

”...when we would be together in the company of guests she would say I mustn’t forget that I have HIV in front of everyone...She did it just to put me down. I was heart broken...” (TA)

“The rest of my family took it badly, they often would insult me. My one uncle refused to eat food that I had cooked, saying that I would make them sick and such things...” (CM)

Three main factors were considered prior to disclosure. A big deterrent was the fear of being perceived as sick and then rejected. Interestingly, wanting to make provision for dependents, was a contributing factor towards disclosure as reported by one participant:

4. Fear of being perceived as ill and infective

"… but when some people find out you have HIV they think that you are sick and will infect them or something. So even my friends, they don't know I have HIV." (MN1)

5. Fear of rejection

" I have never told anyone. Do you believe I have never even told my girlfriend?! I'm still going around in circles. I fear being rejected and all this." (VCN)

6. Fear of dying and leaving dependants uncared for

" I told my best friend because she worried about my kids, they were both still alive, because HIV was a killing people a lot at that time. I thought should I die, what will happen to my children?" (TA)

THE EXPERIENCE OF DISCLOSING MENTAL ILLNESS: WHAT INFORMED THE DECISION TO DISCLOSE AND THE REACTION OF THOSE DISCLOSED TO

The participants were asked whether they had disclosed their psychiatric diagnoses to anyone, and the responses to this.

Most of the participants (those who acknowledged having mental illness) had disclosed their psychiatric diagnosis to a few individuals that they deemed themselves close to, felt could trust and look to for support.

Themes:

Reaction from those disclosed to

1. Increased supervision

2. Support and acceptance

Ideas that inform decision to disclosure

3. Health care professionals disclosing diagnosis first to family

4. Seeking to explain past behaviours and making amends

All the participants noted positive reactions from those that they disclosed to. They were met with empathy, encouragement and support. In one case, next of kin actively sought information about mental illness to further improve support: "She read up on it and told me that it is not a bad disease, I must just take my medication and it would be alright. She then explained it nicely to the rest of my family and my father who is not educated that I have not been bewitched but suffer from mental illness…" (TA)

Only one participant suspected that, despite her spouse's positive reaction , his view of her had been negatively affected by the disclosure of mental illness. This however seemed to be informed more by her own perceptions, a sort of self stigma with rejection sensitivity: "He reacted fine but I think that is what made him stay away from coming back home because when some people hear you are depressed they think you are crazy…" (JA)

The rest of the reactions were perceived as positive:

1. Increased supervision

" She supervised me more." (MM)

2. Support and acceptance

" She reacted well; she is a teacher, so she understood." (MN1)

"They were so kind and gave me hope that everything was going to be good." (MN2)

"She accepted it." (TK)

“He was very supportive. They also supported me with that diagnosis, one of my uncles even came with me to one of the clinic’s family education sessions on how to handle relatives with mental illness.” (CM)

“They said I inherited it from the family, there are others who also have mental illness. They were supportive.” (FP)

3. Health care professionals disclosing diagnosis to family first

Of concern, two of the seven participants reported that they did not really need to disclose to their next of kin, as health care providers disclosed their diagnoses to their family members before they did. The interviewees reported this with no insight to the ethical implications of the way in which this was conducted. They reported it as an expected norm:

” … the doctor in private told her and explained to her that it’s an inherited illness.” (MN1)

“My husband knows, he was told at the hospital. They called him and told him because I was quiet, a little bad at that time so they discussed most things with him.” (JA)

4. Seeking to explain past behaviours and making amends

The only interviewee who readily informed many people, beyond those closest to him, stated that explaining past behaviours, with the hope of mending relations, was the driver of his disclosure.

” I have told everyone that I know to make amends with everyone. I am trying to deal with it and to break away from it. I am trying so hard to tell people that everything that is going on in my life is not by liking, it’s not because I want it to happen, it’s not because I want to hurt people.” (MN2)

THE EXPERIENCE OF DISCLOSING SUBSTANCE USE DISORDER: THE IDEAS THAT INFORM THE DECISION AND THE REACTION OF THOSE DISCLOSED TO

The interviewees were asked whether they had disclosed their substance use disorder diagnosis to anyone, and what the reactions to this were.

The resulting themes were analysed into the descriptions of reactions, and the factors that resulted in either disclosure or non-disclosure.

Themes:

Reactions from those disclosed to

1. Reprimanding to stop

2. Being made to feel bad

3. Feelings of disappointment

Ideas that informed whether or not to disclose

4. Shame about using a substance to cope

5. Choosing to disclose to health care providers rather than family

6. Seeking to explain past behaviours

Those who opted to disclose their difficulties with substance use, typically disclosed to family members. These disclosures were predominantly met with harsh reactions, which the participants described as punitive, filled with blame and judgement, even from those who seemingly meant well and wished to encourage them to stop the use of these substance(s). Interestingly many of these harsh responses were from the same next of kin who had received the psychiatric and HIV diagnoses with sensitivity and support:

1. Reprimanding to stop

”She reacted badly and told me to stop drinking,” (MM)

” that they tell me a lot to reduce use and break away from it” (MN2)

” She encouraged me to stop although she is a person who shouts so at times, I happen to avoid her.” (VCN)

” They told me to stop...” (TK)

” did not want to see me drinking at all.” (CM)

2. Being made to feel bad

” told me to stop drinking, I felt bad.” (MM)

” They told me to stop. I didn’t feel alright because I didn’t want them telling me what to do.” (TK)

3. Feelings of disappointment

” They reacted differently to that one. They were disappointed...” (MN2)

Feelings of shame about being a substance user as well as the fear of judgement and the mistrust of next of kin emerged as driving forces in the decision of non-disclosure. Trust in the confidentiality, and ability of help from health care providers also emerged as a theme.

4. Shame about using a substance to cope

” I didn’t want people to know I am an adult and this thing its usually a substance used by young children mostly. Usually when I used it, I used it to help me sleep at night because I struggled with horrible dreams if I didn’t smoke.” (MN1)

” But somehow it is so hard. It is so hard to break away from alcohol or smoking because sometimes you just need something that can take away everything…” (MN2)

5. Opting to disclose to health care providers than family

” I told the doctor and the ward staff that I have a problem with alcohol; I am drinking a lot. They then helped me...” (TA)

” I spoke to the clinic psychologists and I would go to the social workers and I always talk to my doctor. I have never told anyone else. I once applied for rehab at SANCA...I would still like to go because I am struggling to stop...” (JA)

6. Seeking to explain past behaviours

The sole driver of readily opting to disclose to relatives was once again reported to be the theme of attempting to explain past inappropriate behaviours:

” I told my family that I used to use substances to explain why I was involved in crime.” (JN)

14. PERCEPTIONS OF THE DIFFICULTY IN LIVING WITH A TRIPLE DIAGNOSIS

Lastly the participants were questioned on whether they thought that their condition was harder to live with than other individuals who have different diagnoses to theirs. The reasons for their views were explored.

More than half of the interviewees stated that they felt that living with triple diagnosis did come with more difficulty than having other medical conditions. The burden of multiple diseases, the stigma associated with some of them, and the chronic nature of the HIV were the most common reasons for the perceived challenges. Despite this view, interestingly most of the participants who reported increased hardship were also optimistic about the future. Many reported acceptance and coping with the diagnoses presently, as compared to the distressing feelings encountered on diagnosis. Many also noted that they were cognisant of the difficulties that those with other health conditions also encounter, even if they had less burden of disease. Some even went on to report that they felt there were worse diagnoses to have.

The emergent themes were analysed into factors that worsened the difficulties of being triply diagnosed, and those that eased them.

Themes:

Factors that increase difficulty

1. Burden of illness

2. Illness chronicity with lifelong treatment dependence

3. Stigma and social rejection

Factors that decrease difficulty

4. Attitude and support

5. Treatment availability

The factors that the interviewees found to improve difficulty were:

1. Burden of illness

” it’s not one thing its threeD. Others only have mental illness to deal with.” (TK)

2. Illness chronicity with lifelong treatment dependence

” The hardest part is that your life must change. You must drink pills all the time at the same time so that you can be alright.” (TK)

“this sickness is for the rest of my life. It can't be healed and that is difficult.” (FP)

3. Stigma and social rejection

”...mine is so different to other people’s diagnoses because mine is worse. Wherever I go people look at me differently,”(MN2)

” …but it is challenging because when you get stigmatised and rejected and the only person you can depend on by that time is your own self esteem. You can even go for suicidal thoughts and all that at that time. “(VCN)

The factors that eased living with a triple diagnosis were:

4. Attitude and support

” but it depends on your attitude towards it. Most of the time I don’t focus on what sicknesses I have and just take my pills.”(MN1)

”when you are sick you must just accept it whatever illness you have. I see all illnesses as the same. Some people have cancer and have accepted it. Acceptance and support are the most important things.” (CM)

5. Availability of treatment to manage the diagnoses

”I know if I take my pills accordingly nothing bad will happen.” (MN1)

”...these conditions are manageable; they can be treated and controlled. When you drink your medication you can feel that you are well. You are able to clean, wake up, think clearly, pick up a book and read or watch TV. There are people who are worse off.” (TA)

5. DISCUSSION

The study sought to provide qualitative data that explores the experiences of those who are triply diagnosed in a South African setting. The aim was to gain a deeper understanding of the actual experiences of these individuals. The semi-structured interview was used to obtain the information in a manner that allowed the participants to express their experiences in an unrestricted yet structured fashion.

Despite the individuals who are triply diagnosed in this research not being familiar with the term "triple diagnosis", the results showed that they were in fact knowledgeable about their actual diagnoses, as well as which health behaviours were conducive to good general health. Many were motivated to remain in remission of substance use disorders. The motivating factor to adherence on cART, was to remain healthy despite having HIV. Most of the participants were found to have significant life stressors from childhood, such as neglect, poor attachment in early relationships and abuse by adults. Further hardships plagued many of their adulthoods with difficulties such as years spent in prison, poor social support, unemployment, poor finances, turbulent interpersonal relationships and poor coping skills. These stressors resulted in the initial increased use of substances. There was a recurrent theme of trauma among many of the participants.

Seeking of health care services and the experience of the specialised triple diagnosis clinic

All of the participants except one expressed that the main reason they sought health care was to manage their HIV infection. More than half stated that they also sought health care for a named mental illness or psychiatric symptoms. None of the participants mentioned that they sought services to help them manage their substance use disorder. They only mentioned this

when specifically asked. This may be due to feelings of guilt and shame around this diagnosis. It may also be because substance use is not perceived as an illness that needs management. It is noted in another publication that services for the prevention and treatment of substance misuse and substance use disorders have traditionally been delivered separately from other mental health and general health care services. ”Because substance misuse has traditionally been seen as a social or criminal problem, prevention services were not typically considered a responsibility of health care systems; and people needing care for substance use disorders have had access to only a limited range of treatment options that were generally not covered by insurance” (23). Most participants reported that the reason they attended the clinic was HIV infection and mental illness, without realising that their substance use disorder was also a management target. ”I use zol which often times I use to comfort me with the problems I have... it made me feel bad when I was told my use is a problem...I really love it, it gives me great sleep.” Reporting of substance use was typically reported later only on direct questioning. This has implications on the health seeking of substance use treatment in this group. Future clinic objectives need to entail active direct screening for substance use, as the evidence here suggests that it will not be volunteered. There were misconceptions evident with regards to the actual substances used. ”Usually when I used it, I used it to help me sleep at night because I struggled with horrible dreams if I didn’t smoke. When I use it I would not dream at all. I was told at this clinic that it depletes brain cells and that is why I do not dream when I have smoked it.”

In future these need to be addressed proactively with the patients as they directly influence the readiness to use substances continuously.

Awareness and knowledge of their various health problems

Previous research assessing patients' awareness of their medical conditions that identified the factors affecting their awareness, and assessing patients' satisfaction with their doctors' explanations of their medical conditions, showed that most (64.1 percent) patients know their diagnoses (19). This was significantly associated with level of education, chronicity of disease and the awareness of other issues related to illness, such as complications and names of their medications. In that research a few knew the complications of their disease. It was reported that 70 percent of those patients were satisfied with their doctors' explanation of their disease (19). Patient satisfaction was associated with knowledge of the diagnosis and the disease complications. This literature highlights the importance of adequate patient education at healthcare facilities, by clinicians, for better health outcomes and the improvement of patient experience.

All of the participants in this study were aware of their HIV diagnosis and the importance of treatment adherence. This was an expected finding as in 2019 UNAIDS reported that of all people with HIV worldwide 81 percent knew their HIV status and 82 percent of those were accessing cART (24). Most of them also knew that they had a psychiatric diagnosis and many of those persons knew the name of their illness. However, prior to their diagnosis they had either never heard of the illness or never anticipated that they would be diagnosed with a mental illness. One of the participants admitted to having previously perceived mental illness as a problem that only affects White people. This is in keeping with data that assessed the knowledge of mental illness in the South African community in 2004. It found that misinformation and stigma regarding mental illness exists with cases most often being conceptualised as stress related or due to lack of will power, rather than as a medical disorder (25). All, except one participant who was unaware that she had a substance use disorder, knew prior to being formally diagnosed that their use of substances was problematic. Even a

participant who believed that cannabis helped him socially, and used it to self medicate various symptoms, admitted knowing that his use was a problem.

None of the participants were knowledgable regarding the concept of being triply diagnosed. The only participant who knew and used the term did not know the actual definition of triple diagnosis, and erroneously thought it included his epilepsy diagnosis as opposed to that of mental illness. Many of the participants were also not clear on how their three diagnoses interacted, with a few identifying that substance use negatively affects adherence to cART.

The HIV diagnosis and the experience of being diagnosed

The two overriding themes from the initial experience of being diagnosed with HIV are feelings of devastation and emotional pain, as well as the fear of rejection from people, with a fear of facing loved ones. This is similar to previous qualitative research that explored the emotional responses of 15 individuals diagnosed with HIV in Cambodia. Eighty percent of those respondents reported initial feelings of sadness, guilt and shock. The theme of fear of social rejection was also similar. "They reported being particularly concerned about their social positions and were upset because there is no recovery from HIV infection." (26)

Despite the above feelings and initial negative reactions, all except one participant disclosed their status to at least one family member.

The diagnosis of mental illness and the experience of being diagnosed

The main themes regarding being diagnosed with mental illness were shock and disbelief as well as the confusion of being diagnosed with an illness that is a foreign concept. Whilst there

was also a prominent theme of relief about the diagnosis explaining past problematic behaviours, there was still a sense of sadness at feeling as though they are being seen as cognitively inferior and not being taken seriously by others in the community as a consequence. These themes speak to the findings of past studies that have evaluated the negative impact of stigma, both public and self, on people with a diagnosis of mental illness. ”Self esteem suffers, as does confidence in one’s future.” (27)

However, unlike our study population, previous research also suggests that instead of being diminished by the stigma, many persons become righteously angry because of the prejudice that they have experienced and this reaction paradoxically empowers them to change their roles in the mental health system, becoming more active participants in their treatment plan and often pushing for improvements in the quality of services (27). This is yet to be found in our setting.

Substance use disorder and the experience of being formally diagnosed

Most of the participants acknowledged that they already knew that they had a problem with a specific substance before being clinically diagnosed. Unlike the other diagnoses there was poor global support, and a punitive manner was adopted by those in their lives, in relation to their use of substances. Most of them were simply told by those around them, to stop using , with little empathy. The reaction by the significant others alludes to how substance use is viewed in their settings. Psychiatric conditions and HIV infection resulted in empathy, offers of support and taking on caregiving roles. However, substance use is met with less understanding, less support, a lack of acceptance and the assumption that it is a habit that they can control rather than a mental health condition for which they need support and encouragement. This is in keeping with past research that reveals that while the stigma of substance use disorders share similarities with the stigma of mental illness, important differences exist in people’s attitudes.

Among these differences are criminal stereotypes and subtle prejudice such as curiosity and discrimination (28). This attitude has a number of implications for these individuals with regards to the use of the substance as well as help seeking behaviour. The unsupportive stance may result in the substance users hiding the condition, seeking rehabilitation less readily, as well as feelings of shame. Feelings of shame and a lack of social support may result in increased substance use with even more implications on comorbid mental health conditions and HIV statuses. "Without help and support in the community or at home, it is no wonder that it can be difficult for people with substance use disorders to recover." (28)

Areas of greatest difficulty in general life

Financial difficulties with unemployment, the burden of being stigmatised for having HIV and poor social support with poor interpersonal relations, as well as having to cope with past abuse, were the predominant themes raised. Whilst many patients that attend the clinic live in the surrounding area, socio-economic difficulties affect access as many still need to pay for public transportation to get there. This has negative implications on treatment adherence.

The high unemployment prevalence in this group also means that they have more time at home, potentially ruminating about their woes. This may perpetuate the use of substances. Ongoing motivational counselling at the clinic is therefore important, even to those who are in remission. The significant unemployment in these persons also means that occupational therapy interventions that are focused on enhancing occupational functioning are important.

This group's struggles with the stigma of HIV, then having to attend a clinic that is known to the community to be specifically for those with HIV and other conditions, could deter triply diagnosed individuals from attending such a facility. The results of a community-based South African study suggests that stigmatising attitudes are prevalent in these communities, despite

relatively high levels of exposure to the HIV/AIDS epidemic (29). The socio-demographic factors that were found to be related to the extent of stigmatising attitudes in these communities were older age, male gender and lower levels of education (29). Therefore increased health promotion strategies, where the misconceptions about those who have HIV are dispelled, are important in the clinic setting. These strategies should be aimed at normalising HIV as a chronic illness like any other. This way, even if the community know that the triple diagnosis clinic serves those with HIV, it simply would not matter to those attending.

The common occurrence of trauma; both in childhood and continuing into adulthood, in the form of the loss of those close to them, as well as abuse in their relationships, affects the way in which they cope with daily stressors. This past trauma also informs the quality of interpersonal relations and therefore the quality of their support systems. Inadequate support and poor coping with stressors then once again predisposes these individuals to ongoing substance use. Here the increased availability of the clinic's psychological component of the multidisciplinary team becomes important. Supportive therapy groups and individual sessions need to be readily available. It must also be borne in mind with the clinicians who review all patients in this setting, even those who have not expressed a need for psychological support, that this population needs to be screened continually for poor coping.

Perceptions of the level of difficulty it is to live with triple diagnosis

Many participants found the burden of three chronic conditions, as opposed to one, like other people, difficult. However, the overriding stance was, that whilst being triply diagnosed poses a unique set of difficulties, there are conditions that are more difficult to have. This perception suggests that over time, having triple diagnoses, yet remaining relatively well, with access to specialised health services, may have normalised the health burden that these

conditions previously imposed.. This is in keeping with the findings of a past study that illustrates that availability of health services and a timely diagnosis have a significant relationship with a higher quality of life in those living with HIV (30).

The initial significant difficulties described here do however suggest that specialised clinics of this nature need to be readily available to these patients at diagnosis. This should alleviate the degree of morbidity, increase support and therefore overall lessen the burden of disease from earlier on. Such intervention could then decrease the need for coping by using substances due to lowered stress levels. This would ideally then also translate to improved mental health.

Limitations

The limitations in the research are due to the qualitative nature of the study and hold true for most qualitative research.

The first limitation is that the study outcomes may not be extended to other populations with a degree of certainty. So, our data will not be generalisable. The small sample size, despite having reached sample saturation regarding themes, still also limits the generalisability of the research.

While the demographics of the participants in the study are representative of the patients in the clinic which mainly comprise young to middle aged African males and females, there are a handful of patients in the clinic who belong to other race groups. Those races were not chosen in the process of random convenience sampling and are therefore not represented in the research.

Lastly, the interviews were done in either English, Zulu or Xhosa depending on the interviewee's language of choice. This was done with the aim of enabling the participants to fully express their experiences in a language they can articulate themselves in. There were however three participants whose first language was Sotho. They all spoke Zulu comfortably, but it is possible that they would have been able to articulate themselves more elaborately if the interviewee could have engaged with them in Sotho.

6. CONCLUSIONS AND RECOMMENDATIONS

Despite the individuals who are triply diagnosed in this research not being familiar with the term “triple diagnosis” they were well versed on their actual diagnoses, as well as which health behaviours were conducive to good general health. Many remain motivated to stop using substances with the drive being to remain adherent on the cART, in an effort to remain healthy with HIV.

Most of the participants had significant life stressors from childhood, such as neglect, poor attachment in early relationships and abuse by adults. Further hardships marred many of their adulthoods with difficulties such as years spent in prison, poor social support, unemployment, poor finances, turbulent interpersonal relationships and poor coping skills. These stressors resulted in the increased use of substances.

In light of the recurrent nature of the theme of trauma, it may be of benefit for future research on this population to specifically explore this in greater detail. Fleshing out this topic may provide greater insight on the intricacies of how this past abuse contributes to these individuals becoming triply diagnosed, beyond just how it has affected their general quality of life.

The disclosure of one of the participants that they had not disclosed their HIV status to their partner was dealt with after the interview recording was terminated. He was counselled by the interviewer who is also a medical practitioner with ethical obligation to uphold in the study. After being informed of the benefits of disclosing his status to his partner for both parties, he readily agreed to inform her of his status.

Attending a specialised multidisciplinary clinic that is specifically geared at managing their triple diagnosis has been beneficial for their wellbeing. This is because the facility has not just provided the promotion of physical and mental health but also continually offers a containing space where they are seen and heard. This helps these persons to cope with their multiple hardships and seems to have helped with the reduction of harmful coping strategies used prior such as self-harm with repeated suicidality in one participant. More clinics of this nature need to be available to other triply diagnosed individuals in our setting. However, the relative scarcity of such specialised services in our setting is largely because hosting such a clinic requires multiple resources. These include the availability of infrastructure and trained health care providers to form a multi-disciplinary team that delivers this level of care in a cost-effective manner in our resource limited setting.

The lack of literature looking at the triply diagnosed population in the South African setting means that while this study has provided some insight into the challenges that the triply diagnosed are faced with before their diagnoses are made, at the point of diagnosis and after, there is still a lot of information that needs to be known about this group that is still to be explored.

Recommendations for enhancing quality of life and general health status in this population requires holistic, targeted management of their various conditions.

Increased resources; particularly affordable, public inpatient and outpatient rehabilitation facilities, will be needed to aid abstinence from substance use in this group. At the level of the clinic; ongoing motivational interviewing and substance use support groups are important. The example of this particular triple diagnosis clinic shows that it is possible to provide these services by utilizing existing infrastructure and keeping costs reasonable.

Occupational therapy interventions that are focused on enhancing occupational functioning will be important to provide increasingly for these individuals to combat the high unemployment prevalence and its sequelae.

To address the problem of being stigmatised for having HIV infection for these persons, increased health promotion strategies where the misconceptions around HIV are dispelled will be important.

Additionally, supportive therapy groups and individual sessions need to be readily available in ensuring improved coping in this group with a significant history of trauma, abuse and loss. All patients in this setting, even those who have not expressed a need for psychological support need to be screened regularly for coping difficulties in order to effectively ensure harm reduction.

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APPENDICES

APPENDIX 1: SEMI STRUCTURED INTERVIEW

The following interview will be conducted in English, Zulu or Xhosa depending on the participant's language of preference.

1. Can you tell me why you are at the clinic today?
2. Is the service they provide you with at this clinic different to other places you have attended in the past?
3. What health problems have you been told that you have?
4. Tell me about the different health problems that they help you with here at the clinic.
5. a) Have you ever heard of the term triple diagnosis?
   b) If so, what do you understand by it?
   c) Do you think it applies to you?
6. Has anyone ever told you that you have HIV? If yes; what is that like for you?
7. Has anyone ever told you that you have a mental illness? If yes; what is that like for you?
8. Has anyone ever told you that you have a problem with substance use? If yes; what it was like for you?
9. Which problem do you think is the most challenging in your life?
10. Do you think that these health problems interact with each other?
11. Who have you told about your:
    a) HIV status and how did they react to it?
    b) Mental illness and how did they react to it?
    c) Substance use problem and how did they react to it?
12. Do you think that your condition is harder than someone who has a different diagnosis to yours and why?

APPENDIX 2: INFORMATION SHEETS AND CONSENT FORMS

PATIENT INFORMATION SHEET

STUDY TITLE: HIV, mental illness and substance abuse; a qualitative study of the experiences faced by persons diagnosed with all three conditions at Chris Hani Baragwanath Academic Hospital outpatient clinic.

INVESTIGATOR: Dr S Zuma

SUPERVISORS: Drs G Jonsson, L Paruk & J Furin

INSTITUTION: University of Witwatersrand, Parktown, Johannesburg.

Introduction

Good day, I am Dr S Zuma, a psychiatry registrar (a training doctor) in the Department of Psychiatry at the University of Witwatersrand. I am doing a research project and would be grateful for your help. Before agreeing to participate, it is important that you carefully read the following explanations of the reasons for doing the study, the study procedures, benefits, risks, discomforts, and precautions as well as your right to withdraw from the study at any point in time. This information page is to help you to decide if you would like to participate. You should fully understand what is involved before and if you agree to do so.

Purpose of the study

You attend a clinic that provides treatment and care for people with mental illness, HIV and drug or alcohol use disorders. There are many individuals with all 3 of these conditions in our setting and many of them face the many challenges that come with each of these conditions. Whilst these people may be receiving treatment for these conditions, we know that they come with a lot of different problems and difficulties that may negatively affect their quality of life, maybe more than those that only have 1 or 2 of these conditions. The point of the study is to describe the personal experiences of people diagnosed with HIV, mental illness and drug or alcohol use disorders. Knowing this information may help us in providing specific additional services in order to support these people with their specific kinds of challenges. This will improve the quality of care that is provided at the clinic.

Procedures

If you agree to participate you will be interviewed by the study investigator for 60 to 90 minutes once. You will be asked 15 questions with you giving information on your medical illnesses, your difficulties dealing with them, things that may have helped with those difficulties as well as your experience with the clinic. This interview aims to see what your personal experiences as a person who is living with HIV, mental illness and drug use problem are.

Possible risks and possible benefits

The possible risk of taking part in the study is the sad emotions that you may feel because of telling the interviewer about your personal struggles during the interview. There are however counselling services that will be available should you need them at any point during or after the study. It is not likely that there will be any other risks. The direct benefits to you as a patient will be that your participation would help us to know the type of challenges that people who are living with HIV, mental illness and drug or alcohol use disorders are struggling with in their lives. You should however be cautioned that some questions asked in the interview may be sensitive, about your personal information and medical conditions. If you are unhappy answering any of the questions, please report this with the investigator immediately and you are free to withdraw your permission to take part in the study.

Rights as a participant in the study

It is your decision whether or not you would like to take part take in this study. Your participation is up to you to decide. If you decide to take part, you are still free to change your mind and withdraw from the study at any time and without giving a reason. This will not affect the type or quality of care that you get or the relationship you have with the doctors, nursing, psychology or occupational therapy staff at the clinic. You are free to refuse to participate or withdraw your permission at any point in time. The results of this study will be made available if you ask for them. The results will be confidential, and your name will not be mentioned in the information. There will be no costs to you from the study and there are no medical risks in taking part in the study.

Ethical approval

This clinical study protocol will be submitted to the University of Witwatersrand, Human Research Ethics Committee (HREC) for approval.

For additional information

If at any time you have any questions about this study, please do not hesitate to contact us on the following cellular number: 0741011915 or email: dr.szee.zuma@gmail.com.

If you agree to part take, please sign the consent form.

Thank you

Dr S Zuma

INFORMED CONSENT

I confirm that I have been explained to by Dr S Zuma about the nature, conduct, benefits and risks of the study: "HIV, mental illness and substance abuse; a qualitative study of the experiences faced by persons diagnosed with all three conditions at Chris Hani Baragwanath Academic Hospital outpatient clinic." I have also received, read and understood the above written information about the study. I am aware that the results of the study, including my personal details regarding my medical conditions and my challenges with them will be anonymously stated in the study report. I know that I may at any stage, without prejudice, withdraw my permission and participation in the study. I have had enough opportunity to ask questions and of my own free will declare myself prepared to participate in the study.

_____

Name (Capital letters) Signature Date

STUDY DOCTOR AND PERSON ADMINISTERING THE CONSENT

I, _____ herewith confirm that the above patient has been fully

informed about the nature, conduct and risks of the study

_____

Name (Capital letters) Signature Date

WITNESS

_____

Name (Capital letters) Signature Date

PATIENT INFORMATION SHEET

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SUPERVISORS: Drs G Jonsson, L Paruk & J Furin

INSTITUTION: University of Witwatersrand, Parktown, Johannesburg.

This study involves the audio/ voice recording of your interview with the researcher. The recording will be done using a dictaphone and it will be of the whole 60 to 90-minute interview. Neither your name or any other information that identifies you will be associated with the audio/ voice recording or the transcript (the typed-out words of the recording of the interview). Only the investigator will have access to the dictaphone which the recording will be in. Only the research team will be able to listen to the recording.

The recording will be transcribed (listened to and have the words of the recording typed) by an independent professional and deleted once transcription is completed and has been checked for accuracy by the investigator. The information from the transcript of your interview will be reported in the study write up. Neither your name nor any other identifying information such as your voice will be used in the study write up.

INFORMED CONSENT TO AUDIO RECORDING & TRANSCRIPTION

I confirm that I have been explained to by Dr S Zuma about the nature, conduct, benefits and risks of the study: "HIV, mental illness and substance abuse; a qualitative study of the experiences faced by persons diagnosed with all three conditions at Chris Hani Baragwanath Academic Hospital outpatient clinic" as well as the fact that the entire 60 to 90 minute interview between myself and the study investigator will be recorded. I have been informed about the details of the audio/ voice recording of the interview and its transcription. I understand that the transcribed information from the interview will be anonymously written about in the study report. I know that I may at any stage, without prejudice, withdraw my permission to being recorded and having the transcriptions used in the study. I have had enough opportunity to ask questions and of my own free will declare myself prepared to participate in the study and have the interview between myself and the investigator recorded and transcribed as part of the study. I also understand that this permission for recording is effective until the following date: 31st July 2018. On or before this date, the recordings will be deleted.

_____

Name (Capital letters) Signature Date

STUDY DOCTOR ADMINISTERING THE CONSENT TO AUDIO RECORDING & TRANSCRIPTION

I, _____ herewith confirm that the above participant has been fully

informed about the details regarding the audio recording and transcription of the clinical interview.

_____

Name (Capital letters) Signature Date

WITNESS

_____

Name (Capital letters) Signature Date

APPENDIX 3: ETHICS APPROVAL


Ethics Clearance Certificate.pdf

APPENDIX 4: PERMISSION TO CONDUCT STUDY AT THE SITE



Permission to conduct study certif

APPENDIX 5: TURNITIN REPORT