

Addressing psychosocial problems among persons living with HIV

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Abstract

The large number of persons living with HIV in Southern Africa has implications for mental health services for this population. Data have emerged in recent years showing that a substantial number of persons living with HIV also have mental health problems. Yet, the practice of routine screening for psychiatric disorders in the context of HIV care is controversial. Moreover, common mental health problems, if left undetected and untreated, may have severe consequences for adherence to antiretroviral therapy (ART), which in turn will likely lead to severe health consequences for patients. There are high costs associated with employing professional psychologists, counsellors, and social workers to provide psychosocial support to ART users. As a result, in many contexts lay counsellors and patient advocates have been employed as a less costly alternative. High standards of training of lay counsellors, as well as on-going supervision and support to patient advocates is necessary to ensure optimal outcomes/ results.

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Introduction

The overall national HIV prevalence has been estimated at 29.4% among women aged 15-49 years attending antenatal clinics¹ and at 10.9% in a national household survey conducted by the Human Sciences Research Council.² Despite the availability of antiretroviral drugs and educational and behaviour change campaigns, large numbers of people in Southern Africa continue to become infected with HIV. As such, Freeman noted that developing countries may be heading for a "mental health disaster" (p. 139).³

Mental health and HIV

Freeman called attention to dementia and cognitive disorders, HIV-related delirium, mood disorders, personality disorders, and chronic mental illness among persons living with HIV.³ In a subsequent national survey of 900 persons living with HIV, Freeman et al found that, using the Composite International Diagnostic Inventory, 43.7% had a diagnosable mental disorder.⁴ Of these, 11.1% had major depression; 29.9% had mild depression; 12.4% reported alcohol abuse. The same study reported lower prevalence

of generalised anxiety, posttraumatic stress, and intermittent explosive disorders. Kagee & Martin screened 85 patients diagnosed with HIV for psychological distress using the Hopkins Symptom Checklist (HSCL) and for behavioural manifestations of depression using the Beck Depression Inventory (BDI). Mean scores on the measuring instruments indicated clinically significant psychological distress and psychopathology (HSCL) and moderate depression on the BDI.⁵ More than 50% of the study participants had scores in the clinically significant range on the HSCL and nearly 40% had moderate or severe depression as measured by the BDI. These data are in keeping with similar studies among HIV-positive samples in other parts of the world.^{6,7,8} A recent systematic review of 27 studies of mental health problems among persons living with HIV in Africa reported a prevalence rate of 20% to 35% for depression.⁹

In the study by Kagee and Martin, many participants endorsed symptoms of distress that were ostensibly related to their HIV status, such as decreased levels of energy, feeling everything is an effort, and feelings of hopelessness. It is likely that these symptoms may in large part be due to the sense of hopelessness people may experience from the combination of their illness and living in poverty.⁵ Similarly, high reported levels of excessive worry about things, also a highly endorsed item may have been driven by concerns of impending physical decline, access to treatment, inability to work, and financial well-being. It is likely that HIV is not the only stressor as other stressors may include living under conditions of poverty, poor housing and amenities, unemployment, gender inequality, family problems. Diagnosable psychiatric disorders as well as sub-threshold psychological distress may have a negative effect on

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quality of life, family functioning, adherence to antiretroviral therapy, adherence to infant-feeding guidelines among new mothers. In sum, mental health problems may have a significant influence on physical health and quality of life.¹⁰

Is routine screening for common mental disorders a good idea?

The idea of routine screening for common mental disorders, followed by psychological treatment for those people who screen positive appears to have intuitive appeal. Yet, limited sensitivity and specificity of self-report measures in determining caseness for mental disorders may mean that elevated scores on a self-report measure do not always predict a diagnosable disorder.¹¹ Coyne et al have argued that routine screening may yield high numbers of false-positive and false negative cases. The former may be inappropriately referred for treatment, while the latter group, who may benefit from treatment, may not be detected. An alternative approach is to routinely use structured diagnostic interviews such as the Structured Clinical Interview for the DSM or CIDI to identify cases of common mental disorders. However, such an approach will be both resource and time-intensive as trained clinicians will need to be hired, clinic space will have to be arranged, and large numbers of patients will need to undergo assessment. In addition, the lack of a clear treatment trajectory in the public health care system may mean that those persons identified as being in need of mental health services may not receive such services. Limited mental health services due to insufficient personnel, clinic infrastructure, and administration is a structural barrier endemic to the public health systems in many Southern African countries.

The option of task-shifting has been proposed, where nursing staff take on the role of screening and referral for mental health services.¹² Yet, task-shifting may not be logistically feasible due to competing demands on time combined with large numbers of patients in need of screening. The result may be that common mental disorders may continue to go undetected and therefore untreated.

Common mental disorders and adherence to antiretroviral therapy (ART)

There is growing evidence that major depression is strongly associated with poor adherence.¹³ Depressive symptoms include low motivation, poor concentration, sleep disturbance, psychomotor retardation, fatigue or loss of energy, and feelings of worthlessness.¹⁴ Many depressed persons may be unlikely to have adequate motivation and self-efficacy to attend clinic appointments and take their medication with the required regularity.^{15,16,17} ART users exhibiting these symptoms will likely have difficulty adhering to clinic attendance requirements and medication adherence regimens.

It is likely that ART users who have high levels of anxiety may have considerable difficulty in concentrating on the preparatory tasks associated with taking their medication, such as filling prescriptions, keeping their medication with them, remembering to take the medication on time, and remembering the correct dosages. Brandt found that between 19% and 37% of persons living with HIV in various African countries exhibited elevated levels of anxiety-related symptoms.⁹ Substance-abusing ART users have been shown to have low adherence rates as intoxicated persons often have memory, concentration, and physical coordination impairments.¹⁸ Coetzee, Kagee, & Vermeulen found that nurses reported responding negatively to ART users arriving at the clinic

in a state of intoxication, resulting in impaired patient-provider relationships which in turn affected patients' clinic attendance.²⁰ Poor adherence may take the form of not taking the medication at all, taking medication at the wrong time, taking the wrong doses, prematurely terminating treatment, self-adjusting doses to modulate side effects, not filling prescriptions and not attending clinic appointments. An appropriate level of cognitive and psychiatric functioning is necessary to ensure treatment adherence.

The consequences of untreated common mental disorders among persons living with HIV

Mental health problems among persons living with HIV are closely associated with impaired quality of life, family problems, worker absenteeism, suicide risk and interpersonal difficulties, in addition to poor adherence among ART users. Poor ART adherence has many adverse implications for patients which include a low CD4 count, a high viral load, vulnerability to opportunistic infections, more rapid disease progression, slower recovery times from bouts of illness, and the development of resistance to first-line ART, requiring more expensive second-line treatment. The psychosocial implications of declining health include psychological distress associated with illness, poor quality of life for patients and their families, and mortality and its psychosocial and economic effects on family well-being. Further, the wastage of resources such as medical consultation time, unconsumed medication, worker absenteeism and mortality is also likely to exact an economic toll on society.

On the basis of the data from various studies^{4,5} it is likely that common mental disorders, as well as sub-clinical psychological distress, can be common among persons living with HIV. Persons experiencing psychological distress may be helped by means of problem-solving counselling and information about their condition, and how to access treatment. For the smaller proportion who meet criteria for a psychiatric diagnosis (e.g. Major Depression: 10%-12%), appropriate psychological and psychiatric treatment is indicated.

Providing psychosocial support to ART users

In the context of the national ART roll-out, many patients do not receive appropriate social, psychological, and instrumental support, even though these are necessary to enhance optimal adherence. In addition to mental health problems, numerous individual-level and structural-level factors account for poor adherence. Individual-level barriers include health literacy and the notion that medication adherence is necessary even in the absence of symptoms; social support, which is complicated in the context of widespread stigmatisation and discrimination; forgetfulness, which is exacerbated by psychological difficulties; suspiciousness of treatment; the side effects and complexities of the treatment regimen; and self-efficacy and motivation.²⁰ Structural barriers to adherence are more widespread and go beyond individual-level concerns. They include stigmatisation and lack of access to mental health and substance abuse services; nursing staff who experience overwork and burnout due to large patient numbers; and a lack of clinic infrastructure so that private and confidential counselling can be conducted.²¹ Coetzee et al found that often more than one patient was being counselled in the same room because of insufficient space, making it hard for them to speak about the difficulties they experienced in attending their appointments and adhering to their medication.¹⁹ These authors also found that relationships between patients and clinic nurses

were sometimes acrimonious. In many ways this is a systemic problem and must be seen in the context of very large patient numbers, dissatisfactory working conditions, and poor compensation, leading to staff burnout. The lack of access to mental health and substance abuse treatment is a major structural barrier to optimal ART adherence.

Potential solutions and ways forward

Psychosocial services including mental health care and health promotion interventions in the public health sector in Southern African counties are typically limited in scope and therefore require development. For example, integrating HIV care with other medical services, such as antenatal care and mental health services warrants attention.²² Improving networking between various kinds of service within the system and establishing effective referral trajectories for mental health care is another aspect needing attention. In addition, closer collaboration between mental health, substance abuse services and HIV care is necessary.

There are high costs associated with employing professional psychologists, counsellors, and social workers to provide a support system for ART users. Lay counsellors and patient advocates are a cost-effective alternative in helping to create a health-enabling community for ART users. Yet, the manner in which psychosocial support in general and counselling in particular has been traditionally conceptualised has been in the form of imparting information to patients rather than engaging in a relationship within which to influence behaviour. Indeed, it is usually the case that lay counsellors have been exposed to minimal counsellor training opportunities prior to their work as PA's. Specific, detailed, structured, and monitored training opportunities for lay counsellors and patient advocates are necessary, as is ongoing supervision to ensure that counselling is being provided according to acceptable evidence-based standards. Ideally, lay counsellors should be assessed following training using objective methods of ensuring fidelity to the counselling model adopted. Similarly, supervision should be provided regularly and in a structured format so that a uniform level of counselling quality and content may be achieved. Careful recruitment and selection procedures of counsellors are also necessary rather than accepting all comers, as everyone who volunteers for the position of lay counsellor may not be properly suited for the work, insofar as an empathic and process-oriented manner is concerned. As counselling also requires some higher-order conceptual thinking, those persons who are unable to engage at this level may also be unsuitable for such a role.

Conclusion

Mental health problems, including clinical disorders and clinically significant distress, form part of the experience of many persons living with HIV. Yet, the provision of psychosocial services to persons living with HIV in the public health system is complex. Mental health problems and difficulties regarding adherence are closely related to each other and each play an important role in the patient's health trajectory. Creative approaches to the provision of psychosocial services are required to address the mental health and other needs of persons living with HIV receiving care in the public health system.

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