Mental Health and HIV/AIDS
Report on a round-table discussion, March 2003
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Introduction and reasons for the round-table meeting

The HIV/AIDS pandemic has many serious effects and implications. It is globally recognised as a disease which has massive personal, social, economic and political ramifications. More than 60 million people worldwide have lived with the disease and 20 million of these have already died. It is a disease which needs viewing from many different angles, to be broken down and analysed, but it also needs to be examined as a whole. Research is needed from numerous perspectives to provide information and knowledge for prevention, treatment and mitigation of the impacts. Within this multi-faceted web, an area that has thus far received relatively little attention, (certainly in the developing world) is mental health. This is a serious omission. The disease fundamentally affects people’s mental health in many different ways and this has implications for those infected by the disease, their families and friends as well as for society as a whole. Conversely, mental health also impacts on the course of the pandemic and of the disease within individuals.

Recognising this gap, the Social Aspects of HIV/AIDS and Health Research Unit of the Human Sciences Research Council (HSRC) decided to embark on research to fill in some of the gaps. In formulating a research programme, the following questions arose:

- Was this indeed an area of significant concern?
- What was happening in the area internationally, in other African countries, and in South Africa itself?
- Were there already existing networks of researchers and other stakeholders who were interacting around these issues?
- Given that mental health is such a broad area with so many mental health concerns, were there certain issues that should take priority over others?
INTRODUCTION

The questions prompted the HSRC to call a round-table meeting on Mental Health and HIV/AIDS. The objective was to have a two-day meeting with minimal formal input and lots of discussion between ‘equals’ – hence the round-table.

In assembling the participants the original idea of a group of about ten people grew to more than three times that number. It was important to have representatives from government, NGOs, scientists, academics; people with international experience from both developed and developing countries and people living with HIV/AIDS participating. (The positive response to the meeting was quite overwhelming and the number could easily have tripled again, but the ‘round-table’ objectives forced the organisers to limit the number of participants.)

The result was a forum which produced extremely rich discussion and high quality input. At the conclusion of the meeting it was decided that a record of the discussions was worth sharing with a wider audience in the hope that mental health will find its deserving place amongst HIV/AIDS researchers, government, advocates and activists alike hence this publication.

The main objectives of the meeting were to:
- Determine the main links between HIV/AIDS and mental health.
- Understand the research and service gaps and prioritise these.
- Ensure that what we already know feeds into services.
- Examine possibilities for future research collaborations.
- Consider the issue of advocacy: how do/should mental health issues add to the prevention and treatment agendas?
- Allow space for talking, sharing, learning and intellectual growth.

As can be seen from the presentations and the summary of discussions that follow, all the objectives were covered – though certainly not all exhausted. The importance of mental health and HIV/AIDS was evident to all, and indeed seemed to grow for most of the participants as the discussions evolved. While it would be incorrect to say that this meeting was the start of research and service concerns in mental health and HIV/AIDS in South Africa, it was certainly a landmark in the process and hopefully also a turning point in giving this most important area more prominence and greater direction.
The current situation of HIV/AIDS in South Africa

Dr Olive Shisana

This presentation summarises some of the main findings of the Nelson Mandela/HSRC Study on HIV/AIDS with a particular emphasis on HIV prevalence. This study is the first systematically sampled national community-based survey of prevalence in South Africa.

Dr Olive Shisana is the Executive Director of the Social Aspects of HIV/AIDS and Health Unit at the Human Sciences Research Council. From 1994 to 1998 she served as Special Advisor to the Minister of Health and as Director-General of Health. From 1998 to 2000 she was the Executive Director for Family and Community Health at the World Health Organisation. She holds a Doctor of Science in Public Health from John Hopkins University. This University admitted her into the Society of Scholars class in recognition of her contribution to public health. She is an expert in social aspects of HIV/AIDS and currently is principle investigator in a number of large projects in the area. She has a number of publications in public health.
NELSON MANDELA/HSRC
STUDY OF HIV/AIDS


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INTRODUCTION

- South Africa has a serious HIV/AIDS epidemic, with millions of its people living with the disease
- Accurate information and a comprehensive understanding of the epidemic is needed in order to deal effectively with the problem
- In particular, it is crucial to understand the social, cultural, political and economic context that contributes to vulnerability to HIV infections
- This is the first systematically sampled national community-based survey of the prevalence of HIV in South Africa
INTRODUCTION (contd)

- The survey reviewed risk, risk reduction, HIV/AIDS knowledge, mass media and communication, psychosocial and socio-cultural aspects of HIV/AIDS
- HIV prevalence in the country has been based on the Department of Health’s (DOH) annual antenatal survey of pregnant women
- This study augments the antenatal survey through a population-based sample of South Africans including men, women, children, all races and ethnic groups, people living in urban areas, rural areas and farms, as well as hostel residents

GOAL OF THE STUDY

- Determine the HIV prevalence in the general population

SURVEY METHOD

- The steps in the sample design:

1. Define target population – all people in SA
2. Define sample frame – 2001 census
3. Define Primary Sampling Unit (PSU) – 2001 census EAs
4. Define explicit strata – provinces and geography type
5. Define reporting domain – province, locality-type and population group
6. Define Secondary Sampling Unit (SSU) – visiting point
7. Define Measure of Size (MOS) – 2001 estimate of visiting points
8. Define Ultimate Sampling Unit (USU) – all individuals 2+ years of age
9. Allocation of sample – disproportional to province, population group & locality-type
SURVEY METHOD (contd)

- The steps in the drawing of the sample:

  1. Selection of PSUs – 1 000 EAs →
  2. Produce aerial photos and data kits of EAs
  3. Selection of SSUs – visiting points per EA →
  4. Selection of USUs – 3 people per VP

- Location of master sample PSUs in South Africa:

   ![Map of South Africa showing PSU locations]

   **Legend**
   - Province
   - Metropolitan centres
   - Master sample
SURVEY METHOD (contd)

- Location of unrealised EAs in the survey:

SAMPLE

- 13 518 individuals who were selected and contacted for the survey
- 9 963 (73.7%) persons agreed to be interviewed
- 8 428 (62.5%) gave a usable specimen for an HIV test
RESULTS: NATIONAL PREVALENCE

- The HIV prevalence in the population of South Africa is 11.4%. This amounts to 4.5 million people (Confidence Interval [CI]: 10.0–12.7%)
- 15.6% of persons in the 15–49 age group were HIV positive (CI: 13.9–17.5%)

RESULTS: PROVINCIAL HIV PREVALENCE

HIV prevalence by province, South Africa, 2002.
RESULTS: LOCALITY-TYPE PREVALENCE

HIV prevalence in adults (15–49 years) by locality-type, South Africa, 2002

RESULTS: AGE-GROUP PREVALENCE

HIV prevalence by age, South Africa, 2002
RESULTS: AGE AND SEX DISTRIBUTION OF HIV INFECTION

Prevalence of HIV by sex and age, South Africa, 2002

RESULTS: RACE AND HIV PREVALENCE

HIV prevalence among adults (15–49 years) by race, South Africa, 2002
### WHAT THE HIV PREVALENCE RESULTS MEAN

- HIV is a generalised epidemic in South Africa
- It affects people of all races, all ages and in all localities
- It affects women more than men
- 5.6% HIV prevalence among children aged 2–14 years was unexpected and requires further investigation (CI: 3.7–7.4%)
Overview of care and support provided by the National Department of Health

Dr Zukiswa Pinini

This presentation gives the current situation with regard to care, treatment and support. It includes the goals for meeting the health and psychosocial needs of people living with HIV/AIDS, their families, caregivers and communities, from the perspective of the National Department of Health.

Dr Zukiswa Pinini is the Medical Co-ordinator for HIV/AIDS in the Treatment Care and Support Sub-directorate in the Cluster HIV/AIDS and TB at the National Department of Health. In addition to her medical degree Dr Pinini holds a Diploma in Medical Technology as well as a qualification in Advanced Health Management from Manchester Business School. Prior to her current position Dr Pinini was a prison medical officer and held medical positions in a number of hospitals and clinics.
OVERVIEW OF CARE AND SUPPORT

Dr Zukiswa Plini
National Department of Health
HIV/AIDS & TB Chief Directorate,
Treatment, Care & Support Sub-directorate

CURRENT SITUATION AND PLANS FOR CARE, TREATMENT AND SUPPORT

- Treatment for occupational and non-occupational HIV post exposure (PEP)
- Treatment literacy campaigns
- Treatment for OIs and STI
- Prevention of mother to child transmission
- Provision of HBC kits
- Development of care guidelines

OVERVIEW OF THE RX, CARE & SUPPORT SUB-DIRECTORATE

- Has 3 components: Care, Support & Treatment
  - Care: CHBC; OVC program; HIV infected & affected health care workers, individuals and families
  - Support: PLHA programs (Rx, support groups and advocacy tool kit), VCT
  - Treatment: Training of healthcare workers on Mx of OIs; development & reviewing of guidelines
OVERALL GOAL

- Meeting the overall health and psychosocial needs of people living with HIV/AIDS (PLHAs), their families, care givers and communities

GOALS FOR PROVIDING CARE AND SUPPORT

- Reduce HIV-related mortality and morbidity
- Make VCT accessible to all and prevent further spread of the HI virus (behavioural change)
- Improve the quality of life for PLHAs
- Promote healthy lifestyle

OBJECTIVES

- To strengthen HIV prevention
- To expand greater involvement of PLHAs
- To reduce the burden of the dual epidemic of HIV & TB and other HIV-related opportunistic infections
- To strengthen CHBC programmes/initiative
- Train healthcare workers on Mx of HIV-related OIs
- To improve HIV care for volunteers, young people, pregnant mothers, orphans and vulnerable children (OVC) whose access to care is limited
- To support PLHA programmes in the country
PRINCIPLES AND VALUES OF CARE AND SUPPORT

- Respect and dignity
- Equity (same as non-infected individuals)
- Quality of care and improve quality of life
- Accessibility of services (CHBC, VCT, etc.)
- Sustainability of programmes

RATIONALE FOR CARE AND SUPPORT

- Health and welfare care is a human right
- Access to care also contributes to the prevention of HIV infection
- Alleviation of stigma and discrimination
- Supports GiPA in the fight against the epidemic
- Reduction of suffering due to HIV/AIDS

CONCLUSION

- Education of the public on destigmatisation
- Demystify HIV (chronic disease with no cure)
- Community involvement vital for sustainability of all the programmes
- Reduce drug abuse amongst youth resulting in unacceptable behaviour
Voluntary counselling and testing

Cynthia Nhlapo

The government’s conceptual framework for the provision of voluntary counselling and testing (VCT) is given in this presentation. Government see VCT as an entry point to prevention and care. The presentation then, provides the implementation plans for VCT. This includes plans for increases in VCT service points, improved counselling services, accreditation of counsellors and a mentorship programme for counsellors.

Cynthia Nhlapo is the Deputy-Director in the Voluntary Counselling and Testing Sub-directorate in the Cluster HIV/AIDS and TB at the National Department of Health.
VOLUNTARY COUNSELLING AND TESTING (VCT)

Cynthia Nhlapo
National Department of Health:
HIV/AIDS & TB Chief Directorate

CONCEPTUAL FRAMEWORK

Goal: universal access to VCT services through a public health, and non-governmental sector partnership to an adult population between the ages of 15–49, targeting the worried well, i.e. women, men and youth to facilitate behaviour change and HIV prevention.

- VCT as an entry point to prevention and care:
  - Prevention: PMTCT, TB, STI
  - Care: Treatment, HCBC, Support groups

- Design of VCT service delivery target:
  - Public sector – universal access
  - Private sector – quality of service delivery
  - Other – NGOs (minimum: two per province)

- Design of VCT service delivery:
  **Beneficiaries**
  - Women: ANC, STI, FPC
  - Youth: Love life, youth and recreation centres, youth-friendly clinics
  - Men: unions, mines, hostels, trucking industry

  **Access**
  - Universal: All public clinics and hospitals
  - Partnership with private sector and NGOs

  **Uptake**
  - Involve Health Promotion
  - Link up with Communications unit
  - Provide/use IEC material and Campaigns
IMPLEMENTATION PLANS

1. VCT Service points (sites)
   Establishment of VCT service delivery points by 2005
   • 80% access to public health services by March 2004
   • Establish partnerships with private sector for quality VCT service delivery by March 2004
   • Establish partnerships with NGOs by March 2004

2. Counselling services
   Capacity for counselling services built by March 2004
   • Strengthen provincial training capacity by May 2003
   • Ensure placement of counsellors through NGOs by March 2004
   • Create a database for trained and placed counsellors and trainers by June 2003

3. Accreditation
   Accreditation system to be established by March 2004
   • Tender out the process of setting up accreditation systems by June 2003
   • Monitor the liaison with relevant accreditation structures by September 2003
   • Ensure establishment of the accreditation body by March 2004

4. Mentorship programme for counsellors
   Establish a mentorship programme in provinces by December 2003
   • Tender out the process of setting up a mentorship programme
   • Ensure identification and training of mentors
   • Develop guidelines for mentoring of counsellors
   • Monitor the mentorship implementation process
Mental health in children orphaned by AIDS

Dr Lauren Wild

It has been estimated that by the year 2015, 5.7 million children will have been orphaned by AIDS. This presentation focuses on the psychological impacts on these children. Only a few studies have thus far been conducted in developing countries but these indicate that emotional difficulties are often experienced. Areas for future research and difficulties doing research in this area are identified.

Dr Lauren Wild is a lecturer in the Department of Psychology at the University of Cape Town. She holds a PhD from the University of Cambridge. She has completed a Post-doctoral Research Fellowship at the University of Cape Town’s Department of Psychiatry. She has written a review on the psychosocial adjustment of children orphaned by AIDS which was published in the *Southern African Journal of Adolescent and Child Mental Health*. 
MENTAL HEALTH IN CHILDREN ORPHANED BY AIDS

Lauren Wild
Department of Psychology
University of Cape Town

INTRODUCTION

Projections
- By 2010, over 2 million children under 15 will have lost their mother to AIDS (DoH)
- By 2015 there will be 5.7 million orphans which is equal to 12% of the population and comprises 30% of adolescents aged 15–17 (MRC)

Children orphaned and affected by AIDS face multiple stressors
- Parental illness and death
- Poverty
- Being taken out of school
- Multiple losses
- Stigmatisation and social isolation
- Lack of adequate care and control

CLINICAL REPORTS/DESCRIPTIVE RESEARCH

- Depression, anxiety
- ‘Survivor guilt’
- Loneliness, isolation
- Low self-esteem
- Disruptive, antisocial, high-risk behaviours

But these studies cannot tell us
- How common these difficulties are
- Whether they are attributable to losing a parent to AIDS over and above the many other risk factors these children had been exposed to
COMPARATIVE RESEARCH

- Sengendo & Nambi (1997)
  193 Ugandan orphans (aged 6–20) more depressed and less optimistic about the future than control sample
  41 orphans (aged 10–14) in Tanzania had more internalising problems and were more likely to have contemplated suicide than controls
- Forehand et al. (1998, 1999)
  87 inner-city, African-American children (aged 6–11) whose mothers were HIV-infected showed more depression and externalising problems and less cognitive and prosocial competence than a comparison group from a similar background, but psychological difficulties did not increase still further when the mother died

RECOMMENDATIONS FOR FUTURE RESEARCH

- Are orphans in South Africa at risk for psychosocial adjustment difficulties?
- What are the causes of any symptoms we see?
- What are the protective factors that might facilitate resilience?
- Prospective, longitudinal studies are needed to:
  - Assess children’s needs and coping strategies at various stages
  - Investigate if and how short-term distress relates to long-term outcomes
  - Evaluate effectiveness of interventions
MENTAL HEALTH AND HIV/AIDS

METHODOLOGICAL CHALLENGES FOR FUTURE RESEARCH

- Defining orphans
- Recruiting participants
- Finding valid and reliable instruments
- Understanding norms and beliefs in communities studied

Despite challenges, research is vital for informing interventions and ensuring their effectiveness.
A view of HIV/AIDS and mental health issues in South Africa – from the outside looking in

Dr Francine Cournos and Dr Pamela Collins

This presentation looks at HIV/AIDS in South Africa and makes various important comparisons with the United States. The role of anti-retroviral treatment (ART) and its ability to improve mental health is explored. The interface between neuropsychiatric disorders and HIV/AIDS is highlighted. How research conducted in the USA may be relevant to developing countries is briefly addressed.

Dr Francine Cournos MD, is professor of Clinical Psychiatry at Columbia University in New York City, Director of the Washington Heights Community Service at New York State Psychiatric Institute and Chair of the American Psychiatric Association Committee on AIDS. She has conducted research and training on the mental health aspects of the HIV epidemic, and published widely on the subject. She is editor of the book What Mental Health Practitioners Need to Know About HIV and AIDS published in 2000.

Dr Pamela Collins is an Assistant Professor at Columbia University in the College of Physicians and Surgeons, Department of Psychiatry and the Mailman School of Public Health of Columbia University, Department of Epidemiology. She has specialised in psychiatry, public health, cultural psychiatry and applied medical anthropology. Dr Collins is the principle investigator on NIMH funded research focusing on sexuality, stigma and HIV risk for women with severe mental illness. She has worked in South Africa researching mental healthcare providers perceptions of HIV risk among people with mental illness and is completing a study on HIV prevention in psychiatric settings. She is well published in the field of mental health and HIV/AIDS.
ADULTS AND CHILDREN ESTIMATED TO BE LIVING WITH HIV/AIDS AS OF END 2002

Total: 42 million

ESTIMATES OF HIV IMPACT IN SOUTH AFRICA – END 2001

- Almost 5 million people are living with HIV/AIDS
- About 20% of adults aged 15–49 are HIV infected
- About 25% of women delivering babies in public clinics are infected
- Approximately 660 000 children are orphaned by AIDS

LIFE EXPECTANCY WITH AND WITHOUT AIDS IN SOUTH AFRICA

2000
Without AIDS: 66 years
With AIDS: 51 years

2010 Projection
Without AIDS: 68 years
With AIDS: 36 years
HIV EPIDEMIC IN THE UNITED STATES

- 1978: HIV begins to spread
- 1981: First medical reports of AIDS by CDC
- 1984: Human Immunodeficiency Virus (HIV) identified
- 1985: HIV antibody test becomes available
- 1987: First anti-retroviral medication, AZT
- 1995: Highly Active Anti-retroviral Treatment (HAART) becomes available
- 1996 to present: deaths from AIDS drop dramatically; overall seroprevalence among adults remains below 1%

COMpared TO THE HIV EPIDEMIC IN THE US, THE HIV EPIDEMIC IN SOUTH AFRICA

- Higher rates of HIV infection
- Fewer resources for HIV-related education, diagnosis, and treatment
- Different predominant HIV-1 subtypes (US: subtype B; SA: subtype C)
- Different predominant modes of transmission (US: MSM, IDU; SA: heterosexual)
- Heavier impact on women and children

STRATEGIES IN AFRICA: REDUCING HIV TRANSMISSION

- Sex education for youth
- Strategies to empower women
- Evidence-based prevention campaigns
- Availability of condoms
- Voluntary testing and counselling
- Treatment of STIs
- Male circumcision
- Anti-retroviral treatment to reduce: parent-to-child transmission, sexual transmission, post exposure infection (PEI)
STRATEGIES IN AFRICA: PROLONGING LIFE AMONG HIV-INFECTED PEOPLE WITHOUT ANTI-RETROVIRALS

- Good nutrition and dietary supplements
- Prophylaxis against:
  - TB (isoniazid)
  - Cryptococcal meningitis (fluconazole)
  - PCP pneumonia and toxoplasmosis (cotrimoxazole)
  - Etc.
- Indefinite maintenance treatment following onset of an opportunistic infection
WHY THE PUSH FOR ANTI-RETROVIRAL TREATMENT (ART)

- The HIV epidemic is unique in killing young and middle-aged adults, reducing the workforce, and creating a generation of traumatised, rootless, orphaned children
- Prevention efforts are undermined by the absence of treatment
- World-wide attention has created momentum

THOUGHTFUL ART IMPLEMENTATION

- Cost
- Infrastructure concerns
- Educating patients and clinicians
- Timing of ART (WHO guidelines)
- Choice of regimen (WHO guidelines)
- Clinical and laboratory monitoring
- Viral resistance concerns and adherence approaches
- Stabilisation of other major health problems
- Management of ART drug interactions and toxicities

HIV EPIDEMIC: BEHAVIOURAL AND PSYCHOSOCIAL ISSUES

- Primary and secondary prevention
- Pre- and post-test counselling
- Stigma and disclosure
- Coping, bereavement, and transitions
- Permanency planning for children
- Adherence to treatment
- Related to the above: legal, ethical, cultural, societal, economic, and policy concerns
HIV EPIDEMIC: NEUROPSYCHIATRIC PROBLEMS

Problems seen among patients with HIV/AIDS in the United States
- Substance use
- Anxiety disorders
- Mood disorders (affects women more than men)
- Psychotic illnesses
- Sleep disturbances
- Neuropsychiatric disorders due to a general medical condition, medication side effects, HIV itself

WHEN DO NEUROPSYCHIATRIC DISORDERS OCCUR IN THE COURSE OF HIV INFECTION?

- Prior to infection
  - Due to associations between mental illness/substance use and HIV-related risk behaviours
- With asymptomatic infection
  - Coincidentally
  - Due to psychosocial stresses
  - Possible biological vulnerability?
- With symptomatic infection
  - Neuropsychiatric disorders increase with advancing illness
  - Multiple possible etiologies create diagnostic challenges, e.g., OIs, neoplasms, metabolic
TRIAD OF NEUROPSYCHIATRIC DISTURBANCES CAUSED BY HIV

- Cognitive: impaired attention, mental slowing, impaired memory, confusion, etc.
- Motor: tremor, motor weakness, incoordination, gait disturbances, incontinence, etc.
- Behavioural: social withdrawal, mood lability, agitation, apathy, psychotic symptoms, etc.

HIV EPIDEMIC IN THE US: RESEARCH CONDUCTED RELEVANT TO BEHAVIORAL HEALTH

- HIV-related risk behaviours and primary/secondary prevention interventions (MSM, IDU, heterosexual transmission)
- Psychiatric and neuropsychiatric disorders: description, prevalence, and treatment
- Depression is most commonly studied psychiatric disorder: prevalence, suicidality, immune impact, treatment
- Psychosocial issues (e.g. adherence, bereavement)
- Use of psychotropic medications (limited)
HIV/AIDS and psychiatry: the Toronto experience

Dr Mark Halman

The way in which HIV/AIDS has been handled from a mental health perspective in Canada is presented. The importance of an integrated service with referral to more specialised services is emphasised. Interventions with various psychiatric and psychological symptoms with emphasis on cognitive deficits and depression are explored. Best intervention practices are presented.

Dr Mark Halman is the Director of the HIV Psychiatry Programme at St Michael's Hospital; Psychiatrist at Casey House Hospice, Toronto; Coordinator of academic programmes in HIV psychiatry and Assistant Professor at the University of Toronto. He held a fellowship in medical psychiatry at HIV Massachusetts General Hospital, Harvard Medical School from 1991 to 1994. His interest includes the optimal identification and treatment of psychiatric illness in persons with HIV/AIDS. He has a number of publications in mental health and HIV/AIDS.
HIV/AIDS AND PSYCHIATRY: THE TORONTO EXPERIENCE

Mark Halman MD FRCP(C)
Director, HIV Psychiatry Programme:
St Michael’s Hospital
Assistant Professor, University of Toronto

HIV PSYCHIATRY PROGRAMME

• Vertically integrated clinical service
  • Providers well versed in both HIV and mental health
• Responsive to needs of community as conveyed by HIV and mental health CAPs
• Academically oriented
  • Clinically relevant research
  • Educational program for University of Toronto

HEALTHCARE IN CANADA

• Free availability of healthcare for all
• Access to limited medication formulary for people on general welfare or disability and in some provinces access to formulary for employed with chronic disease after initial co-payment
• Healthcare worker shortages, long waiting lists, funding concerns, issues in both rural and urban/inner city settings
• Relatively good social safety net and HIV/AIDS is on the radar
HIV MENTAL HEALTH OVER THE YEARS

- 1980s: mobilisation of communities, focus on coping with despair and loss, dementia
- 1987: AZT – initial hope then disappointment
- Early 1990s: increased psychiatric involvement, growing acceptance of psychopharmacology for symptom relief
- 1997: HAART, decreased morbidity and mortality, focus on living with HIV/AIDS, dramatic decrease in cognitive syndromes, depression remains major issue
- 2003: limits of psychopharmacology, challenges of HIV+ general psychiatric patients, new models for overcoming institution/community gap

ANTI-RETROVIRALS

<table>
<thead>
<tr>
<th>NRTIs</th>
<th>Protease Inhibitors</th>
<th>NNRTIs</th>
</tr>
</thead>
<tbody>
<tr>
<td>AZT, DDI, DDC, D4T, 3TC, Abacavir, Tenofovir</td>
<td>Saquinavir, Indinavir, Ritonavir, Nelfinavir, Amprenavir, Lopinavir</td>
<td>Nevirapine, Delavirdine, Efavirenz</td>
</tr>
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Highly Active Anti-retroviral Therapy, HAART, is a combination of anti-retroviral drugs usually consisting of a backbone of two NRTIs plus one or two PIs or one NNRTI
ACADEMIC FOCUS: COGNITIVE DISORDERS

- Natural history study: subjective complaints related to both objective neurocognitive deficit and emotional distress
- Impact of HAART on HIV dementia and minor cognitive motor disorder
- Treatment studies: randomised controlled trial of Abacavir vs stable background therapy for ADC
- Living with cognitive impairment
  - Treating depression
  - Attention process training
  - Psychopharmacologic management of behavioural disturbances

ACADEMIC FOCUS: MOOD DISORDERS

- Treatment of mania in HIV+ patients
- Treatment of depression using psychopharmacologic intervention and the impact of these interventions on cognitive complaints

ACADEMIC FOCUS: SYSTEMS OF CARE

- Linkage with Casey House – residential HIV/AIDS hospice
  - Reduced hospital transfers for psychiatric emergencies
  - Increased staff satisfaction in managing complex patients
  - Evaluation of psychopharmacological interventions
- Interagency coalition of social workers in HIV care
  - Pilot evaluation of social group work model for treatment of depression
- Linkage with Casey House home hospice
- Community/institution gap in mental healthcare
ACADEMIC FOCUS: LIVING WITH HIV/AIDS IN HAART ERA

- Adherence to anti-retroviral medications
  - Impact of distress, cognitive decline, personality factors, patient physician relationship
- Coping with lipodystrophy associated with HAART
  - Importance of individual’s story
- Achieving coherence in HIV transmission prevention strategies and rules/duty governing behaviour
  - Policy forum: responsibilities of HIV+ person, counsellors, health and mental health professionals

HIV PSYCHIATRY PROGRAMME

- 568 patients seen since 1994. Predominantly men, white, gay, not working (65%), 86% on medication
- Initial visit: BDI total unchanged on annual basis (range 20–25)
- 33% express high degree of hopelessness and 12% express active suicidal ideation and intent

PSYCHOTHERAPY INTERVENTIONS

- Extremely hard to study – high attrition rates
- Mental health is the last thing on the list to be studied
- Most studies suggest a benefit but most important issue is fit
- Clinically, we stress up front supportive work to overcome scepticism in marginalised patients
HIV-1 ASSOCIATED DEMENTIA

- Acquired abnormality; > 1 month; ≥ two of:
  - Attention/concentration abstraction/reasoning
  - Memory/learning speed of processing
  - Visuospatial skills speech/language
- Cognitive dysfunction leads to impairment in work and activities of daily living
- Abnormality of motor function and/or social/behavioural change

MINOR COGNITIVE MOTOR DISORDER

- Acquired abnormality; > one month; ≥ two of:
  - Impaired attention incoordination
  - Mental slowing slowed movement
  - Impaired memory personality change/emotional lability
- Dysfunction causes impact on work

MORBIDITY ASSOCIATED WITH MILD HIV-RELATED NEUROCOGNITIVE IMPAIRMENT

- Decreased survival (Marder et al., 1998, Ellis et al., 1997, Sacktor et al., 1996)
- Increased unemployment (Heaton et al., 1996, Albert et al., 1995)
- Decreased quality of life (Kaplan et al., 1995)
- Decreased medication adherence (Albert et al., 1999)
- Subjective perception of diminished work performance (Heaton et al., 1994)
TREATMENT DECISIONS

- Prevent onset of process
- Prevent progression of process
- Reversal of dementia
- Symptom management

DEPRESSIVE/COGNITIVE OVERLAP

- Mr A: aged 41 HIV+ male, CD4+ = 180, viral load = 45,000. Psychologically reluctant to take HAART. Feels essentially well but is fatigued, amotivated and depressed. He feels he is doing poorly at his work and is very anxious over having received a reprimand recently. Feels memory is declining and attention is poor
- Mr B: aged 41 HIV+ male, CD4 = 310, viral load < 50. Feels tired, depressed and anguished. Sleep is poor and he worries over his poor performance at work. Increasingly withdrawn and not motivated to do anything. Has sense that his mind is not sharp and he is forgetful
- Both frequently coexist and present with same symptom cluster
- Both syndromes require treatment – HAART for HIV related cognitive impairment and antidepressant treatment for depression
MENTAL HEALTH SYSTEMS

- Medical psychiatry vs. general psychiatry
- Community based vs. institution based
- Cultural issues in mental health delivery
- Closing the gap to mental health service delivery especially with marginalised populations

SUGGESTED REFERENCES

- Halman M H. Management of Depression and Related Neuropsychiatric Symptoms Associated with HIV/AIDS and Antiretroviral Therapy. Canadian Journal of Infectious Diseases 2001; 12 (suppl C); 9C-19C

DEPRESSED FEELINGS AND DISTRESS

- It is not the rule that persons with HIV disease always develop major depression
- Recent meta-analysis confirms rates of MDE in HIV+ patients is at least double general population rates (Ciesla, 2001)
HIV COST AND SERVICES UTILISATION STUDY (HCSUS)

- 60% of HIV+ adults used some mental health services in prior 6 months
- 40% used primary medical services for emotional healthcare
- Minority group, low education, low income predict less use of mental health services
- Adults with HIV account for 1% of inpatient admissions and 2% of ambulatory admissions in US (Barnam, 2001)

HIV AND SPMI

- 1996 Philadelphia – analysis of co-occurrence claims from medicaid data
- Of PWHAs – 12% had SPMI
- Of SPMI: schizophrenics = 1.2% HIV+ and affective disorders (mania) = 2.3% HIV+ (Blank et al., 2002, psychiatric services)

DEPRESSION IN HIV+ WOMEN

- Current MDE: HIV+: 19.4% HIV−: 4.8% p<.01
- Lifetime MDE: HIV+: 47.3% HIV−: 38.7
- Current anxiety D/O: HIV+: 10.8% HIV−: 6.5%
  - older age, caucasian race, less education were associated with increased levels of depression
  - sample of women from rural Florida (n=93+; 62−); 50% CDC A, 33% B, 17% C. no current substance abuse (50% HIV+ substance related history; 31% HIV− group). 55% African American (Morrison et al., 2002 AmjPsych)
WOMEN’S INTERAGENCY HIV STUDY

- Longitudinal study from US (n = 1668 HIV+)
- 73% CES-D ≥ 16 / 47% ≥ 23 on ≥ 1 study visit
- Associations: viral load > 20,000; non-white; history IDU; current alcohol/drugs; no college; public health insurance; more HIV symptoms
- HAART utilisation: women with high depressive scores less likely to be on HAART. Women receiving mental health intervention (regardless of CES-D score) more likely to be taking HAART

In B, survival curves are stratified by level of depressive symptoms from the final Cox proportional hazards model (controlling for baseline CD4 count, viral load, HIV-related symptoms, ARV medication, age, and employment status (Ickovics, 2001).
Some crystal ball gazing: mental health in 2015

Prof Melvyn Freeman

Potential longer-term effects of HIV/AIDS and mental health are explored. Possible cumulative mental health effects arising from issues such as AIDS orphans, multiple deaths and stressors for people infected and their families are addressed. Problems with trying to predict mental health impacts are discussed and a broad research strategy proposed.

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MENTAL HEALTH IN 2015

Can we make an educated projection?
Can we intervene to mitigate the likely impact?

WHO IS LIKELY TO SUFFER FROM MENTAL HEALTH PROBLEMS?

- People who are unsure of their HIV status
- People living with HIV
- Family and care takers of people with HIV/AIDS
- Formal caregivers
- Families and friends of people who die from AIDS
- Children/youth orphaned by AIDS
- People caring for children orphaned by AIDS
- Many people may fit into more than one of these categories
- Many people may not merely ‘pass through’ these categories but be subject to their ongoing impact

What is the cumulative effect of the various stresses likely to be?
What is the likely effect on society as a whole?
Will we become resilient or overwhelmed by the pandemic?
Will we group together to support each other and fight the ‘enemy’ or will we give up to its power?
Can we avoid a potential mental health and consequent social disaster?

The whole will be more than the sum of the parts.

In each ‘stress area’ the above will be true, but then these ‘wholes’ will also be combined to create the bigger whole.
EXAMPLES

Children/youth orphaned by AIDS
Some will find good stable and caring homes, others will become street children, vagrants or part of child-headed households.
- May not have had the early bonding experiences critical for good caring human relationships
- May not have had the modelling, boundary setting and development of value systems necessary for moral development
- May not have had the support, caring and discipline needed for emotional stability
- May be subject to abuse

Is this a recipe for violence and crime?

DEALING WITH DEATH

- Dealing with death on a regular basis may lead to either an ‘overgrieving’ or an ‘undergrieving’
- Being surrounded by death and dying may lead to an obsession with death. All else may lose importance, including work, schooling, moral values, etc.
- Anarchic behaviour may take over amongst certain people or groups

DOING ACCURATE PROJECTIONS

- UNAIDS and others are tracking the course of the pandemic and projecting numbers of infections, numbers of likely deaths, number of likely orphans, etc.
- Others are beginning to look at impact on economy through skill loss, availability of labour, etc.
DOING ACCURATE PROJECTIONS (contd)

- Others looking at human resource implications, e.g. availability of teachers and nurses
- Who is looking at people – and not only how the disease will impact on them, but how will they impact on society, on production and so?
- Is it being alarmist to suggest that productivity will go down because many people will be unable to give their best to their work
- It is alarmist to suggest that many people will turn to crime and violence because they have had poor bonding and caring relationships (on top of being very poor, unskilled for employment, etc.)
- Can we compare the HIV/AIDS pandemic to:
  - The plague (in a 12 year period between 25% and 50% of Europe’s population was wiped out)?
  - War situations?
  - Natural disaster?
- What are the similarities and differences and what can be learned from history?
- To understand these issues will need a combination of:
  - Empirical science
  - Theory
  - Understanding of history
  - Scenario projections
  - Extrapolation
  - Referral to similar situations/pilots, etc.
  - A good round-table discussion!
Day 1: An overview of the key themes

Following short question-and-answer sessions after each presentation and an open floor discussion in which each participant highlighted what they thought the major mental health issues were with regard to Mental health and HIV/AIDS, the following (often interrelated) themes emerged:

- Mental health impacts of the HIV/AIDS pandemic on:
  - People living with HIV/AIDS (adults and children).
  - Orphans and other vulnerable children.
  - Affected families and caregivers.
  - Society as a whole.
- Prevention of HIV/AIDS.
- Psychosocial support.
- Treatment of HIV/AIDS and mitigation of its impact.
- Response systems.
- Cross-cutting issues.

The themes were summarised by Dr Kevin Kelly as follows.

Mental health impacts of HIV/AIDS

*Adults living with HIV/AIDS*

From the research evidence as well as the practical experience of participants the following mental disorders were identified as linked and relevant to HIV/AIDS:

- Mood disorders – depression, manic episodes
- Neurocognitive disorders, including slowing of cognitive processes and memory and attention deficits
- Impaired motor functioning
• High degrees of hopelessness, active and passive suicidal ideation and intent
• Personality disorders
• Psychosis (as a late manifestation of the disease)

The point was made that depressive and cognitive dysfunction overlap. The true neuropsychiatric impact can often only become clear once the depression has been treated. There is also a difficulty in distinguishing between symptoms that have a psychosocial aetiology from neuropsychiatric problems. As the treatments are likely to differ, making an accurate assessment is important.

Delegates from countries where ARTs are easily available shared the extremely positive impact that these drugs have had on mental health. In particular, they mentioned the reduction in HIV dementia and minor cognitive disorder. In addition, the provision of these drugs allowed HIV positive people to have a much less bleak vision of the future and thus helped to lift depression and other mental health symptoms.

The link between HIV/AIDS and substance abuse was also explored. There is often a co-morbidity found, with a tendency towards substance abusers being particularly vulnerable to contracting the virus, but conversely, people infected often turn to substances to help them to cope with their lives.

Research gaps

The meeting agreed that there are huge research deficits in sub-Saharan Africa in almost all of the areas listed above. While it was seen as necessary to draw on the research experience in developed countries, local conditions (including cultural and resource differences) were often found to be so different that much more local research was required.

The need to look closely at traditional mental health resources (familial and community resources as well as traditional healers) was emphasised.

Research suggestions included:
• Evaluation of psychopharmacological interventions.
• Mental health impacts of using anti-retroviral therapy.
• Longitudinal case studies of the mental health of people infected with HIV/AIDS.
• Epidemiological studies of prevalence of depression and other mental health problems (various assessment instruments can be used).
Close examination of the lives of people with HIV including their coping skills and access to resources.

Adults, particularly in African communities, often invest in the education of their children, with the hope that their children will be economically stable and thus able to provide for other family members. Research has shown that HIV/AIDS mostly affects the economically active members of the society. There is a need to investigate coping mechanisms being used by people who have no other income when they see these economically active individuals die of AIDS instead of providing for their family.

Service gaps

- Though pharmacological treatment is known to be generally efficacious for treating mental health symptoms of HIV/AIDS, most health workers are unaware, or take little heed, of this important aspect of treatment.
- Helping people with cognitive deficits is important yet neglected.
- The referral of HIV-infected people for treatment of mental health problems does not occur in a rational and streamlined way.
- Staff dealing with HIV-related mental health issues are not given support despite this being a particularly difficult emotional area to deal with.
- Staff are often not equipped to deal with mental health issues and are not adequately trained to do so either initially or as part of ongoing in-service training.
- There is inadequate liaison within, and between, sectors for example liaison with social workers to ensure adequate care and support for infected people.
- People who are depressed are less likely to look after their own well-being in all areas – including taking treatment for other symptoms.

Children living with HIV/AIDS

It is estimated that more than two million children in South Africa are infected with HIV. This posed many mental health challenges. There has been almost no research on this in sub-Saharan Africa and, as this was hardly a problem in developed countries, there was little that could be extrapolated from these regions.

Cognitive deficits and failure to reach developmental milestones have been identified in children with HIV, and given that neurocognitive decline is often
one of the first signs of HIV, this has important implications for identification and intervention. Significantly, it seems that neurocognitive decline is responsive to anti-retroviral intervention.

The emotional impacts of HIV on children need research. One area that may need particular attention is the psychological issues that arise for HIV positive children reaching puberty.

The need to link with remedial education services was identified. Also the need to work with schools to foster acceptance of HIV positive students and normalise their involvement in school activities was also raised.

Social development issues, such as the need to move beyond AIDS shelters into more comprehensive community programmes, were mentioned. In addition, the need to rationalise the childcare grant system was emphasised.

*Orphans and other vulnerable children (OVC)*

Children may be infected by HIV, affected (for example, being orphans living with, or caring for, an HIV-infected person) or even both. The impacts need to be separated and understood.

The mental health impacts of the death of a parent have not been well researched in the AIDS context, but much could be learned from understanding the impact of parental death in other contexts. What are the protective factors that mediate against poor psychosocial adjustment? What helps certain OVC to cope well while others do not? There is good evidence that there are significant psychosocial adjustment risks associated with inadequate care and socialisation. Support structures around the child also seem to be critically important. These issues need considerably more research in the context of developing countries.

The impact of the numbers of OVCs created by the AIDS pandemic has not been properly thought through. While there is ongoing research looking at the situation of OVCs in South Africa, most work in this area has focused on developing systems of care without much research backing and without being strongly informed by the mental health disciplines which clearly have much to offer.

See also the discussion on Day II.
Affected families and caregivers

Little is known about the mental health impacts on families and caregivers. Concern was expressed about burnout of carers and the need to watch out for this. The burden and stress on the elderly was seen as an area of special concern. Another particularly vulnerable group of carers are orphans looking after younger siblings.

The idea of creating times of ‘respite’ (a short term of intensive care for the infected person, thus creating space for families and caregivers to recover and refresh their coping resources) was felt to be worth further consideration and research.

The need to bring the knowledge and experience of the mental health disciplines to bear in understanding these issues was emphasised. To make decisions in terms of convenience, or on merely economic considerations, may well 'backfire' if people are emotionally unable to deal with their lives.

Society as a whole

While looking at the mental health implications for individuals and families was very important, the mental health impact of HIV on the society as a whole should not be overlooked. It is important to understand how society is responding to the pandemic and how they may respond in the future.

The need to understand what the mental health ramifications are in the general population relating to high levels of AIDS deaths and multiple deaths in families, for example, was seen as important. Determining the impact of HIV/AIDS prevalence and death on the social capital of communities was also seen as a critical research question.

Prevention of HIV/AIDS

The meeting expressed concern that there has been surprisingly little contribution to prevention efforts in sub-Saharan Africa from the mental health disciplines.

The following were identified as areas that require more research and intervention and which would benefit from the expertise of mental health professionals:
• Psychiatric patients as a sub-population have specific prevention needs and these should be addressed. Psychiatric institutions have an important role to play in the prevention of HIV/AIDS.

• Little is known about the relationship between prevention and knowledge of HIV status.

• Little is known about the role of VCT in preventing HIV transmission.

• Service standards of VCT may be of such poor quality that they do not assist in prevention. More data is needed on this.

• Pre- and post-test counselling are only the beginning of a continuum of prevention and support and not an end. If these are not continued VCT may have little value in prevention. There was concern that there is little evidence that a culture of extending VCT services is developing for either people found to be positive or negative.

• The intensity of interventions is an important determinant of success in prevention and once-off interventions are unlikely to have the desired impact.

• Need to understand prevention in the context of changing responses to the epidemic. For example, the availability of anti-retrovirals may impact on prevention practices and this needs to be understood and monitored.

• Surprisingly little attention has been paid to the emotional and cultural vectors of prevention.

• There is a need to understand different contexts in developing prevention strategies and a more contextual, less individual, behaviour-oriented approach may be important in understanding risk-taking and risk-avoiding behaviour.

• Discordant couples are important in prevention and further understanding of issues, including enhanced counselling strategies, in this area is necessary.

The importance of studies looking at efficacy was emphasised, a study on VCT should look at the efficacy of VCT as a practise and not just at how VCT programmes should be implemented.

Psychosocial support

Providing adequate psychosocial support to HIV positive people was seen as extremely important. Mental health professionals had not played a sufficient role in highlighting and providing for this need. It was incumbent on people
within the mental health disciplines to advocate more for a continuum of care/support, which moved beyond the two session pre- and post-test model of VCT. Models needed to be developed which were culturally appropriate and feasible for ongoing support to HIV positive people.

Though the proposal was made for integrating mental healthcare, including ongoing support and care, into general healthcare, the problems with this in terms of time and prioritisation were discussed.

Psychosocial support for orphans and other vulnerable children was identified as critical. The importance of mental health, in addition to other needs such as shelter and education, was emphasised. Even when looking at seemingly unrelated areas such as economic cost-benefit analysis, mental health issues come into consideration. Failing to address mental health issues could lead to longer-term negative effects on the society.

Coping is not an individual issue. Though individual coping mechanisms are important and part of a coping structure, systems which facilitate coping and which involve whole communities are critical.

The social welfare network, including the efficacy of the childcare grant system, needs to be developed for improved mental health. The inter-departmental challenges are great.

Treatment of HIV/AIDS and mitigation of its impact

Stigma is still one of the main obstacles to prevention, care and support of HIV positive people. It was suggested that treatment programmes for AIDS mitigates stigma. The meeting engaged in a number of important discussions around treatment. Problems of adherence and treatment fatigue are extremely important and mental health research needs to play a big role in better understanding this issue and developing concrete recommendations for treatment adherence. Studying the TB experience should prove useful for informing ARV support and adherence. An example of a therapy/support group in Latin America whereby adherence was significantly improved was given. The point was made that there was an opportunity to be 'ahead of the curve' by laying foundations for mental health programmes to go with treatment programmes.

Some of the mental health related concerns in the highly complex issue of treatment include:
- There are significant risks in rolling out anti-retroviral treatment programmes (for example, the development of treatment resistance strains), thus simultaneous strong treatment support programmes are essential.
- 'Readiness' for treatment is not clear cut. This is even more complicated when a person is also taking psychiatric medication.
- Treatment is not necessarily a one-to-one process and families in particular, need to be involved. There are some promising examples from other countries of involving families in treatment support.
- Assisting users to continue care in the face of the extremes of both side-effects and 'wellness' requires careful support.
- It is important to include a prevention component in treatment programmes.
- Experts in both HIV and mental health need to be developed to deal with the dual phenomena.
- The programme approach often needs a combination of psychopharmacology and systems of support and care.
- Even where ARVs are being provided, a number of people are still likely to suffer from depression. It is important to deal with the depression for its own sake, but also because depression has been shown to influence adherence to treatment.
- Ways of helping people to increase their tolerance of side-effects need to be explored and included in treatment protocols.
- It is important to tackle the challenge of teaching what you cannot see in relation to treatment literacy.

It was suggested that HIV practitioners could learn from psychiatric patients who are used to taking medication on a long-term basis and have come to terms with the side-effects. Their coping mechanisms should be studied.

The effectiveness of psychotherapeutic interventions with HIV related problems is not very well established, and very few such interventions have been evaluated in Africa. Many programmes have had a high attrition rate, making conclusions difficult to draw. Nonetheless, such evaluations are needed. Specifics such as the fit between the client and the therapist and different models of therapeutic healing need to be established.
Response systems

A strong view taken by a number of participants was that the ‘prevention effort is undermined by the absence of treatment’. The meeting recommended that there is a need to research the relation between the availability of treatment options and prevention attitudes.

Another ‘response system’ issue that received a lot of attention was the integration and speeding up of services. The need to move beyond strategies, guidelines and toolkits into planning and service provision was suggested. However, there are still a number of unanswered questions, which need more research and thought. For example:

- Is it possible to have mental health-related HIV/AIDS services integrated into de-centrised health services?
- Where should mental health issues be located in the currently polarised NGOs versus a government services framework for responding to HIV/AIDS?
- How should services be standardised to ensure quality service provision?
- Should South Africa go the ‘MTCT plus’ route of mental health training for HIV/AIDS counsellors or proceed more along the ‘Canadian experience’ of a more parallel mental health service/consulting model?
- Can we burden health workers in an already stressed system with additional tasks?

Amongst the more important tasks to still be done are:

- Rationalisation of an ethical framework for VCT.
- Standardisation and monitoring of performance.
- Building mental health surveillance into behavioural surveillance systems.
- Rationalisation of referral networks.
- Ongoing training in mental health and HIV/AIDS issues.

Cross-cutting issues

Cultural issues

Cultural worldview including local explanations of illness, social and hierarchical structures, norms and mores linked to stigma and so on, need careful consideration in all matters related to HIV/AIDS. However, when dealing with the issue of the ‘mind’ that is, mental health, this becomes even
more critical. Finding a balance, which both respects local worldviews, and educates communities in scientific explanations, have to be found.

The roles of traditional healers also become particularly important in dealing with mental health issues. Not only are traditional practitioners an important human resource in fighting the epidemic and its impacts, but they are also a respected and integral part of many South African communities. In both conducting research and in providing interventions, traditional healers need to become involved.

**Media and communications**

The broad programme of media needs to be understood. Media and news have an impact on public perceptions and too little attention has been paid to the role of the media in shaping responses to the epidemic. The meeting felt that mental health practitioners have an important role to play here.

**'Ideological' issues**

The place of mental health in the struggle against HIV/AIDS and in dealing with the consequences needs to be ‘stepped up’ significantly. In the same way as mental health issues linked to violence have become part of public discourse, the same needs to happen with mental health and HIV/AIDS. The psychological processes as well as the consequences need to be highlighted so that they become an integral part of endeavours to deal with HIV/AIDS. This is possible to achieve, but will require a different level of advocacy and involvement from mental health professionals than has been the case up to now.
Day II: Areas requiring further research, policy and service development

Leading on from the discussion of Day I the following broad mental health areas were identified as needing extensive research, policy and service development. Though some information is available on all these topics, most research has been done in developed countries and (depending on the area), holds only limited value for South Africa and other developed countries. Even where more local research has been done, these areas were all seen as needing significantly more work.

- Voluntary Counselling and testing (VCT).
- Support (short and longer term) to people living with HIV/AIDS.
- Support (short and longer term) to people living with and caring for people infected with HIV or living with AIDS.
- Stigma and its ramifications and prevention.
- Social impacts of HIV/AIDS.
- Mental illness.
- Children and adolescents orphaned by AIDS.
- Understanding and developing resilience.
- ‘Asset mapping’ – i.e. information on what positive mechanisms people are using to cope with the pandemic.
- Understanding psychological processes linked with HIV/AIDS which impact on the spread of the virus, such as anger and revenge.

Given the time constraints, only four of these areas were discussed in detail. These were:
- Voluntary counselling and testing.
- Orphans and other vulnerable children.
- Mental illness.
- Support to infected and affected people.
Voluntary counselling and testing (VCT)

VCT was considered as incorporating a wide range of services relevant to mental health. The importance of skilled counselling in both the pre- and post-test situations was emphasised. Issues around who should be accredited to conduct such counselling, by whom and after what level of training, were discussed. In addition, it was asserted that the support that was required by a number of people extended beyond the single pre-test, single post-test counselling situation. Under a broad rubric of VCT could be services such as support clubs for infected individuals; support clubs for non-infected individuals (to stay that way!) and support clubs for families of infected individuals.

It was acknowledged that though a number of support groups are already operating they concentrate very little on mental health issues. The facilitators often do not have the skill or the back-up support to deal with feelings – at least not in any in-depth way. Thus not only are the group members afraid to open up their emotions, but the facilitators themselves appear to be scared that they may become overwhelmed by emotion (their own and those of group members); that they will be unable to cope with the group and, if the emotions were more severe than they were able to deal with, that there would be no-one to refer the person to. Structures were seldom put in place to support the counsellors themselves.

The point was made that at the very least, VCT counsellors needed to be trained to recognise mental health problems. They should then be able to refer clients to other practitioners for medical interventions such as antidepressants for those who needed this and/or for longer term counselling. Ideally the counsellors should also be available and skilled to do more than one post-test session for a certain proportion of users. The ability and skill to know who needs what kind and level of mental health intervention was not easy, but was nonetheless necessary for all VCT counsellors.

Another important point was that there needed to be close links between the health and social services and the community in which they were operating. This is important from the perspective of understanding the problems presented in a culturally integrated way, but also so that other family or community members can be brought into the process for further ongoing support and to ensure prevention.
The key question, however, is: 'is VCT effective?' Within the parameters of the above discussion, this question could have a number of angles. Firstly, given that one of the most often stated goals of VCT is to prevent further transmission, does it in fact do this? Secondly, are there certain VCT interventions that are more successful in doing this than others? Thirdly, is VCT (in any particular form) effective in assisting people with their mental health problems? These were identified as key research questions.

In addition, key questions were raised concerning the structural requirements needed for effective VCT. Research was required to look at models such as more integrated versus more vertically oriented VCT services; services offered as part of health services versus more independent VCT; the relative effectiveness linked to the value which institutions placed on VCT and service user preferences. Research that looked at the links between the community and the VCT services and consequent effectiveness was also suggested.

**Orphans and other vulnerable children (OVC)**

There are a number of important mental health issues in relation to children and adolescents orphaned and/or in other vulnerable circumstances. The following concerns have been identified in various HSRC research proposals: Stress from work, worry, insecurity, stigma, depression, anxiety, withdrawal, aggression (see also, the presentation by Wild in this report).

Research is needed to clarify the exact needs of children in these vulnerable circumstances. This must cover both general and specific needs.

More understanding is needed around how orphans and other vulnerable children are currently coping. It was emphasised that it is critical to build on and strengthen existing systems rather than set up alien systems without proven local efficacy and which may be rejected by local communities.

What happens to orphans and other vulnerable children as they get older? Longitudinal studies are needed to see whether in fact the predicted ‘gloom and doom’ does in fact transpire.

In addition to understanding what the needs of OVCs are, it is important to establish the needs of the family which incorporates such children. Are there families which are better able to incorporate new non-biological family members than others? In addition to economic differences which may make
incorporation easier, is there other ‘social capital’ which facilitates the process?

As the number of people dying from AIDS grows and more and more orphans require incorporation into new family structures, will a ‘saturation point’ develop after which proportionately many more orphans will end up without a home and family? Would more people be prepared to incorporate a family member if they were given some incentive, such as a grant, to do so? Research was suggested which would help to determine who would take whom into their family and under what circumstances/incentives.

A problem of child sexual abuse and even commercial sexual exploitation was expressed if young children were being ‘given’ ‘willy nilly’ to any parent who would have them. Though problems with adoption and foster processes have been identified, the homes to which children are to be moved need careful consideration. This too, is an area for further research.

The impact of a parent dying and transfer to a new home environment also requires more input and evaluation. The need for ‘permanency plans’, including a negotiation of the psychological needs of all involved is very important. Research is needed to establish whether this would indeed facilitate better short and longer term mental health for all concerned. The need to involve people living with HIV/AIDS in such planning was seen as critical.

Other questions which were seen as extremely important and in need of further research were:
- How can child-headed households be more effectively supported? Does such support in fact improve mental health and other social functioning?
- At what age should a child be recognised to head a household?
- How can attitudes be shifted around disclosure of HIV/AIDS status so that a transition can be negotiated?
- Can children and adolescents be assisted with identity issues in transition from one family to another?

Mental illness

A distinction should be drawn between full blown diagnosable mental illness, including neuropsychiatric illness, and psychological disturbance resulting from HIV/AIDS. Both are important and both need a health service response. People’s quality of life can be substantially improved.
The extent of mental health problems in HIV positive and AIDS infected people in Africa is largely unknown. The same can be said of OVC, family members and carers of people living with AIDS and indeed society as a whole. Studies are needed to establish baseline rates in all these groups.

One of the areas where there is probably most knowledge in the area of HIV/AIDS and mental health, is how to treat mental illness resulting from HIV/AIDS (though many questions around counselling and therapy in the African context are not known). However, a number of questions, mainly health systems questions, need answers. For example:

- Who is going to/should provide the treatment?
- Do mental health workers identify mental health problems in their HIV positive patients?
- Can most healthcare providers make the correct diagnosis?
- Do healthcare providers have the correct knowledge to make a diagnosis and treat?
- Which mental health problems linked to HIV/AIDS should be provided within general healthcare and which require specialist intervention?
- What is the likely impact on mental health services as a result of HIV/AIDS?
- When users present with certain mental health symptoms, do health workers, including mental health workers, investigate for possible underlying HIV/AIDS?

It was suggested that questions or a focused questionnaire should be included in a general behaviour study which is being planned. When a study on the situation and needs of people with HIV/AIDS was conducted it should include a mental health component.

**Support to family and community and social impact**

The point was made strongly that there is already a lot of support that is given in communities. Much can still be learned from a closer, more anthropological type, analysis of these support systems. This is important in order to balance the view that societies are grossly breaking down, but also because such existing mechanisms can be strengthened and supported rather than ‘do gooders’ trying to put imported and culturally inappropriate processes into place.
The need to better understand stigma and its psychological as well as sociological underpinnings was emphasised. In-depth interviews, perhaps over an extended period, may be more useful than large surveys. The latter may help understand 'what' stigma exists, whereas the former should assist more with 'why'. The link between emotional problems such as anxiety, depression and emotional shutdown and stigma need further exploration.

The pressures that certain groups, such as women and the elderly, are under need special focus. Women and the elderly are likely to have to bear most of the burden of having to care for ill and dying people, grieving family members, OVC and so on. Women, who have higher rates of HIV infection than men, may find themselves neglecting themselves in carrying out their perceived social roles, with devastating implications for all. Putting additional strains on elderly women is also likely to have major psychological and social implications. This needs more study.

How do families cope with death? It was suggested that an important way to understand this might be to do case studies. How do family patterns change? How do families cope? What happens to the mental health of those involved?

A further question that was posed was how would societies cope with the pandemic from a psychological perspective? The possibility had previously been put forward that people’s inability to cope with multiple deaths, many OVC and so on could lead to social disaster (see the presentation by Freeman). The meeting turned briefly to examining how one may predict whether this would eventuate or not. It was suggested that previous tragedies, including the impacts of other communicable diseases, wars, natural disasters and so on, should be examined. The discussion then turned to looking at how communities unite and mobilise around ‘common enemies’ as a coping mechanism in the face of death and destruction. Whether HIV/AIDS, with its concomitant stigma, was comparable to a war or genocide was debated. This led to the suggestion that it would be good to find and research communities, which had managed to mobilise against HIV/AIDS and to see whether, this has equipped them to cope better with the impacts of the pandemic. If these communities were found, were there particular characteristics, which could be identified as ‘resilience’ features?
Future collaboration

Two of the objectives of the meeting were to identify research priorities, and to encourage research collaborations to meet the country and the continent’s needs in the area of mental health and HIV/AIDS.

The upside of the enormous number of research needs identified at the meeting was that there is no need to compete for a few priority areas. It became clear at the meeting that there is still so much to learn about, and to research in the area of mental health and HIV/AIDS in developing countries that, co-operation and collaboration rather than competition are the keys to meeting the need.

Some time was spent for research organisations, academics, government and others to network around particular interests and needs. Preliminary plans for research collaboration between local, continental and international researchers were discussed, the details of which are not relevant for this report.
Conclusions

The success of the meeting was recognised by all involved and no doubt different people will take different messages back and different impressions will be left on different people. Nonetheless, most participants would, in all likelihood, agree that the following three points are indisputable and are important ‘conclusions’ of the meeting:

- The links between mental health and HIV/AIDS are both profound and highly neglected.
- Research is urgently needed to assist in answering a number of unknowns – especially unknowns in developing countries.
- The most effective way to meet the research needs is through co-operation and collaboration. This must involve local, continental and international partners.
Appendix 1: Acronyms

ART          Anti-retroviral treatment
CHBC         Community home based care
HAART        Highly Active Anti-retroviral Treatment
HBC          Home based care
HCW          Healthcare workers
HIV/AIDS     Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
HSRC         Human Sciences Research Council
IDU          Intravenous drug use
MRC          Medical Research Council
MTCT         Mother-to-child transmission
NDoH         National Department of Health
NGO          Non-governmental organisation
NIMH         National Institute for Mental Health
OI           Opportunistic infections
OVC          Orphans and vulnerable children
PEI          Post-exposure infection
PLHA         People living with HIV and AIDS
PMTCT        Prevention of mother-to-child transmission
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<th>Acronym</th>
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<tr>
<td>Rx</td>
<td>Treatment</td>
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<tr>
<td>SADC</td>
<td>Southern African Development Community</td>
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<tr>
<td>SAHA</td>
<td>Social Aspects of HIV/AIDS and Health Research Programme</td>
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<tr>
<td>STI</td>
<td>Sexually transmitted infections</td>
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<tr>
<td>VCT</td>
<td>Voluntary counselling and testing</td>
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Appendix 2: Overview of the HSRC’s Social Aspects of HIV/AIDS and Health (SAHA) Research Programme

**PROGRESS REPORT ON IMPLEMENTING SAHA’S STRATEGIC FRAMEWORK**

Dr Olive Shisana  
Executive Director: Social Aspects of HIV/AIDS and Health

**HSRC GOALS**

To move from:
- Social databases to social-scientific knowledge-management
- Social research to national socio-economic research programmes
- Educational assessment to policy-impact assessment

**SAHA GOALS**

- Influence policy-makers on the social aspects of HIV/AIDS and public health
- Become the most frequently cited source of scientific information on the social aspects of HIV/AIDS and health in South Africa and the SADC region
- Increase income to achieve the two goals
FOCUS OF THE PROGRAMME

- Social epidemiology of HIV/AIDS and public health in South Africa and the SADC region
- Key socio-cultural, psychological, political, economic and demographic determinants that increase or reduce vulnerability to HIV infection
- Performance of health systems
- Cost-effectiveness and costing of health services
- Demographic and epidemiological projections of various public health problems

SECTIONS IN SAHA

- Behavioural and Social Aspects of HIV/AIDS
- Social Aspects of Health
- Epidemiology and Demography
- Health Economics
- SAHARA
# Appendix 3: Participants at the round-table meeting

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