

# **Mental health in the era of HIV**

Investigating mental distress, its determinants, conceptual models and the impact of  
HIV in Zambia

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*“To the loving memory of Mr Andrew “Ojuku” Mweemba, the epitome of a true educator, a family man and a loving grandfather.”*

## List of Publications

This thesis is based on the following papers

Paper I

Chipimo PJ, Fylkesnes K. **Mental distress in the general population in Zambia: impact of HIV and social factors.** *BMC Public Health.* 2009; **9**: 298.

Paper II

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Paper III

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Paper IV

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## **List of abbreviations**

AIDS- Acquired Immunodeficiency syndrome

AGFI: Adjusted Goodness of Fit Index

AMOS 7: Analysis of Moment Structures version 7.0

ARV: Anti-retroviral drugs

CD4: Cellular differentiation marker 4

CFI: Comparative Fit Index

DSM-IV- Diagnostic and Statistical Manual- IV

EM- Explanatory Models

GFI: Goodness of Fit Index

GHQ12- General Health Questionnaire-12

HAART: Highly Active Anti-retroviral Therapy

HIV: Human Immunodeficiency Virus

ICD-10: International Classification of Diseases-10

IDI: In-depth Interviews

MD- Mental distress

PHC- Primary health care

PLWHA: People living with HIV/AIDS

RMSEA: Root Mean Square Error of Approximation

SCL: Symptom Check List

SEM: Structural Equation Modeling

SRQ-20- Self-Reporting Questionnaire- 20

SRQ-10- Self-Reporting Questionnaire-10

SRQ-5- Self-Reporting Questionnaire-5

SRQ-20- Self-Reporting-Questionnaire 20



## **Abstract**

The world health organisation drew attention to the growing global burden of mental disorders. Current estimates comprised 12% of the Global Burden of Disease and estimated to rise to 15% by the year 2020 which would then make them the second leading cause of health disability in the world. This burden is thought to be worse in low income countries where poverty and other communicable diseases abounds. It is thought that in these regions, the poor are particularly vulnerable through a mechanism mediated by high intensity of social stressors, social marginalisation and the overwhelming burden of communicable and non-communicable diseases. Additionally, mental distress is known to interact and alter the course of many other diseases. Of particular interest to this thesis is its interaction with HIV. HIV is currently considered to be among the major cause of deaths in the most affected sub-Saharan countries. Here HIV infection is compounded by poor access to health services and high stigmatisation. Changes in socioeconomic transmission patterns are interesting in this regard. In the early stages of the epidemic HIV transmission appeared highest among the highest socioeconomic groups. However, this pattern changed dramatically over years, and HIV transmission rates are now highest among the low socio-economic position groups. Assuming that HIV has a negative impact on mental distress, it would suggest that the two disease entities are entangled in a self-perpetuating cycle of increasing morbidity where; poor mental health prevents people from engaging productively in their own lives and also might predispose them to risky sexual behaviour and substance abuse while in turn HIV increases the risk for poor mental health via its biological and psychological impact thereby impeding access to preventive, promotive and even curative health interventions.

This ushers in the need for routine screening for mental distress in general medical patients and especially among HIV-infected patients. However, due to inadequacies in medical

staffing, providing mental health services in Primary Health Care centres involves diagnosing and treating people with mental distress within the currently existing general framework of the available services and personnel. Therefore there is need for a valid screening instrument that is psychometrically sound and sufficiently short (less time consuming) and can be used without specialised training to achieve routine screening. Furthermore, it is imperative that explanatory models for mental distress are explored so as to compare them to those of health care providers as well as for purposes of examining how they are related to help-seeking, coping mechanisms and treatment preferences. This thesis examined all these factors in four scientific papers.

Paper I was based on a population based survey conducted in 2003 in selected urban and rural communities in Zambia which examined the prevalence of mental distress, its distribution patterns and the mechanism by which HIV impacts on mental distress. The HIV prevalence was 13.6% vs. 18% in the rural and urban populations, respectively. The prevalence of mental distress was substantially higher among women than men and among groups with low educational attainment. The structural equation model revealed that HIV infection had both direct and indirect impact on mental distress. Further, it showed that the indirect effects of self-rated health and self-perceived HIV risk and worry of being HIV infected were important mediators between socio-demographic factors, HIV infection and mental distress. In paper II and paper IV, the validation of different well established screening instruments was undertaken among a sample of primary health care clinic attendees in Lusaka, Zambia. This was aimed at assessing their face, content and criterion validity alongside determining the most commonly reported symptoms for mental distress. Results showed that all three instruments (Self-Reporting Questionnaire: SRQ-20, SRQ-10, SRQ-5) had acceptable sensitivity and specificity for identifying mental distress correctly. There were no differences noted by residence, age or gender and so there was no need to have different cut-off points for those

categories. The papers established the utility of the all three instruments as easy-to-use screening instruments for detecting probable cases of mental distress. The abbreviated instruments had an added advantage of being shorter and so less time consuming. In paper IV we aimed at identifying explanatory models employed by HIV-infected and uninfected individuals and to compare them with those employed by local health care providers. Furthermore, we aimed to build a theoretical model linking the perception of mental distress to treatment preferences and coping mechanisms. The results showed that mental distress was expressed primarily as somatic complaints and as autonomic symptoms. Economic difficulties and interpersonal relationship problems were identified as commonest causes of mental distress among the HIV-uninfected individuals. Among the HIV positive, the newly diagnosed HIV patients presented with the highest degree of hopelessness which was linked to poor help-seeking for their symptoms. Poor health seeking behavior was also seen among the HIV-infected patients who were not receiving anti-retroviral drugs (ARV). In contrast, patients already commenced on ARV were best adjusted to their status, expressed hope and valued counseling and support groups. Comparison of explanatory models for the patients and health care providers revealed that the conceptualization was somewhat different.

The findings in this thesis underscore the importance of validating screening instruments to fit the local context and thus to improve the epidemiological knowledgebase on mental health. They also advocate for the adoption and integration of the SRQ in the routine screening for mental distress in Primary health care, and especially in HIV-infected patients. The findings also reinforce the need for Health care providers to be sensitive to patients' explanatory models as they were critical to treatment-seeking decisions and coping.

## **Introduction**

### **Overview of epidemiology of HIV/AIDS**

We are in the third decade of the Human Immunodeficiency virus (HIV) pandemic. Since its identification in the 1980s, the transmission of HIV has intensified and now represents a major public health problem in a high number of countries and accounts for a major part of the global burden of disease. (1) According to the most recent global update, by the end of 2009, 33.3 million people worldwide were estimated to be living with HIV or AIDS. (2) Of these about 68% live in sub-Saharan Africa where the transmission has been high in the general population whereas mostly concentrated among particular population groups (injection drug users, sex workers and their clients, men who have sex with men) in other regions. The global incidence of HIV infections peaked in the late 1990s with greater than 3 million new infections per year and was estimated to be 2.6 million new infections in 2009. Among the new infections, 420,000 were children younger than 15 years. Deductively this means nearly 6,850 new HIV infections globally per day, alongside 2.1 million AIDS-related deaths. In sub-Saharan Africa the incidence is estimated to have peaked in the mid-1990s with 22 of the most serious epidemics showing clear signs of a declining incidence. (3) The transmission rates are still very high with an estimated 1.8 million new HIV infections and 22.5 million living with the virus in sub-Saharan Africa in 2009. The majority are unaware that they are infected. (4)

Although the largest epidemics in sub-Saharan Africa have shown signs of incidence decrease, the estimated 1.3 million HIV/AIDS related death in sub-Saharan Africa in 2009 comprised 72% of the total global deaths attributable to HIV/AIDS. (5) This sets HIV/AIDS as the leading cause of adult mortality in sub-Saharan Africa, and accounting for a large proportion of disability adjusted life years globally. (4, 6, 7) The spread of HIV in the initial

years was due to lack of concerted efforts in identifying and targeting preventive interventions in the face of scarce global resources. However, through the co-operation of the world community from around the year 2000 the resources mobilised for HIV interventions increased steeply which has resulted in, firstly, an improvement in the skills and intervention abilities on the needs to cope with HIV/AIDS worldwide. Secondly, through research efforts, community sensitization and mobilisation there has been an increase in the knowledge regarding risk factors for transmission of HIV as well as preventive measures, and incidence declines have been found to be associated with reductions in risk behaviours. (8-10) Knowledge of how HIV can be transmitted forms the basis for the different preventive approaches.

*Prevention of sexual transmission:* This is perhaps the most common mode of transmission. Prevention of this mode has been based mainly on provision of information and education to achieve behavioural change. School based programs have focused providing information about HIV, condom use, sticking to one sexual partner and delaying sexual debut. (11, 12) This has been done via radio programs, TV, brochures etc. and via peer education. Voluntary counselling and testing (VCT) is another widely used preventive measure and has received the most resources in sub-Saharan Africa. However VCT acceptability has been poor due to low trust in the privacy of patient information at the health care centres. (13) Condom promotion and wide distribution has been another mode used in preventing sexual transmission. Consistent and correct use of condoms has been associated with reduced sexual transmission by at least 90%. (14) There has also been a re-energised campaign program for screening and treatment of other sexually transmitted infections (STI). Primary health care facility personnel have been trained in syndromic management of STI via a carefully laid out set of algorithms. This has increased treatment seeking in the community and contributed to reduced incidence of HIV and STI co-infection. (15, 16) More recently the male circumcision

project has been rolled out in many countries. Male circumcision reduces HIV transmission in heterosexual intercourse by as much as 60%. It has also been associated with reduced self-reports of STI symptoms. (14, 17)

*Blood-borne transmission:* Routine screening of all donated blood and insistence on doing only necessary transfusion reduces or completely removes the risk of HIV infection. Health workers are also trained in infection prevention techniques which involve wearing gloves, masks and appropriate disposal of biomedical waste. This is coupled to post exposure prophylaxis after accidental occupational HIV exposure and in cases of sexual violence. (18, 19)

### **Virology, Immunology and their role in disease progression**

#### *Molecular virology of HIV*

Human immunodeficiency virus is a retrovirus. The term retrovirus refers to the ability of these viruses to reverse transcribe their ribonucleic acid (RNA) to deoxyribonucleic acid (DNA) during the replication purpose. The predominant type of HIV worldwide is type 1 (HIV-1) and is responsible for the global pandemic. HIV-1 is further divided into three subtypes based on sequence analysis of different regions of the genome.

- *Group M (major) Viruses:* this group is further divided into subtypes referred to alphabetically (clades A through K). These subtypes are unevenly distributed around the world with subtypes A, C and D being the most common in Africa and subtype B occurring in Europe and America. It is estimated that 90% of the HIV infection in Southern Africa are due to type C. Viruses with mosaic genomes which are made up of different subtypes (recombinant viruses), are becoming more common where

multiple subtypes are circulating e.g. CRF01\_AE mixture of type A and E and CRF02\_AG, a mixture of subtype A and G

- *Group O(outlier) viruses*: these are restricted to Central African region
- *Group N (non-M, non-O) viruses*: these are rare and have been identified only in a few individuals in Cameroon

HIV-2 has also been identified and likewise causes AIDS but is less pathogenic than HIV-1 and its occurrence in Africa is limited to West African countries with limited spread to other countries.(20, 21) Although it is still unclear whether the genetic diversity of HIV-1 has similar or different transmissibility potential, it is possible that these might explain some of the emerging HIV infection patterns. (22)

#### *Immune system and HIV-1 infection*

The immune system is a complex network of interrelated systems involving cells, cytokines and anatomical lymphoid structures that allow physical meeting points for dispersed T-cells. These meeting points focus all attention to antigens and their removal and once this is achieved the immune system quiets down and the host returns to the normal healthy state. However if these antigens are not removed the immune system remains in a state of hyper activation and could in the process “burn-out and degenerate. This “burn-out” is the hallmark of acquired immunodeficiency syndrome (AIDS). HIV-1 infection hence targets and leads to degeneration of the immune response. HIV infects all cells expressing, primarily CD4 and chemokine receptors, most commonly CCR5 and CXCR4 receptors in different types of cells in the body. Examples of cell expressing these receptors are CD4+ T-Lymphocyte cells, monocytes/ macrophages and microglial cells in the central nervous system.

Early in the process of HIV-1 infection, the CD4 count remains in the normal ranges and there is no clinical manifestation of the infection. However unimpeded viral replication leads to more CD4-T lymphocyte death until it overcomes the replacement capability of the CD4-T lymphocytes by the bone marrow. The normal CD4 cell count is between 700 and 1200 cells/mm<sup>3</sup>. When the CD4 cell count falls below 500cells/mm<sup>3</sup>, a clinically significant threshold would have been reached. With further decline in CD4 cell count, another landmark value of 200cells/mm<sup>3</sup> is reached at which AIDS is defined on a laboratory level, regardless of whether there are overt clinical symptoms. However at this severe immunologic stage there is increased risk of clinical disease and AIDS indicator disease commonly occurs. At a CD4 count below 50cells/mm<sup>3</sup>, severe immuno-suppression has set in which could rest in mortality within 6 months.

However the course of HIV-1 can be altered by current treatment for HIV infection which consists of highly active antiretroviral therapy, or HAART.(23) This has been available since 1996 and has been found to be highly beneficial to many HIV-infected individuals. (21-24)

HIV infection has been known to affect all other organ systems in the human body. Of particular interest to this thesis are the mental distress and neuropsychological presentations of HIV infection. HIV is said to have replaced syphilis as the “great imitator” in the central nervous system and almost any psychiatric or neurological presentation is possible. (25)



## **Overview of epidemiology of mental distress**

Mental disorders make a substantial independent contribution to the burden of disease worldwide. It is estimated that, neuropsychiatric conditions account for up to 15% of all disability-adjusted life-years, and up to 30% of those attributable to non-communicable diseases. Neuropsychiatric disorders also account for 1.2 million deaths every year. (26, 27) These figures are most likely underestimated as official statistics in low and middle income countries are scanty and unreliable. (27) In sub-Saharan Africa, it has been reported that 20–30% of primary health care centre attendees present with depressive symptoms as the first or secondary reason for seeking medical care. (28) A study conducted in Tanzania revealed a 41.6% prevalence of depressive symptoms among primary health care patients while a similar study in Uganda reported a 20–30% prevalence of psychological disorders and depression among health care seekers. (29, 30) These research findings have also shown heightened risk for common mental disorders among the women i.e. a female to male ratio of 1.5–2.0. Other determinants have been found to include low socioeconomic position indicated by poor access to resources, unemployment and low educational attainment. It has also been shown to be higher among those with poor socio-support networks such as the unmarried, widowed and divorced. (31-33) Mental disorders interact with many other health conditions, thus predicting the onset and progression of both physical and social disability. Several studies have established independent associations between mental disorders and an excess in all-cause mortality risk. In a meta-analysis, Saz and Dewey found pooled odds ratio of 1.7 for a diagnosis of depression and subsequent all-cause mortality. (34)

The recognition of mental health as a major contributor to the global burden of disease has led to an increase in the demand for the inclusion of mental health services in primary health care as well as in community-based health surveys in order to improve screening, diagnosis and treatment of mental distress. Several investigations have shown that mental distress is common among health care seekers at primary health care centres but are not often identified, treated or referred. (35)Over the years, there has been increased attention to ways to improve the screening, diagnosis and treatment of mental distress in these patients. In many developing countries, trained staff and specialized psychiatric facilities are few and limited to urbanized areas. (35)Therefore in these countries, quick and low-cost means that do not require specialized training for assessing mental distress are essential. The ideal instrument should therefore be relatively simple to administer, psychometrically sound and valid across cultures, age, sex, socio-economic and language background.

### **Measuring mental distress**

Measurement is of central importance to quantitative research in mental phenomena hence the importance of appropriate, accurate and unbiased instruments. Over the past 40 years, a wide variety of instruments have been developed to estimate mental distress in the population, identify high risk groups for mental disorders and monitor the changes over time. Most measurement strategies are based on eliciting symptoms, either by asking the respondent to complete a self-report questionnaire, or by using an interviewer to question a respondent. These instruments have been increasingly employed in clinical settings or health surveys. Some of these are long, detailed and comprehensive clinical diagnostic instruments while others are shorter or abbreviated instruments aimed at screening for probable cases of a trait or dimension of mental distress or indeed as a measure of an exposure to a possible risk factor for mental distress.

Among the most widely used self-administered tools are the Self Report Questionnaire (SRQ) and the General Health Questionnaire (GHQ). (36, 37) These questionnaires have been tested in multicentre studies and have been translated into many languages. They have also been compared with other standardized psychiatric assessment in community based surveys and in primary care studies in developing countries. (38, 39) In Chile, the SRQ-20 and the GHQ-12 were simultaneously validated against the criterion of the Revised Interview Schedule (CIS-R) in a primary care setting. The results showed small differences between the SRQ and GHQ though the SRQ was found to be slightly more specific than the GHQ (77% vs. 73%) but closely comparable with regards to sensitivity (76% vs 74%). (36) A similar study in Brazil revealed the Pearson correlation between the two scales to be 0.72, with the validity coefficients for SRQ and GHQ being: sensitivity 83% vs. 85% and specificity 80% vs. 79% respectively. This study concluded that both instruments showed similar results. (40) The relatively few studies conducted in Sub-Saharan Africa have shown similar results, for example, Bhagwanjee *et al.* showed an un-weighted sensitivity and specificity of 93.9% and 62.5% when the SRQ-20 was compared against the DSM-IV schedules for common mental disorders, while Reeler and Todd found sensitivity and specificity in the range of 80%. (41) Similar studies have been conducted among highly selected groups such as prenatal and postnatal women and in association with post-traumatic stress disorder in ex-combatants. (42)

## **Screening instrument**

### *General Health Questionnaire- 12 (GHQ-12)*

The General Health Questionnaire is a screening instrument designed for use in general practice but has been shown to be valid for use in community surveys as well. (43) It was originally a 60 item questionnaire but subsequently a number of abbreviated versions have been derived. Thus, there are the 30-, 28-, 20- and 12- item versions. All these versions have been subjected to many validity studies and the authors reported validity indices that suggest that these are widely acceptable tools for detecting psychiatric morbidity. The instrument contains 12 symptom questions which are scored on a four-point likert scale ranging (0-1-2-3) from much-less-than-usual to much-more-than-usual. However, in the analysis this scale is often collapsed to a dichotomous scale (0-0-1-1). Depending on the setting, community surveys or primary care, varied cut-off points have been used although cut-off point of 3+ is widely accepted as indicative of psychiatric morbidity. (44)

### *Self-Reporting Questionnaire-20 (SRQ-20)*

The Self reporting questionnaire (SRQ) was developed as part of a collaborative study coordinated by the WHO, on strategies for extending mental health care. Originally (SRQ-25) it consisted of 25 questions, 20 related to neurotic symptoms, 4 concerning psychosis and 1 asking about convulsions. The study started in 1975 with teams composed of psychiatrists, public health workers and others, in Colombia, India, Senegal and Sudan. (35) The teams were later extended to Brazil, Egypt and the Philippines. The committees strongly endorsed a policy of decentralisation and integration of services and addressed themselves to the urgent problem of adequate coverage of the populations advocating the provision of basic mental health care by primary health workers. (35) As a result the SRQ-20 is now a well-established responder-reported questionnaire for measuring mental distress. (45) It was primarily

developed for use in primary health care settings, especially in developing countries. It consists of 20 yes/no questions which assess the presence of mainly neurotic symptoms (anxiety, depression, psychosomatic). This is mainly because few patients with functional psychosis come spontaneously to primary health centers and so usually more active case finding by primary health workers in the community is required. Secondly, psychotic patients are often easily recognized as being psychotic and in most cases, are unaware of their condition. Hence, the use of a questionnaire to detect psychoses is questionable. The SRQ-20 has been tested in numerous settings. Depending on the setting, community surveys or primary care, varied cut-off points have been used although cut-off point of 7/8 is widely used. Table 2 shows the questionnaire items include in the SRQ-20.

### **Abbreviated Self-Reporting Questionnaires**

Most of these mental distress screening instruments were originally designed to be comprehensive scales covering all dimensions of the universe of psychological/psychiatric constructs. This renders them long and tedious. However, there is a need for abbreviated instruments in order to make for easy use in busy clinic setting as well as in settings where some patients are illiterate and requiring the questionnaire to be read out to them. Studies investigating the correlation, reliability, the sensitivity and specificity between the long versions and the abbreviated versions of the instruments have shown that the later are just as capable (or even better) of identifying psychological distress. (45-47) Good to excellent inter-rater agreement (Kappa coefficients) have been reported with abbreviated instruments and thus they have been judged to be acceptable and appropriate for use in different kinds of contexts. (35-38, 48) Overall these studies concluded that the subscales covering psychological distress functioned well and appeared to reflect a broad dimension of depression and anxiety disorders. The results also suggest that the shorter versions are valid

and perform almost as well as the full versions, if not better, implying that these tools can be used inter-changeably. (46, 47)

#### *Self-Reporting Questionnaire- 10 (SRQ-10)*

One such example of an abbreviated instrument is the SRQ-10. It is basically a sub-scale of the SRQ-20. The instrument contains 10 symptom questions which have dichotomous responses but do not probe to evaluate symptom severity. It has previously been used in Zambia in population based surveys in 1995 and 1999. The basics behind the construction of this scale bare common ground with the construction of other scales screening for common mental disorders. Even as it may not be the exact same scale, the symptom basis is the same.

For example, in their study to evaluate the internal validity of the subscales of the combined SCL-90, SCL-90R, the SCL-92, by item response analyses as compared with several previously reported factor analyses of this questionnaire in literature, Olsen et al (45) found all neurotic scales to be robust and acceptable. They found a few minor problems for the phobic anxiety and obsessive- compulsion disorders. They concluded that the subscales covering psychological distress functioned well and appeared to reflect a broad dimension of depression and anxiety disorders. Similarly, Strand et al (46) undertook a comparison study of the SCL-25, SCL-10, SCL-5 and the MHI-5 among the Norwegian population. They aimed at investigating the correlation between the instruments and to compare and assess the psychometric characteristics of the instruments. They found that the correlation between the various versions of the SCL was between 0.91 and 0.97 while the correlation between the SCL and the MHI-5 ranged from -0.76 to -0.78. These results suggest that the shorter versions of the SCL are valid and perform almost as well as the full versions.

Selection of an appropriate measure is essential to the study design. With this plethora of instruments, selecting an instrument to use could be challenging. Generally speaking, it is not necessary to develop a new measure for each study as it is highly likely that an applicable one has already been developed. However, care must be taken in the adaptations of instruments from one setting to another. The importance of validation of instruments should not be taken lightly as seemingly simple or trivial single questionnaire items may be very sensitive to phrasing or presentation. (49, 50)

### **Validation of instruments**

Validity refers to what extent to which an instrument measures that which it is set out to measure or the degree to which a study accurately reflects or assesses the specific concept that the researcher is attempting to measure. (51) Researchers are concerned with both *external* and *internal* validity. External validity refers to the extent to which the results of a study are generalizable or transferable. Internal validity on the other hand refers to both the rigor with which the study was conducted, i.e. the study's design and the extent to which alternative explanations for any causal relationships are explored. Studies that are not focussed on causal inference concern themselves mostly with the former definition of internal validity. Scholars discuss several types of internal validity.

- *Face validity*: Face validity does not depend on established theories for support but rather is concerned with how a measure or procedure appears. It seeks to answer the following questions: 1. Does it seem like a reasonable way to gain the information the researchers are attempting to obtain? 2. Does it seem well designed? 3. Does it seem as though it will work reliably? Face validity can be assessed in two ways. The first is a validation-by-assumption which is based on a review by a panel of experts. (35, 51)

The second is by asking the study participants themselves what they think the instrument is supposed to measure. (49)

- *Content validity*: Consists of a determination of whether the instrument captures all the relevant concepts and if it is representative of the battery of questions that could have been asked for individuals under study. It is closely related to face validity since it also requires validation-by-assumption by a panel of experts. (35) However content validity can also be assessed by subjective judgment based on a review of the various questionnaire items by the study respondents themselves. (35) For example, the respondents can be asked to interpret each of their responses to the questionnaire items. Additionally they can be asked to give as many examples as possible to support their answer. Answers to these probing questions can then be used as a basis to ascertain whether the responses had the same meaning for the respondent as it did for the investigator. (49)
- *Criterion validity*: also referred to as instrumental validity, is used to demonstrate the accuracy of a measure or procedure by comparing it with another measure or procedure which has been demonstrated to be valid. This entails, for example comparing a screening instrument with a previously widely validated instrument (Gold standard). The common approaches for comparison include using validity indices like sensitivity and specificity, Relative Operating Characteristics (ROC) and predictive values. (51)



**Table 1: 2x2 Decision matrix**

| Screening instrument results  | Truth (criterion instrument results) |                    |       |
|-------------------------------|--------------------------------------|--------------------|-------|
|                               | Disorder present                     | Disorder absent    | Total |
| Positive(above cut-off point) | A (True positives)                   | B(False positives) | A+B   |
| Negative(below cut-off point) | C(False negatives)                   | D(True negatives)  | C+D   |
| Total                         | A+C                                  | B+D                |       |

**Table 2: Validity coefficients**

|   |
|---|
| <p><u>Prevalence independent indices of validity</u></p> <p>Sensitivity = <math>A / (A+C)</math></p> <p>Specificity = <math>D / (B+D)</math></p> <p><u>Prevalence dependent indices of validity</u></p> <p>Positive Predictive Value (PPV) = <math>A / (A+B)</math></p> <p>Negative Predictive Value (NPV) = <math>D / (C+D)</math></p> <ul style="list-style-type: none"><li>• Overall Misclassification Rate (OMR) = <math>(B+D) / (A+B+C+D)</math></li></ul> |
|---|

## **Significance of mental distress**

### **Interaction with other medical conditions**

Mental distress and especially depression commonly affects individuals with medical conditions and has been associated with adverse impacts on several measures of morbidity and mortality. Typically a third of all somatic symptoms remain unexplained, both in the general population and in primary health care centers. (49, 52) Most of these symptoms represent syndromes that are suggestive and strongly associated with common mental disorders. Somatization is independently associated with poor health-related quality of life and increased utilization of health services, after controlling for co-morbid mental disorders. (53) Further, depressed patients have been shown to have "worse physical, social, and role health than other patients. Clinically based follow-up studies have shown that depression is associated with excess mortality from unnatural causes, such as suicide and accidental death. (49, 52)

### **Interaction with non-communicable diseases**

Non-communicable diseases are a global challenge and are the leading cause of death in all the world regions, other than sub-Saharan Africa, accounting for 80% of deaths in low and middle income countries. (54) Evidence from population based research has reported strong association between depression and some non-communicable diseases. Two mechanisms have been postulated to explain this interaction.

- One mechanism linking mental distress to non-communicable is its association to risk factors for non-communicable diseases such as poor diet, obesity and smoking.
- The other mechanism is based on the biological effects on serotonin metabolism (55) which leads to alteration of cardiac function, platelet aggregation and vasoconstriction. The additional effect on cortisol metabolism (56) leads to inflammation, excessive clotting and the metabolic syndrome. This predicts onset and course of cardiovascular disease.

#### *Cardiovascular disease*

Common mental disorders, especially depression and anxiety, have been identified as a common risk factor for heart disease and appear to be related to future complications and recovery from fatal and non-fatal strokes. These findings are largely independent of time (57) and risk factors for cardiovascular disease. (58) Literature has shown a 1.5- to 2-fold increased risk of cardiovascular disease, independent of other known risk factors. People with major depression are less likely to follow medical recommendations for treating cardiovascular disorders, which further increases their risk. In addition, cardiologists may not recognize underlying depression that complicates a cardiovascular problem under their care. (59) Depression is related to a number of heart related factors that can complicate and interfere with the patient's adaptation to and recovery heart disease of all kinds. (60)

It is linked directly or indirectly to risk factors related to lifestyles that contribute to heart disease such as poor diet, lack of exercise, excessive alcohol or other drug use, and social isolation. (61, 62) Finally depression has also been found to make recovery harder for patients. (60)

#### *Neoplastic disease*

Common mental disorders and cancer commonly co-occur. The prevalence of mental distress among cancer patients increases with disease severity with symptoms such as sleeplessness, pain and fatigue. (63) Though literature on mental distress as a predictor of cancer incidence is mixed, divided but stronger evidence predicts increased cancer progression and mortality. However disentangling the effects of disease progression on mood complicates this research, as does the fact that some symptoms of cancer and its treatment mimic depression. There is evidence that providing psychosocial support reduces depression, anxiety, and pain, and may increase survival time of cancer, although studies in this latter area are also divided. (63)

#### *Endocrine disease*

An association between mental disorders and certain endocrine disease has been reported. Population cohort studies have suggested an increase in risk and onset of diabetes in individuals with mental disorder. (64) Depression, for example, has been linked to risk of onset of type 2 diabetes independent of demographic, metabolic and life style factors. (65) However data to this effect is divided with some studies reporting contrary results. (66) These studies have suggested that the prospective associations might be explained by undetected diabetes leading to depression or by help-seeking for depression leading to a diagnosis of diabetes. The evidence for the co-morbidity between endocrine diseases, especially diabetes, and mental distress is much stronger. A meta-analysis of the association between depression and diabetes revealed an odds ratio between the two conditions of 2.0

(95% CI 1.8-2.2). This odds ratio was independent of type of diabetes, method of assessment and study design. (67) Another study showed evidence of benefits of psychological intervention in type 1 and 2 diabetic patients which lead to improved diabetic control. (68, 69)

### **Interaction with Communicable diseases**

There have been four postulated mechanisms linking mental distress to greater morbidity and mortality from communicable diseases.

- One such mechanism has been through an effect on the cell mediated immunity, where it causes impairments in T-cell mediated functions, reduced natural-killer cell counts and cytotoxicity. This has particular relevance to infectious diseases. Depression has reproducibly been associated with decreased numbers and altered functioning of natural killer lymphocytes. (20, 70) This has been said to mediate course of infectious diseases such as Tuberculosis, HIV and Malaria.
- Some disease processes directly affect the brain with the resulting effect being dependent on the site and extent of the brain damage. Hence the effects would range from minor mood changes, behavior changes to overt mental disorder symptoms. Examples include both non-communicable ( cardiovascular diseases) and communicable diseases (Tuberculosis, HIV and Malaria)
- Chronic diseases generally cause psychological arising from the acute effects of learning of the diagnosis, maladjustment to the disease, long-term treatment regimes, stigma and breakdown of social relationships. Further the resulting disability potentiates the risk of mental distress. Examples include both communicable and non-communicable disease processes.
- Co-morbid mental distress can delay health seeking hence reducing the likelihood of diagnosis and so can affect treatment and outcome of other health conditions. They

may also adversely affect adherence to medication and activities to prevent disease and promote health. Examples include both communicable and non-communicable disease processes.

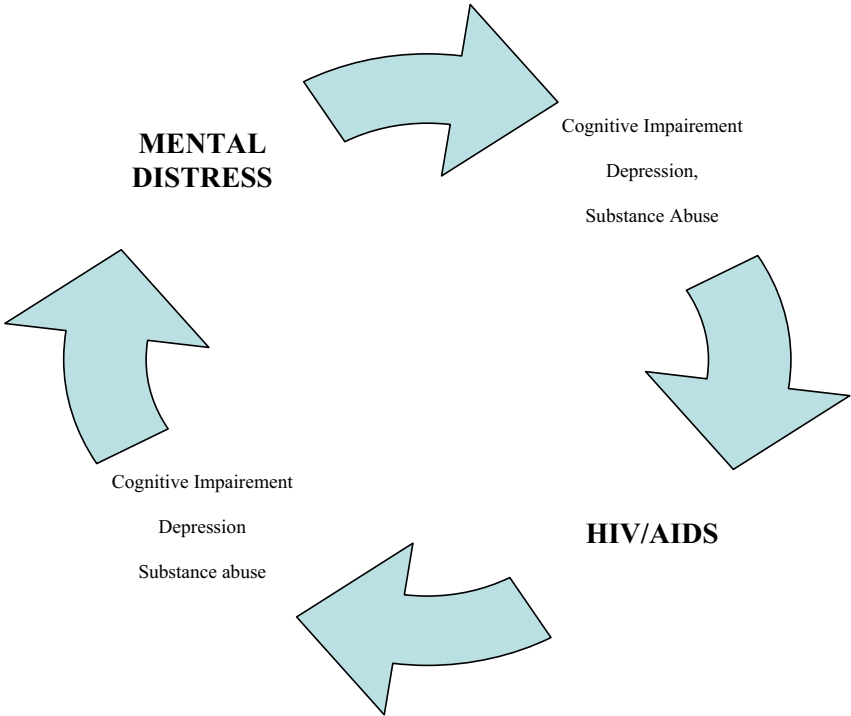
### **Mental distress and HIV/AIDS co-morbidity**

Human immunodeficiency virus (HIV) infection has become a psychiatric epidemic as it both causes and exacerbates mental disorders. (71) In the early stages of the HIV epidemic, the individuals who were affected did not know that their behaviour predisposed them to a potentially fatal disease. The epidemic also mushroomed at the time of a liberal and tolerant culture and dis-inhibited sexual restraint. Hence intravenous drug abuse and multiple sexual partners spread the epidemic in communities where these behaviours were more rampant. (71) Later in the epidemic these risk factors were elucidated and more concerted effort was placed on public education directed at prevention. Since then mental disorders have been recognised as crucial factors to some individual's ability to modify their behaviour to prevent HIV infection. (71) However with effective treatment options now available, care for HIV has become more dynamic and has transformed from terminal care to chronic care. Now mental disorders have been recognised as severely complicating treatment. As shown in figure 1, these factors work in tandem. HIV causes direct damage on the brain creating turmoil in the lives of the infected and further exacerbates mental disorders. Further the mental disorders reduce the individual's ability to effectively change behaviour thus increasing the risk of infection and morbidity. (71)

Published literature showing that individuals with pre-existing mental disorders are at increased risk for contracting HIV/AIDS has been largely indirect. However consistent reports from several countries have suggested that individuals with mental disorders have a higher sero-prevalence for HIV/AIDS and that mental distress generally precedes HIV

infection. (72) This is valid given that significant risk of HIV transmission exists within an individual's network. Frequencies of 30-60% behavioural risk factors that have been identified among individuals with mental distress include: high rates of unprotected sexual contact, poor adherence to condom use and injection-drug abuse. (73) In a study conducted among gay men with depressive symptoms, use of alcohol and drugs before sex were identified as independent predictors for sero-conversion. (73, 74) In a systematic review comparing an HIV sero-positive group and HIV sero-negative control group, the prevalence of depression in the sero-positive group was two times higher than in the sero-negative (OR 2.0, 95% CI 1.3-3.0). (75)

*Figure 1: Self-perpetuating cycle of increasing morbidity: mental distress and HIV/AIDS*



Evidence from Low and middle income countries is limited and less clear. Most of the studies done in Africa with HIV positive participants have shown differing but high percentages of mental distress, for example, Orange free state, South Africa 40% (76), rural Ethiopia 14% (48) and Botswana 28%. (77)A meta-analytic study identified 13 studies on mental disorders and HIV infection in low and middle income countries. The prevalence of mental disorders varied widely among these studies. However the studies revealed that depression was higher among symptomatic HIV patients as compared to either, non-symptomatic cases and the sero-negative control groups. (78, 79)

### **HIV and mental distress in Zambia**

Zambia has one of the world's most devastating HIV and AIDS epidemics. More than one in every seven adults in the country is living with HIV (2)and life expectancy at birth has fallen to just 39 years. (80)In 2009, nearly 76,000 adults were newly infected with HIV that is about 200 new infections each day. (2)The index case for HIV in Zambia was first report in 1984 and surveys conducted the following year revealed 8% prevalence in antenatal mothers, 18.4% among blood donors and 19% among health care workers. (81, 82)It became apparent then that Zambia was experiencing a serious epidemic already and so within two years the National AIDS Surveillance Committee (NASC) and National AIDS Prevention and Control Program (NAPCP) were established to coordinate HIV/AIDS-related activities.

A comprehensive national surveillance system among antenatal clinic attendees were established in 1994 and the first results revealed an adult HIV prevalence of 28.5% and 12.5% in urban and rural areas respectively. Subsequent population-based surveys in 1995 and later have shown prevalence levels very similar to those from the antenatal surveillance system. (8)Follow-up surveys in the general population in 1999 and 2003 reported a downward trend among young people aged 16-24 years in both rural and urban areas in both males and



females. (urban 6.9% to 3.2% (men), 22.5% to 12.5% (women) vs. rural 5.7% to 3.2% (men), 16.1% to 6.8% (women). (9, 83) Similar declines have later been observed in the national surveillance system. (2, 8) The main mode of transmission is through heterosexual intercourse and through mother to child transmission. The epidemic affects more but not limited to urban inhabitants, the women, poorly educated and those with poor social and economic status.

In Zambia, little is known about the extent of mental distress. However evidence shows that Zambia has a mental distress prevalence of 13.5% with depression being its most common form of presentation. (49, 84) Literature concerning specific definitions and the perception of mental distress is also limited, as mental health is generally not prioritized in terms of service provision. (85) However, rates of mental and emotional illness are thought to be increasing in Zambia owing to socio-economic difficulties that precipitate mental problems including HIV/AIDS, poverty and lack of employment. (36, 49, 84, 86) Mental illness is generally viewed from two broad perspectives, community and cultural. (85) The community view perceives good mental health or “a sound mind” as the ability to execute roles and responsibilities expected within a given social and cultural context. In contrast, mental illness, whether mild or severe, is associated with disruptive behavior, straitjackets, and mental institutions. (85, 87) In Zambia, cultural beliefs concerning the cause of mental illness centre on possession by spirits or social punishment; many hold the belief that mental illness is caused by witchcraft and therefore cannot be treated by modern medicine but only through traditional means. A lack of proper information and the dominance of misleading presentation have led to a negative portrayal of mental illness, and sufferers are collectively and unjustifiably categorized and rejected, regardless of the form of mental illness. (85)

Such categorization often leads to mistreatment and isolation of mentally ill individuals. A qualitative study in Zambia revealed that mental health patients utilizing health services felt stigmatized and discriminated against, and a further study investigating the quality of life of women suffering from mental illness revealed similar results. (86)The stigma attached to mental illness caused both community and health decision-makers to view sufferers with low regard, leading to stigmatization of families across generations, institutions that provide treatment, psychotropic drugs and mental health workers. (88)Such attitudes are an obstacle to the provision of care as they result in a reluctance to invest resources into mental health care and discrimination in the provision of services for physical illness among those who are mentally ill. The studies outlined above concluded that mental illness is a complex and diverse disorder, and that there is need to employ a multi-dimensional approach for the diagnosis and management of mental illness in public health institutions.

## **Rationale**

Zambia is now in the second decade of the HIV epidemic. It is safe to say that that HIV is now a mature infection in Zambia in the sense that surveillance committees in the form of the National AIDS prevention and control program and the National AIDS surveillance committee are well established. In addition to these are countless non-governmental organizations all of which are involved in establishing, co-coordinating and monitoring HIV/AIDS activities in the country. Through these efforts a number of prevention approaches have been established:

*Supply of safe blood:* Blood and blood products supply has now been centralized to ensure closely monitored routine screening of donated blood and avoidance of unnecessary transfusion.

*Infection prevention routines:* Country wide trainings have now been done among health care workers. This has a two-fold aim, one of preventing infection from the patient to the health worker and vice versa. This involves treating all bodily fluids as potentially infectious, wearing of gloves and appropriate disposal of waste.

*Post-exposure prophylaxis:* This involves provision of anti-retroviral drugs after accidental needle prick injuries and to sexual assault victims.

*Provision of information:* Mass provision of information to prevent sexually transmission is provided via the media. These include condom promotion, distribution and information on use, screening and treatment of sexually transmitted diseases, male circumcision, peer-education and voluntary counseling and testing.

*Provision of antiretroviral drugs:* A continuum of care has now been established via provision of ART. This has now been rolled out to cover most parts of Zambia in the hope of increasing the number of HIV infected individuals on these life sustaining drugs.

However as far as mental distress is concerned, Zambia lags behind. Mental health services are not prioritized due to the overwhelming impact of communicable disease. Zambia is also plagued with few mental health institutions and mental health workers. Hence the prevalence of mental distress is largely uninvestigated. However evidence from both population-based surveys and primary health care studies now shows that the prevalence of mental distress is high. Further Despite the known benefits, the practice of screening for mental distress as it relates to HIV infection is still low in Zambia. It has been shown that physicians are often oblivious to mental distress in the presence of physical illness. Considering that Zambia has a high prevalence of HIV and assuming that HIV infection negatively affects mental health, this would suggest that the mental distress problem is substantial.

This is thesis represents the first effort at investigating mental distress and HIV co-morbidity in Zambia

### **Thesis Focus**

The focus of this thesis is to describe the distribution and key determinants of mental distress in Zambia and to elucidate how HIV impacts on mental distress. The thesis describes methods of measuring mental distress and presents two validated screening instruments for use in primary health care and population-based surveys (paper II and paper IV). In discussing the impact of HIV on mental distress this thesis builds a structural equation model as it operationalizes how proximate determinants relate to socio-demographic factors and HIV in determining prevalence of mental distress. (paper 1) Further the thesis develops explanatory models for mental distress among the HIV infected and uninfected individuals and discusses how this impact on help-seeking, coping strategies and uptake of treatment services. (paper III)

## **Aims and Objectives**

### **Overall objective**

The aim of the study is to contribute towards improved care of HIV patients by generating information on the impact of HIV on mental distress its distribution and determinants.

### **Specific Objectives**

1. To validate the SRQ-20 as a screening instrument for mental distress in Zambia and to compare its performance with the GHQ-12 using the DSM-IV as the gold standard. (paper II)
2. To validate the performance of an abbreviated instrument for mental distress by investigating the correlation, sensitivity and specificity using the SRQ-20, GHQ-12 as concurrent criteria for each other against the DSM-IV as the gold standard. (paper II & IV)
3. To examine the prevalence of mental distress, its distribution patterns and the ways HIV might influence mental health among men and women in a general population. (paper I)
4. To examine the significance of explanatory models for mental distress among HIV infected and uninfected individuals and how these maybe related to help-seeking, coping mechanisms and treatment preferences. (paper III)

## **Methods**

### **Study area and population**

Zambia is a landlocked country with 9 provinces and 72 districts and is located in the southern part of Africa. Covering an area of 752, 614 km<sup>2</sup> with a population of approximately 13 million people. Zambia is one of the most urbanized countries in Africa with around half of the population concentrated in urban areas. The capital city Lusaka has a population of approximately 3 million people and a density of 44, 285.7 / km<sup>2</sup>. The annual population growth is about 2% and about 51% of the population is below 15 years of age. 64% of the population lives below the poverty line. The adult literacy rate is approximately 75%, this being higher in urban (66%) than in the rural (37%) districts. Zambia's economy is largely dependent on copper mining and farming. The mining sector accounts for 80% of the country's earnings, the remaining 20% being shared between commercial and subsistence farming. The gross domestic product for Zambia is estimated at \$320. The economic growth remains slow and was the lowest in the Southern region of Africa. Health care in Zambia is provided by government institutions, religious missions, industries and other parastatal companies, private clinics, armed forces and traditional healers. The government has been the principal health care provider through its network of health care centres and hospitals. The religious organisations provide 30% of the total hospital beds mainly in the rural districts and in some general hospitals. The number of hospitals in Zambia have remained constant at 83, but the number of health centres has continued to increase reflecting the policy of increasing the rural population's access to basic health care services.

The papers in this study stem from studies conducted both in general population (paper I) and in the primary health centres (paper, II, III & IV) in selected districts.

## **Design, sampling and data collection**

The papers in this thesis are based on the following data materials:

1. Paper I: Population-based survey data from Kapiri Mposhi (central province) and Chelston (Lusaka province) in 2003
2. Paper II & IV: Validation of screening instruments for mental distress in Zambia. Cross-sectional study in selected primary health care centres in Lusaka district in 2010.
3. Paper III: Cohort study to measure mental health changes over time in HIV infected individuals, conducted in selected primary health centres in Lusaka district in 2010.

### **Population-based survey design**

In paper I in which we examined the prevalence of mental distress, its distribution patterns and the ways HIV might influence mental health among men and women in a general population; we used data from a selected rural community, Kapiri Mposhi district, and an urban community, Chelston in Lusaka. The population-based surveys have been conducted in Zambia every third year since 1996 as a way of documenting the dynamics of the HIV epidemic. The surveys were conducted initially (1996) among the urban and rural population of Kapiri Mposhi and in a medium density urban residential area of Lusaka (Chelston). The later was selected to represent urban areas of Zambia. However the subsequent surveys did not include urban Kapiri Mposhi as it did not represent a typical urban area in Zambia.

(89)Stratified random-cluster sampling method was used by employing the mapping systems already established by the Central statistics office. This divides the country into Census Standard Area (C.S.A) and further subdivides these clusters into Standard Enumeration Areas (SEA). Each CSA contains on average three SEA's. Probability proportional to size (PPS)

was used to select clusters for the surveys. We used data collected in the 2003 population-based HIV survey. All residents aged 15 years and above in the selected clusters were asked to participate in an interview and to provide a saliva sample for HIV testing. (83, 89)The data were collected at the household level by trained enumerators using (i) a structured questionnaire administered in an interview with the head of the household for purposes of listing household members above 14 years and (ii) a structured questionnaire administered in personal interviews. Saliva samples, for saliva-based HIV testing were also collected from each respondent after the interview. The data collection tools were initially tested in a pilot study of 20 households. The questionnaire collected information on socio-demographics, health-status, and health seeking behavior, sexual behavior/condom use, stigma, knowledge attitudes and perceptions regarding HIV/AIDS from both sexes. The questionnaire also assessed respondents on mental distress.

Information on Mental distress was collected using the Self reporting questionnaire-10 (SRQ-10). The battery of questions was as follows; In the past 30 days:

1. Do you sleep badly?
2. Do you cry more than usual?
3. Do you find it difficult to enjoy your daily activities?
4. Do you find it difficult to make decisions?
5. Is your daily life suffering?
6. Are you unable to play a useful part in life?
7. Has the thought of ending your life been on your mind?



8. Do you feel tired all the time?

9. Do you often have headaches?

10. Is your digestion poor?

Saliva samples were collected based on an anonymous linked HIV testing protocol. BIONOR HIV 1&2 (BIONOR AS, Skein, Norway) paramagnetic particle assay was used as the first line test. The reactive samples were subsequently tested again using a rapid test (Capillus HIV-1/HIV-2, Cambridge Biotechnology). Sample with discrepant results were sent for a confirmatory Western blot. Respondents expressing the wish to know their HIV status were also tested using blood serum, as per Zambian national policy guidelines for HIV testing.

### **Facility-based study design**

#### **Validation of screening instruments for mental distress**

In paper II & IV we aimed at validating the performance of an abbreviated instrument for mental distress by investigating the correlation, sensitivity and specificity using the SRQ-20, GHQ-12 as concurrent criteria for each other against the DSM-IV as the gold standard. A concurrent nested mixed method research design was used. We assessed attendees at four primary health care centers run by the government of the republic of Zambia between December 2008 and May 2009. These clinics were purposely selected within the city of Lusaka, two of which were clinics in very high density areas (Kalingalinga and Mtendere) while the others were clinics in a medium density area (Chilenje and Chelston). The residents of these areas speak a number of languages but mainly English and Nyanja. A pilot study was first conducted at Kabwata clinic (outside the study sites). Forty-five outpatients were interviewed and based on the results it was decided that the questionnaire would be read to all

the participants irrespective of their education level. A time sample of 400 clinic attendees aged 16 years and over was asked to participate in the study between January and March 2009. The purpose of the study was explained to each participant by the research assistants and consent was asked for. Each clinic was sampled randomly on selected days, 3 times each week. On the selected day, interviews were conducted with consecutive clinic attendees at the clinic outpatients department.

A brief social and demographic questionnaire was administered to all the participants by research assistants who had received training in carrying out interviews. The interviews lasted approximately 10 minutes. Information on participant's demographic characteristics, including age, gender, educational attainment, residence and marital status, was collected using standard questionnaire items. The participants were also asked in what language they wanted the interview to be carried out. Socioeconomic position was assessed using the participant's educational attainment, employment status and an asset index based on items intended to reflect household wealth. The participants were also asked how they rated their own current health status. The recent life events were evaluated by events occurring in the previous 12 months based on whether the participant had experienced; Break-up of a marriage; Break-up of a sexual relationship; Physical abuse; Neglected or disowned by family or loss of a loved one. The SRQ-20 and the GHQ-12 were used to measure global mental distress. These interviews were conducted by interviewers of the same sex as the participant. The participants were then classified into two groups according to their scores on the SRQ-20 (low, 0-7; high 8+) and GHQ-12 (low, 0-3; high, 4+). Subsequently these participants were directed to a medical officer who held a clinical interview with them for the ailments that brought them to the clinic as well as conducting a psychiatric inquiry where the DSM-IV schedules for common mental disorders was used to determine the presence and diagnosis of a psychiatric disorder. The general health assessment and the mental distress assessment were

done at the same time so that the patients were not delayed due to the study. The clinical interview was conducted blind, without the knowledge of the questionnaire results. In the second part of the study, in-depth interviews were conducted in a subsample of 28 participants nested within the quantitative sample. The sample consisted of participants who were classified as being high scorers (14 participants) and low scorers (14 participants), on the basis of the SRQ-20 score  $>7$  and GHQ-12 score  $>3$ . These interviews were used to assess face and content validity. All the instruments were translated into Nyanja and Bemba as these are the most predominantly spoken languages in Lusaka. The results from the pilot study also confirmed that participants who did not speak English opted to be interviewed in Nyanja or Bemba. These instruments were then back translated to English by bilingual translators from the linguistics department of the University of Zambia. Discrepancies that were found were discussed further by a group that included the principle investigator, translators and a medical doctor from the psychiatric hospital. This was to ensure face validity as well as conceptual meaning. Few final changes were made after the pilot study. A team of three male and three female interviewers who had no experience in mental health care administered the SRQ-20 and the GHQ-12. They, however, all had previous experience administering questionnaires in other epidemiological studies. A three day training session was conducted in administering the instruments. This involved explanation and discussion of conceptual definitions of each item in the instruments and role playing. This was followed by a 1 day field test.

In paper IV we evaluated the screening characteristics of a 5 item self-reporting questionnaire. The selection of the questionnaire items was 2 fold; firstly based on the results from the validation study (paper II) and secondly on consultations with a panel of psychiatrists and general practitioners.

Based on the results from paper II the following 5-items were selected as being the best-subset of questions that were best understood by the participants:

1. Do you sleep badly?
2. Do you often have headaches?
3. Do you find it difficult to enjoy daily activities?
4. Are you able to play a useful part in life? I
5. Is your daily life suffering?

This means that these questions were understood by the participants in a manner that was similar to the psychopathology the interviewers meant to unearth. Secondly, three independent psychiatrists with at least three years' experience working in a psychiatric institution in Zambia and three general medical officers, with similar experience, working in primary health care setting, were asked to choose 5-items from the SRQ-10 which they regarded as being the most important indicators for mental distress. After this they were further asked to select another set of 2 questions from the remaining 5 items. It was unanimously agreed among all the medical practitioners that Item 7 (suicidal ideation, for 1 month duration) on its own was a sign of major depression and that presence of this item alone even in the absence of the other items constituted severe mental distress.

### **Explanatory models for mental distress among HIV infected and uninfected individuals.**

Paper III examined the significance of explanatory models for mental distress among HIV infected and uninfected individuals and how these maybe related to help-seeking, coping mechanisms and treatment preferences. This study was conducted as a sub-study of the above described validation study as well as part of a cohort study which followed up for groups of participants namely: HIV negative, HIV positive on anti-retroviral therapy and HIV positive but not on anti-retroviral therapy. This cohort study had the following aimed at; a) assessing the psychopathology in HIV sero-positive and sero-negative subjects over time b) assessing direct impact of HIV on mental distress by using biological markers and c) assessing sexual risk behavioral changes in subjects on Anti-retroviral therapy over time.

To fulfill the aims of the explanatory models for the mental distress study, a sample of 28 informants was taken from the validation study. This sample consisted of 14 informants who were HIV negative and 14 who were HIV positive. Of the 14 informants who were HIV-infected, eight were not eligible for ARVs and the remainder had been taking ARVs for varying durations. An effort was made to balance the gender and age distribution across these categories. Household in-depth interviews were conducted to gather additional and detailed data concerning the explanatory model for mental distress in Zambia. Eight eligible health professionals working in a mental institution were interviewed at their respective public health facilities. Three identified indigenous healers who reported treating mentally distressed people were interviewed. Data were collected using a semi-structured questionnaire and serial in-depth interviews. The questionnaire contained a section comprising questions pertaining to socio-demographic factors such as sex, age, marital status and number of children, education, employment, religion and questions assessing socio-economic position. The other section contained questions concerning mental health. This information was extracted from the

database of the main Validity study. Eligibility for participation was based on the participant's HIV status and being mentally distressed, as determined using a locally validated Self-Reporting-Questionnaire-10 (SRQ-10). Informants classed as mental distress cases underwent further qualitative interviews to elicit the explanatory models. A modified, adapted and contextualized interview schedule developed by Kleinman was used to elicit the explanatory models for mental distress. The battery of questions included the following:

1. What do you call your problem? What name does it have?
2. What do you think caused the problem?
3. Why do you think it started when it did?
4. What does your sickness do to you? How does it work?
5. How severe is it? Will it have a short or long course?
6. What do you fear most about your illness?
7. What are the chief problems your sickness has caused for you?
8. What kind of treatment do you think you should receive? What are the most important results you hope to receive from the treatment

To compare the explanatory models, this interview schedule was administered to all groups in the study (HIV negative individuals, HIV positive individuals and health care practitioners). The interviews with health care practitioners were conducted in English and designed to draw upon their experience of attending to patients and eliciting explanations for the causes of mental distress in the study population profile.

## **Data analysis**

We used SPSS version 15 when analyzing paper I and we adjusted for cluster design alongside carrying out descriptive statistics. We also used Analysis of Moment Structures (AMOS) version 7.0 (90) in the Structural Equation Modelling (SEM) to confirm the theoretical built model that included the underlying factors (demographic and socioeconomic), intermediate factors (self-rated health and HIV risk and worry), HIV status, knowledge of own HIV status and consequently mental distress. We also used SPSS version 15 in paper II and IV to carry out descriptive statistics, Receiver Operating Characteristic (ROC) analysis and in calculating the Area Under the Curve (AUC) for overall accuracy of the screening instruments. In paper III we also used SPSS version 15 for descriptive analysis. In both paper 11 and paper IV content analysis was used to analyse the qualitative components of the papers.

## **Ethical consideration**

The population based survey protocol received clearance from the National AIDS Research council and from the University of Zambia Research Ethics Committee (IRB00001131 of G0000774). Additionally, participation in the survey was based on written informed consent. Participants were counselled and informed that the information obtained was purely anonymous and for research purposes. Participants interested in knowing their HIV status were offered voluntary counselling and testing at home. The HIV testing algorithm used in the population-based surveys complied with both Zambian National protocols and WHO/UNAIDS guidelines for such surveys. The validation study and the cohort study both received approval from the Research and Bioethics Committee of the University of Zambia and the Ministry of Health, through the Lusaka District Health Office. Permission to conduct the study was also further sought from the authorities in charge of the Primary Health Centres.

The study was conducted in accordance with the guidelines of Good Clinical Practices in biomedical research.

## **Results**

### **Participation and distribution**

The response rate in the population-based surveys was 72.3%. The most frequent causes of non-participation were absence (19.8%), interview refusal (3.4%), or refusal to give a saliva sample for HIV testing (6.6%). The most important cause of absence was, away on fishing trip, at school, in hospital or travelled out for temporary reasons. In contrast, only 10 of all participants who were approached in the primary health care centers refused to be part of the study citing that they did not have time to take part. There were, however, no significant differences between the total sample and the participants that refused the clinical interview in sex ratio, wealth status, marital status and educational attainment.

### **Summary of results of individual papers**

#### **Paper 1: Mental distress in the general population in Zambia: Impact of HIV and social factors**

The relationship between HIV infection and mental distress was explored using a sample of 4466 participants in a population-based HIV survey conducted in selected rural and urban communities in Zambia in 2003. The Self-reporting questionnaire-10 (SRQ-10) was used to assess global mental distress. Weights were assigned to the SRQ-10 responses based on DSM IV criteria for depression and a cutoff point set at 7/20 for probable cases of mental distress.



An item by item analysis of the symptoms of mental distress revealed that daily life suffering (27.4%), frequent headaches (27.4%) and difficulty enjoying life (23.6%) were the most common symptoms among the HIV positive rural males. Comparatively, urban males complained more of poor sleep (21.4%), difficulty deciding (18.3%) and daily life suffering (18.3%). Among the HIV infected rural females poor sleep (23.6), daily life suffering (21.6) and frequent headaches (21.6) were the most common complaints. The urban female population presented with difficulty deciding (33.9%), frequent headaches (28.4%) and difficulty enjoying life (24.0%). Thoughts of suicide represented less than 6% of the total study population. Among the HIV infected, women (8.9%) reported contemplating suicide more than their male (3.0%) counterparts ( $p = 0.003$ ). A similar pattern was noted among the HIV uninfected (men 3.6%, women 6.4%,  $p = 0.001$ ). The prevalence of HIV was 13.6% in rural and 18.0% in urban areas. Knowledge of own HIV results was reported by 13.6%, and this knowledge differed clearly by residence, 8.3% in rural and 17.4% in urban ( $p < 0.001$ ). Of these, 43.4% lived in rural areas and 56.6% were urban residents. The mean (SD) age of the men was 27(8.8) years and 27(8.9) years for women. Marital status differed substantially by residence, i.e. proportion being married was 66.7% in the rural and 81.4% in the urban population. Whereas 64.3% of the urban residence had attained at least 10 years of education, the respective proportion was 15.4% among rural residents.

The prevalence of mental distress in men was 12.4% and 15.4% in women ( $\chi^2 = 8.033$ ,  $DF = 1$ ,  $p = 0.005$ , i.e. a prevalence ratio, women: men of 1.24. This ratio was highest in the age-group 15–24 years of 1.6). Mental distress did not differ by residence ( $\chi^2 = 0.190$ ,  $DF = 1$ ,  $p = 0.663$ ) and only tended to increase by age. Mental distress was affected by educational attainment, i.e. the prevalence among urban residents was 2.3 times higher among the group with the lowest vs. the highest level of education, and the respective rural ratio was 1.94. A consistent pattern of higher mental distress among the HIV infected was observed by sex and residence,

and the prevalence ratio infected vs. non-infected was 1.61. ( $\chi^2 = 24.141$ , DF = 1, p = 0.000) Mental distress was correlated to self-rated health (r = 0.22), wealth index (r = 0.07), risk-worry (r = 0.15), HIV status (r = 0.08), age (r = 0.05) and inversely correlated to school years (r = -0.09). Self-rated health was inversely correlated to residence (r = -0.14), school years (r = -0.18), marital status (r = -0.30) and directly correlated to wealth index (r = 0.17) and age (r = 0.18). Risk-worry was correlated to self-rated health (r = 0.14) and age (r = 0.10, p < 0.05). HIV status was correlated to self-rated health (r = 0.15), risk-worry (r = 0.10) and age (r = 0.21).

A structural equation modeling (SEM) was established to assess the structural relationship between HIV infection and mental distress in the model, with maximum likelihood ratio as the method of estimation. The model diagnostics indicated that the underlying factors, residence, school years, ever married and age were inter-correlated. However the error terms of Self-rated health, risk-worry, HIV status and mental distress were not correlated. The observed measures of model fitness were as follows: Chi-square for goodness-of-fit test ( $\chi^2 = 237.7$ , DF = 12.0, p < 0.001), baseline comparisons (NFI = 0.931, CFI = 0.934) and parsimony-Adjusted measures (PRatio = 0.333, PCFI = 0.311, PNFI = 0.310, RMSEA = 0.037). Mental distress was directly related to risk-worry (b = 0.16), HIV status (b = 0.03) and self-rated health (b = 0.22). Self-rated health is related to age (b = 0.17), risk-worry (b = 0.12) and HIV status (b = 0.12). It was also directly related to school-years (b = 0.17). Risk-worry is directly related to both HIV (b = 0.09) while HIV status was found to be directly related to residence (b = 0.10) and age (b = 0.10). Self-rated health and risk-worry appear to be important mediators between underlying factors and mental distress. They are also important mediators between HIV status and mental distress. Age is directly related to HIV status (b = 0.17). It is also directly related to Self-rated health (mediated by risk-worry and HIV status, b = 0.17) and indirectly related to mental distress (mediated by risk-worry and HIV status, b =

0.05). Residence is directly related to HIV status ( $b = 0.10$ ) and indirectly related to mental distress mediated by risk-worry and HIV status with a small total effect  $b = 0.01$ ). Number of school years is directly related to self-rated health ( $b = 0.17$ ) and indirectly related to mental distress (mediated by risk-worry and HIV status,  $b = -0.04$ ). Risk-worry is related to mental distress both directly and indirectly (Total effect  $b = 0.20$ ). Self-rated health is directly related to mental distress ( $b = 0.22$ ). HIV status is related to mental distress both directly and indirectly mediated by risk-worry and self-rated health (Total effect = 0.07).

The results suggest that HIV infection has a substantial effect on mental distress both directly and indirectly. This effect was mediated through self-perceptions of health status, found to capture changes in health perceptions related to HIV, and self-perceived risk and worry of actually being HIV infected.

## **Paper II: Comparative Validity of Screening Instruments for Mental Distress in Zambia**

The screening instruments, SRQ-20, SRQ-10 and GHQ-12 were used as concurrent criteria for each other and compared against a gold standard, DSM-IV. Their correlation, sensitivity and specificity were assessed. All instruments were administered to 400 primary health care clinic attendees and these were subsequently referred to the Medical Doctor for clinical interview using the DSM-IV. These respondents were visiting the four Primary Health Care (PHC) centers for various medical reasons.

The respondents who were ethnically from the Bemba speaking tribes accounted for 26% of the total study population, while 16% were Nyanja and only 12% were Tonga. However almost half of the respondents preferred English as the language for the interview, while the others preferred Nyanja and Bemba (38.8% and 8.5% respectively). The sample had 167

(41.8%) men and 233 (58.3%) women. The male patients ranged in age between 16 and 67 years with a mean of 32 years (SD=11.1). Female patients ranged between 16 and 65 years with a mean of 29 years (SD=9.4). The majority of participants were married (64%). Most of the patients had more than 8 years of education (secondary 56% vs. tertiary 19.5%) while 3.8% were illiterate. There were no statistical differences between the clinics serving the medium and high density catchment areas in terms of marital status ( $t= 1.139$ ,  $p=0.06$ ,  $\eta^2 =0.00$ ), wealth index ( $t=0.198$ ,  $p=0.418$ ,  $\eta^2 = 0.00$ ) and educational level ( $t=0.284$ ,  $p=0.777$ ,  $\eta^2 = 0.00$ ).

The correlation between the SRQ-20 and SRQ-10 was 0.85 while the correlation between these instruments and GHQ-12 scales was found to 0.60 and 0.52 respectively. Independent  $t$ -tests were used to compare differences in the continuous instrument scores between men and women and no significant differences were found. For comparison of definitive psychiatric diagnosis between males and females chi-square test was used and found to be insignificant ( $p=0.370$ ). Overall the prevalence of common mental disorder as diagnosed by the DSM-IV classification was 13.6%, and was found to be mainly depression (10.8%) anxiety disorders (1.8%). The prevalence tended to be higher in females than males (women 14% vs. men 12.9%,  $p=0.743$ ). An item-by-item analysis of the SRQ also revealed that females on average reported more symptoms of mental distress than the males.

The SRQ-20 and SRQ-10 performed well with the area under the curve (AUC) being 0.96 and 0.95 respectively while the GHQ-12 had a modest AUC of 0.81. When analyzed separately for men and women no clear tendencies to perform better by sex were noted. The most appropriate cut-off point was a tradeoff between sensitivity and specificity and the optimal one for both SRQ-20 (sensitivity 0.85, specificity 0.94) and SRQ-10 (sensitivity 0.81,

specificity 0.96) was 7, while that for GHQ-12 was 2 (sensitivity 0.66, specificity 0.86).

Further analysis by sex did not reveal any significant differences in cut-off points.

In-depth interviews were also conducted on a subsample of 28 clinic attendees to assess the content validity. Of these, 15 (53.6%) were male while 13 (42.9%) were female. The respondents had an average of 9 school years being slightly higher in males than in females (10 years vs. 8 years respectively). Over half (53.6%) reported that they were married, 39.3% were single while less than 1% were either, divorced, separated or widowed. Half of the respondents preferred to have the interview conducted in English while 23% preferred Bemba while 28.6% preferred Nyanja. The 28 respondents gave the yes-answer a total of 205 times on the SRQ. Invalidity of these answers was considered on two main stages listed below.

Differences in conceptualization of the question by the respondent were recorded in 25% of the yes-answers given. *“Do you have headaches often?”* All the invalid answers given to this question were attributed to the presence of other intercurrent illness namely hypertension, malaria and toothaches. However the question largely managed to uncover information indicating the headache as a symptom of depression and/or anxiety.

*“Do you have uncomfortable feelings in your stomach?”* - Among those giving invalid answers, this question was understood as an inquiry into presence of gastrointestinal ailment. In Contrast the questions; *“Is your digestion poor?”* and *“Is your appetite poor?”* performed very well and uncovered having many thoughts or problems of the mind as being the underlying cause. The anxiety Items: *“Are you easily frightened? Do your hands shake? Do you feel tense or worried?”* seemed to have a narrow meaning in the context of our study, and were interpreted as being an enquiry into literal feeling or state of being afraid which is associated with, hands shaking or feeling tense or worried. This concept did not seem to exist in our sample unless there was a clear reason for it and so the items failed to uncover the

information suggestive of anxiety. *“Do you feel tired all the time?”* Was interpreted by the respondents as asking about whether they got tired easily as regards work rather than an enquiry pertaining to depression. We assigned a yes-answer to this invalidity category if the question had to be repeated one or more times or if it needed further explanation before an answer was obtained.

We also assigned, to the language and motives invalidity category, respondents who said they didn't understand or who answered “I do not know” to the questions posed. We also included in this category respondents who insisted on the yes-answer but were unable or unwilling to give further details or examples of experiences that would help us to clearly define the underlying psychopathology. Respondents who also directly indicated that they thought by participating in the interview they would be “fast-tracked” to see the doctor were also assigned to this category, although these accounted for less than 1%. This kind of invalid answers were observed in 15.6% of the yes-answers and was attributed to not understanding the content of the question and complexity of the words used.

Within the sub-sample we also assessed the face validity of the SRQ by asking the respondents what they thought the instrument was supposed to measure and we also probed further by asking the respondents what they thought the aim of these questions were. The SRQ was found to have good face validity with 71.4% of the respondents saying that we were assessing mental health. The most common response was that we were measuring “problems of the mind and soul” (53.6%) while 17.9% said we were assessing stress and depression. The proportion who said they did not know the aim of the questions was 28.6%.

The SRQ-10 was found to be a practical and robust tool for measuring mental distress in primary health care when compared to other widely validated tools. (SRQ-20& GHQ-12) It held an operational advantage as it was a shorter scale which made it a more attractive option for use in busy primary health care services, in mental health surveys and also in general health surveys. However, to cover the whole range of mental disorders or to make a diagnosis, it is imperative that it is coupled with other more comprehensive diagnostic scales.

**Paper III: Conceptual models for Mental Distress among HIV-infected and uninfected individuals: A contribution to clinical practice and research in primary-health-care centers in Zambia**

Twenty-eight informants (13 females, 15 males) who met the symptom criteria for mental distress and consented were interviewed. An effort was made to balance the male to female ratio despite clinical demographics demonstrating that more women than men seek health care. The combined mean age was 32 years (35 years male, 29 years female) and the age range was 19-56 years. Of the 28 participants, 50% were HIV positive (eight males and six females) and 50% HIV negative (seven males and seven females). HIV positive informants were divided into two groups depending on whether they were receiving anti-retroviral therapy (ARVs). Nine informants were HIV positive but not receiving ARVs (four male, five female) and six were receiving ARVs (three male, three female).

To aid understanding of the contrasting models for mental distress in the study, taxonomic categories were developed and respondents were classified into one of these representational groups: social, biological, psycho-social and situational models. Attributes of these models were closely interrelated, but certain features and aspects belonged to specific groups.

### *Social Model*

Informants in this model said that their symptoms were due to social events in their lives, either single episodes or long-term stressors. In some cases, informants described multiple sources of social stressors. The social narratives were closely related to recent life events that had traumatized the informants, causing repeated somatic symptoms. The results showed that mental distress was somewhat insensitive to gender. However, certain social stressful situations had more effect on women than on men.

### *Biological Model*

This model was closely related to the social model. The narratives in this category ascribed the symptoms to physical ailments currently being experienced. Unlike the social models, the stressor (physical illness) was a single entity. Expressed worries or symptoms were a direct result of the physical illness. Therefore, the body was seen as mediating the social stressors, which were expressed as symptoms of mental distress. This model predominantly comprised informants who were HIV positive and included individuals with other long-term medical conditions such as hypertension and diabetes. The results revealed that worry concerning the lives of children and spouses if the individual died was a direct contributor to headaches and sleeping badly.

### *Psychosocial Model*

Attributes in this model emphasize the role of psychological stressors in mental distress. Although the stressors were a single entity, they manifested themselves as a psychosocial dimension. However, these narratives focused on themes of self-blame, personal failure and poor self-esteem. Results demonstrated that suffering from certain conditions that left permanent scars on the body hindered access to social agreements such as marriage and hence contributed to mental distress. An inability to bear children was a cited factor contributing to mental distress in women.



### *Situational Model*

In this category, symptoms were the result of a stressor that would result in a change in the respondent's life. Informants in this category viewed their stressor as representing 'the end of the road'. Many responses given by health providers were identified under the theoretical explanatory models, confirming consensus-driven attributable causes, treatment-seeking and response behavioral challenges from institutional and community perspectives. Health professionals reported that HIV infection was responsible for approximately 40% of institutionalized mentally distressed patients. When providers and healers constructed mental distress using reports from users, witchcraft and stigma emanating from HIV positive results emerged as major contributors to symptoms of mental distress. The results revealed that despite noticeable changes in mood including social withdrawal and mood swings in a family member, health services were only sought when physical violence or suicidal tendencies developed. Until that point, most were home-bound. Gender dimensions were noted when attributable causes to mental distress were assessed. Females were more likely to report social problems including stigma owing to HIV status, whereas males attributed causes to ARV treatment. In terms of treatment at home, all providers reported that predominantly women took that responsibility.

The relationship between coping and mental distress holds specific interest in both HIV-infected and uninfected individuals. Among uninfected individuals Informants in the *Social Model*, the cause of their symptoms was related directly to one or multiple social stressors. They relayed that they were unsure how long the stressors would last, that they did not recognize their symptoms as a disease entity and saw no need to seek medical attention. They stated that their symptoms would disappear once the stressors were removed and/or if they found a solution to relieve their financial strain. Their coping strategy was based on the hope

that things would improve. HIV negative informants in the *biological model* viewed their symptoms as part of the whole disease process and they were eager to consult medical personnel for treatment. However, they did not relate their symptoms to mental distress but “worries” for which they did not need psychotherapy or psychotropic medication. They said that their symptoms would not disappear permanently but have a recurring pattern. Their coping strategy was one of longing for longer symptom-free periods. Those falling in the *psychosocial model* did not recognize their symptoms as an illness. They described their symptoms as normal reactions to events in their lives, but were willing to consult medical professionals. They admitted that psychotherapy would help but were very skeptical about the role of psychotropic medication in alleviating their symptoms. Hopelessness was identified as an important factor in this model. They remarked that their symptoms would run a chronic course with no hope of alleviation. The coping mechanism identified was religious faith and/or the hope of meeting somebody who would accept them for who they are.

HIV positive informants fitted into the biological and situational models. Their symptoms of mental distress were ascribed specifically to their HIV status. However, some differences were noted in the health seeking and coping strategies. The differences were a function of how long they had known that they were HIV positive and if they were receiving ARVs. Informants who were newly diagnosed and those who had known of their HIV+ status longer but were not receiving ARVs had a high degree of hopelessness. In contrast, informants receiving ARVs had a lower degree of hopelessness. They recognized their symptoms as an illness requiring medical attention in the form of psychotherapy. However, they did not see the immediate benefit of psychotropic medication, and informants who had been very sick and/or had opportunistic infections prior to starting ARV expressed optimism about their lives and future. Most of the informants in this category did not view psychiatric consultation as

necessary or appropriate for their situation, though they admitted that psychotherapy would be of help.

A general measure of agreement exists between explanatory models among the study groups. The experience of mental distress among patients appeared to have been governed by problems relating to socio-economic problems (poverty), particularly problems in the home (marital problems). However, occasional differences were noticed. Male respondents emphasized economic problems more, while female respondents emphasized social problems (marital, violence in the family, alcohol abuse by spouse). Female respondents mentioned economic problems as a secondary effect of separation, divorce or being widowed. Additional explanatory models were noted in the presence of chronic illness including HIV, hypertension and diabetes. In these circumstances, explanatory models emphasized the role of the physical illness in the experience of mental distress. Perception of the cause of the symptoms, expectations of the course of the illness, severity of the symptoms, family support and presence of stigma, were all predictors of health-seeking behavior

A broad consensus was apparent among the health care providers, although there were some clear differences. Health care providers agreed that symptoms were problems of the mind mediated by socio-economic problems. They were in agreement that these symptoms required some form of intervention (medication, prayer or exorcism) in order to alleviate the suffering of the patient. They agreed that HIV poses special circumstances and that it causes much distress. However, there were occasional differences in emphasis on the cause, course of illness and preferred treatment (Table 4).

However, a greater difference was evident between the patients and the health care providers. Health care providers had a predetermined cause and effect pathway, either: 1.) social circumstances leading to mental distress (stress, depression) and in turn mental distress symptoms; or 2.) bad spirits (witchcraft) leading to mental distress symptoms.

Patients had a somewhat different narration of the illness experience in the different models. HIV positive individuals (regardless of ARV history) and those with chronic medical conditions established a cause and effect pathway, but HIV negative individuals did not; they had a more narrative and experience-based understanding of their illness. They did not readily attribute their mental distress symptoms to an illness entity but to life's problems and a few of them entertained witchcraft as a cause. This impacted profoundly on what treatment choices they made.

Overall patient models concerning mental distress are critical to treatment-seeking decisions and coping mechanisms. Therefore mental health interventions should be further researched and prioritized especially for HIV-infected individuals.

**Paper IV: Case-finding for Mental Distress in Primary Health Care: an evaluation of the performance of a five-item screening instrument.**

There has been increased interest in developing better, shorter and more accurate methods to recognize and manage mental health problems in primary care settings. The present study seeks to investigate whether only a few questionnaire items from the Self-Reporting-Questionnaire can be a robust method in the screening for Mental Distress in Primary Health care. The results show that SRQ-5 is highly correlated to SRQ-10 (0.923,  $P < 0.001$ ), SRQ-20 (0.764,  $p < 0.001$ ) and only moderately correlated to GHQ-12 (0.417,  $p < 0.001$ ). Slightly better correlation was seen between GHQ-12 and SRQ-10 (0.515,  $p < 0.001$ ) and SRQ-20 (0.593,  $p < 0.001$ ). All correlations were significant at  $p < 0.001$ . The Areas Under the Receiver operating characteristic Curve (AUC) was calculated for each of the 4 screening instruments and compared for the different diagnostic groups. These diagnostic groups include i) depression and ii) anxiety disorders. By this measure SRQ-5 was almost equal to SRQ-10 and SRQ-20. However it out-performed GHQ-12 for detection of overall mental distress and

depression and equaled it in the detection of anxiety. All these AUC were significant at  $p < 0.001$ . Furthermore, no major differences are noted when compared by sex and age. Each of the 5 items contributed some diagnostic information across all the criterion diagnosis. Each question performed well in the diagnosis of depression. The best contributor being the question; Do you sleep badly? (0.836, SE= 0.037) and the least being; Do you often have headaches? (0.606, SE= 0.045). All AUC values for detection of overall mental distress and depression for each of the SRQ-5 items were significant at  $p < 0.05$  when compared to the full scale of the SRQ-10. Addition of more items to the 5 did not seem to improve the performance of the SRQ-5

The sensitivity, specificity, positive predictive values, and negative predictive and kappa's values of the scales with different cut-off points were also evaluated. The optimal cut-off for SRQ-5 was 4/12 with sensitivity 0.87 and specificity 0.85. Further analysis by sex and gender or by criterion diagnosis did not reveal any significant differences in cut-off points.

Practically speaking this meant that a patient presenting with either, poor sleep, daily life suffering or inability to play a useful part in life and any one of the other symptoms would be classified as being mentally distressed. A patient presenting with only suicidal ideation as a lone symptom or in combination with other symptoms would also be classified as probable case.

This validation showed that in moving from SRQ with 10 or 20 items to one with merely 5 items, we did not seem to lose the screening prowess of the instrument. The SRQ-5 represented a simplified and less time-consuming screening instrument with strong performance characteristics.

## **Discussion**

The four papers in this thesis stand as pioneer work for mental health research in Zambia. They provide information about the how to screen for mental distress, the determinants of mental distress and the specific definitions of mental distress symptoms across different strata of the affected individuals as well as that of health practitioners. In this section of the thesis key findings in these papers are discussed briefly, as more detailed discussion of results is found in the individual papers. Some key elements of methodological issues are discussed first, as these could impact on the validity of the results. Secondly, some conclusions are drawn based on the results of each study and there after issues relevant to policy and future research avenues are discussed.

### **Methodological issues**

#### **Design and sampling**

##### *Population-based survey*

The main limitation of cross-sectional surveys is that findings are limited to comments about associations as causal relationships cannot be assessed. The preferred study design for eliciting causal relationships is a prospective cohort study which tends to be very expensive since requiring repeated collection of data rounds over time and stringent follow-up of participants to avoid bias. It should be noted here that associations revealed in cross-sectional data have very often provided reliable indications of actual effects. Survey designs are largely aimed at answering a particular question. In paper 1 was concerned with investigating the magnitude and determinants of mental distress with particular emphasis on the mechanisms involved in the way HIV infection impacts mental distress by establishing a linear structural equation model. The main interest was not to establish causality but rather patterns of

interrelationships in the data that would fit to a better or worse degree the assumption of our theoretical premise that HIV infection has an adverse impact on mental distress.

#### *Facility-based survey*

The primary health care facilities that were used in Paper II, III and IV had been selected for convenient reasons like, accessibility, distance between the facilities, catchment area served, and availability of more than one medical officer and so the ability to judge if these clinics were representative of Lusaka province is difficult to judge. However effort was made to randomly select the clinics. The method used was in four stages. The first stage was to identify and list easily accessible facilities. In the second stage these facilities were divided into two groups; serving high density areas and serving low density areas. In the third stage the specific facilities were randomly selected in equal numbers from each of the subdivisions in stage two; two clinics serving high density areas and two clinics serving low density areas. In the fourth stage the days on which the clinics were visited was also randomized so as to have an unbiased distribution between the weekdays and weekends. However, Lusaka being the capital city means that it is most likely a homogeneous. This means that living in a low or high density area does not necessarily mean that the participants are significantly different in terms of education, income etc. Therefore this makes detecting a difference between the two subdivisions a challenge. Further we included only participants in an urban area without a rural reference group. This would tend to give errors in estimation of prevalence and the issue of external generalizability a challenge. Several studies have detected a difference between rural and urban population in terms of prevalence of mental distress; it being higher in rural than in urban population. Therefore the simple assumption would be that by sampling from a rural population, we would be underestimating the prevalence of mental distress.

The sample of clinic attendees was very dynamic, with people coming and leaving all the time. To reduce selection bias the participants were sampled from the outpatient department meaning that the participants could have had any condition, medical, surgical, obstetric, gynecological etc. Further, the study participants in each of the facilities were selected in a systematic and predetermined manner to ensure equal probability of each participant to be selected. Hence on the selected day all consecutive facility attendees at the outpatient department were considered potential participants although only every third patient was requested to participate in the study regardless of the medical problem that brought them to the clinic. The investigators knew not to select severely ill patients or patients with known psychiatric illness. Special effort was also made to ensure that the patients were not delayed due to participation in this study. The response rate among those asked to participate in the study was very high (97.5%) and so it is felt that a representative sample of clinic attendees was obtained.

### **Validity of data collection methods**

The question surrounding the validity of results bears on a number of factors such as; how sensitive the study design is, how representative the sample is, the predictive value of case definition, complete description of participant information, the response rate and statistical methods employed. (91) This same approach could be used to assess the extent to which the findings in this thesis are valid.



## **Validity of data collection methods-Population-based study design**

### *Study design and representativeness of the sample*

The study design was cross-sectional and so the inherent weaknesses of this study design apply. Probability proportional to size sampling method, based on the methods used by the central statistics office of Zambia for carrying out the national census were used in selecting the study clusters. Further, the same criterion was used for the definition of the residential area as either rural or urban. All occupants above 16 years of age in each household, in the selected cluster, were then interviewed. The sampling methods used to select the study participants were thus robust, systematic and in a predetermined manner giving each respondent an equal chance of being selected minimizing selection bias. In so doing internal validity was preserved. The external validity of this study was preserved by its population-based study design. It is thus particularly strong because of its wider coverage of the population. On this basis this sample of men and women in selected urban and rural areas and can be to a larger than less extent representative of the general population of Zambia. (91)

### *Predictive value of case definition*

The testing algorithm used for HIV also adds to how robust these finding are since it employed a WHO guided two-test laboratory-based algorithm. These tests were carried out in a laboratory at a tertiary medical institution with high quality assurance thereby further adding to the predictive value of case definition. (92)This was particularly important to this thesis as HIV status was one of the major variables studied.

### *Description of the study participants and response rate*

Information on all the participants who were found during the survey was collected and documented. This included information on participants who refused to be part of the surveys as well as information on those who were lost to follow up. Information on non-participation was later analyzed to estimate the impact, magnitude and direction of the non-response bias. It was also compared to information on the participants who consented to being part of the survey. About 20% of all eligible respondents were absent from their home at the time of the visit by the interviewer team despite two call-backs. Men were approximately twice as likely to be absent than the female counterparts. Only 1-2% refused to be interviewed while fewer than 10% did not consent to the saliva test for HIV. The refusal rate was found to be similar for men and women. The social and demographic factors of respondents who refused saliva tests were similar to the participants who consented. No major non-response bias was found that was related to HIV. (92)The impact of non-response on information bias for the mental distress is a bit more difficult to judge as this was not the primary objective of the population based survey. The same holds for impact of misclassification of probable cases for mental distress on the estimation of the prevalence. It is however logical to consider that differential non-response due to absence at the time of the visit by the interviewer team may lead to both underestimation (if those who were absent were at a higher risk for HIV and/or mental distress) and over-estimation (if those who were absent were at lower risk for HIV and/or mental distress). Refusals can also arguably have the same effect. However since the refusal rates low (>2%), coupled to the fact that there were no significant differences in the socio-demographic characteristics between responders and non-responders (92)we believe that this could not have had a profound effect on our estimates. Further the fact that the most common reasons for absence among the men were work and school (92)cements our belief that the impact on the estimates was low.

### *Statistical methods*

Data analysis, hierarchical associations and interpretation of the findings were guided by a theoretical built model or conceptual framework. Analysis of Moment Structures was used in a structural equation modeling to confirm the theoretical built model which included underlying factors, intermediate factors which consequently dictated the likelihood of being mentally distressed. The possible pathways of association were considered stage by stage based on the hypothesis that underlying factors were either directly associated to mental distress or indirectly through the intermediate factors which included HIV infection. The association HIV with mental distress was also assessed based on a direct and/or indirect association premise. Therefore in the initial stage the model was fitted based on the above. Secondly, regression coefficients and their level of significance were calculated for each stage then finally chi-square and goodness of fit indices were obtained for model diagnostics. This approach to the data analysis is acceptably robust and ideal for this kind of data and so minimizes concerns about validity.

### **Validity of data collection methods-Facility-based design**

#### *Study design and representativeness of the sample*

This study design was also cross-sectional and so the inherent weaknesses of this study design apply. However, the robust method used in selecting the study participants help to minimize selection bias either by sex or by medical condition. Therefore with high degree of confidence, it can be said that the sample that was selected was representative of primary health care attendees in Zambia. However the issues surrounding external validity are trickier to interpret. It is not easy to immediately judge whether the primary care attendees are significantly different from the general population. Literature on this matter is less clear. Some studies report a clear difference in mental distress, depression and anxiety prevalence

by residential area while yet other have not found this clear difference. This might be a cause of concern. Given the assumption that people who are mentally distressed generally do not present to primary health care facilities for this condition, we may have under-estimated the magnitude of mental distress. Further whether urban and rural populations are significantly different by mental distress is also a thorny issue as literature is less clear. However the prevalence of mental distress and strength of associations with underlying and intermediate factors between results from the population-based survey and the facility-based survey are similar. This could suggest that the findings in the facility-based studies could be extrapolated to the general population but with caution bearing in mind that other literature on the matter is not in agreement.

#### *Predictive value of case definition*

For the definition of mental distress throughout this thesis, we used the SRQ-10, an abbreviated version of the SRQ-20. This instrument was validated in paper II against the SRQ-20 and the GHQ-12 as concurrent criterion for each other using the DSM-IV as the gold standard. Overall the SRQ-10 showed good criterion validity with good sensitivity and specificity for case definition for mental distress. The point prevalence for mental distress closely approximated that from the population survey in Zambia and fell within the range of reported prevalence within the region. The fact that the SRQ-10 performed well against universally accepted etic instruments (SRQ-20, GHQ-12, DSM-IV) which have been widely validated in different countries and cultural settings added to the validity of its predictive value for case definition. Further the validation procedure employed a concurrent mixed methods design which is a relevant tool in illuminating content validity of the individual SRQ items, hence supplementing the overall strength and relevance of the case definition.

### *Description of the study participants and response rate*

Information on all the participants who were found during the survey was collected and documented. The refusal rate was very low as only 10 out of 400 refused to participate. These did not differ from the ones who participated.

### *Data analysis methods*

In paper II and IV, Receiver Operating Characteristics (ROC) was used to identify an optimal cut off point for the abbreviated version of SRQ and to upraise the cut off point for SRQ-20. Further each ROC was characterized by an Area Under the Curve (AUC) which generally indicated the overall accuracy of the instruments accuracy over a wide range of cut-off points. We further assessed, the content, criterion and face validity using in-depth qualitative interviews. The responses were then analyzed using the content analysis technique. In paper III qualitative investigation nested in a cross-sectional study were employed to elicit conceptual models for mental distress in the study population. An interpretive approach was used initially to identify common themes in a data reduction strategy. Common phrases were then grouped together under the same or similar themes providing unique and contrasting features of the narration of the symptom. These were then classed in specific conceptual models with each pattern of symptoms linked to treatment preferences and coping strategies. These are widely accepted methods of analysis in validation studies and in eliciting conceptual models and so, adopting these strategies strengthens the clinical and cultural validity.

## **Main findings**

### *Predictors of Mental distress and the Impact of HIV*

In paper I we reported the overall prevalence of mental distress as 13.9% and found to be somewhat higher among women (15.4%) than among men (12.4%) though no urban and rural differences were found. These findings largely tally well with other finding within the eastern and southern parts of Africa, except for the rural vs. urban differences. Other studies in the same regions have reported a higher prevalence of mental distress in urban vs. rural populations. (93-95) We were unable to detect a statistically significant difference between the rural and urban populations. A possible explanation here could be that the rural site chosen (Kapiri Mposhi) though rural and for about half of the population are actually remote, is also close to a transit point to the Copperbelt and Northern provinces of Zambia. It also serves as a gate way to the eastern part of Africa and so the population tends to be cosmopolitan.

We reported the mechanism involved in the impact of HIV on mental distress as being both direct (biological effects) and indirect (psychological factors). (paper 1) The effects were particularly stronger through the indirect effects mediated by poor self-rated-health and a high self-perceived risk and worry about being HIV infected. In this regard self-rated-health has previously been found to represent changes in HIV related perception of health. (89) Further other social factors such as age, residence and education were reported to be indirectly associated with mental distress in a pathway mediated via psychological factors. These findings, overall, confirm previous finding that have emphasized the psychological impact of HIV on mental distress. Various studies have gone a step further and demonstrated that depressive symptoms are associated with behaviors and relationship characteristics that put young men and women at risk for sexually transmitted HIV. They conclude that depression should be considered as a potential marker of increased HIV risk and that this association maybe causal. (95)

However there are some considerations about the study results. Firstly, our study population had high prevalence for HIV with low awareness of own HIV status. Secondly, the sample also reported symptoms of the distress that ostensibly related to their HIV status. For example symptoms such as “feeling tired all the time”, “frequent headaches”, “poor digestion” may reflect the physical manifestation of living with HIV alongside forming the constellation of symptoms for psychological distress. Thus it is possible that the physical symptoms of HIV could have coincided with those the psychological sequelae. Thirdly reports of concerns about “crying more than usual”, “suicidal ideation”, “difficulties enjoying daily activities” maybe driven by the sense of hopelessness that is associated with being aware of the HIV status and also their situation of living in poverty. Fourthly, general worrying about things and the feeling of “inability to play of playing a useful role in life” maybe largely be due to concerns about the impending physical decline in health, fanatical stability in the case of inability to work due to illness or death and concerns about access to treatment. Therefore, it is thus possible that what we measured was a combination of HIV-related effects both direct and indirect.

The magnitude of the biological impact is difficult to independently judge or to measure based on the results from paper 1. One way of sorting out what could be more biological verses other effects of HIV on mental distress would involve a study design that would take into account the biomarkers for HIV infection *visa vi*, CD4 count, viral loads, WHO staging and effect of anti-retroviral medication. In an unpublished study which we undertook in selected primary health centers in Lusaka, Zambia, preliminary analyses suggest a strong inverse relationship between mental distress and low CD4 count indicating a linear effect.

Another consideration surrounds the effect of duration of being HIV positive on mental distress. HIV epidemiological evidence has shown that, on a group level, most HIV infections in young people are recent and that in older groups we expect that the HIV positive have been infected longer and so will have experienced the most damage on the immune system. A simple assumption will thus be that there would be a difference in mental distress depending on duration of infection and would thus be expected to increase by age. This was assessed in our study to see if the effect differed by age i.e. young vs. old, but there were no clear findings.

#### *Validation of screening instrument for mental distress*

The arguments in favor of routine screening for mental distress among general medical patients are compelling based on prevalence of mental distress, associated personal and social costs and the large number of mentally distressed persons who go untreated in the face of available efficacious treatment. Additionally because it tends to run a recurrent course, there is a need for a rapid means of screening for history of mental distress that is either valid in itself or an efficient means of identifying respondents needing further assessment. Further a number of studies conducted world-over have argued for the use of shorter screening instruments for mental distress. Paper II and IV set out to examine the validity and efficiency of assessment for mental distress by the World Health Organization recommended tool for screening for mental distress in low income countries, the SRQ-20, as well as two of its abbreviated versions, SRQ-10 and SRQ-5. Overall the study showed that the SRQ-10 was a valid instrument for detection of mental distress in the primary health care with good criterion validity at a cut of point of 6/7 and acceptable sensitivity and specificity. It was highly correlated to the SRQ-20 with good face validity. The validity coefficients did not seem to be affected by the socio-demographic factors.



However, a limited content validity loomed around the anxiety items and some of the somatic items. These were attributable to mis-conceptualisation of the individual instrument items and to a less extent the language and participant motives of hoping to be attended to quicker if they appeared more sick or distressed. The overall point estimate of mental distress was similar to the one obtained from the SRQ-20 and closely approximated the one obtained from the population survey

The screening capability of the SRQ-5 did not differ significantly from the SRQ-10 and the SRQ-20 and performed slightly better than the GHQ-12. Comparing the patterns of the ROC curves showed no significant difference in its performance by gender or age. With respect to a cut-off point, ROC did not seem to suggest the need for different cut-off points based on the diagnostic criterion, gender or age.

The most important findings of paper II & IV are that in moving from SRQ with 20 to 10 items and then to merely 5 items, there was no loss of the screening prowess of the instrument and so they represented a simplification of the mental health screening process while retaining strong performance characteristics. These findings match the finding from other studies done elsewhere, although not using the same screening instrument. (46, 47, 96, 97) A meta-analysis of studies investigating the accuracy of ultra-short screening instruments in the detection of depression also came to similar conclusion. In this study they examined screening instruments with varying number of questionnaire items. They concluded that a one-question test would only identify 30% of patients with depression while those with 2 or 3 items performed better identifying 80% of cases. This is at the expense of high false positive rates and so these instruments appear better at ruling out a diagnosis and so should only be used when there are sufficient resources for a two stage screening process of those who screen positive. (85)Using ultra-short screening instruments with 5 items has been found to be more

optimum for the screening of common mental disorders. These screening instruments have been found to have better sensitivities of up to 0.96 and specificities of up to 0.82. These values vary little by gender, age and ethnicity. (87, 96) These values are similar to the ones we found in our studies and we were also unable to find any differences by age or gender and so it was unnecessary to use different cut-off points for different gender or age groups. The major strength of paper II & IV is that they are novel studies in the context of Zambia and so add new knowledge to the current body of knowledge.

Some issues, however, surround our findings. Firstly, we were unable to find directly comparable studies which used both the SRQ-20 and the abbreviated versions and so it was difficult to compare the validity indices directly with other studies. Some of the notable differences with the validity indices in other studies using the SRQ could be attributed to the use of different gold standards and the differences in the study populations. Another issue that could affect the validity of these results is that the study was restricted to urban settings with relatively high educational attainment with about half the participants preferring the interview to be conducted in English. However, it should be said here that the official language in Zambia is English and given that Zambia has a literacy rate of 70% the preference for use of English is not surprising. This could explain why our validity indices were higher than those obtained from other studies. Additionally, the sample was cosmopolitan with socio-demographic factors being similar across all clinics. This could also possibly explain why the validity indices did not seem to be affected by the socio-demographic factors as reported in studies in other countries. However, where sex is concerned caution should be taken when interpreting these results as a large body of evidence from Africa suggests a higher false negative rate among men than among women which is attributed to the fact that an expression of emotion would be stigmatizing among men. Overall the findings indicate that the

abbreviated instruments are rather robust and the findings closely approximate those done in different other communities giving the indication that it is possible to extrapolate these findings to the national level and possibly the regional level.

*Explanatory models for mental distress Vs. HIV sero-status*

Through the pioneering work of Arthur Kleinman we have been provided with a window into the importance of explanatory models for the improving provision of mental health services in general. He asserts that “The explanatory models framework provides the clinician with an expeditious practical method to assess the more accessible meanings that hold clear-cut importance for care”. The picture constructed is doubtlessly crude, incomplete, biased. But it is usually “good enough” for the purpose at hand: namely, to alert the clinician to the psychosocial setting of the sickness and to make available to him appreciation of at least some of the dominant meanings expressed and reproduced by the illness experience”. (97)The study design of the explanatory models for mental distress was thus based on but not limited to the work of Arthur Kleinman and we went a step further by applying it particularly for HIV-infected individuals. The explanatory framework is not a way of thinking or a system of thought but rather provides practical statements about particular expression of illness which may not only guide help seeking for the “sufferer” but also clinical decision making for the “health provider”. It would in essence, have a twofold effect , one being of helping the health provider to be sensitive to the psychological and socio-cultural context of illness as well as in arming the health providers with skills to engage “sufferers” and their families more fully and knowledgably in the clinical process.

The salient findings of this study indicated that chronically ill patients expressed their symptoms mainly through somatic symptoms attributed to poor social circumstances. In HIV infection the symptoms were attributed to the disease process though perpetuated by existing social circumstances and worry about the future. HIV infection particularly added extra strain thus contributing to onset of symptoms. Health-seeking and coping strategies were determined by cause of illness, perceived course of illness, social support (Family support) and perceived duration of illness. The findings also revealed that health care providers were not sensitive to the patient's explanatory models and how they affected health seeking and coping behavior. The findings in this study are very important as they show that explanatory models are important in the clinical care continuum.(86, 98-102) In interpreting these results we need to consider the following issues: diagnostic significance of methods used to elicit explanatory models, the role of gender and generalizability of the findings.

#### *Diagnostic significance*

Qualitative methods were used in collecting this data. The strength of this methodology is that it allowed for a holistic focus centered on flexibility in obtaining a deeper understanding of the subject matter. The flexibility allowed for the respondents to ask questions and raise issues which in some cases may not have been included in the interview guide. (96, 97)This enhanced the quality of data collected and also allowed for comparison of our results to others done in the region with similar robust methods. However, this method of obtaining explanatory models is not without criticism. Whilst this method is adequate and useful in exploring lay concepts of mental distress, it is limited in that it does not explore the process, in an in-depth manner, through which the "sufferer" gave meaning of the illness, coping mechanisms and health seeking patterns. (87, 99)Literature has shown that individuals constantly define and redefine their illness, evaluate and reevaluate the treatment options as

well as constantly challenging the theories about the cause of their illness via repeated medical pluralism. (103-105) The constellations of symptoms here reported are not different from those from other developing countries. The somatic symptoms appear to be more universal across cultures and should probably be used as a basis for comparison with other studies and when considering the diagnostic significance of these symptoms. In this regard the findings in this study equal those done elsewhere as the somatic complaints were a central feature of the narratives. (103, 106) It should also be borne in mind that these somatic symptoms have been known to vary widely depending on the burden of disease, gender perspectives and societal perceptions of the symptoms.

#### *Role of gender*

Gender is a critical determinant of mental distress. Because it also determines the differential power and control men and women have over socioeconomic issues, it is closely related to course, care and support, treatment choices as well as susceptibility and exposure to specific mental health risks. Women have been shown to be affected to a greater extent across cultures and present with early age of onset, higher frequency of symptoms but a shorter course of the illness. Despite men having a more protracted course of the illness, poor social adjustment and poorer long term outcomes, they still report less frequency of symptoms as display of these symptoms from a man is often stigmatized. With the HIV pandemic rife among women and considering that a diagnosis of being HIV positive compounds mental distress, the simple assumption is therefore that women bare an extra burden. In this thesis, this basic difference between men and women may not have been emphasized enough; however it should suffice to say here that gender-specific determinants and mechanism that promote mental health and foster resilience to stress should be prioritized and emphasized in combating mental distress.

### *Generalizability of findings*

Extrapolation of finding to the general population is another challenge when handling this sort of data. Results for the general prevalence of mental distress and its predictors were clearly identical in both the population surveys and in the facility based studies. This gives us confidence in assuming that these finding closely approximate the true picture regarding mental distress in Zambia. The facility-based studies results consisted of a more restricted sample limited only to urban facilities and so future studies should consider a wider area, involving rural communities as well. However, the methods used in collecting the data and analyzing it are rather robust with the findings being closely related to other studies conducted in a variety of communities. (28, 39, 41) This suggests that these finding can be extrapolated to at least the national level and to some extent the region. It is generally felt that the results showing the mechanism by which HIV impacts on mental distress can be extrapolated to the national level and possibly to many other countries in the region. The reason for this is firstly that the communities selected had similar prevalence levels for HIV in both the rural and urban communities as in the national estimates. Secondly, the cultural mix in these communities was also similar to that of other communities in Zambia. Regarding the explanatory models for mental distress, it is felt that these finding too are robust. The explanatory model nomenclature here used might not be similar to that used in other studies, but the content is similar as are the finding. The results for the comparison of explanatory models between the patients and the health care providers are also very similar to reports from other similar studies. (100, 102, 107) We are confident that these models can be used unchanged at national level and provides a basis for comparison with other studies in the region.

### **Implications for research and policy**

To our knowledge this is the first study in Zambia to investigate mental distress, its predictors and the pattern of the relationship between HIV and mental distress. Therefore the finding presented and discussed in this thesis has a huge bearing on policy and implementation research in Zambia. In Zambia, literature concerning specific definitions and the perception of mental distress is limited, as mental health is generally not prioritized in terms of service provision. However, rates of mental and emotional illness are thought to be increasing in Zambia owing to socio-economic difficulties that precipitate mental problems including HIV/AIDS, poverty and lack of employment. Mental illness is generally viewed from two broad perspectives, community and cultural. The community view perceives good mental health or "a sound mind" as the ability to execute roles and responsibilities expected within a given social and cultural context. In contrast, mental illness, whether mild or severe, is associated with disruptive behavior, straitjackets, and mental institutions. In Zambia, cultural beliefs concerning the cause of mental illness center on possession by spirits or social punishment; many hold the belief that mental illness is caused by witchcraft and therefore cannot be treated by modern medicine but only through traditional means. A lack of proper information and the dominance of misleading presentation have led to a negative portrayal of mental illness, and sufferers are collectively and unjustifiably categorized and rejected, regardless of the form of mental illness.

Since this is a rarely studied subject in Zambia, it is important to start from gathering evidence followed by reaching the affected individuals and then finally tackling the special populations where mental distress is compounded or it compounds other health conditions. Of special interest to this thesis is HIV.

## **Policy implications**

The findings in this thesis have three main implications for policy. These can be divided into three categories,

*Mental health services:* This calls for the recognition of mental distress as public health problem and should be a starting point for promotion of routine and active screening for mental distress in primary health care. This thus pushes the agenda for adoption of the SRQ10/SRQ-5 as robust, time-efficient methods for screening for probable cases of mental distress in primary health care facilities.

*Mental health HIV/AIDS:* Screening for mental distress should be paramount in the clinical care continuum of HIV infected individuals. This thesis has demonstrated that mental distress among HIV infected has an effect on coping mechanisms, health seeking and treatment preferences. Other literature has also shown that mental distress can lead to quicker progression on HIV to AIDS. Further, mental distress has been linked to poor compliance to anti-retroviral drugs further compounding the prognosis in HIV infection. Therefore it is of paramount importance that screening for mental distress becomes routinely part and parcel of the decision making process to commence a patient on anti-retroviral drugs.

*Mental health program:* The results of this thesis also highlight the importance of strengthening the current mental health program in Zambia. This would include:

*1. Increased awareness of mental distress in the community-* This requires repackaging of the current information about mental distress/mental illness. Lack of proper information has been the leading cause towards the general outlook the community has towards mental distress in terms of cause, prevention and health seeking. This will entail reaching out to both urban and rural communities. Some strategies include the following:

- Campaigns discussing mental distress, its causes and consequences
- Allay issues surrounding stigma



- Peer education is also an under-utilized strategy in mental health. This strategy appears to have worked very well with other disease such as HIV/TB/STI etc.

*2. Increased awareness of mental distress among health workers-* Alongside increasing awareness is the need to collaborate the efforts of health professionals and the traditional healers. This would also imply active surveillance and prompt treatment of mental distress cases.

*3. Increased interest to fill in Knowledge gaps-* search for knowledge on interventions, strategies, or tools that can enhance the quality, effectiveness, or coverage of programs in mental health research area.

*4. Increased social support and poverty reduction strategies-* Poor social support from families and poverty have been linked to mental distress among the study population. This would require that social support and care groups be established either at the health care centers or in the community. This strategy has been proven effective for many other chronic illnesses and will in the same light stand to benefit individuals with mental distress. Poverty is a major developmental problem that has been linked to HIV/AIDS as well as mental distress. Therefore the information about mental distress and HIV might fall on deaf ears because communities and individuals are poor hence this poverty traps them into the cycle of HIV and mental distress. Therefore poverty reduction strategies must be linked to mental distress and HIV campaigns.

## **Research Challenges**

*1. Validation of mental distress screening instruments-* The results here might under-estimate the prevalence of mental distress given that data was collected conveniently. This suggests the need for a population based survey among men and women in both urban and rural areas. There is as such need for funding and further research to collaborate these results.

*2. Further work on developing and testing theoretical models of mental distress -* The list of determinants for mental distress may not have been exhaustive. Therefore the ubiquitous problem of omitted variables suggests that the underlining and proximate determinants may not have been measured correctly or completely. Mental distress could have been attributed to other variables such as other stress inducers, employment status and socio-economic factors.

*3. HIV and Mental distress-* The relationship between HIV and mental distress can also be attributed to other factors not included in the model. The model singled out only significant variables and omitted the other variable which similar studies have found relevant. Therefore, measurement of socio-economic factors, by way of an asset index, was not included among the variables in the model. Further, we were unable to determine the unique effect of HIV infection per se (biological effect) on mental distress. A more optimal design would measure the biological effect adequately by including information on clinical staging of HIV disease, CD4 counts and viral loads. The effect of anti-retroviral drugs on manifestation of mental distress would also be assessed in an optimal design.

*1. Operational research-* Research on mental distress on its own or the co-morbidity with HIV/AIDS is still lacking in Sub-Saharan Africa. Zambia particularly lags behind when compared to other countries. A novel area like mental distress in a country like Zambia requires a lot of initial investment into

research as this can yield practically-usable knowledge which can improve program implementation. In the light of the results of this thesis, scaling up of mental distress evaluation in all sectors of health would be an investment into better outcome and prognosis for many other associated medical and surgical conditions. To attain this strategic capacity building in primary health care centers is an important step.

## **Conclusion**

Validation of screening instruments is one of the most important steps in investigating mental distress. This allows for construction or adoption of already established instruments that are found to be specific and relevant to the local communities. The Self-Reporting Questionnaire has been shown to be robust when compared to other widely validated instruments. Further, the abbreviated versions of the SRQ-20 hold an operational advantage as they are shorter and are a more attractive option for screening in busy primary health care centers, mental health surveys and in general health surveys. When used in population surveys, these instruments allow for access to prevalence data that is critical to formulation of cogent national mental health policies as well as to the success of such policies. In as much as the screening instruments are unable to provide exact diagnostic classification, they are a reliable flag for detecting the common symptom pathways (mental distress) that then manifest as specific psychiatric diagnosis, especially in primary health care. This provides an entry point to specialized psychiatric treatment for those who are diagnosed with mental illness, or indeed an entry point to counseling services for those with milder forms of mental distress. It is as such a step forward in ensuring that as many people get the mental health care they need.

The ability to diagnose and treat mental distress early has had an added impetus by research evidence that has consistently linked mental distress and other chronic and acute illness. Of special interest to this thesis is the link to HIV infection. It has been shown that HIV infection has a substantial effect on mental distress both directly and indirectly. These effects are socially patterned; mediated through self-perception of health status, self-perceived risk and worry about being HIV infected. The most vulnerable groups; the poor, lowly educated, the women, the widowed were also shown to have heightened risk for mental distress.

Alongside the ability to identify probable cases of mental distress is the equally important role of understanding the social context of mental distress. The patient's conceptual perspectives of mental distress may differ from that of health care providers. These explanatory models have been found to be consistent, coherent and appear to be associated with coping, health-care seeking and treatment preferences. Therefore, provision of medical treatment should take into account these explanatory models in generating a joint treatment plan. This approach is particularly important among the HIV infected individuals.

The results here presented in this thesis emphasize the need for more research in this area. This research would involve the systematic and critical investigation and analysis of the dynamic and contextual processes that influence individuals and population's mental health. It would also focus on how to promote the uptake and successful implementation of evidence-based interventions and policies on mental health

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Research article

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## Mental distress in the general population in Zambia: Impact of HIV and social factors

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### Abstract

**Background:** Population level data on mental health from Africa are limited, but available data indicate mental problems to represent a substantial public health problem. The negative impact of HIV on mental health suggests that this could particularly be the case in high prevalence populations. We examined the prevalence of mental distress, distribution patterns and the ways HIV might influence mental health among men and women in a general population.

**Methods:** The relationship between HIV infection and mental distress was explored using a sample of 4466 participants in a population-based HIV survey conducted in selected rural and urban communities in Zambia in 2003. The Self-reporting questionnaire-10 (SRQ-10) was used to assess global mental distress. Weights were assigned to the SRQ-10 responses based on DSM IV criteria for depression and a cut off point set at 7/20 for probable cases of mental distress. A structural equation modeling (SEM) was established to assess the structural relationship between HIV infection and mental distress in the model, with maximum likelihood ratio as the method of estimation.

**Results:** The HIV prevalence was 13.6% vs. 18% in the rural and urban populations, respectively. The prevalence of mental distress was substantially higher among women than men and among groups with low educational attainment vs. high. The results of the SEM showed a close fit with the data. The final model revealed that self-rated health and self perceived HIV risk and worry of being HIV infected were important mediators between underlying factors, HIV infection and mental distress. The effect of HIV infection on mental distress was both direct and indirect, but was particularly strong through the indirect effects of health ratings and self perceived risk and worry of HIV infection.

**Conclusion:** These findings suggest a strong effect of HIV infection on mental distress. In this population where few knew their HIV status, this effect was mediated through self-perceptions of health status, found to capture changes in health perceptions related to HIV, and self-perceived risk and worry of actually being HIV infected.

## Background

Mental disorders make a substantial independent contribution to the burden of disease worldwide. It is estimated that, neuropsychiatric conditions account for up to 15% of all disability-adjusted life-years, and up to 30% of those attributable to non-communicable diseases. Neuropsychiatric disorders also account for 1.2 million deaths every year. [1,2] These figures are most likely underestimated as official statistics in low and middle income countries are scanty and unreliable. [2] In sub-Saharan Africa, it has been reported that 20–30% of primary health care centre attendees present with depressive symptoms as the first or secondary reason for seeking medical care. [3] A study conducted in Tanzania revealed a 41.6% prevalence of depressive symptoms among primary health care patients while a similar study in Uganda reported a 20–30% prevalence of psychological disorders and depression among health care seekers. [4,5]. These research findings have also shown heightened risk for common mental disorders among the women i.e. a female to male ratio of 1.5–2.0. Other determinants have been found to include low socio-economic position indicated by poor access to resources, unemployment and low educational attainment. It has also been shown to be higher among those with poor socio-support networks such as the unmarried, widowed and divorced. [6-8]

Mental disorders interact with many other health conditions, thus predicting the onset and progression of both physical and social disability. Several studies have established independent associations between mental disorders and an excess in all-cause mortality risk. In a meta-analysis, Saz and Dewey found pooled odds ratio of 1.7 for a diagnosis of depression and subsequent all-cause mortality. [9] Of particular relevance for this investigation is the interaction between mental disorders and HIV infection. Evidence has shown a heightened risk for contracting HIV infection among those with mental disorders. [10,11] Socioeconomic, psychological and biological factors [1,12-14] have been reported as predisposing factors in HIV infection and have also been found to be relevant factors in mental distress related HIV disease progression. [1,12]. Mental disorders can also mediate delayed help seeking, diagnosis, poor compliance to medication [15] and can predict drop out from HIV-risk reduction programmes. [16,17]

Although evidence from low income countries is limited, fairly consistent associations have been reported between HIV and poor mental health with most published studies showing differing but high percentages of mental distress, e.g. observations from South Africa with prevalence of 40% contrasting a study in rural Ethiopia showing 14%. [18,19] A meta-analysis of studies compar-

ing HIV positive and HIV negative groups revealed a significant difference in the prevalence of major depression (HIV positive 9.4% vs. HIV negative 5.2%, OR 2.0, CI 1.3–3.0). [20] These studies have indicated that mental distress can be prevented by increasing the awareness about it among mental health personnel. [10,11] The benefit of screening for mental distress is especially important among the HIV infected. Left undiagnosed mental distress leads to failure of the HIV positive to deal with their sero-status [19] with implications of increased substance abuse and suicides. All these put together build the case for early identification of patients with mental distress and prompt psychotherapy [21].

Despite the known benefits, the practice of screening for mental distress as it relates to HIV infection is still low in many countries. In Zambia, little is known about the extent of mental distress. [22] Considering that Zambia has a high prevalence of HIV [14,23,24] and assuming that HIV infection negatively affects mental health, this would suggest that the mental distress problem is substantial. However, few population based studies, i.e. covering men and women in the general population, have been conducted in sub-Saharan Africa to examine the relationship between HIV and mental distress. The aim of this study was to investigate the magnitude and determinants of mental distress with particular emphasis on the mechanisms involved in the way HIV infection impacts mental distress by establishing a linear structural equation model.

## Methods

### Measuring mental distress

A wide variety of questionnaires and instruments have been developed over the years to estimate psychological distress in the population, identify high risk groups for mental disorders and monitor the changes over time. The Self reporting questionnaire (SRQ) is an example of such a scale developed as part of a collaborative study on strategies for extending mental health care co-ordinated by the WHO. [11] Although primarily intended for use in epidemiological studies of mental disorders, it is also being used extensively for clinical and other research purposes. [11] It has been judged to be acceptable for most subjects and was found to be appropriate for use in different kinds of settings and countries. [11,19,25] It is now a well established responder-reported questionnaire for measuring psychological distress or the degree of global mental distress [11]. In this study we use a Self reporting questionnaire with 10 symptom questions which are scored on a dichotomous scale but do not probe to evaluate symptom severity [11]. It has also been shown that the shorter SRQ-10 performs just as well as the longer scales for evaluating mental distress, for example SCL-25 and SF-36 as well as other shorter scales such as SCL-10, SCL-5 and MHI-5. It

has been suggested that it can be used in the place of longer scales for evaluating mental distress and yield comparable results. [25]

**The model**

In this model, a set of several linear equations are connected in a system. Our central theoretical premise is that mental distress has biological, social and psychological determinants. Therefore four hypotheses have been developed and require further testing. Firstly, we propose that, demographic characteristics and socioeconomic position indicators are directly and indirectly associated with mental distress. [19] Male gender, young age, (15–25 years), educational attainment, social support networks (being married vs. single) and wealth index are found to be positively associated with better mental health status. [26] Secondly, self-rated health, and self HIV risk perception and worries of being infected (HIV risk and worry) are also associated with better mental health. [27] Thirdly, we propose that HIV infection has both direct and indirect effects on mental distress. [27] Direct, mediated by biological factors and indirectly mediated through self-rated health and HIV risk and worry of being infected. [27,28]

**Population and Sampling Procedures**

The population-based HIV surveys have been conducted in Zambia every third year since 1996 in selected rural (Kapiri Mposhi) and urban (Chelston) communities. For this investigation we used data from the survey conducted in 2003 (n = 4466) using stratified random-cluster sampling method. The detailed methods of the surveys conducted have been reported elsewhere. [23,29] The sampling frame consisted of 24 clusters (Standard Enumeration Areas) in Chelston and 26 clusters in Kapiri Mposhi. The cluster defined the primary sampling unit of the study. Using probability proportional to size, 10 clusters were selected from each of the areas. All household members 15–59 years in the selected clusters were listed and invited to participate in the study

**Data Collection**

*Personal Interviews*

The data was collected at household level by trained enumerators. Personal interviews were carried out with all eligible and willing household members in order to collect information on socio-demographic characteristics, health seeking behaviour, sexual behaviour and perception regarding HIV. Details of data collection methods have been described elsewhere. [23]

Information on mental distress was collected using Self-reporting questionnaire-10 (SRQ-10) which is a 10 item questionnaire containing basically two domains namely, depressive symptoms and somatisation. The SRQ-10 is based on a dichotomous response answer system to the questions given in table 1 "In the past 30 days".... It is apparent from the review of studies done using the SRQ that no global or generally applicable cut-off score can be recommended and that each study should determine its own cut-off point. [11,25] The rationale for setting the cutoff point of >7/20 in this study was based on the DSM-IV classification. Firstly each symptom was weighted according to severity with the more severe symptoms getting higher ranking, while the less severe symptoms got lower ranking (table 1). The cutoff point was then based on the DSM-IV requirement of 5 or more symptoms under the headings; thoughts of suicide, loss of interest or pleasure and depressed mood. These raw weights are then summed up in a transformed summative index ranging from 1–20. This continuous mental distress variable was used in the SEM model. Based on the DSM-IV criteria for depression which requires 5 or more items of the above that would represent a change in previous functioning, or at least either a depressed mood or loss of interest or pleasure, a cut off point of ≥7 for mental distress was set. [30]

*Laboratory Investigation*

At the end of the interview the participants were requested to provide a saliva sample for HIV testing. The saliva sam-

**Table 1: SRQ-10 diagnostic symptoms and weights**

| Diagnostic Symptom              | Question  | Weight |
|---------------------------------|---|--------|
| A. Thoughts of Death            | <i>Has the thought of ending your life been on your mind?</i>   | 5      |
|                                 | <i>Is your daily life suffering?</i>                            | 3      |
| B. Loss of interest or pleasure | <i>Are you unable to play a useful part in your life?</i>       | 3      |
|                                 | <i>Do you find it difficult to enjoy your daily activities?</i> | 3      |
|                                 | <i>Do you sleep badly?</i>                                      | 1      |
| C. Depressed mood               | <i>Do you cry more than usual?</i>                              | 1      |
|                                 | <i>Do you have difficulties deciding?</i>                       | 1      |
|                                 | <i>Are you tired all the time?</i>                              | 1      |
|                                 | <i>Do you often have Headaches?</i>                             | 1      |
|                                 | <i>Is your digestion poor?</i>                                  | 1      |

ples were collected on an anonymous linked HIV testing protocol. BIONOR HIV 1&2 (BIONOR AS, Skein, Norway) paramagnetic particle assay was used as the first line test. The reactive samples were subsequently tested again using rapid test (Capillus HIV-1/HIV-2, Cambridge Biotechnology). Samples with discrepant results were sent for a confirmatory Western blot. [29]

### Statistical Analysis

Data was analysed using SPSS version 15.0 and cluster effect accounted for in the analyses. Characteristics of the study population in terms of demographic, socioeconomic and HIV status were described using descriptive statistics. These were compared by sex, residence and HIV status in cross-tabulations. Only respondents with valid HIV results and aged 15–49 years were included in the subsequent analysis (N = 4466).

Analysis of Moment Structures (AMOS) version 7.0 was used in the Structural Equation Modelling (SEM) [31] to confirm the theoretical built model that included the underlying factors (demographic and socioeconomic), intermediate factors (self-rated health and HIV risk and worry), HIV status, knowledge of own HIV status and consequently mental distress. Firstly the model was designed and fitted based on the hypotheses. Secondly, regression coefficients and their significant levels for each parameter were calculated. Thirdly, relative chi-square statistic, goodness of fit index (GFI), [32] adjusted goodness of fit index (AGFI), [32] comparative fit index (CFI) [33] and root mean square error of Approximation (RMSEA) [33] index model fitness were obtained for model diagnostics. The criteria used were chi-square statistic of more than 0.50, GFI of equal or greater than 0.95, AGFI of equal or greater than 0.90, CFI greater or equal to 0.90 and RMSEA of less or equal to 0.08. [31-33] Addition of correlations between error terms, considering only the significant correlations as well as putting constraints on the parameters was done to improve the model. The total direct and indirect effects of the underlying and intermediate factors were calculated using standardised regression weights of each pathway with the maximum likelihood ratio as the method of estimation.

In the model, marital status was dichotomised to ever married variable grouped as, single (single, engaged, Living as married) vs. married (Married, divorced, separated, widowed). Level of education was used as a continuous variable (number of years in school). A wealth index scale was constructed using factor analysis from six questions assessing wealth status. A second summative index (HIV risk and worry) was constructed which combined responses to the questions concerning self perceived risk of HIV infection (In your situation, do you think that you are risk of getting (catching) HIV? 1 = you are not at risk,

2 = the risk is moderate or 3 = the risk is high or 4 = the risk is very high) and worry about being HIV infected (How worried are you about actually being infected by HIV/AIDS? 1 = Always worried, 2 = Sometimes worried, or 3 = Seldom worried, or 4 = Never worried). Self-rated health was also used as a continuous variable. (How would you say your health is at the moment? Is it 1 = Excellent, 2 = Good, 3 = Fair, 4 = Poor, 5 = Very poor). The dependant variable mental distress was also used as a continuous variable with scores ranging from 1–20. There was insignificant evidence of interaction between the variables and so no interaction terms were included. Measures were also done to account for design effect which had the effect of widening confidence interval.

### Ethical Clearance

The survey received ethical clearance from the University of Zambia Ethics Committee. Additionally, participation in the survey was based on written informed consent. Participants were counselled and informed that the information obtained was purely anonymous and for research purposes. Participants interested in knowing their HIV status were offered voluntary counselling and testing at home.

### Results

#### Characteristics of study population and extent of mental distress

Table 2 shows a pattern observed from an item to item analysis of the symptoms of mental distress. Daily life suffering (27.4%), frequent headaches (27.4%) and difficulty enjoying life (23.6%) were the most common symptoms among the HIV positive rural males. Comparatively, urban males complained more of poor sleep (21.4%), difficulty deciding (18.3%) and daily life suffering (18.3%). Among the HIV infected rural females poor sleep (23.6), daily life suffering (21.6) and frequent headaches (21.6) were the most common complaints. The urban female population presented with difficulty deciding (33.9%), frequent headaches (28.4%) and difficulty enjoying life (24.0%). Thoughts of suicide represented less than 6% of the total study population. Among the HIV infected, women (8.9%) reported contemplating suicide more than their male (3.0%) counterparts (p = 0.003). A similar pattern was noted among the HIV uninfected (men 3.6%, women 6.4%, p = 0.001)

The prevalence of HIV was 13.6% in rural and 18.0% in urban areas (Table 2). Knowledge of own HIV results was reported by 13.6%, and this knowledge differed clearly by residence, 8.3% in rural and 17.4% in urban (p < 0.001). Of these, 43.4% lived in rural areas and 56.6% were urban residents. The mean (SD) age of the men was 27(8.8) years and 27(8.9) years for women. Marital status differed substantially by residence, i.e. proportion being married

**Table 2: Observed Symptoms of Mental Distress by Sex, Residence and HIV status**

| Symptom                                  | Rural          |                 |                 |                   |        |                 | Urban           |      |        |                   |                 |      |        |                  |                 |      |
|--|----------------|-----------------|-----------------|-------------------|--------|-----------------|-----------------|------|--------|-------------------|-----------------|------|--------|------------------|-----------------|------|
|  | Male (n = 818) |                 |                 | Female (n = 1050) |        |                 | Male (n = 1042) |      |        | Female (n = 1540) |                 |      |        |                  |                 |      |
|  | Total%         | neg%<br>n = 712 | pos%<br>n = 106 | P                 | Total% | neg%<br>n = 902 | pos%<br>n = 148 | P    | Total% | neg%<br>n = 911   | pos%<br>n = 131 | P    | Total% | neg%<br>n = 1206 | pos%<br>n = 334 | P    |
| Sleep badly                              | 13.6           | 12.8            | 17.9            | 0.15              | 15.7   | 14.4            | 23.6            | 0.00 | 11.5   | 10.1              | 21.4            | 0.00 | 16.2   | 14.6             | 21.9            | 0.00 |
| Cry more                                 | 3.1            | 2.9             | 3.8             | 0.65              | 8.4    | 7.8             | 12.8            | 0.04 | 3.4    | 3.2               | 4.6             | 0.41 | 10.7   | 10.0             | 13.5            | 0.06 |
| Difficulty<br>enjoying life              | 15.8           | 14.7            | 23.6            | 0.02              | 14.4   | 13.7            | 18.9            | 0.10 | 19.4   | 19.7              | 17.6            | 0.57 | 18.9   | 17.4             | 24.0            | 0.01 |
| Difficulty<br>deciding                   | 20.2           | 20.2            | 20.8            | 0.90              | 14.5   | 14.2            | 16.2            | 0.52 | 23.1   | 23.8              | 18.3            | 0.16 | 27.3   | 25.5             | 33.9            | 0.00 |
| Daily life<br>suffering                  | 20.0           | 19.0            | 27.4            | 0.04              | 18.3   | 17.7            | 21.6            | 0.26 | 14.0   | 13.4              | 18.3            | 0.13 | 15.0   | 12.8             | 22.8            | 0.00 |
| Unable to<br>play useful<br>part in life | 11.4           | 11.2            | 13.2            | 0.55              | 10.7   | 10.2            | 13.5            | 0.23 | 9.9    | 9.1               | 15.3            | 0.03 | 10.3   | 9.6              | 12.9            | 0.08 |
| Thoughts of<br>suicide                   | 2.0            | 2.2             | 0.9             | 0.38              | 5.1    | 4.5             | 8.1             | 0.07 | 5.2    | 5.3               | 4.6             | 0.74 | 8.1    | 7.8              | 9.3             | 0.38 |
| Tired all the<br>time                    | 13.3           | 12.4            | 19.8            | 0.04              | 12.0   | 11.0            | 18.2            | 0.01 | 7.7    | 6.8               | 13.7            | 0.01 | 11.8   | 10.8             | 15.6            | 0.02 |
| Headache<br>often                        | 18.2           | 17.0            | 27.4            | 0.01              | 23.8   | 24.1            | 21.6            | 0.51 | 17.3   | 17.4              | 16.8            | 0.87 | 27.6   | 27.3             | 28.4            | 0.69 |
| Poor<br>Digestion                        | 14.3           | 13.1            | 22.9            | 0.01              | 8.6    | 8.2             | 10.8            | 0.30 | 7.0    | 6.7               | 9.2             | 0.30 | 6.2    | 5.3              | 9.3             | 0.01 |
| Mental<br>distress*                      | 13.6           | 12.9            | 18.1            | 0.15              | 15.4   | 14.3            | 21.6            | 0.02 | 11.5   | 11.1              | 13.7            | 0.38 | 15.4   | 13.0             | 24.1            | 0.00 |
| Positive<br>Negative<br>ratio:           |                |                 | 1.40            |                   |        | 1               | 1.51            |      |        | 1                 | 1.23            |      |        | 1                | 1.85            |      |

\* Mental distress cut off 7/20 questions given weights and arbitrary cut off point set from literature based on the DSM IV criterion for depression

**Table 3: Proportion of participants and the prevalence of mental distress by residence and background characteristics**

| Characteristics                  | Rural  |      |                     | Urban  |      |                     | Total  |      |                     |
|----------------------------------|--------|------|---------------------|--------|------|---------------------|--------|------|---------------------|
|                                  | Number | %    | Mental distress (%) | Number | %    | Mental distress (%) | Number | %    | Mental distress (%) |
| <b>Age</b>                       |        |      |                     |        |      |                     |        |      |                     |
| 15-19                            | 338    | 18.0 | 12.1                | 480    | 18.5 | 11.8                | 818    | 18.3 | 11.9                |
| 20-24                            | 362    | 19.3 | 13.3                | 464    | 17.9 | 12.3                | 826    | 18.5 | 12.7                |
| 25-29                            | 290    | 15.5 | 16.2                | 391    | 15.1 | 15.5                | 681    | 15.2 | 15.8                |
| 30-39                            | 387    | 20.6 | 15.8                | 614    | 23.7 | 15.3                | 1001   | 22.4 | 15.5                |
| 40-49                            | 242    | 12.9 | 13.9                | 351    | 13.6 | 14.2                | 593    | 13.3 | 14.0                |
| <b>Sex</b>                       |        |      |                     |        |      |                     |        |      |                     |
| Male                             | 822    | 43.8 | 13.6                | 1042   | 40.2 | 11.5                | 1864   | 41.7 | 12.4                |
| Female                           | 1055   | 56.2 | 15.4                | 1547   | 59.8 | 15.4                | 2602   | 58.3 | 15.4                |
| <b>Number of years in school</b> |        |      |                     |        |      |                     |        |      |                     |
| 0-6                              | 867    | 46.7 | 16.1                | 195    | 7.5  | 23.8                | 1062   | 23.8 | 17.5                |
| 7                                | 406    | 21.8 | 14.8                | 254    | 9.8  | 22.8                | 660    | 14.9 | 17.9                |
| 8-9                              | 301    | 16.2 | 14.0                | 472    | 18.3 | 16.2                | 773    | 17.4 | 15.3                |
| 10-11                            | 93     | 5.0  | 15.2                | 410    | 15.9 | 11.5                | 503    | 11.3 | 12.2                |
| >12                              | 194    | 10.4 | 8.3                 | 1250   | 48.4 | 10.2                | 1444   | 32.5 | 9.9                 |
| <b>Ever married</b>              |        |      |                     |        |      |                     |        |      |                     |
| Single                           | 538    | 33.3 | 13.6                | 481    | 18.6 | 13.9                | 1019   | 22.8 | 13.7                |
| Married                          | 1079   | 66.7 | 15.1                | 2102   | 81.4 | 13.8                | 3181   | 71.2 | 14.2                |
| <b>Wealth index</b>              |        |      |                     |        |      |                     |        |      |                     |
| Low                              | 503    | 79.3 | 17.4                | 820    | 75.5 | 26.0                | 1323   | 76.9 | 19.1                |
| Medium                           | 101    | 15.9 | 15.1                | 210    | 19.3 | 17.3                | 311    | 18.1 | 15.8                |
| High                             | 30     | 4.7  | 10.6                | 56     | 5.2  | 12.4                | 86     | 5.0  | 12.1                |
| <b>HIV</b>                       |        |      |                     |        |      |                     |        |      |                     |
| Negative                         | 1621   | 86.4 | 13.7                | 2122   | 82.0 | 12.2                | 3707   | 83.8 | 12.9                |
| Positive                         | 256    | 13.6 | 20.2                | 467    | 18.0 | 21.2                | 716    | 16.2 | 20.8                |

was 66.7% in the rural and 81.4% in the urban population. Whereas 64.3% of the urban residence had attained at least 10 years of education, the respective proportion was 15.4% among rural residents.

The prevalence of mental distress in men was 12.4% and 15.4% in women ( $\chi^2 = 8.033$ ,  $DF = 1$ ,  $p = 0.005$ , i.e. a prevalence ratio, women: men of 1.24. This ratio was

highest in the age-group 15-24 years of 1.6). Mental distress did not differ by residence ( $\chi^2 = 0.190$ ,  $DF = 1$ ,  $p = 0.663$ ) and only tended to increase by age. Mental distress was affected by educational attainment, i.e. the prevalence among urban residents was 2.3 times higher among the group with the lowest vs. the highest level of education, and the respective rural ratio was 1.94. (Table 3) A consistent pattern of higher mental distress among the HIV

**Table 4: Pearson correlation coefficients matrix of the measured variables**

|                                 | 1.      | 2.      | 3.      | 4.      | 5.      | 6.     | 7.     | 8.     | 9.     | 10.  | 11. |
|---------------------------------|---------|---------|---------|---------|---------|--------|--------|--------|--------|------|-----|
| <b>Variables</b>                |         |         |         |         |         |        |        |        |        |      |     |
| 1. Residence                    | 1       |         |         |         |         |        |        |        |        |      |     |
| 2. Sex                          | 0.04*   | 1       |         |         |         |        |        |        |        |      |     |
| 3. Age                          | -0.17** | -0.01   | 1       |         |         |        |        |        |        |      |     |
| 4. Ever married                 | 0.17**  | -0.07** | -0.05** | 1       |         |        |        |        |        |      |     |
| 5. School years                 | 0.54**  | -0.13** | -0.07** | 0.82**  | 1       |        |        |        |        |      |     |
| 6. Wealth index                 | -0.71** | -0.01   | -0.15** | -0.09** | 0.57**  | 1      |        |        |        |      |     |
| 7. Self rated health            | -0.14** | 0.06**  | 0.18**  | -0.03** | -0.18** | 0.17** | 1      |        |        |      |     |
| 8. Risk-worry                   | -0.02   | -0.01   | 0.10*   | 0.01    | -0.01   | 0.02   | 0.14*  | 1      |        |      |     |
| 9. HIV                          | 0.06**  | 0.08**  | 0.21*   | 0.00    | 0.00    | -0.02  | 0.15** | 0.10*  | 1      |      |     |
| 10. Knowledge of own HIV status | -0.31** | -0.07   | 0.08*   | -0.01   | -0.25** | 0.24*  | 0.09*  | 0.05   | 0.03   | 1    |     |
| 11. Mental distress             | -0.01   | 0.04**  | 0.05**  | 0.01**  | -0.09** | 0.07** | 0.22** | 0.15** | 0.08** | 0.04 | 1   |

\* Correlation significant at 0.05

\*\* Correlation significant at 0.01



infected was observed by sex and residence, and the prevalence ratio infected vs. non-infected was 1.61. ( $\chi^2 = 24.141$ ,  $DF = 1$ ,  $p = 0.000$ )

**Correlation Coefficients**

Table 4 shows the Pearson correlation coefficients matrix of the observed variables. Mental distress was correlated to self-rated health ( $r = 0.22$ ), wealth index ( $r = 0.07$ ), risk-worry ( $r = 0.15$ ), HIV status ( $r = 0.08$ ), age ( $r = 0.05$ ) and inversely correlated to school years ( $r = -0.09$ ). Self rated health was inversely correlated to residence ( $r = -0.14$ ), school years ( $r = -0.18$ ), marital status ( $r = -0.30$ ) and directly correlated to wealth index ( $r = 0.17$ ) and age ( $r = 0.18$ ). Risk-worry was correlated to self rated health ( $r = 0.14$ ) and age ( $r = 0.10$ ,  $p < 0.05$ ). HIV status was correlated to self rated health ( $r = 0.15$ ), risk-worry ( $r = 0.10$ ) and age ( $r = 0.21$ ).

**Final Model**

Figure 1 illustrates the final model with significant pathways and their associated goodness of fit indices. The model diagnostics indicated that the underlying factors, residence, school years, ever married and age were inter-correlated. However the error terms of Self-rated health, risk-worry, HIV status and mental distress were not corre-

lated. The observed measures of model fitness were as follows: Chi-square for goodness-of-fit test ( $\chi^2 = 237.7$ ,  $DF = 12.0$ ,  $p < 0.001$ ), baseline comparisons (NFI = 0.931, CFI = 0.934) and parsimony-Adjusted measures (PRatio = 0.333, PCFI = 0.311, PNFI = 0.310, RMSEA = 0.037).

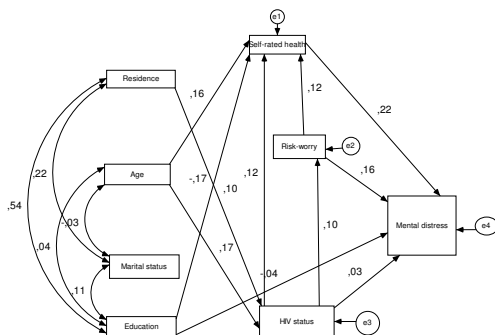
**Structural relationships between observed variables**

Table 5 shows significant structural relationships between the underlying, intermediate and outcome variables. Mental distress was directly related to risk-worry ( $b = 0.16$ ), HIV status ( $b = 0.03$ ) and self-rated health ( $b = 0.22$ ). Self-rated health is related to age ( $b = 0.17$ ), risk-worry ( $b = 0.12$ ) and HIV status ( $b = 0.12$ ). It was also directly related to school-years ( $b = 0.17$ ). Risk-worry is directly related to both HIV ( $b = 0.09$ ) while HIV status was found to be directly related to residence ( $b = 0.10$ ) and age ( $b = 0.10$ ).

**Mediating Factors**

Table 6 shows the total, direct and indirect effects of the observed independent variables on the dependant variables. Self-rated health and risk-worry appear to be important mediators between underlying factors and mental distress. They are also important mediators between HIV status and mental distress. Age is directly related to HIV status ( $B = 0.17$ ). It is also directly related to Self-rated health (mediated by risk-worry and HIV status,  $B = 0.17$ ) and indirectly related to mental distress (mediated by risk-worry and HIV status,  $B = 0.05$ ). Residence is directly related to HIV status ( $B = 0.10$ ) and indirectly related to mental distress mediated by risk-worry and HIV status with a small total effect  $B = 0.01$ . Number of school years is directly related to self-rated health ( $B = 0.17$ ) and indirectly related to mental distress (mediated by risk-worry and HIV status,  $B = -0.04$ ). Risk-worry is related to mental distress both directly and indirectly (Total effect  $B = 0.20$ ). Self-rated health is directly related to mental distress ( $B = 0.22$ ). HIV status is related to mental distress both directly and indirectly mediated by risk-worry and self-rated health (Total effect = 0.07).

Path diagram of structural equation model



The goodness of fit indices (Standardised estimates)

|            |       |      |       |         |        |
|------------|-------|------|-------|---------|--------|
| Chi-square | 237.7 | DF   | 12.0  | P-Value | <0.001 |
| NFI        | 0.931 | CFI  | 0.934 | PRATIO  | 0.333  |
| PCFI       | 0.311 | PNFI | 0.310 | RMSEA   | 0.037  |

**Figure 1**  
**Significant pathways of the final model and goodness-of-fit indices.** DF = degrees of freedom, NFI = Normed fit index, CFI = comparative fit index, PRatio = Parsimony ratio, PCFI = parsimony comparative fit index, PNFI = parsimony Normed fit index, RMSEA = Root mean square error approximation.

**Discussion**

We investigated the magnitude and distribution patterns of mental distress and employed a structural equation model to explore mechanisms involved in the impact of HIV on mental distress. Data stem from a population based HIV survey in Zambia using the SRQ-10 as the tool to measure mental distress. The prevalence of HIV was 13.5% and 18.2% for the rural and urban population, respectively, and most of the survey participants (86.4%) did not know their own HIV status. The prevalence of mental distress was somewhat higher among women (15.4%) than among men (12.4%,  $p = 0.005$ ), but no urban-rural difference was revealed. The results suggest the effect of HIV infection on mental distress to be both

direct and indirect, and particularly strong through the indirect effects of poor health ratings and high self perceived risk and worry of HIV infection. In this regard it should be noticed that self-rated health has previously been found to capture changes in health perceptions related to HIV.[28] In the model, this impact appears to be socially patterned with the number of school years being indirectly related to mental distress in a pattern mediated by self-rated health, risk-worry and HIV status. Age and residence were found to be directly related to HIV status but indirectly related to mental distress in a path mediated also by risk-worry and self-rated health.

Although complex, our model obviously represents an oversimplification of the factors at play. The empirical basis for this structural model might be somewhat shaky, but we judge the plausibility of most specifications to be fairly strong. The theoretical basis underlying the specifications of the model is also thought to be fairly strong as the introduced measures in the present model have been judged to cover most of the dimensions postulated by other authors. The fit indices for our model show a close fitting model. However, the chi-square test as a measure of fit is best for models with N = 75 to N = 100. [31,33,34] For N>100, chi square is almost always significant since the magnitude is affected by the sample size, as in our case where N = 4466 (p = 0.000). Chi-square is also affected by the size of correlations in the model: the larger the correlations, the poorer the seeming fit of the model. [34]

The results confirm previous findings suggesting a strong impact of HIV infection on mental distress. [35,36] In this present study only 13% knew their own HIV status, accordingly, we are likely to have measured a combination of HIV-related effects both biological and psychological. Based on HIV epidemiological evidence we can assume that, on a group level, most HIV infections in

young people are resent and that in older groups we can expect that the HIV positive on average have been infected longer and thus will have experienced much more serious impact on their immune system. A simple assumption in our analysis will thus be that the difference in mental distress between HIV infected and uninfected will increase by age. The data did not provide clear evidence of this. However, in the suggested path diagram, to model the determinants of mental distress, self-rated health and self perceived risk and worry about being HIV infected (risk-worry) were assumed to capture indirect effects of HIV on mental distress. Self-rated health has previously been found to capture changes in health perceptions related to HIV. [28] Literature on predictors of self-rated health has shown depression as a strong independent determinant even after accounting for physical illness and functional disability. [37,38] Therefore, self-rated health and risk-worry appear to be sensitive indicators of health changes linked to HIV and mental distress. [28,37] We found strong independent associations between HIV and self-rated health, HIV and risk-worry and between self-rated health, risk-worry and mental distress. A possible interpretation is that the three variables are together capturing effects of HIV – being direct as a biological – or an indirect as a psychological effect. These findings need to be followed up by further studies trying to sort out what could be the more biological versus other effects of HIV infection on mental distress. The estimates may also have been biased by measurement errors. We were unable to find comparable studies on mental distress covering the general population of men and women. Most studies found were conducted among selected groups such as homosexuals, injection drug users and hospital/clinic attendees. [18,35,39,40] It was as such difficult to make direct comparisons with other published literature. However, the patterns of association appear to be similar to other published literature. [18,19,41-43]

**Table 5: Structural relationships between observed variables**

| Observed variables |                       | b <sup>b</sup> | B <sup>a</sup> | P-value <sup>c</sup> |
|--------------------|-----------------------|----------------|----------------|----------------------|
| Age                | --->HIV status        | 0.06           | 0.10           | < 0.001              |
| Residence          | --->HIV status        | 0.07           | 0.10           | < 0.001              |
| HIV                | --->Risk-worry        | 0.47           | 0.09           | < 0.001              |
| HIV                | --->Self-rated Health | 0.23           | 0.12           | < 0.001              |
| School year        | --->Self-rated Health | 0.03           | 0.17           | < 0.001              |
| Risk-worry         | --->Self-rated Health | 0.05           | 0.12           | < 0.001              |
| Age                | --->Self-rated Health | 0.01           | 0.17           | < 0.001              |
| HIV                | --->Mental distress   | 0.27           | 0.03           | 0.04                 |
| Self-rated Health  | --->Mental distress   | 1.05           | 0.22           | < 0.001              |
| Risk-worry         | --->Mental distress   | 0.32           | 0.16           | < 0.001              |
| School years       | --->Mental distress   | -0.04          | -0.04          | 0.002                |

b<sup>b</sup> = Unstandardised regression Coefficients  
 B<sup>a</sup> = Standardised regression Coefficients  
 P-value<sup>c</sup> = P-value for unstandardised regression coefficients

**Table 6: Total, direct and indirect effects of observed variables**

| Observed variables | Effect <sup>a</sup> | Age  | Residence | School years | Risk-worry | HIV status | Self-rated Health |
|--------------------|---------------------|------|-----------|--------------|------------|------------|-------------------|
| HIV Status         | Total               | 0.17 | 0.10      | -            | -          | -          | -                 |
|                    | Direct              | 0.17 | 0.10      | -            | -          | -          | -                 |
|                    | Indirect            | -    | -         | -            | -          | -          | -                 |
| Risk-worry         | Total               | 0.02 | 0.01      | -            | -          | 0.10       | -                 |
|                    | Direct              | -    | -         | -            | -          | 0.10       | -                 |
|                    | Indirect            | 0.02 | 0.01      | -            | -          | -          | -                 |
| Self-rated health  | Total               | 0.19 | -0.01     | 0.17         | 0.12       | 0.13       | -                 |
|                    | Direct              | 0.17 | -         | 0.17         | 0.12       | 0.12       | -                 |
|                    | Indirect            | 0.02 | 0.01      | -            | -          | 0.01       | -                 |
| Mental Distress    | Total               | 0.05 | 0.01      | -0.08        | 0.20       | 0.07       | 0.22              |
|                    | Direct              | -    | -         | -0.04        | 0.17       | 0.03       | 0.22              |
|                    | Indirect            | 0.05 | 0.01      | -0.04        | 0.03       | 0.04       | -                 |

<sup>a</sup> Standardised regression weight

The SRQ-10 appears to be a practical tool for measuring mental distress although more needs to be done to validate its use in the Zambian context. In order to attain a more accurate standard for the diagnosis of global mental distress, the 10 indicator questions were weighted and a cut off point of 7 set based on the adapted criterion for the DSM-IV classification for depression. [30] The question of generalization of findings (national, regional levels) is difficult to judge. The communities from which this study was conducted were selected on the basis of being reasonably representative in terms of HIV prevalence and cultural mix to the other communities in Zambia. It is likely that the HIV-mental distress relationship can be extrapolated to the national level and to many other countries in the region as well. [29]

Non-participation might have been one of the possible sources of biases in prevalence estimates and associations in this investigation. Whereas refusal to participate was low, the non-participation due to absence was relatively high among men. The 2003 population-based survey was a follow-up of previous surveys in the same populations (since 1995). Previous publications investigating the HIV prevalence trends on the basis of these repeated surveys reported marked HIV declines since 1995, and the authors did not find any sign of substantial bias due to non-response. [29] For the present analysis we are concerned about the extent to which non-response might have biased prevalence of mental distress and the associations. Given an assumption that non-responders were more likely to be mentally distressed than responders, we would have under-estimated the magnitude of distress and most likely reduced the strengths of associations. Men were substantially more likely to be absent, and a possibility given the above scenario is that the difference between men and women was actually under-estimated. However, there were limited opportunities to further assess the magnitude and direction of this type of bias.

There are a number of limitations of this study. One is the cross-sectional nature of the survey data, which limits the validity of statements of causation to statements only about associations. However, our main interest was not to establish causal pathways, but rather patterns of interrelationships in the data that would fit to a better or worse degree the assumptions of our theoretical premise. Strictly speaking just as mental distress can predispose to HIV infection, the converse is also theoretically possible. It should be noted that the associations revealed in cross-sectional data have very often provided reliable indications of actual effects, and the revealed strong indirect association between HIV status and mental distress is in agreement with previous findings [35,40] The ubiquitous problem of omitted variables is also a factor in this present study. The relationship between mental distress and HIV could also be attributable to other factors not included in our analysis. Examples include employment status, other social and economic factors or indeed other stress inducers not included in our analysis. Further, a more optimal design would have been needed to measure the biological effect of HIV infection adequately to include information on HIV clinical staging and CD4 counts. The data were not affected by antiretroviral treatment effects, since such treatment in practical terms was not available in these populations in 2003.

## Conclusion

The results suggest that HIV infection has a substantial effect on mental distress both directly and indirectly. This effect was mediated through self-perceptions of health status, found to capture changes in health perceptions related to HIV, and self-perceived risk and worry of actually being HIV infected. To our knowledge this is the first study to investigate the pattern of relationship between HIV and mental distress by using the structural equation modeling. The use of the structural equation modeling allowed for simultaneous evaluation of the direct and

indirect effects of background and intermediate factors on mental distress within the framework of the model. More research is urgently needed into this area in order to understand the epidemiology of mental distress and the complex inter-relationship with HIV infection. This may provide many new challenges and open other avenues for dealing with the HIV epidemic and its many facets. Subsequent research needs to be directed to local validation of the SRQ-10. It would also need to assess the mental and behavioral changes occurring in individuals who are HIV positive and are commenced on highly active anti-retroviral drugs. Among the many challenges is how to improve prevention, screening and diagnosis for mental distress as targeted at the most vulnerable groups, such as the poor, the lower educated, the women, the widowed and predominately the HIV infected. Another challenge is strengthening existing mental health facilities and capacity building in order to improve access to universal basic mental health care. This is of critical importance as it would provide knowledge, confer skills necessary for assimilating health promotional information on HIV which in turn is likely to be linked to both reduced risk of mental distress and HIV transmission.

### List of Abbreviations

HIV: Human Immunodeficiency Virus; AIDS: Acquired Immunodeficiency Syndrome; CD4: Cellular differentiation marker 4; HAART: Highly Active Anti-retroviral Therapy; SRQ-10: Self Reporting Questionnaire-10; DSM IV: Diagnostic and Statistical Manual IV; ICD-10: International Classification of Diseases version 10; AMOS 7: Analysis of Moment Structures version 7.0; SEM: Structural Equation Modeling; GFI: Goodness of Fit Index; AGFI: Adjusted Goodness of Fit Index; CFI: Comparative Fit Index; RMSEA: Root Mean Square Error of Approximation.

### Competing interests

The authors declare that they have no competing interests.

### Authors' contributions

PJC and KMF contributed to the analysis and drafting of the manuscript. KMF also contributed to the design, conduct, and critical revision of manuscript and approval of final version.

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## Comparative Validity of Screening Instruments for Mental Distress in Zambia

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### Abstract:

**Background:** The recognition of mental health as a major contributor to the global burden of disease has led to an increase in the demand for the inclusion of mental health services in primary health care as well as in community-based health surveys in order to improve screening, diagnosis and treatment of mental distress. Many screening instruments are now available. However, the cultural validity of these instruments to detect mental distress has rarely been investigated in developing countries. In these countries, limited trained staff and specialized psychiatric facilities hamper improvement of mental health services. It is therefore imperative to develop a quick, low cost screening instrument that does not require specialized training. We validated different well established screening instruments among primary health care clinic attendees in Lusaka, Zambia. We also assess the face, content and criterion validity of the SRQ's and determined the most commonly reported symptoms for mental distress.

**Methods:** The screening instruments, SRQ-20, SRQ-10 and GHQ-12 were used as concurrent criteria for each other and compared against a gold standard, DSM-IV. Their correlation, sensitivity and specificity were assessed. All instruments were administered to 400 primary health care clinic attendees. In-depth interviews were also conducted with 28 of these clinic attendees.

**Results:** Both the SRQ-20 and SRQ-10 had high properties for identifying mental distress correctly with an AUC of 0.96 and 0.95 respectively while the GHQ-12 had modest properties (AUC, 0.81). The optimum cut-off points for this population were 7 and 3 for the SRQ and GHQ-12 respectively. The SRQ was also found to have good face and content validity.

**Conclusion:** The study establishes the utility of the SRQ-20 for detecting mental distress cases and also underscores the importance of validating instruments to suit the context of the target population. It also validates the SRQ-10 as the first reliable abbreviated and easy-to-use screening instrument for mental distress in primary health care facilities in Zambia.

**Keywords:** Mental distress, Screening instruments, Validity, Primary health care, SRQ-10, SRQ-20, GHQ12, DSM-IV, Zambia.

### BACKGROUND

Several investigations have shown that mental distress is common among health care seekers at primary health care centres but are not often identified, treated or referred [1]. Over the years, there has been increased attention to ways to improve the screening, diagnosis and treatment of mental distress in these patients. In many developing countries, trained staff and specialized psychiatric facilities are few and limited to urbanized areas [1]. Therefore in these countries, quick and low-cost means that do not require specialized training for assessing mental distress are essential. The ideal instrument should therefore be comprehensive, psychometrically sound and valid across cultures, age, sex, socio-economic and language background. This would require that the instrument be tested in different settings to enable comparisons between population groups within and across countries.

Among the most widely used self-administered tools are the Self Report Questionnaire (SRQ) and the General Health Questionnaire (GHQ) [2, 3]. Since the development of these instruments, detection rates for mental distress have steadily been increasing when employed in clinical settings or health surveys. Studies conducted in Ethiopia have revealed that between 6-18% of attendees at general outpatient clinics have mental distress [4-8]. These questionnaires have been tested in multicentre studies and have been translated into many languages [1, 3]. They have also been compared with other standardized psychiatric assessment in community based surveys and in primary care studies in developing countries [9, 10]. In Chile, the SRQ-20 and the GHQ-12 were simultaneously validated against the criterion of the Revised Interview Schedule (CIS-R) in a primary care setting. The results showed small differences between the SRQ and GHQ though the SRQ was found to be slightly more specific than the GHQ (77% vs. 73%) but closely comparable with regards to sensitivity (76% vs 74%) [2]. A similar study in Brazil revealed the Pearson correlation between the two scales to be 0.72, with the validity coefficients for SRQ and GHQ being: sensitivity 83% vs. 85% and specificity 80% vs. 79% respectively. This study concluded that both

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instruments showed similar results [11]. The relatively few studies conducted in Sub-Saharan Africa have shown similar results, for example, Bhagwanjee *et al.* showed an unweighted sensitivity and specificity of 93.9% and 62.5% when the SRQ-20 was compared against the DSM-IV schedules for common mental disorders [12], while Reeler and Todd found sensitivity and specificity in the range of 80% [13]. Similar studies have been conducted among highly selected groups such as prenatal and postnatal women and in association with post-traumatic stress disorder in ex-combatants [14, 15]. From, Zambia we could only find two studies which used the SRQ to measure mental distress. The first study validated the SRQ-20 by elucidating explanatory models for mental illness among low-income women while the other investigated the prevalence and determinants of mental distress and discussed the factors mediating its impact on HIV using the SRQ-10 as a screening instrument [14, 16]. Both studies, however, did not compare the SRQ to other established instruments and did not investigate the optimum cut-off point to be used for the Zambian population.

Most of these mental distress screening instruments started off as long, tedious and comprehensive scales which covered all dimensions of the universe of psychological/psychiatric constructs under study. However, with time they have been abbreviated in order to make them easy for use in busy clinic setting as well as in settings where some patients maybe illiterate and requiring the questionnaire to be read out to them. Emerging epidemiological studies investigating the correlation, reliability, the sensitivity and specificity between the long versions and the abbreviated versions of the instruments have shown that the later are just as capable (or even better) of identifying psychological distress. [17-19]. Good to excellent inter-rater agreement (Kappa coefficients) have been reported with abbreviated instruments and thus they have been judged to be acceptable and appropriate for use in different kinds of settings and countries [1, 20]. Overall these studies concluded that the subscales covering psychological distress functioned well and appeared to reflect a broad dimension of depression and anxiety disorders. The results also suggest that the shorter versions are valid and perform almost as well as the full versions, if not better, implying that these tools can be used inter-changeably, at least where depression is concerned [17, 18]. Along side considerations for an instrument's ability to identify cases, the factors that influence misclassification of cases also need due consideration. Several investigations have shown that misclassification by these questionnaires are significantly associated with social and demographic variables (education and sex), males being more likely than females to be misclassified as false negatives while the poorly educated respondents as false positives [2]. Other studies have attributed misclassification to language barriers, motives and cultural differences [21]. In a feasibility study conducted in Ethiopia using the SRQ-24, only moderate criterion validity was found. The limitations for this instrument in this study, was attributed partly due to it being very sensitive to help-seeking patterns of behavior by the participants. As a result, participants were found to be mentally distressed even in the absence of any mental illness. The study also revealed problems in trans-cultural communication because many of the diagnostic concepts used in this instrument were too "west-

ern" to be transposed unchanged to the Ethiopian culture. It was thus concluded that the items in the instruments needed fairly extensive modification to be applicable in the Ethiopian context [22].

In this paper we investigate the correlation, sensitivity and specificity, and we calculate the area under the curve (AUC) of receiver operating characteristics for various cut off points for the SRQ-20, SRQ-10 and GHQ-12 among primary health care clinic attendees in Lusaka, Zambia. The SRQ's and GHQ-12 are used as concurrent criteria for each other against the DSM-IV as the gold standard. We also assess the face, content and criterion validity of the SRQ's and determine the most commonly reported symptoms for mental distress in these scales.

## METHODS

### The Setting and Study Design

A concurrent nested mixed method research design was used (Fig. (1)). We assessed attendees at 4 primary health care centers run by the government of the republic of Zambia between December 2008 and May 2009. These clinics were purposely selected within the city of Lusaka, two of which were clinics in very high density areas (Kalingalinga and Mtendere) while the others were clinics in a medium density area (Chilenje and Chelston). The residents of these areas speak a number of languages but mainly English and Nyanja.

### Procedure

A pilot study was first conducted at Kabwata clinic (outside the study sites) (Fig. (1)). Forty-five outpatients were interviewed and based on the results it was decided that the questionnaire would be read to all the participants irrespective of their education level. A time sample of 400 clinic attendees aged 16 years and over was asked to participate in the study between January and March 2009. The purpose of the study was explained to each participant by the research assistants and consent was asked for. Each clinic was sampled randomly on selected days, 3 times each week. On the selected day, interviews were conducted with consecutive clinic attendees at the clinic outpatients department.

### Quantitative Procedures

A brief social and demographic questionnaire was administered to all the participants by research assistants who had received training in carrying out interviews. The interviews lasted approximately 10 minutes. Information on participant's demographic characteristics, including age, gender, educational attainment, residence and marital status, was collected using standard questionnaire items. The participants were also asked in what language they wanted the interview to be carried out. Socioeconomic position was assessed using the participant's educational attainment, employment status and an asset index based on items intended to reflect household wealth. These included household ownership of appliances (TV, radio, refrigerator, electricity, bicycle, plough, cattle and donkey) and other household resources (running water in the home, type of toilet, type of floor, and type of roofing material). A summative wealth index was then constructed which was categorized into low, medium and high wealth index. The participants were also asked to rate their own health status by answering the ques-

tion: How would you say your health is at the moment? Is it, (1) Very poor, (2) Poor, (3) Fair, (4) Good, or (5) Excellent? The recent life events were evaluated by events occurring in the previous 12 months based on whether the participant had experienced (1) Break-up of a marriage (2) Break-up of a sexual relationship, (3) Physical abuse, (5) Neglected or dis-owned by family or (6) loss of a loved one.

The SRQ-20 and the GHQ-12 were used to measure global mental distress. These interviews were conducted by interviewers of the same sex as the participant. The participants were then classified into two groups according to their scores on the SRQ-20 (low, 0-7; high 8+) and GHQ-12 (low, 0-3; high, 4+). Subsequently these participants were directed to a medical officer who held a clinical interview with them for the ailments that brought them to the clinic as well as conducting a psychiatric inquiry where the DSM-IV schedules for common mental disorders was used to determine the presence and diagnosis of a psychiatric disorder. The general health assessment and the mental distress assessment were done at the same time so that the patients were not delayed due to the study. The clinical interview was conducted blind, without the knowledge of the questionnaire results.

### Qualitative Procedures

In the second part of the study, in-depth interviews were conducted in a subsample of 28 participants nested within the quantitative sample. The sample consisted of participants who were classified as being high scorers (14 participants) and low scorers (14 participants), on the basis of the SRQ-20 score >7 and GHQ-12 score >3. These interviews were used to assess face and content validity.

#### Face Validity

This facet simply indicates if on the face of it, the SRQ appears to assess meaningful and relevant qualities. Normally this facet is based on a review by a panel of experts. In its original development the SRQ was assessed by a panel of experts from different countries who selected SRQ items from different questionnaires. In this study the approach to assess face validity was to ask the target population what they think the instrument is suppose to measure.

#### Content Validity

This consists of a determination of whether the instrument captures all the relevant concepts and if it is representative of the battery of questions that could have been asked for individuals under study. It is closely related to face validity since it also requires validation-by-assumption by a panel of experts. However the concept of content validity that we adopt here is a subjective judgment based on a review of the various items by the respondents. We thus asked the respondents to interpret their "yes" responses to the items in the SRQ-20. We also asked them to give us as many examples as possible to support their answer. We additionally asked them what remedy they think would work to abate the symptoms. Answers to these probing questions were used as a basis to ascertain whether the yes-answer had the same meaning for the respondent as it did for the investigator. The three stages considered in this study at which a yes-answer maybe invalid were the language of the interview, concepts

and motives behind the "yes" answer. The interviews took approximately 20 minutes per session.

### Instruments

#### Self-Reporting Questionnaire- 20 (SRQ-20)

The SRQ-20 was developed by the World Health Organisation (WHO) as a screening tool for common mental disorders [1]. It was primarily developed for use in primary health care settings, especially in developing countries. Originally (SRQ-25) it consisted of 25 questions, 20 related to neurotic symptoms, 4 concerning psychosis and 1 asking about convulsions. This study concentrates on the SRQ-20, which (consists of 20 yes/no questions) assesses presence of neurotic symptoms (anxiety, depression, psychosomatic) mainly because few patients with functional psychosis come spontaneously to primary health centres and so usually more active case finding by primary health workers in the community is required. Secondly, psychotic patients are often easily recognised as being psychotic and in most cases, are unaware of their condition. Hence, the use of a questionnaire to detect psychoses is questionable. The SRQ-20 has been tested in numerous settings. Depending on the setting, community surveys or primary care, varied cut-off points have been used although cut-off point of 7/8 is widely used [1]. As far as we know no such study with equal representation of men and women has been conducted in Zambia.

#### Self-Reporting Questionnaire-10 (SRQ-10)

The SRQ-10 is basically an abbreviated version of the SRQ-20. The instrument contains a weighted sum of 10 symptom questions which have dichotomous responses but do not probe to evaluate symptom severity. The scale measures the following symptoms over the preceding 30 days by asking: In the past 30 days: *Do you sleep badly?*, *Do you cry more than usual?*, *Do you find it difficult to enjoy your daily activities?*, *Do you find it difficult to make decisions?*, *Is your daily life suffering?*, *Are you unable to play a useful part in life?*, *Has the thought of ending your life been on your mind?*, *Do you feel tired all the time?*, *Do you often have headaches?*, *Is your digestion poor?* We have previously used this instrument in population based studies in Zambia and yielded results that were comparable to those of studies done using the SRQ-20 [16]. However, to our knowledge comparisons between the abbreviated versions and the full versions of Self-Reporting Questionnaires have not been done in Zambia and we could not find similar studies done elsewhere.

#### General Health Questionnaire- 12 (GHQ-12)

The General Health Questionnaire is a screening instrument designed for use in general practice but has been shown to be valid for use in community surveys as well [19]. It was originally a 60 item questionnaire but subsequently a number of abbreviated versions have been derived. Thus, there are the 30-, 28-, 20- and 12- item versions. All these versions have been subjected to many validity studies and the authors reported validity indices that suggest that these are widely acceptable tools for detecting psychiatric morbidity. The

instrument contains 12 symptom questions which are scored on a four-point likert scale ranging (0-1-2-3) from much-less-than-usual to much-more-than-usual. However, in the analysis this scale is often collapsed to a dichotomous scale (0-0-1-1). Depending on the setting, community surveys or primary care, varied cut-off points have been used although cut-off point of 3+ is widely accepted as indicative of psychiatric morbidity [23].

### Gold Standard

#### *Diagnostic and Statistical Manual of Mental Disorder 4<sup>th</sup> Edition (DSM-IV)*

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is the standard classification of mental disorders used by mental health professionals. It is intended to be applicable for use across settings, inpatient-outpatient clinics, primary care, and with community populations. It has been used by clinicians and researchers of many different orientations such as psychiatrists, psychologists, social workers, occupational and rehabilitation therapists, and other health and mental health professionals. It is also a necessary tool for collecting and communicating accurate public health statistics. The DSM has a diagnostic classification, which is the list of the mental disorders that are officially part of the DSM system and making a DSM diagnosis consists of selecting those disorders from the classification that best reflect the signs and symptoms that are afflicting the individual being evaluated. For each disorder, a set of diagnostic criteria indicating what symptoms must be present (and for how long) in order to qualify for a diagnosis are provided [24]. The use of these diagnostic criteria has been shown to increase diagnostic reliability (i.e. likelihood that different users will assign the same diagnosis) [23]. The DSM-IV is widely accepted and used as the gold standard for psychiatric diagnosis in Zambia.

### Instrument Translation

All the instruments were translated into Nyanja and Bemba as these are the most predominantly spoken languages in Lusaka. The results from the pilot study also confirmed that participants who did not speak English opted to be interviewed in Nyanja or Bemba. These instruments were then back translated to English by bilingual translators from the linguistics department of the University of Zambia. Discrepancies that were found were discussed further by a group that included the principle investigator, translators and a medical doctor from the psychiatric hospital. This was to ensure face validity as well as conceptual meaning. Few final changes were made after the pilot study.

### Training of Study Staff

A team of three male and three female interviewers who had no experience in mental health care administered the SRQ-20 and the GHQ-12. They, however, all had previous experience administering questionnaires in other epidemiological studies. A three day training session was conducted in administering the instruments. This involved explanation and discussion of conceptual definitions of each item in the instruments and role playing. This was followed by a 1 day field test.

### Ethical Issues

The Research and Bioethics Committee of the University of Zambia and the Ministry of Health, through the Lusaka District Health Office approved this study. Permission to conduct the study was also further sought from the authorities in charge of the Primary Health Centres. The study was conducted in accordance with the guidelines of Good Clinical Practices in biomedical research.

### Statistical Analysis

The data was analysed using SPSS version 15. In this study, receiver operating characteristic (ROC) analysis was used to identify a cut-off point for the SRQ-10, SRQ-20 and GHQ-12 as defined with the DSM-IV as the gold standard. This plots sensitivity against 1-specificity for each possible cut-off point. The sensitivity and specificity here being the fraction of true positive cases and true negative cases correctly identified by the screening tools respectively. Each ROC is characterised by an area under the curve (AUC) which generally indicates the overall accuracy of the questionnaire over a range of cut-off points to distinguish between cases and non-cases. AUC ranges between 0.0 to 1.0 with 1.0 indicating perfect prediction and 0.5 indicating a prediction equal to chance. Hence we used the AUC to compare the screening tools over the total range of scores. We performed a factor analysis with varimax rotation to check for measurement equivalence. This refers to the equivalence of construct or theoretical validities across populations, which is a prerequisite for the comparison of prevalence rates or mean scores of the scales [25]. Independent t-tests were performed to compare the scales between sexes while the Pearson Chi-square was used to compare the psychiatric diagnosis in the same groups. We also calculated Pearson correlation coefficients to examine the relationship between the scales.

## RESULTS

### Socio Demographic Characteristics

The sample was composed of 400 respondents who completed the SRQ-20 and the GHQ-12 and were subsequently referred to the Medical Doctor for clinical interview using the DSM-IV. These respondents were visiting the four Primary Health Care (PHC) centres for various medical reasons. Ten patients were not included because they refused the clinical interview. There were, however, no significant differences between the total sample and the participants that refused the clinical interview in sex ratio, wealth status, marital status and educational attainment. The respondents who were ethnically from the Bemba speaking tribes accounted for 26% of the total study population, while 16% were Nyanja and only 12% were Tonga. However almost half of the respondents preferred English as the language for the interview, while the others preferred Nyanja and Bemba (38.8% and 8.5% respectively). The sample had 167 (41.8%) men and 233 (58.3%) women (Table 1). The male patients ranged in age between 16 and 67 years with a mean of 32 years (SD=11.1). Female patients ranged between 16 and 65 years with a mean of 29 years (SD=9.4). The majority of participants were married (64%). Most of the patients had more than 8 years of education (secondary 56% vs. tertiary

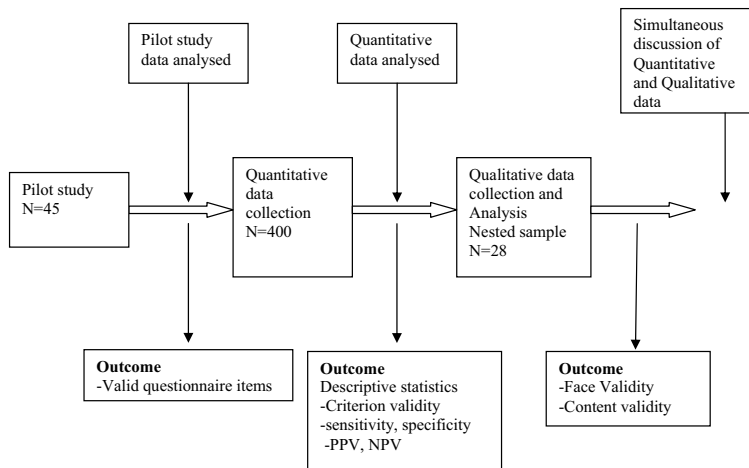


Fig. (1). Study design.

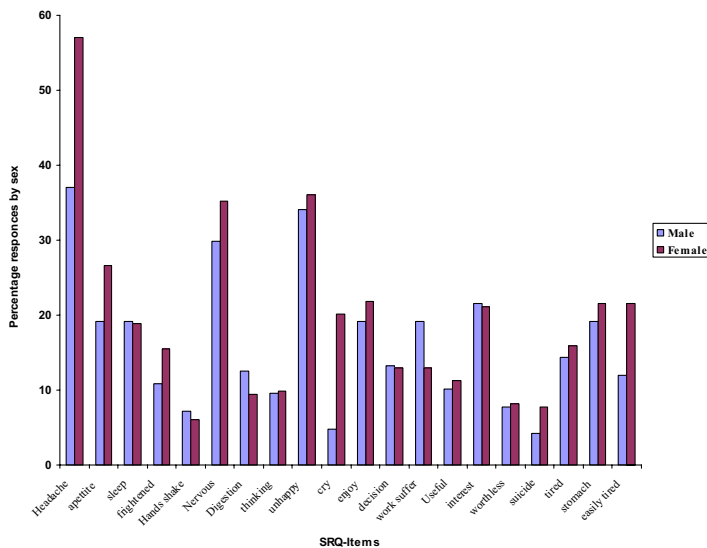


Fig. (2). Item by Item analysis of responses to SRQ-20.

19.5%) while 3.8% were illiterate. There were no statistical differences between the clinics serving the medium and high density catchment areas in terms of marital status ( $t= 1.139$ ,  $p=0.06$ ,  $\eta^2 =0.00$ ), wealth index ( $t=0.198$ ,  $p=0.418$ ,  $\eta^2 = 0.00$ ) and educational level ( $t=0.284$ ,  $p=0.777$ ,  $\eta^2 = 0.00$ ).

**Outcomes on SRQ-20, GHQ-12 and SRQ-10**

Principal component analysis with varimax rotation of the SRQ-20 items revealed a two factor model (common disorders and social disability) that explained 50.1% of the variance.

A similar model was extracted from the SRQ-10 and explained 50.2% of the variance, while three factors (Common

disorders, social dysfunction and loss of confidence) were extracted from GHQ-12 items by the same procedure explaining 49.9% of the variance. The factor structure of these instruments was similar to that reported in other studies [2, 26, 27]. We as a result found support for the measurement equivalence between the SRQ and GHQ-12 instruments. The correlation between the SRQ-20 and SRQ-10 was 0.85 while the correlation between these instruments and GHQ-12 scales was found to 0.60 and 0.52 respectively. Independent  $t$ -tests were used to compare differences in the continuous instrument scores between men and women and no significant differences were found. For comparison of definitive psychiatric diagnosis between males and females chi-square test was used and found to be insignificant ( $p=0.370$ ). Over-

Table 1. Social and Demographic Factors

| Characteristic        |            | Number (%) of Respondents |                 |                |
|-----------------------|------------|---------------------------|-----------------|----------------|
|                       |            | Male (N= 167)             | Female (N= 233) | Total (N= 400) |
| Age                   | 16-24      | 31.7                      | 36.6            | 34.6           |
|                       | 25-29      | 13.2                      | 25.9            | 20.6           |
|                       | 30-39      | 29.9                      | 25.9            | 27.6           |
|                       | 40-49      | 16.2                      | 7.3             | 11.0           |
|                       | 50+        | 9.0                       | 4.3             | 6.3            |
| Marital status        | Single     | 44.3                      | 30              | 36.0           |
|                       | Married    | 55.7                      | 70              | 64             |
| Education             | Illiterate | 1.8                       | 5.2             | 3.8            |
|                       | Primary    | 11.4                      | 27.2            | 20.6           |
|                       | Secondary  | 60.5                      | 53.0            | 56.1           |
|                       | Tertiary   | 26.3                      | 14.7            | 19.5           |
| Wealth index          | low        | 24.8                      | 39.1            | 33.4           |
|                       | middle     | 33.3                      | 33.5            | 33.4           |
|                       | High       | 41.8                      | 27.4            | 33.2           |
| Language of Interview | English    | 62.3                      | 39.9            | 49.3           |
|                       | Nyanja     | 29.3                      | 45.5            | 38.8           |
|                       | Bemba      | 6.0                       | 10.3            | 8.5            |
|                       | Other      | 2.4                       | 4.3             | 3.5            |
| Gold standard         | DSM-IV     | 12.9                      | 14.0            | 13.6           |
|                       | Depression | 11.0                      | 11.0            | 11.0           |
|                       | Anxiety    | 0.6                       | 2.6             | 1.8            |

all the prevalence of common mental disorder as diagnosed by the DSM-IV classification was 13.6%, and was found to be mainly depression (10.8%) anxiety disorders (1.8%). The prevalence tended to be higher in females than males (women 14% vs. men 12.9%,  $p=0.743$ ). An item-by-item analysis of the SRQ also revealed that females on average reported more symptoms of mental distress than the males (Fig. 2).

#### Criterion Validity

This part of the analysis focuses on the ability of the SRQ-20, GHQ-12 and SRQ-10 to screen for psychopathology (mental distress). Fig. (3) shows that SRQ-20 and SRQ-10 performed well with the area under the curve (AUC) being 0.96 and 0.95 respectively while the GHQ-12 had a modest AUC of 0.81. When analyzed separately for men and women no clear tendencies to perform better by sex were noted (Figs. 4, 5). Table 2 shows the sensitivity, specificity, positive predictive values, and negative predictive and kappa's values of the scales with different cut-off points. The most appropriate cut-off point was a trade off between sensi-

tivity and specificity. Since these instruments are meant to be used as screening instruments, the optimal cut-off point is one with high sensitivity and an acceptable specificity. The optimal cut-off for both SRQ-20 (sensitivity 0.85, specificity 0.94) and SRQ-10 (sensitivity 0.81, specificity 0.96) was 7, while that for GHQ-12 was 2 (sensitivity 0.66, specificity 0.86). Further analysis by sex did not reveal any significant differences in cut-off points.

#### Content Validity of the SRQ

The study to assess the content validity was conducted in a subsample of the quantitative study. It included 28 respondents, 15 (53.6%) of whom were male while 13 (42.9%) were female. The respondents had an average of 9 school years being slightly higher in males than in females (10 years vs. 8 years respectively). Over half (53.6%) reported that they were married, 39.3% were single while less than 1% were either, divorced, separated or widowed. Half of the respondents preferred to have the interview conducted in English while 23% preferred Bemba while 28.6% preferred Nyanja. The 28 respondents gave the yes-answer a total of

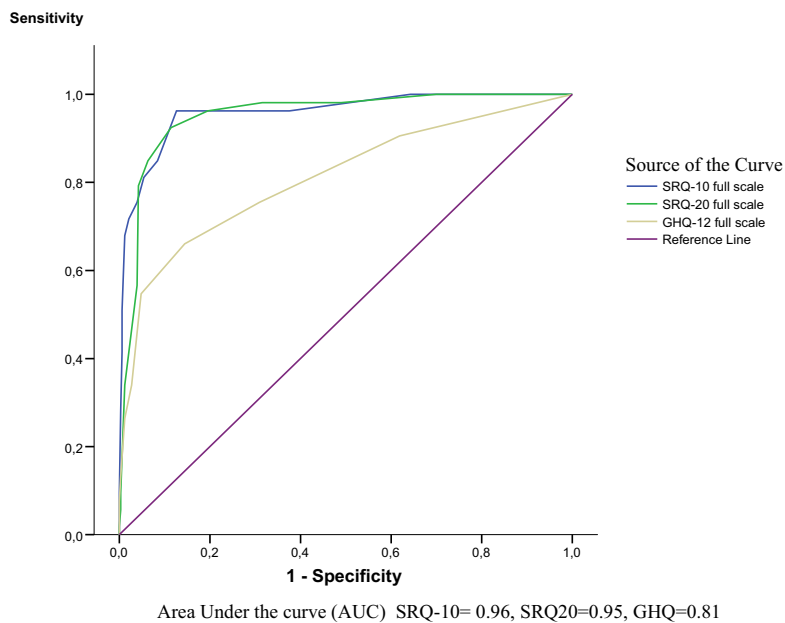


Fig. (3). Sensitivity, Specificity AUC for SRQ-20, SRQ-10 and GHQ-12 (combined).

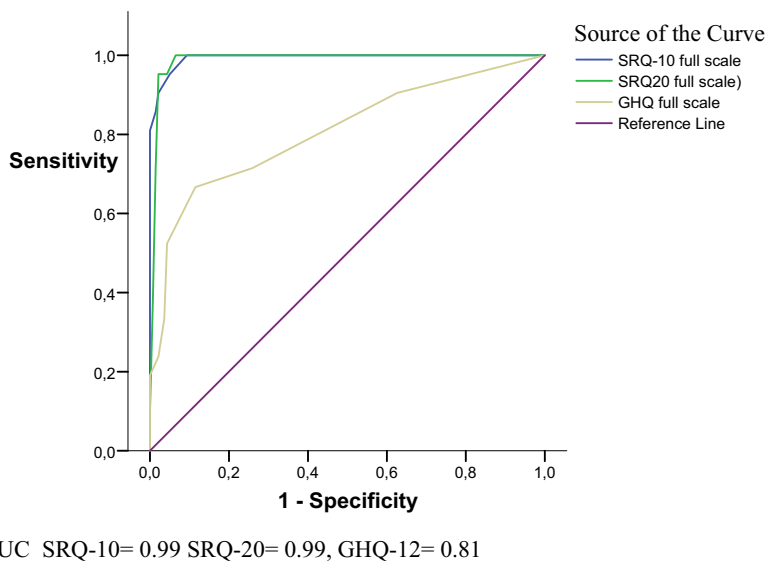
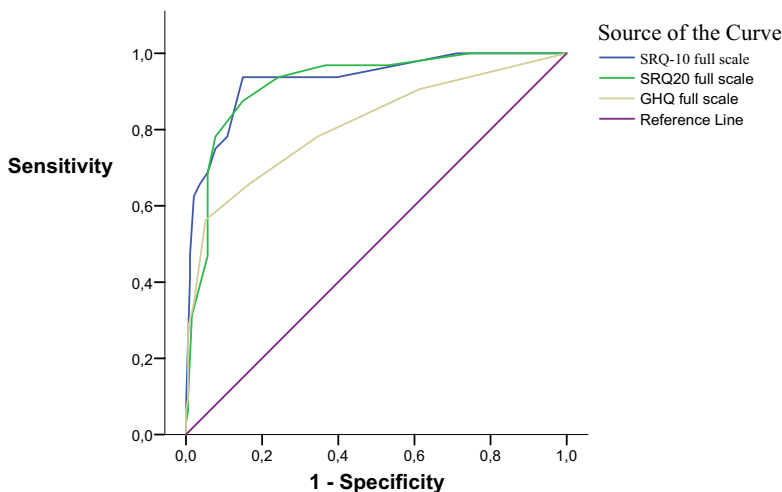


Fig. (4). Sensitivity, Specificity AUC for SRQ-20, SRQ-10 and GHQ-12 (Males).

205 times on the SRQ. Invalidity of these answers was considered on two main stages listed below. The results are presented in Table 3.

**Conceptualization**

Differences in conceptualization of the question by the respondent were recorded in 25% of the yes-answers given.



AUC SRQ-10=0.93, SRQ-20=0.92, GHQ-12= 0.81

Fig. (5). Sensitivity, Specificity AUC for SRQ-20, SRQ-10 and GHQ-12 (Females).

Table 2. Criterion Validity for SRQ-20, SRQ-10 and GHQ-12

|       | Scale  | Cut-off | Sensitivity | Specificity | PPV  | NPV  | % of Cases Screened Correctly | k    | %Cases |
|-------|--------|---------|-------------|-------------|------|------|-------------------------------|------|--------|
| Total | SRQ-20 | 7       | 0.85        | 0.94        | 0.68 | 0.97 | 92.6                          | 0.71 | 16.5   |
|       |        | 8       | 0.79        | 0.96        | 0.75 | 0.97 | 93.6                          | 0.73 | 14.0   |
|       |        | 9       | 0.57        | 0.96        | 0.70 | 0.93 | 90.8                          | 0.57 | 10.8   |
|       | SRQ-10 | 7       | 0.81        | 0.95        | 0.71 | 0.97 | 92.8                          | 0.71 | 15.3   |
|       |        | 8       | 0.76        | 0.96        | 0.76 | 0.96 | 93.3                          | 0.72 | 13.3   |
|       |        | 9       | 0.71        | 0.98        | 0.84 | 0.96 | 94.4                          | 0.74 | 11.3   |
|       | GHQ-12 | 2       | 0.66        | 0.86        | 0.43 | 0.94 | 83.2                          | 0.42 | 21.6   |
|       |        | 3       | 0.57        | 0.95        | 0.67 | 0.93 | 90.2                          | 0.56 | 11.9   |
|       |        | 4       | 0.34        | 0.97        | 0.67 | 0.90 | 88.6                          | 0.39 | 6.8    |

“Do you have headaches often?” All the invalid answers given to this question were attributed to the presence of other intercurrent illness namely hypertension, malaria and toothaches. However the question largely managed to uncover information indicating the headache as a symptom of depression and/or anxiety.

“Do you have uncomfortable feelings in your stomach?” - Among those giving invalid answers, this question was understood as an inquiry into presence of gastrointestinal ailment. The reasons most frequently given were: “Yes because I suffer from “gas” in my stomach” and “Yes I get uncomfortable feeling when I eat beans”. Contrary the questions; “Is your digestion poor?” and “Is your appetite poor?” performed very well with the most frequent answer among

the valid answers being: “Yes, I don’t feel like eating because I have many thoughts and even when I feel like eating I have problems swallowing or I get full easily”.

Anxiety Items: “Are you easily frightened? Do your hands shake? Do you feel tense or worried?” These items seemed to have a narrow meaning in the context of our study, and were interpreted as being an enquiry into literal feeling or state of being afraid. The most frequent answer was: “Sometimes, especially if I am threatened or if I am in trouble with spouse”. We also probed the no-answers to these items and we found the same responses suggestive of the fact that being frightened, hands shaking or feeling tense or worried is associated with literal fear. This concept does not seem to exist in our sample unless there is a clear reason



**Table 3. Content Validity of SRQ**

| SRQ-Items   | Yes-Answers<br>N= 205 | Reasons for Invalid Answers |                        |           |
|---|-----------------------|-----------------------------|------------------------|-----------|
|   |                       | Concepts n (%)              | Language/Motives n (%) | Total (%) |
| 1. Headache*  | 16                    | 4 (25)                      | -                      | 25        |
| 2. Appetite   | 9                     | 2 (22.2)                    | 2 (22.2)               | 44.4      |
| 3. Sleep*   | 17                    | 3 (17.6)                    | 1 (5.9)                | 23.5      |
| 4. Easily frightened  | 5                     | 5 (100)                     | -                      | 100       |
| 5. Hands shaking  | 5                     | 3 (60)                      | 2 (40)                 | 100       |
| 6. Feel nervous   | 6                     | 1 (16.7)                    | -                      | 16.7      |
| 7. Poor Digestion*  | 7                     | 2 (28.6)                    | 5 (71.4)               | 100       |
| 8. Trouble thinking clearly                                     | 11                    | 1 (9)                       | 1 (9)                  | 18.2      |
| 9. Unhappy  | 16                    | -                           | -                      | -         |
| 10. Cry more*   | 11                    | 1 (9)                       | 1 (9)                  | 18.2      |
| 11. Enjoy activities*   | 7                     | -                           | 2 (28.6)               | 28.6      |
| 12. Difficulty deciding*  | 5                     | -                           | 1 (20)                 | 20        |
| 13. Work suffering*   | 16                    | 4 (26.7)                    | 2 (13.3)               | 37.5      |
| 14. Useful in life*   | 13                    | 1 (7.7)                     | 4 (30.8)               | 38.5      |
| 15. Loss of interest  | 10                    | 4 (40)                      | 2 (20)                 | 60        |
| 16. Worthlessness   | 10                    | -                           | -                      | -         |
| 17. Thoughts of suicide*  | 5                     | -                           | -                      | -         |
| 18. Always tired*   | 9                     | 7 (77.8)                    | 1 (11.1)               | 88.9      |
| 19. Stomach   | 8                     | 4 (50)                      | 3 (37.5)               | 87.5      |
| 20. Easily tired  | 9                     | 7 (77.8)                    | 1 (11.1)               | 88.9      |
| Depression Items <sup>§</sup><br>(Items 10, 11, 12, 13, 14, 17) | 57                    | 6 (10.5)                    | 10 (17.9)              | 28.4      |
| Somatic items <sup>§</sup><br>(Items 1,3, 7, 18)                | 49                    | 16 (32.6)                   | 7 (14.3)               | 46.9      |

\* <sup>§</sup> Items included in SRQ-10.

for it and so the items failed to uncover the information suggestive of anxiety.

“Do you feel tired all the time?” Was interpreted by the respondents as asking about whether they get tired easily as regards work rather than an enquiry pertaining to depression. The most frequent answer was “Yes I get tired because of work since I work very long hours”.

### Language and Motives

We assigned a yes-answer to this invalidity category if the question had to be repeated one or more times or if it needed further explanation before an answer was obtained. We also assigned, to this category, respondents who said they didn’t understand or who answered “I do not know” to the questions posed. We also included in this category respondents who insisted on the yes-answer but were unable or unwilling to give further details or examples of experiences

that would help us to clearly define the underlying psychopathology. Respondents who also directly indicated that they thought by participating in the interview they would be “fast-tracked” to see the doctor were also assigned to this category, although these accounted for less than 1%. This kind of invalid answers were observed in 15.6% of the yes-answers and was attributed to not understanding the content of the question and complexity of the words used.

### Face Validity of SRQ

Within the subsample we also assessed the face validity of the SRQ by asking the respondents what they thought the instrument was supposed to measure and we also probed further by asking the respondents what they thought the aim of these questions were. The SRQ was found to have good face validity with 71.4% of the respondents saying that we were assessing mental health. The most common response

was that we were measuring “problems of the mind and soul” (53.6%) while 17.9% said we were assessing stress and depression. The proportion who said they did not know the aim of the questions was 28.6%.

## DISCUSSION

We employed a concurrent nested mixed methods research design (QUAN qual) in a cross-sectional study conducted in four primary health care centers in the city of Lusaka aimed at comparing the validity of the SRQ-10 against that of the SRQ-20 and GHQ-12 in the screening for mental distress. DSM-IV was used as the gold standard. Overall the SRQ-10 showed good criterion validity at the optimum cut off point of 6/7 with the area under the curve (AUC) being 0.96 with good sensitivity and specificity (0.85 and 0.94 respectively). It was highly correlated to the SRQ-20 and only modestly to GHQ-12. (0.85 vs. 0.52) The SRQ-10 was also found to have good face validity. Content invalidity was found surrounding the anxiety items (Frightened, handshaking and nervous) and some somatic items (Headache, abdominal symptoms and tiredness). This was attributed mostly to conceptualization and to a less extent Language and motives. The prevalence of mental distress was found to be 13.6% compared with 15.3% based in the SRQ-10. This point prevalence is close to what was found in a population survey conducted in Zambia [16], and falls within the range of reported prevalence of mental distress in the region [28, 29].

We compared the abbreviated SRQ-10 with the widely validated SRQ-20. Different validation coefficients have been reported for the SRQ-20 in these countries [1, 11]. A study in Kenya validated SRQ against the Clinical Interview Schedule (CIS) and reported specificity of 93.3% and specificity of 89.2% [10], while a study in Ethiopia reported a sensitivity range of 68.4%-85.7% and specificity ranging between 62%-75.6% when they validated the SRQ against the Edinburgh postnatal depression scale (EPDS) [15]. In our study we found very high correlation coefficient between SRQ-10 and SRQ-20 with similarly high validation coefficients. The minor differences in the coefficients could be due to the use of different gold standards. It might also be attributed to the differing samples to which the instruments were applied. The validation coefficients reported here might also be somewhat higher because the study was conducted in an urban population with an average of education of 8 years and 50% of whom preferred English as the language of the interview. Comparison of the SRQ-10 and the GHQ-12 revealed a rather modest correlation coefficient despite GHQ-12 having acceptable validation coefficients. The validation coefficients we found were lower than those reported in other studies [2, 19]. This could be attributed to the negative phrasing of its items. Often the questions had to be rephrased several times for the respondent to understand. The likert scale also proved to be confusing for the respondents and challenging to score for the research assistants. This challenge with scoring the GHQ-12 has also been reported by other authors who have questioned the best method of scoring [30-32] and the value of the using the likert scoring system [29, 32]. Another plausible reason is the cut off point we used for the GHQ-12. Although the cut off point we used is similar to that used in other studies, evidence suggests that using the median score

as the cut off point is better than using the mean score or other predetermined cut off points, especially in population which are “GHQ naïve” [33].

Broadly speaking, the validity coefficients did not seem to be affected by the socio-demographic factors as there were no statistically significant relationships noted. It was therefore unnecessary to use a different cut off point for men and women. These findings are different from some other studies that have suggested a higher false negative rate in men than in women attributed to the fact that expression of emotion would be stigmatizing among men [11].

The SRQ-10 showed good criterion validity overall although a limited percentage of participants gave invalid answers to some items on somatic symptoms. Several reasons can be given to explain this but the most important seemed to be related to communication problems based on different conceptual meaning. Improvement of the translation and further adjustment tailored to culturally understandable concepts may solve this problem. Other studies have reported poor criterion validity possibly related to health seeking behavior of the clinic attendees, i.e. a tendency to give more yes-answers in an attempt to receive special attention, a medical certificate or in order to be “fast-tracked” along in the queue [21, 22]. However, this was not revealed in our study. The anxiety items on the SRQ-20 appeared to have performed poorly, a finding that has also been reported in other studies as well. An investigation in Lesotho reported similar low reporting of anxiety symptoms due in part to poor understanding of the anxiety items. Respondents in this study tended to be moderately impaired by anxiety and often reported that they did not know what caused their symptoms [29]. It was suggested that understanding of these items can be enhanced by adjusting and translating the items into a locally palatable context. These anxiety items are however, not part of the SRQ-10 and the benefits of including them into the SRQ-10 were not immediately apparent. Literature has shown before that depressive disorders in Sub-Saharan Africa are more common than anxiety disorders [29, 34]. This has been confirmed in our study. It has also been reported that generalized anxiety disorders presents mainly as a mixed syndrome with depressive features in developing countries. A simple assumption can therefore be made that the depressive items in the SRQ-10 will also capture cases of anxiety disorder [1, 12, 35].

This study has limitations and strengths. Participants were restricted to urban settings with relatively high education attainment compared to rural populations. The external validity of the validation results might be difficult to judge. However, the instrument seems to be rather robust and the findings were closely related to studies conducted in a variety of communities, and this gives an indication that these findings can be extrapolated to the national level and even above – to the regional level. Furthermore, the sample size was relatively small and future validations should consider employing larger sample sizes. The main strength of the study stems from the fact we were able to draw upon universally acceptable etic instruments (SRQ-20 & GHQ-12) which have been used extensively in various countries and cultural orientations as comparatives for the SRQ-10. We also made an effort to strengthen the clinical and cultural validity via a

standard translation and back-translation process and ensuring retention of the original meaning of the questions. This process gave us reasonable confidence to use these instruments across cultures [36, 37]. We also adopted a concurrent nested mixed methods design which was a powerful tool in illuminating the content validity of the SRQ-items, hence supplementing the overall strength of these results. We believe therefore that these validation results can form a valid and reliable basis for further research in this field in the region.

## CONCLUSION

The present study has found that the SRQ-10 is a practical tool for measuring mental distress in primary health care. It has been shown to be robust when compared to other widely validated tools. (SRQ-20& GHQ-12) It has also been shown that the dichotomous response system appears to hold an advantage over the likert scales as it appeared to be easier to understand and yielded better results than those of an instrument scored on a likert scale. (GHQ-12) This has been shown to be true in other studies as well where the instruments were used for screening purposes [16, 29]. The SRQ-10 also holds an operational advantage as it is a shorter scale making it a more attractive option for use in busy primary health care services, in mental health surveys and also in general health surveys. To cover the whole range of mental disorders or to make diagnosis, it is imperative that it is coupled with other more comprehensive diagnostic scales [1].

## IMPLICATIONS OF THE STUDY

It has been reported previously that somatic symptoms associated with physical illness are often signs of mental distress [1, 37, 38]. In our study the respondents did not come to the clinic primarily for mental health problems but for other physical illnesses. This underscores the usefulness of screening questions for mental distress to patients with various medical conditions as this will help to identify at-risk individuals. The study is also a call for the adoption of the SRQ-10 as preferred simple, straightforward protocol screening tool as most mental health screening tools are long and tedious imposing unbearable strain on the busy and understaffed health workers. We feel that the question items can easily be incorporated into existing patient assessment protocols, thus enhancing case finding at primary health care level.

## LIST OF ABBREVIATIONS

|        |   |  |
|--------|---|--|
| SRQ-20 | = | Self-Reporting Questionnaire 20  |
| SRQ-10 | = | Self-Reporting Questionnaire-10  |
| GHQ-12 | = | General Health Questionnaire   |
| DSM-IV | = | Diagnostic and Statistical Manual of Mental Disorder 4 <sup>th</sup> Edition |
| QUAN   | = | Quantitative   |
| qual   | = | qualitative  |
| ROC    | = | Receiver Operating Characteristics   |
| AUC    | = | Area Under the Curve   |

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RESEARCH ARTICLE

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# Conceptual models for Mental Distress among HIV-infected and uninfected individuals: A contribution to clinical practice and research in primary-health-care centers in Zambia

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## Abstract

**Background:** Mental distress is common in primary care and overrepresented among Human Immunodeficiency virus (HIV)-infected individuals, but access to effective treatment is limited, particularly in developing countries. Explanatory models (EM) are contextualised explanations of illnesses and treatments framed within a given society and are important in understanding an individual's perspective on the illness. Although individual variations are important in determining help-seeking and treatment behaviour patterns, the ability to cope with an illness and quality of life, the role of explanatory models in shaping treatment preferences is undervalued. The aim was to identify explanatory models employed by HIV-infected and uninfected individuals and to compare them with those employed by local health care providers. Furthermore, we aimed to build a theoretical model linking the perception of mental distress to treatment preferences and coping mechanisms.

**Methods:** Qualitative investigation nested in a cross-sectional validation study of 28 (male and female) attendees at four primary care clinics in Lusaka, Zambia, between December 2008 and May 2009. Consecutive clinic attendees were sampled on random days and conceptual models of mental distress were examined, using semi-structured interviews, in order to develop a taxonomic model in which each category was associated with a unique pattern of symptoms, treatment preferences and coping strategies.

**Results:** Mental distress was expressed primarily as somatic complaints including headaches, perturbed sleep and autonomic symptoms. Economic difficulties and interpersonal relationship problems were the most common causal models among uninfected individuals. Newly diagnosed HIV patients presented with a high degree of hopelessness and did not value seeking help for their symptoms. Patients not receiving anti-retroviral drugs (ARV) questioned their effectiveness and were equivocal about seeking help. Individuals receiving ARV were best adjusted to their status, expressed hope and valued counseling and support groups. Health care providers reported that 40% of mental distress cases were due to HIV infection.

**Conclusions:** Patient models concerning mental distress are critical to treatment-seeking decisions and coping mechanisms. Mental health interventions should be further researched and prioritized for HIV-infected individuals.

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## Background

Mental disorders contribute substantially to the global burden of disease, accounting for 15% of all disability-adjusted-life-years and up to 30% of those attributable to non-communicable diseases[1,2]. Factors emphasizing the role of poverty including economic deprivation, lack of social support structures, gender disadvantage [3]and medical illnesses are major determinants of mental distress and risk factors for new episodes of affective disorders[3]. There is much debate concerning the most effective way to measure mental distress. Several instruments, most of which are based on self-report systems, have been suggested for detecting mental distress, including the Self-Reporting questionnaire (SRQ), Symptom Check List (SCL) and General Health Questionnaire (GHQ), and the validity of these methods have been published[4-6]. Cultural construction of mental distress is important[7,8]. Debate concerning the significance of cultural construction in relation to mental distress has led to increased interest in explanatory models that focus on mental disorders in different communities [9-11]. Such models influenced the inclusion of an outline for the cultural formulation of "culture-bound syndromes" in the fourth version of the Diagnostic Statistical Manual of Mental Disorders (DSM-IV revised) [12]

In Zambia, literature concerning specific definitions and the perception of mental distress is limited, as mental health is generally not prioritised in terms of service provision [13]. However, rates of mental and emotional illness are thought to be increasing in Zambia owing to socio-economic difficulties that precipitate mental problems including HIV/AIDS, poverty and lack of employment[4,5,14]. Mental illness is generally viewed from two broad perspectives, community and cultural[13]. The community view perceives good mental health or "a sound mind" as the ability to execute roles and responsibilities expected within a given social and cultural context. In contrast, mental illness, whether mild or severe, is associated with disruptive behaviour, straitjackets, and mental institutions[12,13]. In Zambia, cultural beliefs concerning the cause of mental illness centre on possession by spirits or social punishment; many hold the belief that mental illness is caused by witchcraft and therefore cannot be treated by modern medicine but only through traditional means. A lack of proper information and the dominance of misleading presentation have led to a negative portrayal of mental illness, and sufferers are collectively and unjustifiably categorized and rejected, regardless of the form of mental illness [13,15].

Such categorization often leads to mistreatment and isolation of mentally ill individuals [15]. A qualitative

study in Zambia revealed that mental health patients utilizing health services felt stigmatized and discriminated against, and a further study investigating the quality of life of women suffering from mental illness revealed similar results[14,15]. The stigma attached to mental illness caused both community and health decision-makers to view sufferers with low regard, leading to stigmatization of families across generations, institutions that provide treatment, psychotropic drugs and mental health workers [15]. Such attitudes are an obstacle to the provision of care as they result in a reluctance to invest resources into mental health care and discrimination in the provision of services for physical illness among those who are mentally ill. The studies outlined above concluded that mental illness is a complex and diverse disorder, and that there is need to employ a multi-dimensional approach for the diagnosis and management of mental illness in public health institutions.

## Explanatory Models

Explanatory models (EM) are defined as an understanding or explanation of episodes of illness and treatment, framed within the context of cultural beliefs and norms of a given society, and employed by all engaged in the clinical process and the interaction between healer and patient that is central to the health care system[14]. Rather than adopting a single explanatory perspective, as is often the case with traditional theories of science, i.e. etiological models, a range of compelling evidence indicates that mental distress involves causal pathways that act both within and outside the individual[12]. Therefore, it is imperative that mental distress is understood in terms of biological, psychological, social and cultural perspectives. In order to do this, probing questions must be answered in a qualitative interview leading to multi-layered responses that include information concerning social factors, knowledge, coping strategies and symptom narratives. Information relating to a patient's view leads to a better understanding of their illness, its cause and meaning, treatment regimes and the recovery process. Individual variations in a patient's conceptualisation of the illness have been identified as important in determining help-seeking and treatment behaviours, preference of treatment, ability to cope and quality of life, [12,13] and these may differ substantially from conventional medical concepts held by health professionals but must be taken into account in the clinical process. This is particularly important in developing countries where pluralistic health systems are commonplace and pose challenges to health planning because the socio-cultural context of the illness leads to 'traditional' therapy rather than focusing on conventional medical concepts.



### **Explanatory Models, Mental Distress and HIV infection**

HIV infection is associated with psychological problems and psychiatric disorders, and in a study carried out in Zambia the effects of HIV infection on mental distress were demonstrated to be direct (biological) and indirect (psychological)[3]. Psychological effects were prominent and socially patterned, and females with poor socio-economic position and poor social support were at highest risk of developing mental distress. Furthermore, evidence suggests a heightened risk of contracting HIV infection among individuals suffering from mental disorders[1,15]. Mental distress is relevant to HIV disease progression as it can lead to decreases in CD4 T lymphocytes and increases in viral load, and is associated with an increased risk of clinical decline and mortality [16]. Mental disorders can mediate delayed help-seeking and therefore diagnosis, and poor compliance in terms of taking prescribed medication, and can predict individuals dropping out of HIV-risk reduction programmes. Although there are many data concerning the association between HIV infection and mental distress and the importance of explanatory models of mental distress, there has been little research concerning explanatory models for mental distress during HIV infection. There is a high prevalence of HIV and mental distress in the general population of Zambia [3] but only one study has investigated explanatory models of mental health among low-income women and health care practitioners[9]. This study revealed that the most commonly-used phrase among women to define and explain mental health problems was "problems of the mind" but only physical symptoms were defined as an illness. The results identified socio-economic standing and the home environment as key factors in mental distress, particularly the quality of marital relationships. The study concluded that greater awareness of explanatory models was essential and would have beneficial effects on the formulation of health policies concerned with mental health[9].

The present study considers the importance of explanatory models for improving the provision of mental health services. As far as we are aware, there have been no studies in Zambia or elsewhere in the sub-Saharan region to investigate explanatory models for mental distress during HIV infection. Therefore, this study compared explanatory models used by HIV-infected individuals, uninfected individuals and local health care providers (traditional healers and health professionals). We aimed to explore the narratives of the personal lives and health of individuals using the following key research questions: 1. what are the explanations used for mental distress in Zambia? 2. Are the explanatory models used by people attending primary health care clinics consistent with those of health professionals working in

these institutions? 3. What is the significance of explanatory models in mental health in Zambia? In addition, we aimed to build a theoretical model linking the perception of illness to the course of the illness and resultant coping mechanisms, based on a locally validated self-reporting questionnaire. (SRQ-10)

### **Methods**

#### **Setting and study design**

This research was part of a larger study aimed at validating the use of SRQ-10 as a screening instrument and to assess mental health changes in people living with HIV/AIDS (PLWHA)[3,4]. We assessed primary health seekers at four primary health care centers in Lusaka, Zambia between December 2008 and May 2009. The clinics were purposely selected within the city of Lusaka; two were situated in very high population density areas (Kalingalinga and Mtendere) and the others were situated in a medium density area (Chilenje and Chelston). The residents of these areas speak a number of languages but predominantly English and Nyanja.

#### **Sampling procedure**

In the validation study, a sample of 400 clinic attendees aged 16 years and over was asked to participate in the study between January and March 2009. Each clinic was sampled randomly on selected days, three times each week. On the selected day, interviews were conducted with consecutive clinic attendees in the outpatients department. The purpose of the study was explained to each participant by research assistants and verbal consent was obtained. Details of the methodology are published elsewhere[3]. To fulfill the aims of the explanatory models for the mental distress study, a sample of 28 informants was taken from the validation study. This sample consisted of 14 informants who were HIV negative and 14 who were HIV positive. Of the 14 informants who were HIV-infected, eight were not eligible for ARVs and the remainder had been taking ARVs for varying durations. An effort was made to balance the gender and age distribution across these categories. Household in-depth interviews were conducted to gather additional and detailed data concerning the explanatory model for mental distress in Zambia. Eight eligible health professionals working in a mental institution were interviewed at their respective public health facilities. Three identified indigenous healers who reported treating mentally distressed people were interviewed.

#### **Data collection**

Data were collected using a semi-structured questionnaire and serial in-depth interviews. The questionnaire contained a section comprising questions pertaining to

**Table 1 SRQ-10 diagnostic symptoms**

|                                 |  |
|---------------------------------|--|
| A. Thoughts of Death            | <i>Has the thought of ending your life been on your mind?</i>  |
| B. Loss of interest or pleasure | <i>Is your daily life suffering?<br/>Are you unable to play a useful part in your life?<br/>Do you find it difficult to enjoy your daily activities?</i>                                       |
| C. Depressed mood               | <i>Do you sleep badly?<br/>Do you cry more than usual?<br/>Do you have difficulties deciding?<br/>Are you tired all the time?<br/>Do you often have Headaches?<br/>Is your digestion poor?</i> |

Chipimo PJ, Fylkesnes K. *Mental distress in the general population in Zambia: impact of HIV and social factors*. BMC Public Health. 2009; 9 (298). doi:10.1186/1471-2458-9-298

socio-demographic factors such as sex, age, marital status and number of children, education, employment, religion and questions assessing socio-economic position. The other section contained questions concerning mental health. This information was extracted from the database of the main Validity study[4-6]. Eligibility for participation was based on the participant's HIV status and being mentally distressed, as determined using a locally validated Self-Reporting-Questionnaire-10 (SRQ-10), a 10 item questionnaire containing two domains, namely depressive symptoms and somatisation. The SRQ-10 is based on a dichotomous response answer system (Yes/No) to the questions presented in table 1. Each symptom was weighted according to severity based on the DSM-IV criteria, with more severe symptoms ranked higher than less severe ones[4-6]. The raw weights were summed up in a transformed summative index ranging from 0-20. A cut-off point of >7/20 (for mental distress cases) was selected on the basis of the DSM-IV requirement of five or more symptoms under the headings: thoughts of suicide, loss of interest or pleasure, and depressed mood, which would represent a change in a participant's previous functioning[4-6].

Informants classed as mental distress cases underwent further qualitative interviews to elicit the explanatory models. A modified, adapted and contextualised interview schedule developed by Kleinman [17] was used to elicit the explanatory models for mental distress

(Table 2). To compare the explanatory models, this interview schedule was administered to all groups in the study (HIV negative individuals, HIV positive individuals and health care practitioners). The interviews with health care practitioners were conducted in English and designed to draw upon their experience of attending to patients and eliciting explanations for the causes of mental distress in the study population profile.

#### Data analysis

Socio-demographic characteristics were extracted from the database of the main study[4-6]. Tape-recorded in-depth interviews (IDIs) were transcribed verbatim either directly in the case of interviews conducted in English or from the language of the interview (Nyanja or Bemba) to English. Initial analyses were carried out manually using the code sheet, which is an interpretative approach to identifying common themes in a data reduction strategy[18]. A sheet containing all phrases representative of the five models was created and the names of models were used as codes. These standardized codes were assigned to the same or similar phrases. In this case, phrases refer to responses given according to the question posed. Common phrases were grouped together and placed under the same or similar sub-theme. Themes described the codes, and the codes were representative of names of models. Themes that were grouped together provided unique and contrasting

**Table 2 Kleinman Interview schedule for explanatory models**

|    |   |
|----|---|
| 1. | <i>What do you call your problem? What name does it have?</i>   |
| 2. | <i>What do you think caused the problem?</i>  |
| 3. | <i>Why do you think it started when it did?</i>   |
| 4. | <i>What does your sickness do to you? How does it work?</i>   |
| 5. | <i>How severe is it? Will it have a short or long course?</i>   |
| 6. | <i>What do you fear most about your illness?</i>  |
| 7. | <i>What are the chief problems your sickness has caused for you?</i>  |
| 8. | <i>What kind of treatment do you think you should receive? What are the most important results you hope to receive from the treatment</i> |

Kleinman A. *Patients and healers in the context of culture*. Berkeley, CA: University of California Press. 1980.

features of the narration of the symptoms[18]. To confirm consensus relating to codes assigned to phrases, two authors independently produced code sheets with identical standard codes, and switched them. This allowed agreement and disagreement about standard codes assigned to phrases to be identified. Where there were disagreements, the phrase was re-coded. Therefore, atypical data were selectively discarded, allowing the study to focus on the most common answers. To ensure validity of responses, transcripts were read and re-read. The frequency and occurrence of common phrases was noted. To ensure reliability of phrases, occurrences and frequencies of common phrases within single IDIs and across IDIs were compiled and noted.

The data were entered in SPSS to enable basic statistics such as frequencies and cross tabulations to be analyzed electronically. A theoretical taxonomic model was developed to aid the classification of contrasting symptom narratives. The narratives were grouped into representational categories that mirrored the contrasting models between the role of social circumstances, worries and emotional experience. A link was drawn between the perceptions of the symptoms and attitudes towards treatment and coping strategies.

**Results**

Twenty-eight informants (13 females, 15 males), who met the symptom criteria for Mental distress (Table 1) and consented, were interviewed. An effort was made to balance the male to female ratio despite clinical demographics demonstrating that more women than men seek health care. The combined mean age was 32 years (35 years male, 29 years female) and the age range was 19-56 years. Of the 28 participants, 50% were HIV positive (eight males and six females) and 50% HIV negative (seven males and seven females). HIV positive informants were divided into two groups depending on whether they were receiving ARVs. Nine informants were HIV positive but not receiving ARVs (four male,

five female) and six were receiving ARVs (three male, three female).

Table 3 presents the factors associated with mental distress and the most commonly associated symptoms; this is a summary of the broad categories of explanations given by the informants for their mental distress symptoms. The numbers in each category are higher than the sample size as several informants related more than one symptom in describing their experiences.

**The Explanatory Models**

To aid understanding of the contrasting models for mental distress in the study, taxonomic categories were developed and respondents were classified into one of these representational groups: social, biological, psychosocial and situational models. Attributes of these models were closely interrelated, but certain features and aspects belonged to specific groups as demonstrated in table 3.

**1. Social Model**

Informants in this model said that their symptoms were due to social events in their lives, either single episodes or long-term stressors. In some cases, informants described multiple sources of social stressors. The social narratives were closely related to recent life events that had traumatized the informants, causing repeated somatic symptoms.

**Social Narratives** A 48 year old unemployed man with six children ascribed his symptoms to the lack of a job.

*"I only went up to grade seven in school because my parents died early and so there was no one to educate me. My life has been tough. I am 48 years old and been married twice. I have six children spread in two homes. The biggest problem I am facing is I do not have a job and I cannot educate my children. My life is so unstable and all I do is piece work. How can I pay for two homes? How can I pay for the house and buy food? When I think like this I get*

**Table 3 Factors associated with Mental Distress as identified by the informants**

| Category of factor                          | Frequency | Symptoms/comments  |
|---|-----------|--|
| Worries about money                         | 51        | Concerns about rent, day-to-day living, school fees  |
| Problems of the mind                        | 47        | Recurrent headaches, sleeplessness, unhappiness, trouble thinking, loss of appetite, night mares   |
| Unknown cause of symptoms                   | 32        | Most common among informants not acknowledging symptoms as an illness or as mental distress, suggested witchcraft  |
| Relationship with spouse and family members | 26        | Commonest among women, included crying more than usual, unhappiness, headaches, sleeplessness.   |
| Ill health                                  | 24        | Sleeplessness, daily life suffering, inability to play useful role in life, tiredness  |
| Low self-esteem                             | 16        | Worthlessness, loss of interest, unhappiness, crying more than usual, difficulty enjoying daily activities, experience of stigma                                     |
| Recent life events                          | 6         | Bereavement, divorces, newly diagnosed with chronic disease including HIV. Included symptoms of restlessness, sleeplessness, trouble thinking, headache, unhappiness |

*headaches and I cannot sleep. I have no taste for food in my mouth. I am suffering a lot.*

Another 29-year-old married woman with four children said her problems had started when her husband died.

*"I have a lot of thoughts, often I sit and cry by myself and I cannot remember the last time I had a good night's sleep. I feel so alone. I am the one who has to think about where the money for food and rent is going to come from. When my husband was alive, this was automatic. I pray that his soul has found a better place. I sell some tomatoes by the roadside but this does not make any money at all. I am already one month in arrears for rent and I do not get any help from my in-laws. I worry a lot about how I am going to take care of my four children and about how I am going to pay for their school fees. My mind comes to a stand still and I feel like such a worthless person".*

The results showed that mental distress was somewhat insensitive to gender. However, certain social stressful situations had more effect on women than on men.

## 2. Biological Model

This model was closely related to the social model. The narratives in this category ascribed the symptoms to physical ailments currently being experienced. Unlike the social models, the stressor (physical illness) was a single entity. Expressed worries or symptoms were a direct result of the physical illness. Therefore, the body was seen as mediating the social stressors, which were expressed as symptoms of mental distress. This model predominantly comprised informants who were HIV positive and included individuals with other long-term medical conditions such as hypertension and diabetes.

**Biological Narratives** A 29-year-old unemployed man with 10 years of education said his symptoms were due to HIV and worsened by worries concerning his family (married with two children).

*"As I told you, I am HIV positive and I have been on ARVs for three years now. Yes, I often have stomach problems and trouble sleeping. Sometimes my hands shake and I wake up abruptly at night due to bad dreams, but I do not know why. I think that it may be due to the HIV since I have been HIV positive for seven years now. I think these are complications of the illness, maybe the virus is in my brain now. I am not worried about my health, but I do get worried often about the future of my children who will suffer and live on the streets when I die. I have repeated headaches when I think too much about this and I*

*lose sleep. I am currently unemployed and occasionally get paid for fixing people's radios, but I am always short of money for food and paying rent. If this is happening now, imagine after I am buried six feet under."*

A 55-year-old self-employed man with 14 years of education ascribed his symptoms to hypertension (BP). He is married with five children.

*"BP is a bad disease as you know. They call it a silent killer. I could be talking to you right now but maybe I'll collapse the moment I stand up... Headaches are my daily problems, I think it is these BP medicines. Also they say BP itself cause headaches, I also sleep very badly because I sweat a lot at night and have bad dreams. These are worse when I have a lot on my mind. I worry everyday that I will have a stroke... I am not worried about dying because I know my family will live a good life, but if I have a stroke it means that my wife and children have to change their lives to care for me. Maybe I will not be able to walk or feed myself, maybe my wife will have to wash me and take me to the toilet. I don't want to be a burden. These thoughts stress me a lot and I even get depressed".*

The results revealed that worry concerning the lives of children and spouses if the individual died was a direct contributor to headaches and sleeping badly.

## 3. Psychosocial Model

Attributes in this model emphasize the role of psychological stressors in mental distress. Although the stressors were a single entity, they manifested themselves as a psychosocial dimension. However, these narratives focused on themes of self-blame, personal failure and poor self-esteem.

**Psychosocial narrative** A 26-year-old married woman with 17 years of education attributed her symptoms to her failure to have children.

*"I am well educated and have a good job, but unfortunately my marriage is on the rocks and I think it is entirely my fault. You see the Good Lord has given me everything else but the ability to have children. When I dwell on this I often cannot think straight, I am not even sure how to describe my state of mind. I get so anxious and depressed. I feel I am a worthless person and my time here on earth is meaningless. I always feel like something bad is going to happen. I often avoid going to kitchen parties or women's meetings at work. They all have kids and I know they talk about me. My husband has two children with another woman and he spends most of his time there*

*and comes home only to change clothes. Once I confronted one of the other women and she shouted at me and said I was not a woman. Those words have never left my mind."*

A 34-year-old woman working as a secretary attributed her symptoms to her physical disability. The physical disability was mentioned as the cause of the distress, although the psychosocial reality was emphasized in the narrative, making it more salient than the physical disability.

*"... I had polio when I was young and it left me in a bad way... I am 34 years now and slowly getting old. I have never been married and don't have any children. Last year I had a boyfriend and I hoped that the year would not end before I got married but this didn't happen. Now I am just an object of pity. Both my young sisters are now married and have children. I have nothing to show at family gatherings. I always just go alone. I think this depresses me and I wonder what this entirely means."*

Results demonstrated that suffering from certain conditions that left permanent scars on the body hindered access to social agreements such as marriage and hence contributed to mental distress. An inability to bear children was a factor contributing to mental distress in women.

#### 4. Situational Model

In this category, symptoms were the result of a stressor that would result in a change in the respondent's life. Informants in this category viewed their stressor as representing 'the end of the road'. For example, this category included a 22-year-old university student who had discovered that he was HIV positive less than a week before the interview.

*"This is a tragedy to me, I am young and my life is ruined before it has started. I stopped going to class because there is no point. I don't even know how to tell my parents. I have not slept in a week. I tried to drink beer so that maybe I sleep, but the beer tastes sour. This is pressure. I have no appetite, my mouth is sour. I sweat at night and I have a pounding headache."*

The results demonstrated that HIV positive results contribute to mental distress.

#### Perspectives of health professionals and healers

Many responses given by health providers were identified under the theoretical explanatory models, confirming consensus-driven attributable causes, treatment-seeking

and response behavioural challenges from institutional and community perspectives. Health professionals reported that HIV infection was responsible for approximately 40% of institutionalized mentally distressed patients. When providers and healers constructed mental distress using reports from users, witchcraft and stigma emanating from HIV positive results emerged as major contributors to symptoms of mental distress.

*"Because when you are told that you are HIV positive you think that you will die any time, so they have that fear."* (Indigenous healer, male 39 years old, six years experience of treating HIV-infected persons.)

*Most of the time these people are in denial. They say that I am not HIV positive, me I am not mentally sick, I have been bewitched, so it's very difficult. Some of them deny they are restless, they are... they can't see... you can see that this person is not as he used to be, moving up and down, shouting, me I am not sick, even if you are not talking about the... the topic they are just guilty somehow they have feelings like maybe these people they know that I am HIV positive.* (Female health professional, 43 years old, 11 years of service.)

*Yes. Some they come here and say "Bana lilowa" (they have bewitched me) "Nima shabe" (It is evil spirits).* (Female health professional, 42 years old, 18 years of service)

*Okay, I have forgotten one thing, some of them they say he slept with someone who aborted, she has "kapopo" you know what I mean.* (Female health professional, 42 years old, 18 years of service)

The results revealed that despite noticeable changes in mood including social withdrawal and mood swings in a family member, health services were only sought when physical violence or suicidal tendencies developed. Until that point, most were home-bound.

*Most of the time, it's when they become violent. They are short tempered or start threatening that they would kill themselves, breaking things, things like that. That's when they rush there.* (Male health professional, 42 years old, 18 years of service)

Gender dimensions were noted when attributable causes to mental distress were assessed. Females were more likely to report social problems including stigma owing to HIV status, whereas males attributed causes to ARV treatment. In terms of treatment at home, all providers reported that predominantly women took that responsibility.

*A close relative, someone they trust, someone who has been caring for them in the hospital. It's usually women.* (Male health professional, 42 years old, 18 years of service)

When age was isolated, there was agreement between professional providers and healers regarding the age

group (15-35 years) of people frequently presenting with mental distress symptoms due to HIV. Furthermore, positive responses to treatment were obtained from professional providers and healers.

*We traditional healers, we use leaves and roots, so we have the roots that we give them and sometimes we send them to test and most of them are responding well to treatment (Indigenous healer, male 39 years old, six years practice with HIV positive persons.)*

Despite the reported treatment response, integration of these persons remains a challenge.

*That one is a problem and is still difficult. A long time ago there used to be community psychiatry outreach where we would follow up patients to see how they were integrated but that was causing more problems. Even from their own families, they would say look he has come to visit that one who wafuntila (that one who was mentally distressed), he has not recovered fully. So that was causing too much stigma on those who may have completely recovered. That was the other reason causing relapse. Family members would keep reminding them that "Ichi ni cho funta" (this one is mentally distressed). It's a big problem. (Male health professional, 42 years old, 18 years of service.)*

#### **Significance of explanatory models: Health-seeking and coping strategies**

A large body of research has documented a strong relationship between stressful situations and mental distress. Therefore, the relationship between coping and mental distress holds specific interest in both HIV-infected and uninfected individuals. Coping mechanisms can be described as the sum total of ways in which we deal with minor stress, major stress and trauma. Many of these processes are unconscious, others are learned behaviours, and some are skills we consciously master to reduce stress and intense emotions such as depression. However, not all coping mechanisms are equally beneficial, and some can be detrimental.

#### **Health seeking and coping strategies among uninfected individuals**

Informants in the *Social Model* were able to identify the cause of their symptoms and relate the cause directly to one or multiple social stressors. They relayed that they were unsure how long the stressors would last, that they did not recognise their symptoms as a disease entity and saw no need to seek medical attention. They stated that their symptoms would disappear once the stressors were removed and/or if they found a job to relieve the financial strain. Their coping strategy was based on the hope that things would improve.

*"... I do not think my symptoms are an illness, its just problems with life. What can a doctor do for me unless he gives me a job to work at his house? I am just unfortunate but I am sure, God willing, I will find a job soon so that I can pay for my rent, buy food and take my children to school."*

In the *biological model*, informants viewed their symptoms as part of the whole disease process and they were eager to consult medical personnel for treatment. However, they did not relate their symptoms to mental distress but "worries" for which they did not need psychotherapy or psychotropic medication. They said that their symptoms would not disappear permanently but have a recurring pattern. Their coping strategy was one of longing for longer symptom-free periods.

*"As you know "sugar disease" (Diabetes) has no cure. It is here to stay. The doctors and nurses have told me what I should eat and what I shouldn't. The problem is, sometimes, even if I follow their advice, I still find myself admitted to hospital. Since I am self employed, it means for the period I am sick, there is no money coming into the house to pay my "nkon-gole" (debts). My family upkeep then becomes tricky... There is little I can do about this disease but to follow the doctor's advice and pray to God that I don't fall sick often, so I can care for my family."*

Informants in the *psychosocial model* did not recognize their symptoms as an illness. They described their symptoms as normal reactions to events in their lives, but were willing to consult medical professionals. They admitted that psychotherapy would help but were very skeptical about the role of psychotropic medication in alleviating their symptoms. Hopelessness was identified as an important factor in this model. They remarked that their symptoms would run a chronic course with no hope of alleviation. The coping mechanism identified was religious faith and/or the hope of meeting somebody who would accept them for who they are.

*"God never gives everything that a person needs. He always leaves out something. If he gives intelligence, he takes away beauty; if he gives you beauty, then he takes away the riches. There is nothing I can do about my situation. I guess I need to undergo some counseling because I think I am depressed... I cannot commit suicide because then I would be ungrateful for the life God has allowed me to have. I just hope that God has one more gift for me and I pray hard for that."*

### Health seeking and coping strategies among HIV-infected individuals

HIV positive informants fitted into the biological and situational models. Their symptoms of mental distress were ascribed specifically to their HIV status. However, some differences were noted in the health seeking and coping strategies. The differences were a function of how long they had known that they were HIV positive and if they were receiving ARVs. Informants who were newly diagnosed and those who had known of their HIV+ status longer but were not receiving ARVs had a high degree of hopelessness.

*"My life is not worth living, I do not know how this happened. I feel worthless; I cannot contribute to my children's future... I will die soon. I don't even think these new medicines work. People say the medicines themselves can kill because of all the side effects... why take them if they are just prolonging misery... The whole disease is just stressing, it has left me helpless. When I see the disease finally cripples me and my hair falls off, everyone will know that I have AIDS and will say I have been sleeping around... it's just better to avoid everyone and stay alone."*

In contrast, informants receiving ARVs had a lower degree of hopelessness. They recognized their symptoms as an illness requiring medical attention in the form of psychotherapy. However, they did not see the immediate benefit of psychotropic medication, and informants who had been very sick and/or had opportunistic infections prior to starting ARV expressed optimism about their lives and future. Most of the informants in this category did not view psychiatric consultation as necessary or appropriate for their situation, though they admitted that psychotherapy would be of help.

*"You should have seen me three months ago. I was finished, I had had TB three times and I was half my weight. I thought I was going to die. I had lost all hope and every time I saw my kids I felt so low and hopeless. But now I am much happier and I have hope that I will see my children grow to adulthood. All this in just six months of taking ARVs... Yes I still get headaches when I think a lot, especially that life is rough and money is a big problem. I get a lot of worries about it but these come and go... At least I am much better now and when I feel bad I just go and see the clinic people... the counseling works and we get a lot in the support group meetings. After these meetings I often go home in a better mood."*

### Comparison of explanatory models: Perspectives of the patient, health-care professionals and healers

Table 4 presents a summary of the comparative models used by the patients and health care providers. A general measure of agreement exists between explanatory models of the study groups. The experience of mental distress among patients appears to have been governed by problems relating to socio-economic problems (poverty), particularly problems in the home (marital problems). However, occasional differences were noticed. Male respondents emphasized economic problems more, while female respondents emphasized social problems (marital, violence in the family, alcohol abuse by spouse). Female respondents mentioned economic problems as a secondary effect of separation, divorce or being widowed. Additional explanatory models were noted in the presence of chronic illness including HIV, hypertension and diabetes. In these circumstances, explanatory models emphasized the role of the physical illness in the experience of mental distress. Perception of the cause of the symptoms, expectations of the course of the illness, severity of the symptoms, family support and presence of stigma, were all predictors of health-seeking behaviour.

A broad consensus was apparent among the health care providers, although there were some clear differences. Health care providers agreed that symptoms were problems of the mind mediated by socio-economic problems. They were in agreement that these symptoms required some form of intervention (medication, prayer or exorcism) in order to alleviate the suffering of the patient. They agreed that HIV poses special circumstances and that it causes much distress. However, there were occasional differences in emphasis on the cause, course of illness and preferred treatment (Table 4).

However, a greater difference was evident between the patients and the health care providers. Health care providers had a predetermined cause and effect pathway, either: (1) social circumstances leading to mental distress (stress, depression) and in turn mental distress symptoms; or (2) bad spirits (witchcraft) leading to mental distress symptoms. Patients had a somewhat different narration of the illness experience in the different models. HIV positive individuals (regardless of ARV history) and those with chronic medical conditions established a cause and effect pathway, but HIV negative individuals did not; they had a more narrative and experience-based understanding of their illness. They did not readily attribute their mental distress symptoms to an illness entity but to life's problems and a few of them entertained witchcraft as a cause. This impacted profoundly on what treatment choices they made.

**Table 4 Summary of comparative explanatory models used by patients and health care providers**

| Components of explanatory model               | HIV -  | HIV +   | Health care providers  | Comments   |
|---|--|---|--|--|
| 1. Name given to symptoms                     | -Problems of the mind  | -Problems of the mind<br>-Depression and stress                                       | -Depression, stress<br>-problems of the mind   | -Occasional differences exists in the name given to symptoms between the health professionals and the traditional healers                                      |
| 2. Cause of symptoms                          | -Poverty, marital problems, -witchcraft  | -Worries about course of disease, worry about future of family - HIV infection        | -Social-economic problems, intercurrent illnesses - bad spirits                            | Witchcraft was cited as a cause among some the traditional healers. HIV infection was cited as a cause mostly among HIV+ not on ARV's                          |
| 3.Common symptoms of experience               | Headache, sleeplessness, poor appetite, worthlessness, crying  | Worthlessness, loss of hope. Somatic symptoms   | - Somatic symptoms, - Social withdraw  | Significant differences noted based on HIV status and (if on) duration on ARVs   |
| 4. Greatest fear about their experiences      | - Worries about future of children, - death, - disability from illness, - not ever getting married                             | - Children's future, - Death, - Stigma from relatives and friends - Course of illness | - Future of family, - Death, - Stigma from family and friends, - Short life expectancy     | - Worries about future of family were the majority. Short life expectancy was next and the newly diagnosed worried more about stigma                           |
| 5. Severity of experience                     | - Severe but can have a remedy   | Extremely severe, no way back, hope for the best                                      | Severity depends on other circumstances such as poverty and family support                 | Severity depended a lot on level of adjustment to HIV status and severity of circumstances   |
| 6. Choice of treatment                        | Clinic, pain killers, majority no treatment  | Clinic, counselling, - Religion, - no treatment                                       | - Counselling, - Exorcism, - Support groups, family involvement, - Antidepressants         | Choice of treatment depended on what was thought to cause the problem  |
| 7. Factors leading to choice of treatment     | Severe symptoms (headache, tiredness, loss of sleep)   | Severity of symptoms, - family support, - Disclosure                                  | Severity of symptoms, cause of symptoms, previous failed consultations, Family involvement | Factors associated with treatment options were, perceived cause of illness, family support.  |
| 8. Course of symptoms and alleviating factors | - Short course, - Finding cure, - Solution possible (finding a job, improved marital relationships), may have a chronic course | Chronic course, - ARVs, - Family support, social support groups, - Prayer - No hope   | - Can be modified by counselling and medication - Support groups - Traditional medicine -  | - Course of illness associated with perceived course of illness, ARVs - Alleviation of symptoms dependent on adjustment to illness, medication and counselling |

## Discussion

This paper outlines the findings of a qualitative study nested within a cross-sectional validation study investigating the importance of explanatory models for improving the provision of mental health services, particularly for HIV-infected individuals. Explanatory models used by HIV-infected and uninfected individuals were elicited and compared to those of local health care providers. The relationships between these explanatory models, health seeking behaviour and coping strategies were investigated. The salient findings of this research are that patients without chronic illness, who are identified as having mental distress, express these symptoms through an array of somatic symptoms that they attribute to social disadvantage and strained family relationships. In contrast, those with chronic illnesses such as HIV attribute their experience of mental distress to the disease process. However, their symptoms are perpetuated by existing social circumstances and worry concerning the future. HIV infection added strain and this contributed to the onset of symptoms and compounded other existing social stressors. Health-seeking and coping strategies were

determined by the cause of the illness, its perceived course, family support and perceived duration of illness. The explanatory models of the patients and the health care providers did not differ as much as expected. While health care providers had a predetermined structure in which they recognised mental distress, patients had an illness experience-based rationalisation of symptoms. The findings suggested that health care providers were unfamiliar with how the patient's explanatory models affected health-seeking and coping behaviours, similar to the findings of previous studies.

The constellation of somatic presentations in this study has previously been reported in Zambia [3,4,9] and other developing countries[19-21]. However, the diagnostic significance of these symptoms for identification of mental distress is not universal. They may vary widely among societies according to the burden of disease, gender perspectives and the societal perception of the symptoms. For example, some societies would emphasize fatigue [22] while others would emphasize headache[4]. Somatic symptoms appear to be more consistent universal indicators for mental distress across cultures, and this has been



demonstrated in this study where somatic complaints were a central feature of the narratives.

Causes of mental distress symptoms were somewhat different in the taxonomic models illustrated. However, two main causes stood out; with the exception of the biological model, economic difficulties and difficulties in marital relationships were most cited. The informants conceptualised their distress as a direct consequence of poverty and attached no significance to a biochemical cause. The more adverse the social circumstances, the worse the symptoms; this finding has been confirmed by other studies[10]. In the biological models (HIV and other chronic illness), there was a direct link between the illness and the symptoms. However, the symptoms were compounded by social difficulties and stigma. Several studies examining the relationship between HIV and psychological variables have demonstrated that patients well-adjusted to their HIV-positive status tended to have lower levels of mental distress and expressed hope[23].

Gender is a critical determinant of mental distress and is closely related to course, care and support. Gender determines the differential power and control men and women have over the socioeconomic determinants of their mental health, their social position, treatment choices and their susceptibility and exposure to specific mental health risks[24]. Women appear to be affected to a greater extent than men across different countries and different settings. Women present with an earlier age of onset of symptoms, a higher frequency of somatic symptoms but less severe illness[24]. Men have a protracted course of illness and they exhibit poor social adjustment and a poorer long-term outcome[25]. Gender-specific risk factors for mental distress that disproportionately affect women include co-morbid circumstances such as gender-based violence, low income and income inequality[26]. Other factors include severe life events that cause a sense of loss, inferiority or humiliation. In addition, women have a responsibility to care for others [27,28]. Pressures created by these multiple roles combine and account for the poor mental health of women. A positive correlation has been reported between the frequency and severity of these social factors and the frequency and severity of mental distress in women[25]. Gender differences exist in terms of patterns of seeking help for mental distress, with women more likely to seek help from and disclose mental health problems to their primary health care physician than men[29]. Therefore, gender-specific determinants and mechanisms that promote and protect mental health and foster resilience to stress and adversity should be emphasized.

Research investigating the psychosocial impact of HIV has demonstrated that the level of mental distress is high among HIV-infected individuals,[3] particularly

those recently diagnosed or who have developed opportunistic infections. Several intervening reasons for the onset of mental distress have been discussed, ranging from psychosocial to biological factors. Evidence has linked effecting coping styles to better compliance with ARVs and positive health-seeking tendencies[30,31]. Furthermore, effective health-seeking is associated to a better quality of life, reduction in risk-taking behaviour, and higher total lymphocyte and natural killer cell counts[32]. Therefore, it is imperative that the relationships between coping, treatment choices and psychological morbidity are elucidated. The findings presented herein confirm results from previous studies and demonstrate a significant association between the severity of mental distress, maladaptive coping strategies and poor health-seeking behaviour, particularly among the newly diagnosed.

There are a number of limitations to this study including its qualitative nature, which limits the findings to statements concerning association and not causality. However, the main aim of this study was to describe the explanatory models for mental distress among HIV-infected and uninfected individuals, and how these are associated with coping mechanisms and treatment preferences. This study was conducted in the capital city of Zambia, which has a comparatively high concentration of local and international institutions that support improved quality health services. Furthermore, the urban population has higher educational attainment than rural populations and easier access to private and public healthcare systems. Therefore, generalization of these findings should be limited to settings that have similar social organizational and economic structure as it is unknown if the same model would be applicable in rural parts of the country. A validation study or further research carried out in a different setting and culture with a larger sample size would be useful to confirm the findings of the present study.

## Conclusion

The results of this study support the findings of studies carried out in other developing countries that emphasize the role of social context for understanding mental distress. The patient's conceptual perspective of mental distress is rarely studied and this research demonstrates that the patient's models of illness may differ somewhat from those of health care providers. Their explanatory models are consistent and coherent, and appear to be associated with health-care-seeking behaviour and coping strategies. Therefore, provision of medical treatment should take into account the patient's explanatory models to generate a joint treatment plan. The results in this study suggest that a balance between the professionals' and patients' models is particularly important among

HIV-infected individuals. Therefore, we recommend the use of contextualised conceptual models as defining clinical features for understanding the conceptualisation of the clinical syndrome of mental distress for clinical and public health interventions.

#### List of Abbreviations

SRQ-20: Self-Reporting-Questionnaire 20; SRQ-10: Self-Reporting-Questionnaire 10; SCL: Symptom Check List; DSM-IV: Diagnostic and Statistical Manual of Mental disorders, fourth edition; HIV: Human Immunodeficiency Virus; PLWHA: People living with HIV/AIDS; ARV: Antiretroviral drugs; IDI: In-depth Interviews; PHC: Primary Health Care; EM: Explanatory Models

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#### Authors' contributions

PJC, MT and KF contributed to the analysis and drafting of the manuscript. PJC and MT further contributed to the design and conduct of the study. All authors contributed to the critical revision and final approval of the manuscript.

#### Competing interests

The authors declare that they have no competing interests.

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Title:

Case-finding for Mental Distress in Primary Health Care: an evaluation of the performance of a five-item screening instrument.

Study type:

Crosssectional study

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## **Abstract**

**Background:** There is an increased interest in developing better and more accurate methods to recognize and manage mental health problems in primary care settings. Abbreviated screening instruments for mental distress are useful tools for research and clinical practice. The present study seeks to investigate whether only a few questionnaire items from the Self-Reporting-Questionnaire-10 (SRQ-10) can be a robust method in the screening for Mental Distress in Primary Health care.

**Methods:** We compared the screening accuracy of a short, five-item (SRQ-5) version of the SRQ-10 with that of the SRQ-20, General Health Questionnaire 12 (GHQ-12) using the DSM-IV axis as a gold standard and analyzed its performance in different diagnostic entities. We also assessed the correlation, sensitivity and specificity between the 4 instruments. All the instruments were administered to 400 primary health care attendees.

**Results:** The estimated prevalence of mental distress was 13.6% in the study sample (Depression 11%, anxiety disorders 1.8%). The SRQ-5 was highly correlated to SRQ-10 (0.923,  $P < 0.001$ ), SRQ-20 (0.764,  $p < 0.001$ ) and only moderately correlated to GHQ-12 (0.417,  $p < 0.001$ ). The SRQ-5 had high properties for identifying mental distress. The AUC for overall mental distress was 0.925 while that for depression and anxiety were 0.915 and 0.849 respectively.

**Conclusion:** This validation showed that in moving from SRQ with 10 or 20 items to one with merely 5 items, we do not seem to lose the screening prowess of the instrument. The SRQ-5 represents a simplified and less time-consuming screening instrument with strong performance characteristics. We therefore recommend it for inclusion into existing patient assessment protocols, thus enhancing case finding at primary health care level.

## **Background**

Mental distress is a term used by both mental health practitioners and the users of mental health services. It is used to describe personal experiences of one's internal life that are commonly held to be out of the ordinary, troubling, confusing etc. (1) It presents as a wide range of symptoms and has a wider scope than the related term mental illness. Some users of mental health services advocate for use of the term mental distress in describing their experience as they feel it better captures the sense of the uniqueness and personal nature of their experience, since everyone experiences distress at different times. The term also fits better with the social model of disability. Mental illness on the other hand, refers to a specific set of medically defined conditions. A person with mental distress may exhibit symptoms described as psychiatric, such as: depression and anxiety, without actually being 'ill' in a medical sense. (1) These symptoms may resolve without further medical intervention, although people who endure such symptoms in long run are more likely to be diagnosed with mental illness. Predictors known to induce mental distress include life situations such as: poor social and economic situation, bereavement, use of drugs or alcohol, abuse or accidents. This definition is not without controversy as some mental health practitioners would use the terms mental distress and mental illness interchangeably. (1)

Mental health is an important foundation for attainment of intellectual, economic, emotional, social and educational well being. (2) Accordingly, mental ill health is a major contributor to the global burden of disease. (3) Estimates of the current prevalence of mental distress in Sub-Saharan Africa generally range between 6 and 20% of the adult population (4-6) though higher prevalence has also be reported in Ethiopia 49.1%, (7) South Africa 65.1%, (8) and are even higher in some subgroups such as the elderly, the chronically ill and in institutionalized people (9, 10). The World Health Organization (WHO) states that a quarter of the world's

population who have common forms of mental illness should be treated in Primary Health Care settings. (3) Despite the high prevalence of mental distress revealed in epidemiological studies, physicians in primary health care often overlook the salient symptoms of mental distress, especially in African countries.(5, 11, 12) Therefore a high number of patients who have mental distress do not receive any treatment. However, many screening instruments are available to aid in identification of the signs and symptoms of mental distress. These instruments have been developed for use in three major settings i.e. primary care, psychiatric outpatient services and for community surveys. It has been noted, however, that these instruments remain under utilized mostly due to the fact that most of them contain too many questionnaire items and have somewhat difficult likert system of scoring. (13) This study stems from efforts to improve the screening procedure in primary care. It also stems from the need to address the concerns of the general physicians, who are often pressed for time, for a convenient, accurate and brief instrument.

We have previously reported on the comparative validity of three screening instruments in detecting mental distress in a primary care setting using receiver-operating-characteristics as the quantitative measure of performance.(13) We also used the three instruments as concurrent criteria for each other and compared them against a gold standard, DSM-IV.(13) The three instruments studied were the SRQ-20, GHQ-12 and SRQ-10. The SRQ-20 is a 20 item mental health questionnaire that was developed by the World Health Organization (WHO) (14). The SRQ-10 is an abbreviated version of the SRQ-20 and is similarly based on a dichotomous response system. The GHQ-12 is a 12 item questionnaire designed for use in general practice of medicine and is also an abbreviated version on the original GHQ-60. These instruments have been validated in different setting and found to function well in the detection of mental distress. (13-15) Overall it was demonstrated that the SRQ-10 performed



just as well as the SRQ-20 and was even better than the GHQ-12 according to the ROC analysis in detecting mental distress.

In this paper, we extend our investigation of the SRQ by comparing the performance of its shortest version, the five item SRQ-5 with that of the SRQ-10, SRQ-20 and the GHQ using the DSM-IV as the gold standard. Receiver-Operating-Curves (ROC) is here used as the main technique for comparison.

## **Methods**

### **Participants**

As has been previously reported elsewhere, (13) a concurrent nested mixed methods design was used to assess 400 primary health care clinic attendees aged 16 years and above who were selected on random days from 4 different clinics in the city of Lusaka, Zambia between December 2008 and May 2009. The clinics were purposely selected within the city of Lusaka. Each clinic was sampled randomly on selected days, 3 times a week. On the selected days, interviews were conducted with consecutive clinic attendees at the clinic outpatients department. Participants were recruited based on their age, giving consent to participation as well as attendance to the out-patient department on the day of the study. Participants who were known to be psychiatric patients or those who were acutely or chronically ill or showed overt signs of psychiatric disorder were excluded from the study. The purpose of the study was explained to each participant by the research assistant and consent obtained. None of the participant approached declined being involved in the study. All participants were asked to answer a brief questionnaire concerning social and demographic characteristics as well as the SRQ-20 and GHQ12 which were used as tools to identify probable “cases” of mental distress. Participants were then grouped as cases (based on scores of 7+ for SRQ-20 and 4+ for GHQ-

12) or non-cases. They were then directed to one of the two general medical officers who held a clinical interview for the ailments that brought them to the clinic as well as conducting a psychiatric interview using the DSM-IV (gold standard). The medical officers used their clinical judgment along side the DSM-IV criteria to make the psychiatric diagnosis, and they were blinded as to the result of the initial screening with the SRQ-10 and GHQ-12. In depth interviews were also carried out with in a subsample of 28 participants nested within the quantitative sample. Based on the results of the screening, this sub-sample consisted of 14 cases and 14 non-cases of mental distress. These interviews were used to assess face and content validity of the screening tools.(13)

### **Screening instruments and diagnostic interview**

The SRQ-20 was developed by the World Health Organisation (WHO) as a screening tool for common mental disorders primarily in primary health care settings in developing countries.(14) It consisted of 20 questions related to neurotic symptoms as opposed to psychotic symptoms in part due to the fact that for functional psychosis more active case finding in the community is required. Psychotic patients also tend to present to primary health care centres spontaneously and are often easily recognised by their pathognomonic features in most cases.(14) This instrument was not designed to specifically screen for depression or anxiety. The SRQ-20 has been validated in numerous settings with a widely accepted cut-off points of 7/8.(14)

The SRQ-10 is derived from the SRQ-20 which, in this study, was specially constituted with weighted sum of 10 symptom questions with a dichotomous response system (Yes/No) but neither probed for symptom severity nor designed to specifically screen for depression or anxiety. We have previously validated this tool (13) and used it in population based surveys in

Zambia and yielded results that were comparable to other studies done elsewhere using the SRQ-20. (5, 14) It is a symptom inventory inquiring about the symptoms over the preceding 30 days presented as SRQ-10 items in Table 1.

The SRQ-5 is an abbreviated version of the SRQ-10. The selection of the questionnaire items was based on the results from the validation study conducted in Zambia, (13) and on consultations with a panel of psychiatrists and general practitioners. (13) The questions selected in this symptom inventory inquired about the following symptoms over the preceding 30 days: *Do you sleep badly? Do you often have headaches?, Do you find it difficult to enjoy daily activities?, Are you able to play a useful part in life? Is your daily life suffering?*

The General Health Questionnaire is a screening instrument originally designed for use in general practice but now found to be valid for detecting psychiatric morbidity in community surveys as well.(15) It contains 12 symptom questions scored on a four-point likert scale ranging (0-1-2-3) from much-less-than-usual to much-more-than-usual. However, in the analysis this scale is often collapsed to a dichotomous scale (0-0-1-1). Varied cut-off points have been used depending on the setting although cut-off point of 3+ is widely accepted as indicative of psychiatric morbidity.

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is the standard classification of mental disorders intended to be applicable for use across settings; inpatient-outpatient clinics, primary care, and in the community. In this study it was used as the gold standard. It has a diagnostic classification comprising a list of the mental disorders that best reflect the signs and symptoms that are afflicting the individual being evaluated. For each disorder, a set of diagnostic criteria indicating what symptoms must be present (and for how

long) in order to qualify for a diagnosis are provided. (16) The use of these diagnostic criteria has been shown to increase diagnostic reliability (i.e., likelihood that different users will assign the same diagnosis).(17) The DSM-IV is widely accepted and used as the gold standard for psychiatric diagnosis in Zambia.

All the instruments were translated into Nyanja and Bemba as these are the most predominantly spoken languages and then subsequently back translated to English by bilingual translators from the linguistics department of the University of Zambia. This was to ensure validity in conceptual meaning. A team of three male and three female interviewers who had no experience in mental health care administered the SRQ-20 and the GHQ-12. They, however, all had previous experience administering questionnaires in other epidemiological studies. A three day training session was conducted in administering the instruments. This involved explanation and discussion of conceptual definitions of each item in the instruments and role playing. This was followed by a 1 day field test.

### **Selection of SRQ-5 items**

Firstly, based on the results obtained from the validation study of the SRQ-20, (13) the following 5-items were selected as being the best-subset of questions that were best understood by the participants: *Do you sleep badly? Do you often have headaches? Do you find it difficult to enjoy daily activities?, Are you able to play a useful part in life? Is your daily life suffering?* This means that these questions were understood by the participants in a manner that was similar to the psychopathology the interviewers meant to unearth.

Secondly, we independently asked three psychiatrists with at least 3 years experience working in a psychiatric institution in Zambia and three general medical officers, with similar experience, working in primary health care setting to choose 5-items from the SRQ-10 which

they regarded as being the most important indicators for mental distress. After this we further asked them to select another set of 2 questions from the remaining 5 items. These are presented in Table 1. It was unanimously agreed among all the medical practitioners that Item 7 (suicidal ideation, for 1 month duration) on its own was a sign of major depression and that presence of this item alone even in the absence of the other items constitutes severe mental distress.

### **Analytic Methods**

The validity of the SRQ-5 was examined using the specificity (rate of participants correctly identified as non-cases) and sensitivity (rate of participants correctly identified as cases). Receiver-Operating-Curves (ROC) were computed using SPSS version 15 and the area under the curve (AUC) used to compare the performance of SRQ-5 with the other instruments (SRQ-10, GHQ-12) using DSM-IV as the gold standard. ROC was also used to compare the performance across of SRQ-5 across the different diagnostic groups (Depression and Anxiety). ROC permits the exploration of the entire range of sensitivities and specificities at each of the possible cut-off points through demonstrating sensitivity at the y-axis and 1-specificity at the x-axis. Reliability was assessed using Cronbach's alpha (Internal consistency). Further independent t-tests were performed to compare the instruments by sex and age and a Pearson's Chi-square was computed to compare the psychiatric diagnosis in the same groups.

## Results

In all 400 participants, visiting the primary care (PHC) centers for various medical reasons, completed the SRQ-20 and the GHQ-12 and also completed the clinical interview (using the DSM-IV) administered by the medical officer. Ten respondents were not included because they refused the clinical interview, however, and no significant differences appeared between the total sample and the participants that refused the clinical interview in sex ratio, wealth status, marital status and educational attainment. Almost half of the respondents preferred English as the language for the interview, while the others preferred Nyanja (38.8%) and Bemba (8.5%). The interviewed sample tended to be women (58.3%), younger than 40 years (82.7%) and married (70%). The male participants were on average 32 years ( $SD=11.1$ ). About 56% of them were married and 61% of them had secondary school education. Female participants averaged 29 years ( $SD=9.4$ ) and had an average of more than 8 years of education (secondary 56% vs. tertiary 19.5%) while 3.8% were illiterate. The estimated prevalence of mental distress was 13.6% (Depression 11%, anxiety disorders 1.8%)

Table 2 shows the correlation matrix of the screening instruments. The results show that SRQ-5 is highly correlated to SRQ-10 (0.923,  $P<0.001$ ), SRQ-20 (0.764,  $p<0.001$ ) and only moderately correlated to GHQ-12 (0.417,  $p<0.001$ ). Slightly better correlation was seen between GHQ-12 and SRQ-10 (0.515,  $p<0.001$ ) and SRQ-20 (0.593,  $p<0.001$ ). All correlations were significant at  $p<0.001$ . In Table 3, areas under the receiver operating characteristic curve (AUC) was calculated for each of the 4 screening instruments and compared for the different diagnostic groups. These diagnostic groups include i) depression and ii) anxiety disorders. By this measure SRQ-5 is almost equal to SRQ-10 and SRQ-20. However it out-performs GHQ-12 for detection of overall mental distress and depression and equals it in the detection of anxiety. All these AUC are significant at  $p<0.001$ . Figures 1 to 4

shows a graphic representation of the performance of the screening instruments, areas under the ROC curve. From the figures it is clear that the SRQ perform very well with curves that are similar in pattern across the criterion diagnosis. Furthermore, no major differences are noted when compared by sex and age.

Table 4 shows the AUC values when ROC is applied to the individual items that make up the SRQ-5. Each of the 5 items contributes some diagnostic information across all the criterion diagnosis. The table shows that each question performs well in the diagnosis of depression. The best contributor being the question; Do you sleep badly? (0.836, SE= 0.037) and the least being; Do you often have headaches? (0.606, SE= 0.045). All AUC values for detection of overall mental distress and depression for each of the SRQ-5 items were significant at  $p < 0.05$  when compared to the full scale of the SRQ-10. What is explored here is simply the range of the response frame itself for each of the five items. Addition of more items to the 5 did not seem to improve the performance of the SRQ-5

Table 5 shows the results of the analysis which focused on the ability of the SRQ-5 to detect mental distress at different cut-off points. The sensitivity, specificity, positive predictive values, and negative predictive and kappa's values of the scales with different cut-off points are here shown. The most appropriate cut-off point was a trade off between sensitivity and specificity. Since it is meant to be used as screening instruments, the optimal cut-off point is one with high sensitivity and an acceptable specificity. The optimal cut-off for SRQ-5 was 4/12 with sensitivity 0.87 and specificity 0.85. Further analysis by sex and gender or by criterion diagnosis did not reveal any significant differences in cut-off points. Practically speaking this means a patient presenting with either, poor sleep, daily life suffering or inability to play a useful part in life and any one of the other symptoms would be classified as

being mentally distressed. A patient presenting with only suicidal ideation as a lone symptom or in combination with other symptoms would also be classified as probable case.



## **Discussion**

This is the first study examining the validity of the SRQ-5 in primary care and providing the DSM-IV diagnoses as a gold standard. The SRQ-5 had an AUC 0.925 and did not differ significantly from the SRQ-10 and the SRQ-20 but performed slightly better than the GHQ-12 (AUC; 0.925 vs. 0.811 respectively). Comparing the patterns of the ROC curves showed no significant difference in its performance by gender or age. The results show that SRQ-5 performed better for detecting diagnosis of depression than for anxiety and are in agreement with the content of the items in the questionnaire (AUC 0.915 depression vs. 0.849 anxiety). Analysis of item by item performance revealed that the items: do you sleep badly, and do you find it difficult to enjoy daily activities? performed best across all diagnostic criteria. With respect to a cut-off point, ROC does not seem to suggest different cut-off points based on the diagnostic criterion. Using the weighted sum of scores for the items suggests that the best balance between sensitivity and specificity is a cut-off point of 4/12. Based on this cut-off point the sensitivity is 0.87 and the specificity is 0.85. For general practitioners, this would mean that a patient presenting with either, poor sleep, daily life suffering or inability to play a useful part in life and any one of the other symptoms would be classified as being mentally distressed. Further a patient presenting with only suicidal ideation as a lone symptom or in combination with other symptoms would also be classified as probable case.

We compared the screening capability of the SRQ-5 with that of 3 validated tools. The SRQ-20 and GHQ-12 are widely validated tools and have been found to be acceptable in different settings and population groups.(14, 15) We have previously shown that the SRQ-10 is an acceptable screening tool with comparable, if not better, screening characteristics than the SRQ-20 and the GHQ-12. (13) A number of other studies have been conducted world-over which have argued for the use of shorter screening tools for mental distress. Although we

could not find directly comparable studies that have used the SRQ-5, we feel that the results are comparable to other studies since the content base of these other tools are similar. In their study aiming at validating the abbreviated MHI-5 version, Rumpf et al (18) demonstrated acceptable AUC for the MHI-5 using DSM-IV as the gold standard. They concluded by recommending the MHI-5 as a screening tool for mood disorders. Similarly, Jacobsen et al. (19) reported a strong association between the abbreviated GHQ-4 version and the full GHQ-20 and that this was similar by all examined subgroups of the study population. They thus concluded that very short versions of the GHQ questionnaires could be used effectively in population surveys on mental distress.(19) Friedman et al. (20) examined the criterion and construct validity of the five-item (MHI-5) of the SF-36. Using AUC they demonstrated that the MHI-5 had adequate criterion validity and satisfactory sensitivity and specificity. They concluded that MHI-5 exhibited adequate properties for measuring presence of depression.(20)

Though the cited studies were not particularly validating the SRQ, the item bases are very similar and focus more on neurotic disorders. It would suffice to say from the reviewed literature that even a shorter, and only slightly less powerful screening tool, maybe used in place of a longer more comprehensive questionnaire to achieve acceptable results. (21) The authors selected SRQ over the other “competing tools” (GHQ, CIS-R, PHQ-9, CHAT) because it was derived from a wide variety of cultural backgrounds and was endorsed in 1994 by WHO for use in primary health care in developing countries. The instrument also assumes that the population of interest may have poor infrastructure, have low literacy levels which make phone interviews and self completion infeasible, as is often the case in developing countries. The use of an abbreviated version of the SRQ therefore adds dimension and depth to other studies which have used the SRQ in broader social science research.

The selection criteria of the 5 items of the SRQ-5 took on a two fold approach. The first being based on the validation study of the SRQ conducted in Zambia (13), which rendered half of the questions in the SRQ-20 invalid based on misconceptualisation of questions on the part of the participants. The other questions, though found to capture the psychopathology sort by the medical practitioner, were also found to be invalid in the face of intercurrent illness or co-morbidity. We therefore did not include these questions in the SRQ-5. (13) The second strategy involved eliciting expert advice from 3 experienced psychiatrists and 3 general medical practitioners. The items selected by the medical practitioners were similar in at least 4 of the 5 questions. They additionally unanimously agreed that suicidal ideation of at least 1 month constituted severe depression and so even when found as alone symptoms would be enough to make a diagnosis of mental distress. The fact that these two selection criteria yielded somewhat similar results, further added impetus to the robustness of this selection strategy. Similar selection strategy was used by Jacobsen et al. and yielded comparable results. (19)

Scale developers have traditionally evaluated performance of screening tools by comparing the sensitivity and specificity by gender and age. In our study the validity coefficients did not seem to differ in these sub-groups. This would suggest that it is unnecessary to use different cut-off points in these groups. These results are somewhat similar to other studies investigating abbreviated screening tools. Cleary et al.(22), in their study to evaluate the use of mental health screening scales in primary care also found no statistical difference by gender or sex. They however cautioned that the interpretation of these results is not clear cut as literature on this subject is not in agreement. They advised that the presence of these gender

and sex differences (23) should be born in mind as test results could differ substantially by patient group, even when the overall validation is similar.(23)

In conclusion, this validation showed that in moving from SRQ with 10-20 items to one with merely 5 items, we do not seem to lose the screening prowess of the instrument. The SRQ-5 represents a simplification of the mental health screening process while exhibiting strong performance characteristics. This has implications in the clinical settings as well as in the policy formulation sector. It is of importance in the clinical setting in that such an abbreviated scale allows for its administration without being overly time consuming. In as much as the SRQ-5 is unable to provide an exact diagnostic classification, it has been shown to be a reliable flag for detecting the common symptom pathways (mental distress) that then manifest as specific psychiatric diagnosis, especially in primary health care. This provides an entry point to specialized psychiatric treatment for those who are diagnosed with mental illness, or indeed an entry point to counseling services for those with milder forms of mental distress. It is as such a step forward in ensuring that as many people get the mental health care they need. Additional impetus for such an instrument is added by the growing body of evidence for the consistent linkage between mental distress and other chronic and acute illness and the recognition that feasible actions within a primary health setting which identifies and treats mental distress have a long-run better outcome for other intercurrent illness. It is important from a policy perspective because, when used in population surveys, it allows for access to prevalence data that is critical to formulation of cogent national mental health policies as well as to the success of such policies. Further the need for a cost-effective instrument to measure mental health, especially in developing countries, has increased over the last decade. The paper provides a method of measuring mental distress that is cost-effective (in-terms of time

and level of human resource) and provides a window which allows for access to assurance of specific annual budget allocation to mental health.

### **List of abbreviations**

SRQ-20 = Self-Reporting Questionnaire 20

SRQ-10 = Self-Reporting Questionnaire-10

SRQ-5= Self-Reporting Questionnaire-5

SRQ's= Self-Reporting Questionnaires

GHQ-12 = General Health Questionnaire

MHI- Mental Health Interview

SF-36- Short Form-36

DSM-1V = Diagnostic and Statistical Manual of

Mental Disorder 4th Edition

ROC = Receiver Operating Characteristics

AUC = Area Under the Curve

SE= Standard error

NPV= Negative predictive Value

PPV= Positive predictive value

### **Keywords**

Mental Distress, Screening instruments, Validity, Primary health care, SRQ-5, SRQ-10, SRQ-20, GHQ12, DSM-IV, Zambia.

### **Competing interests**

The authors declare that they have no competing interests

### **Authors' contributions**

PJC and KF both contributed to the analysis and drafting of the manuscript. PJC also contributed to the design and conduct of the study while KF contributed to the critical revision of manuscript and approval of final version.

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## Tables

Table 1: SRQ-10 items and the independently selected five and seven item combinations selected by six experienced medical practitioners.

| <b>SRQ-10 Items:</b><br>In the past 30 days.....               | <b>Item weight<sup>§</sup></b>        |   |
|--|---------------------------------------|---|
| 1. Do you sleep badly?   |                                       | 1   |
| 2. Do you cry more than usual?                                 |                                       | 1   |
| 3. Do you find it difficult to enjoy your daily activities?    |                                       | 3   |
| 4. Do you find it difficult to make decision?                  |                                       | 1   |
| 5. Is your daily life suffering?                               |                                       | 3   |
| 6. Are you unable to play a useful part in life?               |                                       | 3   |
| 7. Has the thought of ending your life ever been on your mind? |                                       | 5   |
| 8. Do you feel tired all the time?                             |                                       | 1   |
| 9. Do you often have headaches?                                |                                       | 1   |
| 10. Is your digestion poor?                                    |                                       | 1   |
| <b>Selected SRQ-5 Items</b>                                    | <b>5-Item combination<sup>#</sup></b> | <b>7-item combinations<sup>#</sup></b><br>(2 items in addition to the 5 item combination) |
| Validation study*  | 1, 3,5,6, 9                           | -   |
| Medical practitioners  |                                       |   |
| Psychiatrist I   | 1, 5 6, 7, 9                          | 7, 8  |
| Psychiatrist II  | 1, 3, 5, 8 9                          | 6, 7  |
| Psychiatrist III   | 1, 3, 5, 6, 9                         | 7, 8  |
| General medical officer I                                      | 1, 3, 6, 8, 9                         | 2, 5  |
| General medical officer II                                     | 1, 5, 6, 8, 9                         | 4, 7  |
| General medical officer III                                    | 1, 2, 6, 7, 9                         | 7, 8  |

\* Selection based on: *Chipimo PJ, Fylkesnes K. Comparative Validity of Screening Instruments for Mental Distress in Zambia. Clinical Practice & Epidemiology in Mental Health. 2010;6:4-15.*

§ Weights based on: *Chipimo PJ, Fylkesnes K. Mental distress in the general population Zambia: Impact of HIV and social factors. BMC Public Health, 2009; 9:298*

# Numbering based on: *SRQ-10 Items*

Table 2: Correlation matrix for SRQ-5, SRQ-10, SRQ-20 and GHQ-12

| Screening instrument | 1     | 2     | 3     | 4 |
|----------------------|-------|-------|-------|---|
| SRQ-5                | 1     |       |       |   |
| SRQ-10               | 0.923 | 1     |       |   |
| SRQ-20               | 0.764 | 0.846 | 1     |   |
| GHQ-12               | 0.417 | 0.515 | 0.593 | 1 |

Table 3: Performance of the questionnaires: Areas under the ROC curve

| Criterion diagnosis     | SRQ-5        | SRQ-10       | SRQ-20       | GHQ-12       |
|-------------------------|--------------|--------------|--------------|--------------|
|                         | AUC (S.E)    | AUC (S.E)    | AUC (S.E)    | AUC (S.E)    |
| Overall Mental Distress | 0.925(0.021) | 0.959(0.015) | 0.951(0.014) | 0.811(0.037) |
| Male                    | 0.964(0.020) | 0.994(0.005) | 0.989(0.007) | 0.807(0.059) |
| Female                  | 0.896(0.032) | 0.931(0.025) | 0.921(0.024) | 0.813(0.047) |
| 15-29 years             | 0.886(0.038) | 0.961(0.021) | 0.967(0.013) | 0.835(0.052) |
| 30-67 years             | 0.966(0.017) | 0.963(0.020) | 0.945(0.023) | 0.795(0.052) |
| Depression              | 0.915(0.018) | 0.951(0.018) | 0.931(0.018) | 0.774(0.043) |
| Anxiety                 | 0.849(0.038) | 0.879(0.030) | 0.924(0.025) | 0.868(0.063) |

\* All figures  $p < 0.001$

Table 4: Performance of the single SRQ-5 Items- Areas under the ROC curve

| Criterion diagnosis     | SRQ-10 full scale | SRQ-5 Individual items     |                            |                            |                            |                            |
|-------------------------|-------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
|                         | AUC (SE)          | Sleep<br>AUC (SE)          | Enjoy<br>AUC (SE)          | Suffer<br>AUC (SE)         | Useful<br>AUC (SE)         | Headache<br>AUC (SE)       |
| Overall Mental Distress | 0.959 (0.015)     | 0.815 (0.037) <sup>c</sup> | 0.826 (0.035) <sup>c</sup> | 0.779 (0.041) <sup>c</sup> | 0.709 (0.045) <sup>c</sup> | 0.623 (0.040) <sup>a</sup> |
| Depression              | 0.951 (0.018)     | 0.836 (0.037) <sup>c</sup> | 0.813 (0.039) <sup>c</sup> | 0.790 (0.044) <sup>c</sup> | 0.726 (0.049) <sup>c</sup> | 0.606 (0.045) <sup>a</sup> |
| Anxiety                 | 0.879 (0.030)     | 0.693 (0.080)              | 0.757 (0.100)              | 0.637 (0.118)              | 0.589 (0.120)              | 0.689 (0.086)              |

<sup>a</sup> SRQ-10 vs SRQ-5 item p<0.05

<sup>b</sup> SRQ-10 vs SRQ-5 item p<0.01

<sup>c</sup> SRQ-10 vs SRQ-5 item p<0.001

Table 5: Sensitivity and specificity of SRQ-5 for overall Mental Distress

| Screening Instrument | Cut-off | Sensitivity | Specificity | PPV  | NPV  | % of cases screened correctly | k    | %cases |
|----------------------|---------|-------------|-------------|------|------|-------------------------------|------|--------|
| SRQ-5                | 4       | 0.87        | 0.85        | 0.48 | 0.98 | 85.4                          | 0.54 | 24.3   |
|                      | 5       | 0.72        | 0.94        | 0.64 | 0.96 | 90.8                          | 0.63 | 15.0   |
|                      | 6       | 0.64        | 0.96        | 0.70 | 0.97 | 91.6                          | 0.63 | 12.0   |
|                      | 7       | 0.64        | 0.97        | 0.77 | 0.95 | 92.6                          | 0.65 | 11.0   |
|                      | 8       | 0.49        | 0.98        | 0.81 | 0.92 | 91.6                          | 0.54 | 8.0    |





# QUESTIONNAIRE-POPULATION BASED SURVEY

## APPENDIX I: ZAMCORE 2003 EPI QUESTIONNAIRE

1. Cluster identification:

CSA SEA Rural/Urban

2. Housing identification:

Building Unit Household

3. Personal number:

---

4. AGE

5. SEX (Male=1, Female=2)

6. What is your mother Language?  
(1=Bemba, 2= Kaonde, 3=Lozi, 4=Lunda,  
5=Luvale, 6=Nyanja, 7=Tonga, 8=other)

7. For how long have you been living  
continuously in this household?  
(if less than 1 year, code 0, else years)

8. Just before you moved here, did you  
live in a 1=Village, or 2=Lusaka, or  
3=other city or town?

9. Marital status: Are you now  
(1)Single, never married, (2) Single but engaged, (3) Living as married, (4) Married, (5)Widowed, (6)  
Separated/div.

If single, never married, skip to Q 14

10. For how long have you  
been married to this person?  
(if less than 1 year, code 0, else years)

11. How old is this person (spouse)?

12. How old were you when  
you first got married?

13. Now think back to the past. Apart from this spouse, how many have you been  
married to/living with in your whole life?

14. For how many years did you go to school?

15. What is your highest level of education completed? (1=Never attended, 2=Grade 1-4, 3=Grade 5-7,  
4=Grade 8-9, 5=Grade 10-12, 6=Higher)

16. Are you still in school?

Score for all yes/no Qs: Yes=1, No=2

17. Are you employed at present?  
(1=Unemployed, 2=Unpaid family worker,  
3=Self employed, 4=Employee, 5=Employer)

Does your household have  
18. Electricity?

19. A radio?

20. A refrigerator?

21. A bicycle?

22. A plough?

23. A donkey?

24. What is your religion?  
(1=None, 2=Catholic, 3=Liberal protestant,  
4=Strict protestant, 5=Muslim, 6=other)

25. Have you during the past years been on  
regular trips where you have to stay away from home for several days or more? (1=Never, 2=Sometimes,  
3=Often,  
4=Very often)

26. How would you say your health is at  
the moment? Is it (1 =) Very poor,  
(2 =) Poor, (3 =) Fair, (4=) Good,   
(5 =) Excellent

During the last one year, how many times did you visit



27. A traditional healer?
28. A spiritual healer?
29. Private doctor/clinic?
30. The local health centre?
31. The hospital?
32. How many times were you admitted  
in hospital during the last one year?
33. If ever admitted in hospital, did you  
ever receive blood (transfusion)?
34. Are you on any type of medication?
- (1=No, 2=Traditional, 3=Professional)
- During the last one-year, did you suffer from
35. Malaria
36. TB
37. Any STD (sexually transmitted disease)

Now I will ask you some few questions related to certain pains and problems, that might have bothered you the last 30 days. If you think the question applies to you and you have had the problem in the last 30 days, answer Yes. If not, answer No.

(Codes: Yes=1, No=2, Don't know=3)

38. Do you sleep badly?
39. Do you cry more than usual?
40. Do you find it difficult to enjoy your  
daily activities?
41. Do you find it difficult to make  
decisions?
42. Is your daily life suffering?
43. Are you unable to play a useful part  
in life?
44. Has the thought of ending your life  
been on your mind?
45. Do you feel tired all the time?
46. Do you often have headaches?

47. Is your digestion poor?

Do you agree or disagree with the following statements?: (Read and obtain a response for each statement: Code 1 when Agreeing, 2 when Disagreeing).

48. Condoms are safe preventing HIV/AIDS

49. Most women don't like men to use condoms

50. Condoms are embarrassing to obtain

51. Using condoms shows responsibility

52. Most men do not like using condoms

53. Condoms are too expensive

54. Using condoms is against my religion

55. Have you ever had sexual relations?

If no, skip to Q 67

56. At what age did you first have sex?

57. Have you had sex the last 12 months?

58. Have you ever used a condom?

59. Did you use a condom last time you had sex?

60. Is it easy to get a condom when needed?

61. Did you have a regular sex partner during the last 12 months?

62. Did you have sex with anyone else apart from your regular sex partner last year?

63. If yes on Q62: Approximately how old was the last casual sex partner?

64. Did you use a condom when you

last had sex with a casual partner?

65. With how many different people  
have you had sex in the last 12 months? (include spouse)

66. How many different people have  
you had sex with in your life?

67. Have you ever contracted any STD?

If no, skip to Q 69

68. Did you tell your partner?

**Do you agree or disagree with the following statements: (Read and obtain a response for each statement, code 1 when Agreeing, 2 when Disagreeing)**

69. I have less sexual partners at present  
compared to some years ago

70. My friends have not changed their  
sexual behaviour despite the AIDS risk

71. Some years ago I did not use condoms

72. Most of my friends never use condoms

73. I always use a condom nowadays

74. In your situation, do you think that you  
are at risk of getting (catching) HIV?

Would you say that

1= You are not at risk, or

2= the risk is moderate, or

3= the risk is high, or

4= the risk is very high

75. How worried are you about actually  
being infected by HIV/AIDS?

1= Always worried, or

2= Sometimes worried, or

3= Seldom worried, or

4= Never worried

**Now I will ask you some hypothetical questions**

76. If a member of your family became sick with the HIV/AIDS virus, would you be willing to care for him or her in your household?

77. If you knew that a shopkeeper or food seller had the HIV/AIDS virus, would

you buy fresh vegetables from him?

78. If a female teacher has the HIV/AIDS virus but is not sick, should she be allowed to continue teaching in school?

79. If a member of your family became infected with the AIDS virus, would you want it to remain a secret?

MALES ONLY:

80. Have you been circumcised?

81. How many wives do you have?

FEMALES ONLY:

82. Have you ever given birth?

83. Are you pregnant at present?

If not given birth, skip to 91

84. How many have you given birth to all in all?

85. How long is it since you last gave birth?   
(if less than 1 year, code 0, else years)

86. Do you want another child?

87. How did the last pregnancy end?   
(1=live, 2=still, 3=abortion)

88. Did you visit any antenatal care services during last pregnancy?  
1= No; 2= Yes, traditional practitioner or midwife  
3= Yes, clinic/hospital  
4= Yes, Private clinic

89. Have any of your children died before the age of one?   
Code the number, if none, score 0.

90. Have any of your children died before the age of 5?   
Code the number, if none score 0.

91. Do you use any of the following contraceptive methods currently?

(mention all)

1= Pill; 2= Injections; 3= IUD; 4= Condom; 5= Natu  6= Traditional; 7= Any other;

8=None

92. Have you ever used a condom  
as your contraceptive method?

93. Does your husband have other  
wives?

94. Do you often use traditional agents  
like herbs or other agents for self-  
treatment when experiencing vaginal discharge or itching?  
(1=Most often, 2=Sometimes, 3=Never)

95. Do you often use traditional agents  
like herbs or a cloth before having sex?  
(1=most often, 2=sometimes, 3=never)

96. Is your usual (regular) male  
partner circumcised?   
Yes=1, No=2, don't know=3

Do you agree or disagree with the following statement: 1=agree, 2=disagree

97. If my husband had a STD, I could either refuse to have sex with him or I would get him to use a condom?

ALL RESPONDENTS

Inform on saliva samples; anonymity,  
consent; and on the voluntary option of  
being counselled and tested

98. Have you ever been HIV tested?

99. If tested: Did you receive the test  
result?

100. Would you like us to arrange for

you to be HIV tested?

101. Attendance

1=Completed (both interview and saliva)

2=Refused saliva

3=Refused interview

4=Refused both interview and saliva

5=Not found

102. Number of interviewer

103. Date: day:..... /month...../year.....

# QUESTIONNAIRE MENTAL HEALTH SCREENING INSTRUMENTS

Questionnaire – Validating the use of SRQ-10 as a screening tool in Primary health care centres in Zambia

## 1. Clinic identification:

## 2. Data collector's identification:

## 3. Respondent's number:

---

Score for all yes/no Qs: Yes=1, No=2

---

## 4. Sex

(MALE=1, FEMALE=2)

## 5. (a) How old are you?

(b) When were you born

## 6. What is your mother Language?

(1=BEMBA, 2= KAONDE, 3=LOZI, 4=LUNDA, 5=LUVALE, 6=NYANJA, 7=TONGA, 8=OTHER)

## 7. What is your religion?

(1=CATHOLIC, 2= LUTHERAN, 3=ANGLICAN, 4=OTHER CHRISTIAN, 5=MUSLIM, 6=TRADITIONAL, 7=OTHER)

## 8. What is the reason for your coming to the clinic today?

( 1=General consultation, 2= review, 3=antenatal, 4= child Immunisation, 5= escorted a patient)

## 9. Marital status: Are you now

(1)Single, never married, (2) Single but engaged, (3) Living as married, (4) Married, (5) Widowed, (6) Separated/div.

*If single, never married, divorced/separated or widowed, skip to Q13*

## 10. How long have you been married? If less than 1 year code 0, else in years

## 11. Is your spouse/partner living with you now or is he/she staying elsewhere?

1=LIVING WITH HIM/HER

2=STAYING ELSEWHERE

## a) WOMEN: Does your husband / cohabiting partner have other wives or does he live with other partners?

(1 = YES, 2 = NO)

**12. How old is your spouse?**

(only fill in spouse 1 for women)

Spouse 1

Spouse 2

Spouse 3

**13. Are you still in school?**

(1 = YES, 2 = NO)

**14. For how many years did you go to school?**

**15. What is your highest level of education completed?**

1=NEVER ATTENDED

2=GRADE 1-4

3=GRADE 5-7

4=GRADE 8-9

5=GRADE 10-12

6=HIGHER

**16. Are you employed at present?**

(1=unemployed, 2=unpaid family worker, 3=self employed, 4=employee, 5=employer)

**17. What is the main source of drinking water for members of your household?**

1= PIPED WATER

2=WATER FROM OPEN WELL

3=WATER FROM COVERED WELL OR BOREHOLE

4=SURFACE WATER

5=RAINWATER

6=TANKER TRUCK

7=BOTTLED WATER

9=OTHER (SPECIFY) \_\_\_\_\_

**18. What kind of toilet facilities does your household have?**

1=FLUSH TOILET

2=PIT TOILET/LATRINE

3=NO FACILITY / BUSH / FIELD

9=OTHER (SPECIFY) \_\_\_\_\_

**19. Does your household have?**

(1 = YES, 2 = NO)

a. Electricity

b. A radio

c. TV

d. A refrigerator

e. A bicycle

f. A plough

g. A donkey

h. Cattle



**20. Material of floor.**

*Record observation.*

1 = CONCRETE ONLY

2 = COVERED CONCRETE

3 = MUD

4 = WOODEN ONLY

5 = OTHER, SPECIFY \_\_\_\_\_

**21. Has your household had enough food to eat during the last full year (12 months)? Would you say usually, sometimes, seldom or never?**

1=USUALLY

2=SOMETIMES

3=SELDOM

4=NEVER

----- SECTION 2 –Health-----

**22. Have you ever suffered from mental illness?**

(1=yes, 2=No)

**23. Have you ever been treated for depression?**

(1=Yes, 2=No)

**24. Has anyone in your family ever suffered from mental illness?**

(1=Yes, 2=No)

**25. Has anyone in your family been treated for depression?**

(1=Yes, 2=No)

**26. Has anyone in your family attempted suicide?**

(1=Yes, 2=No)

**27. Has anyone in your family ever committed suicide?**

(1=Yes, 2=No)

**28. How would you say your health is at the moment?**

Is it (1) Very poor, (2) Poor, (3) Fair, (4) Good, (5) Excellent

**29. During the last one year, were you admitted to hospital**

(1 = YES, 2 = NO)

If no skip to question 26.....

**30. How many times were you admitted to Hospital?**

(1= 1-2 times, 2=2-3times, 3=more than 4 times)

**31. What was the reason for admission?**

(1=respiratory, 2=cardiac 3=Urogenital, 4=CNS, 5=GIT)

**32. Are you on any type of long term medication?**

(1=Yes, 2=No)

**32a). If yes is it.....**

(1=traditional medicine 2=Western medicine)

ALL RESPONDENTS:

33). The following questions are related to certain pains and problems, that may have bothered you the last 30 days. If you think the questions applies to you and you had the described problem in the last 30 days, answer YES.

On the other hand, if the questions do not apply to you and you did not have the problem in the last 30 days, answer NO.

|  | yes | no |
|--|-----|----|
| a Do you often have headaches?                             | 1   | 2  |
| b Is your appetite poor?                                   | 1   | 2  |
| c Do you sleep badly?                                      | 1   | 2  |
| d Are you easily frightened?                               | 1   | 2  |
| e Do your hands shake?                                     | 1   | 2  |
| f Do you feel nervous, tense or worried?                   | 1   | 2  |
| g Is your digestion poor?                                  | 1   | 2  |
| h Do you have trouble thinking clearly?                    | 1   | 2  |
| i Do you feel unhappy?                                     | 1   | 2  |
| j Do you cry more than usual?                              | 1   | 2  |
| k Do you find it difficult to enjoy your daily activities? | 1   | 2  |
| l Do you find it difficult to make decisions?              | 1   | 2  |
| m Is your daily work suffering?                            | 1   | 2  |
| n Are you unable to play a useful part in life?            | 1   | 2  |
| o Have you lost interest in things?                        | 1   | 2  |
| p Do you feel that you are a worthless person?             | 1   | 2  |
| q Has the thought of ending your life been on your mind?   | 1   | 2  |
| r Do you feel tired all the time?                          | 1   | 2  |
| s Do you have uncomfortable feelings in your stomach?      | 1   | 2  |
| t Are you easily tired?                                    | 1   | 2  |

34. Have you in the last 6 months experienced

(1 = YES, 2 = NO)

- a) Break-up of a marriage
- b) Break-up of a sexual relationship
- c) Physical abuse
- d) Neglected or disowned by family

**e) loss of a loved one,**

**IF NO END OF INTERVIEW**

**f) if yes to e, was it a:**

**1. child**

**2. spouse**

**3. parent**

**4. sibling**

**5. close relative**

**END OF INTERVIEW**



# QUESTIONNAIRE MENTAL HEALTH COHORT STUDY

Questionnaire – Assessing mental health changes and changes in sexual risk behaviour in PLWHA

1. Clinic Identification:

2. Name of respondent:

3. Contact address of respondent:

4. Contact phone number of respondent:

5. HIV status: (0=negative, 1= positive, 2= unknown)

6. Drug regime (if HIV positive) (1=1<sup>st</sup> line, 2=2<sup>nd</sup> line, 3= 3<sup>rd</sup> line)

7. Duration on ARV'S (0=<6 months, 1= 6-1 year, 2=1-2 year, 3= 2-4 years 4= >4 years)

8. Starting CD4 count (1=<50, 2=50-100, 3= 100-200)

9. Current CD4 count (1<100, 2=100-200, 3=200-300, 4=400-700, 5=> 700)

10. Viral load

11. Name, Address and contact of next of kin:

12. Respondents identification number:

13. Interviewer's number:

---

Score for all yes/no Qs: Yes=1, No=2

---

14. Sex   
(MALE=1, FEMALE=2)

15. How old are you?

16. What is your mother Language?   
(1=BEMBA, 2= KAONDE, 3=LOZI, 4=LUNDA, 5=LUVALE, 6=NYANJA, 7=TONGA, 8=OTHER)

17. What is your religion?   
(1=CATHOLIC, 2= LUTHERAN, 3=ANGLICAN, 4=OTHER CHRISTIAN, 5=MUSLIM, 6=TRADITIONAL, 7=OTHER)

18. For how long have you been living continuously in this household?   
(if less than 1 year, code 0, else years)

19. Marital status: Are you now

**(1) Single, never married, (2) Single but engaged, (3) Living as married, (4) Married, (5) Widowed, (6) Separated/div.**

*If single, never married, divorced/separated or widowed, skip to Q13*

**20. Is your spouse/partner living with you now or is he/she staying elsewhere?**   
1=LIVING WITH HIM/HER  
2=STAYING ELSEWHERE

**21.a) MEN: How many wives and other partners live with you?**

**b) WOMEN: Does your husband / cohabiting partner have other wives or does he live with other partners?**   
(1 = YES, 2 = NO)

**22. How old is your spouse?**  
(only fill in spouse 1 for women)  
Spouse 1   
Spouse 2

**23. For how many years did you go to school?**

**24. What is your highest level of education completed?**   
1=NEVER ATTENDED  
2=GRADE 1-4  
3=GRADE 5-7  
4=GRADE 8-9  
5=GRADE 10-12  
6=HIGHER

**25. Are you still in school?**   
(1 = YES, 2 = NO)

**26. What is the main source of drinking water for members of your household?**   
1= PIPED WATER  
2=WATER FROM OPEN WELL  
3=WATER FROM COVERED WELL OR BOREHOLE  
4=SURFACE WATER  
5=RAINWATER  
6=TANKER TRUCK  
7=BOTTLED WATER  
9=OTHER (SPECIFY) \_\_\_\_\_

**27. What kind of toilet facilities does your household have?**   
1=FLUSH TOILET  
2=PIT TOILET/LATRINE  
3=NO FACILITY / BUSH / FIELD  
9=OTHER (SPECIFY) \_\_\_\_\_

**28. Does your household have?**

(1 = YES, 2 = NO)

- a. Electricity
- b. A radio
- c. TV
- d. A refrigerator
- e. A bicycle
- f. A plough
- g. A donkey
- h. Cattle

**29. Material of floor.**

*Record observation.*

1 = CONCRETE ONLY

2 = COVERED CONCRETE

3 = MUD

4 = WOODEN ONLY

5 = OTHER, SPECIFY \_\_\_\_\_

**30. Has your household had enough food to eat during the last full year (12 months)? Would you say usually, sometimes, seldom or never?**

1=USUALLY

2=SOMETIMES

3=SELDOM

4=NEVER

**31. Have you during the past years been on regular trips where you had to stay away from home for several days or more?**

1=NEVER

2=SOMETIMES

3=OFTEN

4=VERY OFTEN

**32. How would you say your health is at the moment?**

Is it (1) Very poor, (2) Poor, (3) Fair, (4) Good, (5) Excellent

**During the last one year, did you suffer from**

(1 = YES, 2 = NO)

**33. Malaria**

**34. TB**

**35. Genital discharge or ulcer**

**36. When you last had a genital discharge or ulcer, did you seek any kind of advice or treatment?**

(1 = YES, 2 = NO)

**37. Now I would like to ask you some questions about medical care for you and your family. Many different factors can prevent people from getting medical advice or treatment. When you**

are sick and want to get medical advice or treatment, is each of the following a problem or not for you?

- 1=BIG PROBLEM,
- 2=SLIGHT PROBLEM
- 3=NOT A PROBLEM

- a. Knowing where to go
- b. Getting money needed for treatment or transport
- c. The distance to the health facility
- d. Availability of transport

38. The last time you visited a clinic or hospital, where did you go?
- 1=GOVERNMENT HOSPITAL
  - 2=GOVERNMENT HEALTH CENTER
  - 3= OTHER PUBLIC (SPECIFY)
  - 4=PRIVATE (FOR PROFIT) CLINIC
  - 5=PRIVATE (FOR PROFIT) HOSPITAL
  - 6=OTHER (FOR PROFIT) PRIVATE (SPECIFY)
  - 7=MISSION/NGO CLINIC (NON-PROFIT)
  - 8=MISSION/NGO HOSPITAL (NON-PROFIT)
  - 9=OTHER (SPECIFY)

39. Was this facility the nearest one?   
(1 = YES, 2 = NO)

*MEN: Skip to introduction to Q41.*

FEMALES ONLY:

40. Have you ever given birth?   
(1 = YES, 2 = NO)

*If not given birth, skip to Q40*

41. How many have you given birth to all in all?

42. How long is it since you last gave birth?   
(if less than 1 year, code 0, else years)

43. When you were pregnant last time, did you seek antenatal care?   
(1 = YES, 2 = NO)



ALL RESPONDENTS:

The following questions are related to certain pains and problems, that may have bothered you the last 30 days. If you think the questions applies to you and you had the described problem in the last 30 days, answer YES.

On the other hand, if the questions do not apply to you and you did not have the problem in the last 30 days, answer NO.

|   | YES | NO |
|---|-----|----|
| 44 Do you often have headaches?                             | 0   | 1  |
| 45 Is your appetite poor?                                   | 0   | 1  |
| 46 Do you sleep badly?                                      | 0   | 1  |
| 47 Are you easily frightened?                               | 0   | 1  |
| 48 Do your hands shake?                                     | 0   | 1  |
| 49 Do you feel nervous, tense or worried?                   | 0   | 1  |
| 50 Is your digestion poor?                                  | 0   | 1  |
| 51 Do you have trouble thinking clearly?                    | 0   | 1  |
| 52 Do you feel unhappy?                                     | 0   | 1  |
| 53 Do you cry more than usual?                              | 0   | 1  |
| 54 Do you find it difficult to enjoy your daily activities? | 0   | 1  |
| 55 Do you find it difficult to make decisions?              | 0   | 1  |
| 56 Is your daily work suffering?                            | 0   | 1  |
| 57 Are you unable to play a useful part in life?            | 0   | 1  |
| 58 Have you lost interest in things?                        | 0   | 1  |
| 59 Do you feel that you are a worthless person?             | 0   | 1  |
| 60 Has the thought of ending your life been on your mind?   | 0   | 1  |
| 61 Do you feel tired all the time?                          | 0   | 1  |
| 62 Do you have uncomfortable feelings in your stomach?      | 0   | 1  |
| 63 Are you easily tired?                                    | 0   | 1  |

64. Have you in the last 6 months experienced  
(1 = YES, 2 = NO)

- a) Break-up of a marriage
- b) Break-up of a sexual relationship
- c) Physical abuse
- d) Neglected or disowned by family

**Question 65 and 67 only for HIV negative**

**65. In your situation, do you think that you are at risk of getting (catching) HIV? Would you say that**   
1= You are not at risk, or  
2= the risk is moderate, or  
3= the risk is high, or  
4= the risk is very high

**66. How worried are you about actually being infected by HIV/AIDS? Are you**   
1= Always worried, or  
2= Sometimes worried, or  
3= Seldom worried, or  
4= Never worried

**67. Have you ever been HIV tested?**   
(1 = YES, 2 = NO)

*If no, skip to Q99*

**68. How long ago was your (last) test?**   
(COMPLETE ONLY ONE OPTION.)  
ENTER 'MONTHS AGO' ONLY IF 11 MONTHS OR LESS. ENTER 'YEARS AGO'  
ONLY IF ONE OR MORE YEARS AGO.  
WEEKS AGO..... 1 [ ][ ]  
MONTHS AGO ..... 2 [ ][ ]  
YEARS AGO..... 3 [ ][ ]

**69. Why were you tested (last time)?**

**70. Did you receive the test result last time you were tested?**   
(1 = YES, 2 = NO)

**71. If “no” to HIV tested: Why have you never taken the test?**  
*Circle all that are mentioned*  
a) NO ACCESS  
b) DID NOT KNOW WHERE TO GO  
c) CONCERNED ABOUT PRIVACY  
d) FEAR/DO NOT WISH TO KNOW RESULT  
e) DISCOURAGED BY PARTNER  
f) NOT INTERESTED/NOT RELEVANT  
g) AFRAID TO BE SEEN AT THE VCT CLINIC

**72. Have you ever had sexual intercourse? (1 = YES, 2 = NO)**

*If no, skip to Q124*

**73. At what age did you first have sex?**

**74. How old was your first sex partner?**

**75. Have you had sex the last 12 months?**   
(1 = YES, 2 = NO)

**76. Have you ever used a condom?**   
(1 = YES, 2 = NO)

**77. Did you use a condom last time you had sex?**   
(1 = YES, 2 = NO)

**78. Is it easy to get a condom when needed?**   
(1 = YES, 2 = NO)

**79. Did you have a regular sex partner during the last 12 months?**   
(1 = YES, 2 = NO)

**80. If yes to Q110, did you use a condom when you last had sex with your regular partner?**  
(1 = YES, 2 = NO)

**81. Did you have sex with anyone else apart from your regular sex partner last year?**   
(1 = YES, 2 = NO)

**82. If yes to Q112, did you use a condom when you last had sex with a casual partner?**   
(1 = YES, 2 = NO)

*If no, skip to Q116*

**83. What was the main reason you used a condom on that occasion?**

- 1=RESPONDENT WANTED TO PREVENT STD/HIV
- 2=RESPONDENT WANTED TO PREVENT PREGNANCY
- 3=RESPONDENT WANTED TO PREVENT BOTH STD/HIV AND PREGNANCY
- 4=DID NOT TRUST PARTNER/FELT PARTNER HAD OTHER PARTNERS
- 5=PARTNER REQUESTED/INSISTED
- 6=OTHER (SPECIFY) \_\_\_\_\_
- 7=DON'T KNOW

*If YES to Q114, skip to Q117*

**84. What was the main reason you did not use a condom that time?**

- 1=NOT AVAILABLE AT PLACE WHERE USUALLY GETS THEM
- 2=COST TOO MUCH / NO MONEY
- 3=TRUSTED HIS PARTNER
- 4=PARTNER TESTED NEGATIVE / NO RISK OF DISEASE
- 5=RESPONDENT DOESN'T LIKE
- 6=PARTNER OBJECTED / REFUSED
- 7=PARTNER DRUNK / ON DRUGS
- 8=WANTED TO GET PREGNANT
- 9=CONDOMS ARE NOT SAFE
- 10=OTHER – SPECIFY \_\_\_\_\_

**85. In the last month, how often have you used condoms with non-regular partners?**

- 1= ALWAYS
- 2=SOMETIMES
- 3= NEVER

**86. How many different people have you had sex with in the last month?** (include spouse)

**87. With how many different people have you had sex in the last 12 months?** (include spouse)

**88. Have you had sexual contact with anyone else while you were sexually active involved with any of these partners?**   
(1 = YES, 2 = NO)

**89. How many different people have you had sex with in your life?**

**90. In the last 12 months have you exchanged gifts for or paid for sex or been paid or received gifts to have sex?**  
(1 = YES, 2 = NO)

**91. Have you contracted any STI in the last 12 months?**   
(1 = YES, 2 = NO)

**Husbands and wives do not always agree on everything. Please tell me if you think a wife is justified in refusing to have sex with her husband when:**

**92. She knows her husband has a sexually transmitted disease?**   
1=YES, 2= NO, 3= DON'T KNOW

**93. She knows her husband has sex with other women?**   
1=YES, 2= NO, 3= DON'T KNOW

**94. She has recently given birth?**   
1=YES, 2= NO, 3= DON'T KNOW

**95. She is tired or not in the mood?**

1=YES, 2= NO, 3= DON'T KNOW

**Do you think that if a woman refuses to have sex with her husband when he wants her to, he has the right to...**

**96. Get angry and reprimand her?**

1=8ES, 2= NO, 3= DON'T KNOW

**97. Refuse to give her money or other means of financial support?**

1=YES, 2= NO, 3= DON'T KNOW

**98. Use force and have sex with her even if she doesn't want to?**

1=YES, 2= NO, 3= DON'T KNOW

**99. Go and have sex with another woman?**

1=YES, 2= NO, 3= DON'T KNOW

**100. Is it acceptable to have sex in order to obtain money or gifts?**

(1 = YES, 2 = NO)

**101. Is it acceptable for young men and women to engage in sex before marriage?**

(1 = YES, 2 = NO)

**102. Is it acceptable for a married man to have other sexual partners than his wife?**

(1 = YES, 2 = NO)

**103. Is it acceptable for a married woman to have other sexual partners than her husband? (1 = YES, 2 = NO)**

**Interviewer**

**Date**



# QUESTIONNAIRE MENTAL HEALTH QUALITATIVE INTERVIEWS

## VALIDATING THE USE OF SRQ-10 IN ZAMBIA.

### Suggested question Guide for Professions

**Sex:**

**Age:**

**Date:**

- Tell me about your qualifications and work experience?
- For how long have you been working at this health facility?
- What is your job description?
- What are the common illnesses reported at this health center?
- What screening tools do you use for mental illness?
- Have you heard about the SRQ-20?
- What do you know about the Self Reporting Questionnaire-20?
- How you ever used the SRQ-20? If yes where did you use it?
- What do your patients say causes the mental illness?
- What are the most commonly patient reported symptoms for common mental disorders? (e.g. Anxiety, depression)
- What do they say the sickness does to them?
- What do your patients call their mental problem? What name does it have?
- What do they fear most about their sickness?
- What problems do they say their sickness has caused to them and/or in their lives?
- How do they assess/report severity?
- What kind of treatment do they say they should receive and or what type of treatment do they often seek?
- What influences choice of treatment? (family, friends, type of illness etc)
- What results do the patients hope for from the treatment received?

## **PROMOTING MENTAL HEALTH IN THE ERA OF HIV- VALIDATING THE USE OF SRQ-10 IN ZAMBIA.**

Qualitative methods via in-depth interviews will be used to find out the HAART related beliefs about HIV transmission and to examine whether these are associated with unsafe sexual practices. The qualitative data will be derived from a sub-study of 20 potential informants of various ages, level of education, marital status and profession. The interview will be conducted in a private place convenient to the informant. Permission to tape record the interview and notes will be taken during the interview will be sort from the informant prior to beginning the interview. Each interview will be expected to take about half an hour. Data will be collected over a period of 10 days.

### **Suggested question guide for study two**

- Tell me about yourself (Age, where you live, for how long you have lived here, marital status, what you do for a living)
- Have you tested for HIV?
- When did you test?
- Would you like to tell me your HIV status?
- Tell me about your experience when you went for VCT(When, Why, How, Where, Who)
- What do you know about HIV/AIDS?
- How is it transmitted? (probe for any other transmission)
- How is it prevented?
- How is it treated? (If ARVs is mentioned probe for any other medical treatment apart from ARVs e.g. traditional)
- What are ARV's?
- When did you start coming for ARV's?
- What is your experience during ARV's visits?
- Are you satisfied with the services you receive at ARV's?
- What recommendations do you have for ARV's?
- Has a thought of stopping going for ARV's been in your mind?
- Can a person on ARV's transmit the virus to the other person?
- What effect do ARV's have on the human body?



- What happens when a person on ARV's has unprotected sex with another person?
- Are people on ARV's immune to getting sicker/developing AIDS?
- Do you use a condom every time you have sex?
- If no what are the reasons you do not use condoms consistently?
- Who did you have unprotected sex with (spouse or regular partner or casual)?
- Have you had unprotected sex with your partner since you started ARV's?
- How many sexual partners do you have?
- Has the number of sexual partners increased or reduced since u started ARV's?  
probe if yes or no



# CONSENT FORM

## Appendix II: Survey Consent form

### 1 - Why are we giving you this form?

We are giving you this form, telling you what it means and giving you the chance to ask questions about a study. Then you can decide if you would like to take part in this study that is trying to find many issues regarding the HIV epidemic in our country.

### 2 - Who is carrying out this study?

The Government of the Republic of Zambia through Central Statistical Office and the University of Zambia, Department of community Medicine. The persons responsible from these institutions are Kumbutso Dzekedzeke, Seta Siziya, Charles Michelo and Knut Fylkesnes.

The study is being done under the auspices of the Norwegian government through the Research Council (NUFU) of the University of Bergen, Centre for International Health.

The official name of the study is Population Based Survey on HIV in Chelstone & Kapiri Mposhi.

### 3 - Background Information

You are being asked to take part in a research study because you live in Chelstone or Kapiri Mposhi. We would like to know the extent of the HIV problem in our communities and we can only do so by working with people like you. This is made possible if you agree to participate. By participating we will be able to get the information that we need in order to make relevant policies and interventions for this problem. On the other hand if we do not know the extent of the problem in the community, it is very difficult to plan for effective policies and interventions. In view of this you will also be asked to take a test unlinked to your name but with the sole purpose of knowing how big or small the HIV problem is in Zambia.

We believe this is very vital information to all of us and you would help by participating in this study.

### 4 - What Happens In This Research Study?

You will be interviewed and tested for HIV by examining your saliva. Several other things will also take place:

Before the interview, we will list all members of your household so that we know who is there and who is eligible to participate in the survey. Those below the age of 15 will not be eligible to participate.

Then eligible people within your household will be interviewed. You will be asked about a wide range of issues. In addition you will be provided counselling service at a place of your preference, choosing between either your home or at the clinic. Since an HIV test will be necessary in this study, this process will help you to understand the need to take an HIV test. Therefore you will also undergo pre and post test-counselling sessions for HIV. If you do not agree to have your HIV test done you will not be discriminated against in any way in the provision of your health services.

Once all this has been done and you consent, you will be interviewed and tested for HIV. If you would like to know the results of the HIV test, please let the interviewer know so that arrangements will be made to give them to you.

At the end of the study, we hope to gather enough information regarding HIV so that relevant policies and interventions are advised.

#### **5 - Possible Problems**

We believe that the processes being used to test for HIV in you will not be harmful. The saliva tests that will be done to you are done elsewhere and have never been found harmful. However if we notice anything peculiar to you after taking the saliva specimen, we will let you know so that it helps you on whether you want to continue taking part or not.

#### **6 - Benefits**

You may not benefit from participating in this study. However we find that you have any medical problem, we will offer immediate referral to nearest health centre for treatment. We may be able to handle general ailments through our medical staff with us on the survey.

#### **7 - Your Rights to Participate, Not Participate, or to Withdraw from the Study**

Taking part in this study is voluntary. You do not need to take part in this study - it is up to you. You may choose to either or not participate. If you want to take part in the study, you can later change your mind and stop participating in the study. You are not obliged to give reasons but if you give reasons they will be treated with utmost confidence because they are very useful to us. You will suffer no penalty and lose no benefits that you may be entitled to if you do not take part in this

study. Your present or future medical care in Chelstone or Kapiri Mposhi will be the same whether or not you take part in the study.

## **8 - Confidentiality**

Your name will never be made public by the investigators. The medical record will be treated the same as all medical records at the health centres. A code number that makes it very difficult for anyone to identify you will identify the research information gathered during this study from you. All information will be stored in a secure place. Information from this study may be used for research purposes and may be published; however, your name will not be made public by the investigators. It is possible that, after the study is over, we may want to look again at the laboratory and interview record data collected during this study to help us answer another question. If this happens, still your name will not be made public by the investigators.

## **9 - Payment for A Research Related Injury:**

In the event that a problem results from a study-related procedure, either Dr. S. Siziya, Mr K. Dzekedzeke or Dr C. Michelo in LUSAKA should be notified, and you will be provided with free medical care at the Health Centre for the treatment of this complication.

## **10 -Consent Formalities**

### **10.1 Participant**

I \_\_\_\_\_ (participant's name, signature or thumb-print) have been informed about the Population Based Survey on HIV. I will provide saliva samples for analysis and will participate fully up to the best of my ability. A copy of this form signed by me and one of the study investigators is being given to me.

Signature\_\_\_\_\_

Date\_\_\_\_\_

### **10.2 Interviewer**

I have explained this research study to the subject. I am available to answer any questions now or in the future regarding the study and the subject's rights. The project administrator Dr. Seta Siziya can be reached at Department of Community Medicine, School of Medicine, UNZA on at the following

telephone numbers: 260-1-254414. You can also contact Dr. Charles Michelo on the following telephone numbers: 260-1-261987, 260-096-754920.

Signature of Investigators & Printed Names

Date of signature

Date \_\_\_\_\_