Psychosocial Support and HIV/AIDS: Current Research and Programming

Meeting Report

Organised by the Children Affected by AIDS and Care and Support Working Groups

30th October 2012
Psychosocial Support and HIV/AIDS

The UK Consortium on AIDS and International Development is a network of around 80 not-for-profit, faith-based and academic agencies. Based in the UK, with strong links to governments, international and multilateral agencies, the Consortium has been working at the heart of the response to HIV and AIDS for over 25 years.

To view all presentations from the event please visit our dedicated psychosocial support page http://aidsconsortium.org.uk/events-2/psychosocial-support/

The objective of the day was to explore current evidence based research and programming on PSS in regards to HIV and AIDS.

To join the Children Affected by AIDS (CABA) or Care and Support Working Groups please email Deborah@aidsconsortium.org.uk

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<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Speaker/Institution</th>
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| 09.30-09.45 | Welcome and overview of the day                                         | Ben Simms  
  Director, UK Consortium on AIDS                        |
| **Overview of PSS**  | Chair = Rachel Albone (Chair of UK Consortium’s Care and Support Working Group)  |   |
| 09.45-10.05 | Mind Matters - an overview of psychosocial challenges in HIV            | Dr Rosie Mayston  
  Institute of Psychiatry, Kings College London           |
| 10.05-10.20 | Personal experience of PSS                                              | Silvia Petretti  
  Positively UK                                            |
| 10.20-11.00 | What do we mean by PSS?                                                 | Facilitated by Rachel Albone                             |
| 11.00-11.20 | Coffee Break                                                           |                                                          |
| 11.20-11.35 | The hidden epidemic: Pathways of psychosocial risk for HIV-affected children and youth | Dr Lucie Cluver  
  Department of Social Policy, Wolfson College, Oxford University |
| 11.35-11.50 | Facilitating the resilience of HIV-affected children and youth through coping-enabling social environments | Dr Morten Skovdal  
  Department of Health Promotion and Development, University of Bergen |
| 11.50-12.05 | Delivering high quality HIV care in sub-Saharan Africa                 | Dr Lucy Selman  
  Department of Palliative Care, Policy & Rehabilitation, King’s College London |
| 12.05-12.20 | Psychosocial support - how can we measure effectiveness?               | Oonagh O’Brien  
  Institute for International Health & Development, Queen Margaret University |
| 12.20-13.00 | Q+A (panel discussion)                                                 | Facilitated by Claire Morris                              |
| 13.00-14.00 | Lunch                                                                  |                                                          |
| **PSS: Programming**  | Chair = Stuart Kean (Chair of UK Consortium’s Children Affected by AIDS Working Group)  |   |
| 14.00-14.15 | The BasicNeeds Model for Mental Health and Development                 | Chris Underhill MBE  
  BasicNeeds                                                  |
| 14.15-14.30 | Psychosocial support and child protection training programme- Thogomelo | Rita Muyambo  
  International HIV/AIDS Alliance                           |
| 14.30-14.45 | Peer support and patient engagement: A holistic approach               | Chris Sandford  
  Mortimer Market Centre                                      |
| 14.45-15.00 | Stepping Stones: Psychosocial support in the Community                 | Gill Gordon  
  Salamander Trust                                           |
| 15.00-15.15 | An Overview of REPSSI’s approach to psychosocial support               | Gabriella Sozanski  
  REPSSI                                                      |
<p>| 15.15-15.30 | Panel Q+A                                                               | Facilitated by Stuart Kean                                |</p>
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<th>Time</th>
<th>Session</th>
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<td>15.30-15.50</td>
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| 15.50-16.55 | What makes a good PSS programme?  | Chair = Kate Iorpenda (Chair of UK Consortium’s Children Affected by AIDS Working Group)  
- From today’s presentations what do you think are the key components that make a good PSS programme?  
- Topline take-away messages from today’s meeting  
Group work |
| 16.55-17.00 | Wrap up and thank you’s          | Ben Simms  
*Director, UK Consortium on AIDS* |
What do we mean by mental health in regards to HIV and AIDS? So often it is equated with depression. When operationalising HIV, anxiety and depression are common mental disorders but underlying issues of substance use and alcohol may also be present in some high risk HIV populations. PTSD is a particular type of anxiety disorder – there is less evidence of the relationship between PTSD and HIV but there is probably an increase in incidence of PTSD in PLHIV. Levels of bipolar disorder, psychosis and schizophrenia do not differ in PLHIV and the general population but these disorders do have a negative impact on HIV outcomes including by reducing ART adherence. A study in the US found that 36% of PLHIV suffered depression but studies in low and middle income countries were varied – ranging from 0-63% prevalence.

HAND (HIV Associated Neurological Disorders) are the direct cognitive effects of HIV infection. Prevalence ranges from 20-37% in high income settings and 31-56% in low and middle income settings. Treatment with ARVs reduces the symptoms of HAND. A growing issue in high income countries is the onset of HIV related dementia. Substance and alcohol misuse can be both a cause and consequence of HIV infection. Research shows high levels of misuse in some HIV high risk populations.

PLHIV face complex challenges – divided into individual level factors and social factors. Gender is a cross cutting issue.

What are the options for treating HIV related mental disorders? Pharmacological – with antidepressants – which have been found to be as effective among PLHIV as amongst the general population, or psychological interventions including group psychotherapy, stress management interventions and cognitive behaviour therapy.

With regard to the policy context in low and middle income countries WHO’s “Scaling up care for mental, neurological, and substance use disorders” provides relevant guidelines (http://www.who.int/mental_health/mhgap_final_english.pdf)
Psychosocial Support and HIV – a Personal Perspective
Silvia Petretti

What is psychosocial support? Psycho is about the soul – what goes on in the heart and social is about relationships. Why do we need psychosocial support?

- The trauma of diagnosis – it is a profound moment and a turning point in anyone’s life. With diagnosis comes trauma – even in circumstances where there are expert services people still feel isolation.
- Stigma experienced by PLHIV is isolating. So many people are living with HIV and are on ARVs but have not disclosed their status as they are scared of being rejected.
- There are power imbalances experienced by key populations living with HIV. Now that an individual has HIV it can make it more difficult to overcome already existing mental health issues. In key populations at risk of HIV, drug use is often higher than in the general population.
- Institutions and their control can have an impact – hospitals are hierarchical where the doctor knows everything and a PLHIV is given instruction after instruction. It is very disempowering for someone who has been newly diagnosed or isn’t used to the loss of control.
- HIV has an impact on relationships and intimacy. It affects how a person relates to their children and even the idea of having children. It makes people question themselves.
- PLHIV have to make many difficult choices throughout their lifetime – it is on-going – so support is needed.

What should people get out of psychosocial support?

- The ability to cope with trauma and crisis
- An identity – I am HIV positive – it is what I am but how do I find myself through this process? How do you process this new identity?
- The ability to process complex information – medical terms into lay language
- Through PSS an individual can make informed decisions about participating in care. The UK BHIVA Standards of Care say that PLHIV are participants and should be part of decisions on care.
- Psychosocial support can restore dignity through support that you don’t get through the hospital
- It can help in developing a voice and advancing the rights of PLHIV
- Psychosocial support will lead to increased health

Peer led psychosocial support offered by Positively UK [http://positivelyuk.org/] offers an opportunity to meet role models – you will hear many positive stories and think “if they can do it, I can do it!”. Peer led support is about equality – feeling equal with the peer that is supporting you as opposed to the power imbalance felt with medical staff – it helps to readdress power imbalances. Peer led support is holistic – it looks at an individual as a whole human being.

Questions and comments to the first two presentations
- Must differentiate between psychological support and psychosocial support – they are different things
- Is data on mental health in PLHIV adjusted for confounders e.g. other risk factors for mental ill health in PLHIV?
- Why do you think the issue of mental health is gaining increased attention in the global arena? Lots of research has been conducted but it is only recently that it is being linked to the MDGs and the wider development sector. We now recognise that mental health can help us to achieve the MDGs. It links in so much with gender issues. Globally, there are powerful advocates for mental health who are well connected and seek to integrate mental health into wider issues. The recent Lancet series on mental health [http://www.thelancet.com/series/global-mental-health] also helped to raise the profile.
- Why hasn’t this increased recognition been transferred to the HIV sector? Mental health and HIV is complex and there is a lack of clear messages. So far the focus has been on getting people onto treatment but people are now recognising that if we are to move forward we need to look at the...
Psychosocial Support and HIV/AIDS

wider PSS context. It is likely that NGOs are already doing PSS but not packaging it as a mental health or PSS intervention.

What do we mean by Psychosocial Support?
Group work exercise facilitated by Rachel Albone. Attendees were asked to write down key words that they think reflect psychosocial support. The exercise was not meant to result in a comprehensive definition of psychosocial support but rather to gather thoughts and perspectives on what PSS means to different people.
Psychosocial Support and HIV/AIDS

The hidden epidemic: Pathways of psychosocial risk for HIV-affected children and youth
Dr Lucie Cluver

Presentation relates to two linked longitudinal studies carried out between 2005-2012 in South Africa that surveyed 8000 children. The surveys included an orphan resilience study and a national young carers study. Researchers thought that AIDS orphaned and other orphaned children would do the same but in actual fact AIDS orphans fared worse. They started worse and got worse. The surveys found that AIDS orphaned children suffer increased levels of depression, post-traumatic stress, peer problems and delinquency. They also have higher anxiety scores. Children who have a carer sick with AIDS also suffer similar levels of anxiety and depression. Familial AIDS predicts child educational difficulties with an increase in these children missing school (often to look after a sick carer), dropping out of school, unable to concentrate in class and hungry when in school. Parental AIDS also predicts child abuse with an increase in physical, emotional and domestic violence.

What can we do? Social protection, including free school meals and child focused grants, results in a decrease in the prevalence of transactional sex in girls. Providing/supporting free schooling also results in better grades for boys. An interactive model of risk shows modifiable pathways from familial AIDS to child risks. Reducing extreme poverty, abuse, stigma and psychological distress could interrupt these risk pathways. Social protection programmes can reduce risks for vulnerable children. Need to think about whether programmes should target just AIDS orphans or all poor children. We know that poverty impacts children but independent of poverty, having a carer ill with HIV or being an AIDS orphaned child also has an impact.

Facilitating the resilience of HIV-affected children and youth through coping-enabling social environments
Dr Morten Skovdal

Morten presented studies from the upcoming special issue of African Journal of AIDS Research http://www.ajol.info/index.php/ajar that focuses on child resilience. Why coping and resilience? There are differences in that some people do well against all the odds. It is important to understand why this is so. We need to listen to children to get the full picture. There is a difference between coping and resilience. Coping is individualistic – the science, but resilience is more vague – the story of how remarkable someone can be. The special issue of AJAR includes research from Tanzania, Uganda, Kenya, South Africa and other countries.

Commonalities to resilience include the level of resources available to the child, social enablers (the quality of the community) and resilience through participation and agency.
Delivering high quality HIV care in sub-Saharan Africa
Dr Lucy Selman

An HIV diagnosis raises profound existential/spiritual questions. What do we mean by ‘the spiritual’? It relates to ‘the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred’. Spiritual is multidimensional, personal and relational and includes the existential as well as the religious. Research has shown that spiritual support is a unique contributor to increased quality of life. African countries are highly religious and spirituality is often seen as a coping resource but the extent and effectiveness of spiritual care is unknown. There are now three new multidimensional tools with spiritual items validated in African palliative care/ HIV populations:

- APCA African Palliative Outcome Scale (POS)
- Missoula Vitas Quality of Life Index (MVQoLI) – Spirit 8 spiritual well-being
- WHOQOL-HIV
Psychosocial support - how can we measure effectiveness?
Oonagh O’Brien

The Institute for International Development (IIHD), Queen Margaret University formed a psychosocial support working group (PWG) in 2000 with the aim of developing a common framework around psychosocial interventions. The PWG framework focuses on moving away from working largely with individuals towards interventions with bigger social units such as families, households and communities. The psychosocial well-being of individuals and of the larger social units is seen to be affected by three key issues: human capacity, social ecology and culture & values. The IASC Guidelines on Mental health and Psychosocial support in emergency settings is an important tool in addressing PSS.


When attempting to measure effectiveness how do we be specific and consistent when so much of what we want to measure is culturally determined? It is also important to provide support but not to label or stigmatise. We can measure social interactions which are closely linked to social capital. The challenge is how to measure outcomes and not the process. We also need to look at ways of measuring quantity of social connections as well as their quality. IIHD have developed a tool to map social connection. It involves developing three scenarios theoretically driven from literature on PSS and well being. Questions relate to emotional support, practical support and access to rights. Mapping occurs using a simple participatory tool based on a chapati or venn diagram.

http://mhpss.net The MHPSS Network is a growing global platform for connecting people, networks and organisations, for sharing resources and for building knowledge related to mental health and psychosocial support both in emergency settings and in situations of adversity. The Network aspires to building and shaping good practice in support of people affected by difficult events or circumstances.
Questions and comments

- There are measurement issues – the cross over between the biomedical model, spiritual wellbeing and social capital – what exactly is it that we are measuring?
- Need better coordination between researchers and practitioners – need to share tools where they are overlapping
- With the drive for value for money and results based funding, clear outcomes of interventions are needed to attract funding. There are certain things we can measure but is this enough?
- Researchers need advice on how to engage PLHIV in research. How do you meaningfully and ethically include children in research? The PLHIV Stigma Index http://www.stigmaindex.org/ allows PLHIV to carry out research on themselves.
- After research we need to ensure that PLHIV are enabled and empowered – to strengthen their capacity. There is no incentive for researchers to do proper capacity building – something that is not tokenistic (like adding their name on the end of an academic paper). Need clear guidelines on how to do this right and sensitively – particularly with HIV key populations who may have complex needs and lifestyles.

PSS: Programming

The BasicNeeds Model for Mental Health and Development

Chris Underhill

BasicNeeds http://www.basicneeds.org/ aims to enable people with mental illness and epilepsy to live and work successfully in their communities. It implements its programmes through capacity building, community mental health, sustainable livelihoods, research, and management and administration. BasicNeeds empowers people with mental disorders, their carers and families, and mobilises their communities, the government and other key stakeholders to influence mental health practice and policy. People with mental health needs come together to do the action research – programme participants carry out the research themselves. Whilst not against the pharma/pill-based interventions, there are very few psychiatrists in African countries e.g. Ghana.

Its strategy to 2018 aims to scale up its model by strengthening partnerships, entering new markets, franchising the Mental Health and Development Model, and creating a virtual international centre of excellence.

Psychosocial support and child protection training programme- Thogomelo

Rita Muyambo

The Thogomelo Project aims to build the Capacity of Community Caregivers in South Africa so that they can provide the best possible service to children and families. In South Africa there are about 266 orphans to every 1 social worker. The project works through improving psychosocial wellbeing of caregivers, improving child protection knowledge of supervisors and improving supportive supervision skills of supervisors. There are three accredited curricula. The Project measures its impact through baseline questionnaires, pre & post training tests, a psychosocial wellbeing scale, focus group discussions, and in-depth interviews.

Lower wellbeing scores were associated with lower educational levels, no respect or appreciation from organisation, no support from within the organisation, and no supervisor or coordinator. Those experiencing significantly higher levels of burnout were women, people who had lower educational levels,
people who had no organisational support, people who were not being valued and appreciated within their organisation, and people who had no support from someone at work.

Peer support and patient engagement: A holistic approach

Chris Sandford

Patient representatives at Mortimer Market Centre, London offer five day a week drop in and appointment service - one to one peer support, advice and advocacy, early intervention – at diagnosis, peer led motivational workshops, educational forums, newly diagnosed courses and above all hope. Peer support is effective as it breaks the feeling of isolation. Peer support workers can empathise and are role models – they are living positively with the virus, they take medication every day with no visible side effects, and they have experience of the psychological issues of HIV - the crisis of diagnosis, disclosure, fears of rejection, stigma and discrimination. Issues and concerns raised during peer support include social isolation and exclusion, disclosure and confidentiality issues, stigma and discrimination, social and psychological support, diagnosis and life expectancy, starting treatment and adherence.

Workshops on subjects outside the medical model but of great importance to patients are a part of the PSS package. They include workshops on positive thinking, nutrition, love, sex & relationships and disclosure. Forums are also held that aim to empower through information. Newly diagnosed courses cover the impact of diagnosis, disclosure, medical aspects and therapy, love, sex, relationships and transmission, maintaining wellbeing – mind & body, and building support networks.
Stepping Stones: Psychosocial support in the Community
Gill Gordon

Stepping Stones is a training package on HIV, communication and relationship skills between genders and generations. Stepping Stones Plus focuses on care, mutual respect, support, rights, safety and security for all people with HIV. [http://www.steppingstonesfeedback.org/](http://www.steppingstonesfeedback.org/). During Stepping Stones training participants are split into peer groups by gender and age. Role play, drawing, games and discussions are used to deal with subjects difficult to express so that people can understand each other’s point of view, feelings and situations. The training is based on holistic theoretical models for behavioural change.

The Stepping Stones Wheel of Change

![The Stepping Stones Wheel of Change](image)

The training looks at individual psychological aspects of human experience and the wider social experience, knowledge, self-esteem, feelings and skills, and social well-being in relationships, community networks, traditions, economic status, school and work. A new package of Stepping Stones is being developed for children aged 5-14 years and their caregivers, with HIV or affected by it. It aims to support younger children and caregivers with communication and relationships, growing up, safer sex, HIV testing, treatment, resilience, caring, grief, psychosocial well-being, abuse, school, and discipline. It is based on appreciative enquiry – building on strengths and positive aspects of life.

An overview of REPSSI’s approach to psychosocial support
Gabriella Sozanski

REPSSI [http://www.repssi.org/](http://www.repssi.org/) provides expert assistance on emotional and social (psychosocial) support for children and youth living with the effects of poverty, conflict, HIV and AIDS. Psychosocial support is a continuum of love, care and protection that enhances the cognitive, emotional and spiritual wellbeing of a person and strengthens their social and cultural connectedness. REPSSI develops strategic partnerships with NGOs, development partners and governments. They train partner NGOs to provide social and emotional services, produce publications and tools, run a distance-learning Certificate for community workers, and measure community psychosocial support interventions.

To measure the effectiveness of their interventions, REPSSI developed a psychosocial support monitoring and evaluation tool. It tracks the impact of psychosocial support programmes on children aged 6 to 18. The tool is designed for child or beneficiary level measurement of psychosocial wellbeing. Programme personnel can generate, record and report simple qualitative and quantitative data using this tool. The interactive tool can be used for informative assessment, process evaluation and end of phase evaluation. The tool was developed to provide conceptual clarity in five areas of PSS measurement: interpersonal,
Psychosocial Support and HIV/AIDS

intrapersonal, adaptability, broadening coping alternatives and state of being and has a set of 13 proxy indicators of PSS. It uses a range of participatory approaches/activities and addresses age based appropriateness of indicators.

Challenges experienced with the tool indicate that a lack of appropriate training can compromise the quality of data; that an understanding of what is to be measured depends on an initial comprehension of key psychosocial wellbeing outcomes; interpretation of indicators at community level differs based on level of understanding and cultural background; and that the data collection process requires elaborate time investments to allow for quality community input.

Questions and comments

• Today we have heard about some successful UK based models but how do we translate these UK models for use in low income countries? Peer support is a low cost intervention – it is all about getting the correct information. What you can do to help yourself and how you can help people to make a living. It is about dignity and self-respect. The most difficult part is finding the right person to do peer support and then train and support them through mentoring – it is a long process.
• Could teenagers do peer support? No reason why not – giving them responsibility has been shown to work
• There is a lot of task shifting occurring in mental health. For instance, BasicNeeds are training farmers to carry out basic community activities.
• A lot of programmes look at clinical outcomes and not social wellbeing outcomes e.g. changes in self esteem.
• It is important to involve faith leaders in PSS – especially spiritual support. There is a long legacy of faith communities working on mental health. Traditional healers must also be included in PSS approaches – there are more traditional healers then psychiatrists. Many FBOs are implementing projects that educate faith leaders on HIV – that look at scriptures to challenge views on sexuality and intimacy.
• How can we include spiritual measures in quantitative research? What are the right questions to ask?

What is PSS? What is it not? What makes a good PSS programme? Are there still unanswered questions?

Group work facilitated by Kate Iorpenda. Attendees were asked to work in groups to reflect on the content of the day and write down key messages from the day and highlight any gaps and questions that remain.

Things to remember
PLHIV is not a homogenous group
There is a double stigma- mental health and HIV
Spirituality does not equate to religion
Don’t look for short term outcomes – its slow long work – hang on in there
Partner and connect – academia and practitioners

Outstanding Issues
We need effective mental health services accessibility
Measuring PSS in Quality of Life is based on surveys which are expensive and resource intensive. Donors would rather leave it
We need research that evidences faith based peer support
Research for children/youth is limited by use of language in faith and spirituality
Psychosocial Support and HIV/AIDS

We need to have the right questions to capture quantitative data on PSS for FBOs
How to sustain PSS long term?
What helps to motivate peer outreach workers?
How to measure PSS interventions? PSS interventions are often happening at low/no cost
We need PSS indicators
What are the role of primary caregivers within a PSS scheme? Needs clarification
We need a further symposium on how to use faith positively
How can we support people to become HIV advocates through PSS?
How do you do the holistic approach?

PSS is/is not...
PSS is not a single counselling intervention
We need a community wide approach to PSS – not just targeting PLHIV
There is a need for community development programmes to be mental health and PSS wellbeing sensitive
Psychosocial support should be budgeted for/written into original programme designs – not tacked on at the end
Programmes that build solidarity and community peer support for mental health are an evolution of programmes e.g. from IGA focus
Strategy should be an integrated approach towards mental health and PLHIV
Listening comes first
Need to create a safe space
Should sign post to services
Should be an early intervention
Remember the individual transformational impact of pss interventions – change agents/multiplier effect
Appreciating the service user in their entirety – holistic approach
Yes hope is important but wellbeing is also about coming to terms with how things are now/acceptance
Need to also tackle/challenge stigma
Link with other health services (referral)
Give correct information on HIV and transmission
Use tools that encourage self-reflection and celebrate progress
Provide care and supervision to caregivers
Provide basic needs and services (food, shelter)

Next steps from the event
The decision was made that the best forum to continue discussion on PSS is the MHPSS online platform.
Attendees were encouraged to engage with this group: http://mhpss.net/