



THE UGANDA NATIONAL HEALTH RESEARCH SYMPOSIUM

"Achieving Universal Coverage
for Quality Mental Health Care
in Uganda"

REPORT

Wednesday, 10th April 2019
Hotel Africana, Kampala





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Acronyms

| | |
|----------|---|
| ADRD | Alzheimer's disease and its Related Dementias |
| ARD | Alzheimer's and Related Dementias |
| ART | Anti Retroviral Therapy |
| AUD | Alcohol Use Disorder |
| AUDIT | Alcohol Use Disorder Identification Test |
| BELL | Butabika East London Link |
| BREC | Butabika Recovery College |
| CA-HIV | Children and Adolescents - Human Immunodeficiency Virus |
| CDC | Centre for Disease Control |
| CHWs | Community Health Workers |
| CREDU | Consortium for Clinical Research Regulation and Ethics Capacity Development in Uganda |
| CRT | Community Recovery Team |
| DFID | Department of Foreign and International Development |
| DGHS | Director General of Health Services |
| DRC | Democratic Republic of Congo |
| EAC | East African Community |
| EBP | Emotional and Behavioral Problems |
| EDCTP | European and Developing Countries Clinical Trials Partnership |
| ELFT | East London Foundation Trust |
| FGDS | Focus Group Discussions |
| HC IVs | Health Centre IV |
| HCIIIs | Health Centre III |
| HCIIIs | Health Centre II |
| HIV | Human Immunodeficiency Virus |
| HIV/AIDS | Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome |
| KII | Key Informant Interviews |
| LMICs | Low and Middle Income Countries |
| LSHTM | London School of Hygiene and Tropical Medicine |
| MADRI | Mbarara Alzheimer's and Related Dementias Research Initiative |
| Mak | Makerere University, Kampala |
| MDD | Major depressive Disorder |
| MHGap | Mental Health Gap |
| MoH | Ministry of Health |
| MRC/UVRI | Medical Research Council/ Uganda Virus Research Institute |
| NCRI | Natural Chemotherapeutics Research Institute |
| NDA | National Drug Authority |
| NGOs | Non Governmental Organisations |
| OPD | Out Patients' Department |
| PHC | Primary Health Care |
| PSWs | Peer Support Workers |
| RCT | Randomized Control Trial |
| STDs | Sexually Transmitted Diseases |
| SWOT | Strength, Weaknesses, Opportunities and Threats |
| TASO | The AIDS Support Organisation |
| THPs | Traditional Health Practitioners |
| TOC | Theory of Change |
| UK | United Kingdom |
| UKAID | United Kingdom Agency for International Development |
| UNCST | Uganda National Council of Science and Technology |
| UNHRO | Uganda National Health Research Organisation |
| UPDF | Uganda Peoples' Defense Forces |
| UPSIDES | Using Peer Support In Developing Empowering Mental Health Services |
| USA | United States of America |
| USAID | United Stated Agency for International Development |
| WHO | World Health Organisation |

Acknowledgements

The Health Research Symposium on Mental Health Care in Uganda was yet another great success with research on primary and tertiary mental health care and services presented. The newly enacted Mental Health Act was discussed that promotes rights of persons with mental illness and improved access to and quality services since Uganda's Independence.

We therefore take this opportunity to thank our partners for the various forms of contributions made towards the success of the symposium. We are grateful to the European and Developing Countries Clinical Trials Partnership (EDCTP) for the financial support. We would also like to thank Dr. Sam Okware Director General, UNHRO for spearheading this important event, and in addition, acknowledge support from Dr. Joseph Baguma – THETA; Dr. Grace Nambatya - the Natural Chemotherapeutics Research Institute; Prof. Peter Olupot-Olupot - Mbale Clinical Research Institute (Mbale Regional Referral Hospital); MoH and Mr. Delius Asiimwe - Kabano Development and Research Centre.

Our sincere appreciation goes to Dr. Henry Mwebesa, Director General Health Services, MoH, Kampala who presided over the opening ceremony and Prof George Kirya, Chairperson Board Butabika National Referral Hospital who honored the closing ceremony. Their commitment for continued support of mental healthcare to ensure timely and cost effectiveness of health service delivery in the country and beyond was a great inspiration to symposium participants.

The rich experiences and great insights shared at the symposium were the relentless efforts of special resourceful persons that we must appreciate: Prof Segane Musisi, Department of Psychiatry; School of Medicine, College of Health Sciences, Makerere University who delivered a key note address on history and development of healthcare in Uganda. Dr. Hafisa Lukwata of MoH and Dr. Basangwa, Director, Butabika National Referral Hospital, who presented and discussed the Mental Health Act respectively. Our heartfelt appreciation goes to the presenters of the original research on mental health care and services at primary and tertiary levels.

To the participants, we commend your most knowledgeable and expert contributions throughout the symposium.

We are very grateful to the organizations and individuals that spared their valuable time, resources and knowledge to be a part of the steering committee. Mr. Delius Asiimwe (Chairperson), Dr. Harriet Nabudere, Mr Robert Apunyo, Ms. Hilda Rukundo, Ms. Angella Asiimwe, Mr. Henry Tumusiime, Ms. Nambejja Cissy, Mr. Simon Dembe Kasango and Mr. Isaac Kyeyune.

We shall always be indebted to you all and look forward to sharing the fruits of your great contributions at all times.

1.0 Background and context

The National Regulatory Authorities for health research; Uganda National Health Research Organisation (UHNRO), Uganda National Council for Science and Technology (UNCST) and the National Drug Authority were successfully awarded a 24-month EDTCP grant – the Consortium for Clinical Research Regulation and Ethics Capacity Development in Uganda (CREDU), (July, 2017).

One of the objectives of the project was to increase opportunities for information sharing, dialogue, knowledge translation and networking among researchers, regulatory officials and research ethics committees. Of which; one of the strategies was to organise two national symposia on health research findings. A symposium was held for each 12-month period. The second symposium focused on Mental Health Care.

1.1 The Theme of the Symposium

Main Theme:

“Achieving Universal Coverage for Quality Mental Health Care in Uganda”

Sub-themes for original research and research syntheses

Mental Health Services (Secondary/Tertiary Health Care): the presentations and papers featured original research regarding organization of mental health services; psychosocial and psychotherapeutic interventions for both in and out-patient care; day treatment; community-based psychiatric care; community residential services, forensic facilities, human rights and equity issues.

Mental Health Services (Primary Health Care): this sub-theme focused on training in mental health care for primary care staff; mental health in primary health care; prescription in primary health care.

Human Resources: numbers/skills of human resources in mental health care; training professionals in mental health; consumer and family associations.

Public education and links with other sectors: public education and awareness campaigns on mental health; legislative and financial provisions for persons with mental disorders.

Policy and Legislative Framework: the presentations and papers provided insight on developments within the draft Mental Health Act; information pertinent to the mental health policy and the mental health strategic plan; financing of mental health services; and human rights policies (including legislative and financial provisions for persons with mental disorders).

1.2 Rationale for the Theme

Uganda spends 9.8% of gross domestic product on healthcare, or US\$146 annually per person. Less than 1% of this goes into mental healthcare as compared with 10% for many other countries. (Ssebunnya et al, 2010). Uganda has made significant strides in reducing poverty over recent years and this has translated into greater investment in healthcare overall. However, funding remains low by international standards and the proportion allocated for mental healthcare disproportionately so.

National mental health services are very inadequate, with little or no community care and the in-patient services which are available are insufficient to satisfy demand. 90% of the population suffering from mental illness receive no treatment (WHO, 2006). The situation is exacerbated by many skilled healthcare workers leaving Uganda to work in high-income countries, reducing what had been described as a highly skilled and motivated workforce.

New legislation (draft Mental Health Act) has been in preparation for some years but its enactment has been repeatedly delayed. The mental health system currently operates on an outdated mental health law of 1964. This obsolete legislation focuses on custodial care of mentally ill persons and is not in accordance with contemporary international human rights standards regarding mental health care. There are a number of shortcomings such as failure to distinguish voluntary and involuntary care, inadequate protection and promotion of the human rights of people with mental illness and the presence of derogatory and stigmatizing language. The draft Mental Health Act contains important advances, such as stipulations for a scrutiny body and mechanisms for appeal, but it still leaves many gaps, such as the lack of definition of a mental illness and the provision for an individual to be held in seclusion, among others.

Objectives: This symposium aims to highlight advances in both clinical and community mental health research in Uganda.

Target audience: This include but not limited to researchers from academia, other research institutions, policymakers, health managers and practitioners; and civil society representatives. Government entities such as the Mental health division (Ministry of Health), Department of Psychiatry; School of Medicine (Makerere University); Makerere University Institute of Psychology; Butabika National Referral Hospital; Uganda Nurses and Midwives Council; Mental Health non-government organizations (NGOs) and health consumer associations, Private Sector and Development Partners.

2.0 Opening Remarks

2.1 Welcome remarks

The Director General, Uganda National Health Research Organization, Dr. Sam Okware welcomed all the participants to the Symposium on Mental Health Research in Uganda. He said this was an initiative by the Consortium for Clinical Research Regulation and Ethics Capacity Development in Uganda (CREDU). He reminded the participants that they were here to discuss mental health research and how it supports the health development plan to ensure delivery of quantity and quality mental health services.

Dr. Okware re-stated the theme and objectives of the symposium thus:

Theme: Achieving universal health coverage for quality mental health care in Uganda.

The main objective is to disseminate information and share opportunities through dialogue, and evaluation of findings and knowledge translation. The main aim is to promote use of evidence based interventions to expand universal healthcare coverage.

He appreciated the presence of participants from several stakeholders such as academia, regulatory agencies namely National Drug Authority (NDA), Uganda National Health Research Organization (UNHRO), Uganda National Council of Science and Technology (UNCST) among others. He made special recognition of mental health professional present; Prof. Fred Kigozi, Dr. David Bisangwa, and Prof. Segane Musisi who was the Keynote Speaker.

He was very optimistic that outcomes from the symposium deliberations will lead to better use of evidence based interventions and generating new Terms of Reference to manage mental health in Uganda.

Finally, he took a special privilege to invite the guest of honor Dr. Mwebesa Henry, Acting. Director General, Health Services, Ministry of Health (MoH), Kampala to deliver opening remarks and then declare the Symposium on Mental Health care in Uganda officially open.

2.2 Opening Remarks

Dr. Henry Mwebesa, Acting Director General of Health Services, MoH, Kampala started by extending his appreciation to the Director General, UNHRO, Prof. Segane Musisi the Keynote Speaker, the Executive Director Butabika National Referral Hospital Symposium session Chairs, Chief Medical Officer, Uganda Peoples' Defense Forces (UPDF), Dr. Fred Kigozi as a senior mentor, senior colleagues from the MoH, senior colleagues from the academia and all the other participants for the roles in the symposium.

He thanked the steering committee for organizing this very important meeting and especially with the theme: "Achieving Universal Coverage for Quality Mental Health Care in Uganda". This theme, he said is very relevant and timely coming right after the World Health day which was commemorated yesterday, whose theme was; 'Access to Universal Health Coverage'.

He extended greetings from the MoH especially from the senior top management, which includes the ministers, Permanent Secretary and Directors and commissioners. On behalf of MoH he welcomed all participants to this very important meeting, very important symposium where they are sharing a lot of information from research findings on mental health.

He was gratified that when discussing achieving universal coverage for quality mental health services, we feel we are all moving together in the right direction and thanked everyone here for supporting that cause. He said with universal health coverage, it means that our people have access to health services without catastrophic expenditure such as selling their goats in order to go and seek medical care. It is where whoever can go to a health facility get services without economic injuries in their homestead. He like most of the participants was aware of the frustrations of some of our people especially those with chronic diseases, when they have to sell land, goats and cows to meet cost health services that are quite expensive in this country.

He informed the participants that later in the afternoon, the MoH was having a meeting with the Attorney General to discuss the national health insurance scheme that is highly related to universal health coverage but has stalled for so many years. This he emphasized that it is important, because if you are going to talk about people access, providing services without catastrophic expenditure, then there must be some form of health insurance. He lamented that Uganda is the only country in the East Africa region without an elaborated national health insurance scheme.

He explained that health insurance coverage in Uganda is only 2%, and that is mainly the private sector those who are working for corporate organizations and a few communities which have community health insurance. He noted that the health burden is still a big challenge. The Out of pocket expenditure in this country still at 46%, means that most people continue spending a lot from their own pockets in order to meet the cost of healthcare.

Dr. Mwebesa turned his focus to symposium's topic. He pointed out research studies in Kampala and Gulu which showed that 40% of admissions at Butabika hospital, were related to drug and alcohol abuse. He made reference to a very good symposium in this very hotel (Africana) where studies were presented pointing out the challenge of alcohol and drug abuse.

He noted that mental health presents a great challenge in accessing services as the patients and the communities are unable to identify potential mental health sufferers who may need care. Patients often go underground while the communities do not make the situation any better because they usually ignore and victimize patients thus creating a lot of stigma. He reasoned that mental health is a health condition like any other that can be treated and managed by modern medicine, rather than subjecting the mentally ill to traditional healing or be relegated, abandoned and tied on ropes at home.

He pointed out that these shortcomings were exuberated by the obsolete Mental Treatment Act from 1964 which focused on custodial care of the mentally ill with little regard to individual rights. He said that actually they were challenges with people who attempted suicide. When such a person died, they had to beat the body with specified number of canes (kiboko), but they don't know that this is a mental condition. In circumstances where an individual attempts to commit suicide but survives, instead of being taken to hospital for treatment, he/she is taken you prison. He appealed to all that it is high time to appreciate those are medical conditions that need to be supported because failure to distinguish voluntary and involuntary care and the presence of derogatory and stigmatizing language further undermines access of conventional care.

He acknowledged that mental health services in this country are improving but remain inadequate to satisfy the ever increasing demand especially at hospitals and community level.

He reported that the MoH has done a lot to build the capacity both of infrastructure, human resource and finance. For example, with the African Development Bank loan, Butabika hospital was renovated. Those of you who remember Butabika hospital in the early 1980s, Butabika hospital of today is a state of the art in this region. This is all because of the government intervention and the realization that mental health services is a core priority of the government and therefore the need to invest a lot in improving mental health services. He was grateful to people like Prof. Kigozi, who saw the transition from the old Butabika hospital where goats were sleeping in the ward with patients and ceilings were coming down to the state of the art hospital now which is more like a hotel facility.

In the same way government has been able to equip the hospitals and also built mental health units of 32-34 bed facilities at all regional hospitals. Previously at regional hospitals like Mbarara, the only people who were providing services were psychiatric clinical officers, psychiatric nurses, but plans are underway ensure that at each regional referral hospital there is a specialist who can provide all the support to avoid unnecessary referral of patients to Butabika hospital. The government is trying to decentralise the service to eliminate overcrowding, reduce costs on the part of the community and make access to mental health services easier than today. In so doing the ministry has also conducted a lot of training, especially for psychiatrists, psychiatric clinical officers, and psychiatric nurses with dedicated scholarships for psychiatrists in MMed. However, the challenge is that of fewer applications.

The other related problem is that despite government intervention, there is brain drain which sees most trained specialists moving out of the country. In addition, Primary Health Care (PHC) workers need training and orientation in order to handle the challenges of mental health at their community. He promised to take up the task of ensuring that the MoH, provides training of PHC health workers in mental health to enable general hospitals, HCIV and perhaps HCIIIs and HC IIs, manage some of the simple conditions. He was optimistic that studies and findings on sub-theme on PHC of this symposium would be informative of what is going on at that level, especially management of mental health services. The ministry would be interested to know what is happening at lower levels there where most of patients seek care.

Government is addressing most of mental health challenges with Health Sector Development and Investment Plan as one of the minimum healthcare packages. A unit of the MoH which was overseeing mental health, was last year elevated to a department of non- communicable diseases. In addition, human resource, financing and infrastructure are already in place or planned for to address these and other challenges in mental health services.

Dr. Mwebesa retaliated that the theme for this national symposium provides an opportunity for the MoH to identify the research evidence that will support delivery of national mental healthcare. He informed the participants that any potential strategy and intervention should be based on evidence and requested them to align research against the national health priorities.

He was convinced that such a symposium provides strategic platforms for information sharing, and dissemination of research findings in mental healthcare and also promotes dialogue that leads to knowledge translation. He viewed this as a framework of networking among stakeholders, including researchers, regulators, policy makers and service providers at all levels. He thanked the academia for spearheading these and many other researches.

He also thanked the UPDF for their participation well knowing by the virtue of your occupational hazards they are very prone to mental health issues as a result of war related issues. You may wish to know that we have had some of our soldiers who have come back from Somalia, and then they reach here to find a number of things have not gone right, some of them families have been disorganized and end up being violent. In such cases, Uganda should also have a mechanism or a system for supporting those returnees to manage some of the stresses. This goes well with colleagues from police and prison participating in this symposium.

He urged the symposium participants to identify clear frameworks for the utilization of research findings that should lead to community responsive innovations. He emphasized that Public engagement is key for advocacy and sustained progress in order to fight stigma at community level.

Dr. Mwebesa thanked UNHRO and the consortium for Clinical Research Regulation and Ethics Capacity Development in Uganda (CREDU) for organizing the Symposium. He also thanked the EDCTP for their support. He concluded that this initiative will harmonize the efforts of the various regulatory agencies in the coordination and conduct of mental health research in this country.

Finally, Dr. Mwebesa was privileged to declare the Symposium on Mental Health care in Uganda officially opened and wished all the participants fruitful deliberations.

3.0 Key Note Address

Prof. Segane Musisi, Department of Psychiatry; School of Medicine, Makerere University College of Health Sciences delivered a Key Note address on Mental Health. He started his address by putting the participants into perspective as far as Mental Health is concerned.

He said that WHO defines health as a state of complete physical, mental and social well-being and not merely absence of disease. Then defines mental health as a subjective sense of well-being, perceived self efficacy, autonomy, competence to handle life's challenges, intergenerational dependence, self actualization of one's intellectual and emotional potential and many other things; and not merely the absence of mental disorders.

He argued that once you bring in that subjective well-being and sense of perceived self efficacy, it brings in something you cannot measure, and because of that we begin to have problems of people saying; so what are you talking about mental health?

He stated that mental health is an illness with psychological, emotional or behavioral distressing symptoms or impairment in functioning depriving one of happiness, satisfaction in personal and social relationships or fulfillment. Mental disability is a state of personal disequilibrium not allowing the individual capacity to fulfill social roles, take on responsibilities, tell right from wrong, handle frustration, cope with challenges or enjoy life.

Then pointed out that there cannot be wealth without health; can never be national wealth without national mental health? So what does mental healthcare entail he asked. The answer is prevention, treatment and rehabilitation of mental dysfunction to enhance total health of and advance wealth of individuals, and therefore families, communities and nations. He emphasized that Mental healthcare cannot be divorced from general healthcare. It should not be talked about in isolation, as that is a mistake which happened before and because of that we need to have these kinds of things always in our minds which are elusive. He enumerated 10 of them as:

All mental health ailments are treatable completely. In other words, we believe that mental health is like malaria or jiggers or something like that.

That we shall have enough psychiatrists to cover every single case in Uganda. Prof. Ndeteri says that if we aim at doing that, for the next 100 years we shall still be trying to do that, and will never succeed. That medications can eradicate all mental health problems. Some of them are just issues of existence.

He said that one the he enjoys most is that governments will listen to us because we are mental health workers.

- We have spoken and spoken, same issues, sometimes over decades.
- That we can train enough mental health workers; this is impossible.
- That mental hospitals are what is needed to treat all mental disorders. It is not possible so we have to think of something different.
- That alternative therapies never help the mentally ill; pain killers and stuff like that.
- That expatriates will understand our mental health problems better. So we first show someone from Atlanta to come to Uganda and they come and tell you, epilepsy.
- That conventional public health principals do not work in mental health
- That only mental health workers know what to do.

In such a circumstances, how do we approach mental health in order to achieve universal mental health coverage he asked. The answer is a humble approach to mental health problems by addressing the following questions. We ask ourselves these questions:

What are the mental health problems beyond the disorders like depression and stuff? What is now being done about them? What should be done? But what can be done? What cannot be done by us? Who needs to do what? Whom can we work with? What is the role of external influences in either perpetuating mental health problems? What is beyond our control? What are these global forces affecting mental health?

The approach is to conduct a SWOT analysis to be able to know that is our Strengths, Weaknesses, Opportunities and Threats. The most important thing is to know that the things we do must be sustainable. It starts going from one year to next year, and maintain its operations, services and benefits. We must know the threats to achieving universal mental health coverage.

Prof. Musisi noted that there is a colonial legacy even today regarding treatment of mental health. When the European doctors came here, Dr. Felkin from Germany in 1800s he found people here, having mental illness being treated by what we call native African doctors without prejudice or stigma. Mental illnesses enjoyed the same model as physical illnesses and they used the same approaches to treat mental illness. When Albert Cook came here, he also noted cases of mental illness but never treated them. In colonial Uganda therefore attempts were made to disregard many of our African faith including mental health and they began to demonize and deregulate traditional African systems including medicine, cultures, religions, and governance. Many of them were banned. The resolve was that it went underground. Up to now we are dealing with that problem.

He pointed out that the Guest of honor, said that people still go for traditional healers. It means that somehow, your own view of mental illness cannot be treated in hospitals. It may be witchcraft, and interestingly, the missionary hospitals that first came to this country, and are still around never had mental health units. Up to now I don't know whether the psychiatric ward in Mengo hospital or Rubaga or Kibuli, or Kitovu or Lacor hospital which has been recently built.

This dichotomization of physical illness from mental illness is a colonial legacy which is still ongoing today in many parts of Africa. And sometimes they give labels to those who don't agree with them as being mental ill.

The colonial understanding of scientific of mental illness was rudimentary and supremacist. Their idea as we are defining this was to build asylums for post lunatics and idiots. So you become ill, you are an idiot or a lunatic.

Sadly, Prof, Musisi said that this was imbedded in the Mental Health and Treatment Act of 1964, which uses those very terms; lunatics and idiots when it is actually supposed to be helping them. For the last 55 years, it has been a struggle to deal with dichotomization of physical illness from mental illness using a mental health law which is full of 'lunatics and idiots'. The only thing they did was to build centers for lunatics and idiots in Uganda starting with a prison in Masindi and later Butabika Hospital.

He wondered whether the origin of the word, Butabika was not coined from stigma. For a Luganda language speaker, Butabika has a word 'kutabuka' literally translated as being mad. Whether Butabika was the name of the place in the beginning or politically motivated one, the fact is it became part of the stigma and we are still fighting. Such are the problems that are going to bedevil the universality in care.

In short, he said colonial medicine summarily excluded psychiatry, the European doctors' pre-occupation was with treating their own, chiefs and nobility, to show them the power of their medicine but not for mental illness.

Elaborating on mental health treatment exclusion, Prof. Musisi, said that in the colonial times when the missionaries got mentally ill they were taken to Europe with a pretext that they were suffering from tropical neurasthenia and needed to rest. The idea that when you are mentally ill you need to rest; sedate aggressors is still being promoted up to now.

He pointed out that Albert Cook's first hospital in Uganda, [pointing to a picture on the power point] Mengo Hospital of 1897 had no mental facility. When this hospital was burnt for some reason not know to him and another one was built [pointing to current Albert Cook building] no mental health facility again. It was renovated and now it looks like this right now [pointing at current Mengo hospital building] no mental health unit on that hospital again.

He posed a few questions in relation to that history: So what do we do? Where do we go with psychiatry? How can we begin therefore to talk about universal coverage?

He was again saddened that as the exclusion persisted, the colonialists continued to comment on Africans' mental illness. In the 1960s, Allan wrote. "On the mile-high East African Plateau, mental illness flourishes despite little trappings of modern civilization". In other words, there is mental illness. John Orley, the Prince wrote about Africans getting distressed near exams in schools, feeling their brains were tired calling it brain fog.

Prof. Musisi views this as a big challenge to achieving universal mental healthcare. The colonial legacy is still in people's minds, it is in your minds unless you have liberated them, it is in the minds of the policy makers, it is in the minds of society, it is causing problems for us, it perpetuated into religions and traditional medicines among others.

He enumerated a number of other challenges to achieving universal mental health coverage care in Uganda. The new medical schools they are building now, and that have been there, have considered many of them, and also Mengo one, have a department of psychiatry.

The treatment of severe mental illnesses and traditional religions have continued however. Traditional healing has continued because that is the only thing that we have left.

Up till today, mental healthcare remains centralized from the only mental hospital they built at Butabika which is isolated to institutional care.

Though some regional centers have been built, the high and institutionalized mentality still persists in us. Even parliament finds it very difficult to discuss mental facts. They seem not to understand what it means by treating mental illness, locally, generally in the neighborhood. They still feel you should keep those patients isolated.

There are funding challenges from government funding and other funding agencies, but private public partnerships have also availed grants. But above all we need health insurance which must include mental healthcare.

Prof. Musisi discussed the way forward to universal mental health coverage care in Uganda.

He said in order to achieve universal mental healthcare, there is a need to brand mental illness differently. Using words that people used long ago that are less traumatized to talk about mental illness.

There is need for psychiatry of Africans by Africans for Africans. The need to understand how to assess the African way; understand the idioms; verbal expressions; somatic presentations of mental distress by our people.

The need to understand the cultural social morals of mental illness and with some of that work. The need to understand that we have syndromes that happen to be culturally bound. The case in point is mass hysteria for schools; they reported being attacked by demons. Then religious people pray for them, traditional healers and all kinds of people. What they do not understand that this is mental illness on a mass scale.

The need to fight this dichotomization of mental illness from other diseases, reduce what we call asylum psychiatry as well as reduce fight the stigma of mental illness. There is need to combat mental health illiteracy and stigma among health professionals, politicians and administrators.

The need to build psychiatric hospitals, psychiatric clinics with good conditions, rehabilitation centers, additions, chronic diseases such that when one has a mental health breakdown, he/she should be able to walk to a general hospital, a clinic and get some help there. The need to make mental health treatment that is accessible, affordable and friendly in health insurance.

The need to develop new mental health policies that integrate mental healthcare in our general healthcare, and mental health ACT to that effect. Making reference to Photographs taken from Eastern Uganda, Prof. Musisi made a case for the need for integrated services. In Soroti [pointing to a picture] a woman was very stressed, taking her convulsing child to hospital, hoping that somebody is going to help them. But as far as he knows, the whole of Eastern region does not have a psychiatrist nor a psychologist. There are some clinical officers who offer services to which people hope that they can get some help. In another photo under the tree [pointing to a group photo] there were people who were waiting for care. Pointing to the old lady holding a stick; he said these people are very distressed but they had not come for mental healthcare, they had come for other care. But by looking at them, you see depression and anguish. He concluded that the dire need is integration of psychiatric care, and changing mindset about mental health and branding it without stigma connotations. There is also need to mainstream mental healthcare from health center II all way to tertiary institutions as well as entrench mental health in all community healthcare programs, using public health principles.

The need to have a multidisciplinary training and approaches to mental healthcare, and increased funding for training and research. Many trained Psychiatrists, Psychologists, Social Workers, Nurses, Counselors and a way of engaging mental traditional healers.

The research should be integrated to deal with the most challenges that are present to us on daily basis and with this approach to reach everyone, mental health should be borne in mind. He expounded on point with an example of the little kids who go for nursery school today, or secondary school. They prep up to after 10.00PM, rest a bit then resume studies up to after 1.00PM, and then they sleep. At 4.00AM they wake up for morning preps. And then school begins at 7.00AM and they have breakfast at 10.00AM, and study all day, including the 6 days of the week, Monday to Saturday. On Sunday they will have prayer session and then start studying again. With such a situation do you expect these kids to have normal mental health?

Prof. Musisi pointed out that a number of human resource challenges persist.

In Uganda, there are only a few psychiatrists. The need is to incorporate other health care cadres by task shifting to offset the gap in human resource. For example, a midwife can deliver a baby, so can an obstetrician; but not everybody is going to be an obstetrician. Currently, every mental indication needs a psychiatrist; but we need to engage traditional mental health attendants and VHTs. If other medical professionals have engaged them; that is traditional birth attendants; nutritionists, then why not mental health? The country needs to find ways of reducing on brain drain; super-specialization in publication to support quality services and regional units to become very useful.

Prof. Musisi then turned to societal dynamics and their implications for mental health. He said it has been an age old practice for health professionals from big hospitals to come and examine pupils in primary schools of their eyes, teeth and general hygiene. More recent outreach programmes involve mobile clinics in villages, but not mobile mental health clinics and yet alcoholic abuse and suicide are rampant. The people are more depressed and stressed than ever before.

He pointed out that the population structure in Uganda has greatly changed. With about 85% of people below age 30 and 50% below the age of 15, it is absurd that there not enough mental health care units or hospitals in Uganda. There is also increased urbanization and population overgrowth but public mental health is hardly addressed and there are no actual centres to address their concerns.

He was happy to note that the armed forces had come on board. Many people in defence services are traumatized and many of them require care - in prisons, army, local defense units and the general public.

Way forward

Enumerating the way forward, Prof. Musisi acknowledged that a lot of research has been done in HIV mental healthcare, post-traumatic stress disorder care among refugees and psychiatric units/wards in general hospitals. Others are liaison psychiatry, geriatric services, child and adolescent health clinics, orphan care, mental health problems related to birthing and depression among others.

However, a key research question remains: what is driving the rising rates of mental ill health? The most common is trauma, new and emerging diseases and disasters; HIV disease, Ebola, landslides, terrorism, substance abuse, floods, famine, storms and poor service provision. The causal/associations, trauma/disasters, HIV/AIDS, poverty, childbirth, old age, adolescents and youth are known. The forces driving the high rates of mental disorders, culturally sensitive test tools/instruments, and also devise culturally sensitive therapies are also known.

There is need to do research in all aspects of mental health care to find solutions for problems, not only in diseases but the organization of care, alternative and complementary mental health workers, the mentality of our national and global factors.

There is need to integrate and streamline mental healthcare at all levels from the village, health center II up all the way so as to ensure accessibility, affordability, funding, universality, and reduced stigma.

There is need for partnership of various stakeholders, not working alone but as allies with the locals taking initiatives. The local voice should be heard in every effort so as to ensure that mental illness should not be excluded from the national health insurance scheme.

As a country, there is need to develop measures to prevent mental development distress. For example, peaceful conflict resolution not wars. In Africa there is a tendency to change leaders forcefully; usually it takes 30 to 50 years before peace is restored. How many years has it taken to get peace again in Democratic Republic of Congo (DRC) next door after removing Mobutu; and Libya after Gaddafi? In both countries forces are still fighting up to now.

There is need to combat substance use. In Kampala alcoholism is rampant, marijuana, and new ones such as kuba and shisha are causing distress.

4.0 Policy and Legal framework for mental health

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| Sub-Theme: | Policy and Legislative Framework |
| Topic: | The Mental Health Act (2018) |
| Session Chair: | Prof. Peter Olupot-Olupot, Mbale Clinical Research Institute (Mbale Regional Referral Hospital), MoH |
| Presenter: | Dr. Hafisa Lukwata, Senior Medical Officer, Mental Health Division, MoH |

Dr. Hafisa Lukwata, presented key tenets of the draft Mental Health Act. She enumerated the key objectives as:

- To establish the Uganda Mental Health Advisory Board
- To provide for mental health treatment at PHC
- To provide for emergency, involuntary, voluntary and assisted admission and treatment
- To provide for treatment of foreigners with mental illness,
- To provide for the rights of people with mental illness
- To provide for treatment of prisoners and other offenders with mental illness
- To repeal the mental treatment act and other related purposes

Dr. Lukwata enumerated the various modes of treatment and admission of persons with mental illness as provided for in the Act. She said with voluntary admission of someone with a mental illness, someone just walks in, consents to treatment and treatment is provided.

Both emergency and involuntary patient admission on the other hand are provided where those around that person, are in danger if this person is not treated. Such a patient will continue to be treated as an inpatient or outpatient from any formally established public or private facility offering mental health care services within Uganda.

The assisted admission or treatment is where it can still be voluntary but can also be involuntary. This is where someone is just helped by another person to get care. In this case the patient may or not be necessary conscious of the treatment that they are provided and may not necessarily consent to treatment.

In cases where involuntary patient care is going to be provided, the psychiatrist or other health care professional, does so beyond reasonable doubt that this person actually needs health care. The involuntary admission and treatment can only happen in a specialized mental health unit and not a primary health care centre. Emergency patients can be treated in a PHC facility for as long as they are admitted there. Other places where treatment can be sought include mental health units, general health facilities for both OPD and inpatient close to where they reside as well as in the community.

The law also provides for treatment for prisoners and other offenders with mental illness. In some instances, people get into prison because they have mental illness but it could also be that while in prison someone may develop mental illness. In such cases, a police officer on arresting someone suspected to have mental illness is required to first take them for assessment of their mental health status within 24 hours of arrest. The psychiatrist or whoever is receiving this patient should be able to decide whether they should be left at the facility or taken out of prison. Where someone was brought in prison not because of mental illness but later found out to have the illness, the prisoner should be taken to a health unit for admission and treatment the same way non-prisoners are. In circumstances where a person with known mental illness is in detention, has ever been treated and got better, the law provides that this person for as long as they are serving a term more than a year, they should be reviewed at least once a year by a psychiatrist. The police officer may use restraining measures to apprehend or arrest a person with mental illness but the law also provides for police officers to revise measures where necessary and to cater for feeding and certain types of treatments.

In the event that a patient does not consent for treatment within a PHC facility, he/she should be referred. Where someone initially had accepted to receive care, one has a right to change their mind and be referred. However, where a patient or relatives cannot consent for treatment they can either be treated as involuntary or referred to the specialized mental health unit.

The law provides for treatment of persons not ordinarily resident in Uganda. These could be outpatients or inpatients and where possible the patient should produce all previous treatment documents. Where necessary the person may have to pay for the services rendered as the services may not be free of charge all the time. In instances where the patient has to be repatriated to their country of origin, the person has to be assessed whether he/she is fit to travel and that the unit they are being referred to is ready to receive them.

There are some special treatment options that were provided for that have created a lot of debate in parliament, arguing that most of the treatments were not necessary. For example, the law allows for electroconvulsive therapy under anesthesia and where it has to be given to the patient it is considered the best option there is at the time.

- The law provided for continuous existence of seclusion rooms for patients but only in mental health units and only used when authorized by a specialist/psychiatrist. The mechanical bodily restraints are some of the things users were against, but remain necessary.
- The law provides for protection of human rights of people with mental illness.
- The person, the human dignity and privacy shall be respected. People with mental illness shall not be discriminated against on grounds of their illness. There are employers who have retired their staff because of mental illness, or where people with mental illness have been denied employment. The law states that people shouldn't be discriminated against on grounds of mental illness.
- The right to information: This is where a patient has to be told what they are suffering from, what treatments are indicated and the likely effects of care that is provided.
- The right to consent to treatment.
- The right to appeal to the board against any decision that was taken for them when they were being cared for by either by their relatives or within the health facilities.
- The right to withdraw consent for treatment. If someone does not want to continue to be treated in a certain place they can withdraw their consent and in that case, they can be referred and be treated elsewhere.
- Capacity and guardianship: A person with mental illness has the right to manage their affairs. Unlike the old law, where as long as you have unsound mind then you did not have the capacity to own the things like someone else, it is okay to manage their affairs. The person also has a right to choose a personal representative in case they are not able to manage and make decisions about his or her affairs, they can choose a person on their behalf. If not, the court shall appoint a suitable relative to be the personal representative.

However, the rights of a patient may be restricted or denied if the psychiatrist considers it to be in the patient's interest to do so. The access to information may also be denied if disclosure may seriously prejudice the patient or conduct himself or herself in a manner that may seriously prejudice their health and also the health of others.

Dr. Lukwata said the last section of the law is on protection from liability. This protects the providers, where someone commits or omits something in the care of the patient, one cannot be held liable for as long as it is in the best interest of that patient. It also provides that all deaths within a mental health unit shall be investigated and reported to the board. The law also gives the Minister powers to make regulations in consultation with the board, and be cleared by Parliament.

The law has only two (2) schedules; Schedule 1: Currency Points = 20,000. If a health worker helps a patient to escape when they are mentally unwell, there is a penalty to it and also denying any rights, there are some penalties.

There is a community treatment order; when a patient is discharged from anywhere, from any facility or any mental health unit and they need to be taken care of at the community level – then a community treatment order that has been written. The referring specialist or health worker has to fill this form for the patients as they go back to the community.

4.1 Discussion of the legal framework

Dr. David Basangwa, Executive Director, Butabika National Referral Hospital discussion centered on the Mental Health Act. He began by appreciating the submissions made by Prof. Segane most of which were about a number of good things. He emphasised that in order to achieve all that, there must be a good law in place to enhance and regulate the practices. The law he noted protects patients as well as practitioners among others.

He observed that the law that was in use had been assembled in 1964, which certainly is a long time. He further observed that the old law was enacted when most of us in this symposium were not yet born, was certainly an obsolete one that does not really address what currently needs to be done.

Dr Basangwa retaliated that the old law favored custodial care as opposed to community and clinical practice. It was devoid of community mental health care which the keynote speaker clearly elaborated. Furthermore, the law in many ways was in conflict with mental health policy that was advocating for community mental health care. In short, he said it was hostile to patients and probably most practitioners which perhaps also made mental health care a less attractive profession. The hostility extended to other things including the demeaning language used against patients, places and care. He lamented that the old law never observed the human rights of mental health patients, thus failing to realize that these are people who needed to be helped and respected.

Dr. Basangwa was happy to note that the new law as presented by Dr. Lukwata clearly observed the common guiding principles in mental health care in the country. He was optimistic that it will be able to promote mental health care and support reduction of mental illness in any community. He appealed to participants to ensure that mental health care is made more accessible and benchmark the law to increase access to care. He hoped the law would help the address issues of human rights and also support existing policy framework.

Dr. Basangwa highlighted key aspects of the Mental Health Act. He said the law puts emphasis on provision of mental health care at primary level. The provision for decentralization and integration of mental health services in general healthcare is certainly the way to go, he asserted. He expressed his gratitude to the voluntary admission legal provision that has come out to support patients to improve quality of care in the country.

He praised the importance of the Board and its associated tribunals in circumstances of conflicts with the patients. He noted that people get all kinds of disagreements; sometimes genuine or not genuine. The board therefore provides a shortcut to mitigating most of such problems. He was also happy with the provision on foreigners which will help sort out grappling with the many foreigners at the mental health referral hospital and many other places. Currently, most of people in this category assert themselves in different ways and we can fail to handle them in our setting. The provision is a very good guidance as laid out in the new law.

Dr. Basangwa called upon participants to realize that although this is a new law, the process of drafting it started way back around 2005. He cautioned that 14 years down the road some of the things considered in there may be out of date requiring review. He hoped that this may happen because after all there should always be opportunity for law reform with time.

4.2 Plenary discussion on policy and legal environment

4.2.1 Questions and comments

The presentation shared that the new law will be protecting those suffering from mental ill health. An employee should not be dismissed because one is mentally unfit or has mental illness. This, of course, is very positive. But thinking of mental situations, like alcoholism - policies of most organizations indicate that if staff is found drunk at work, one should be dismissed. Given the new law, it means that many organizations will have to review their policies. The question put to Dr. Basagwa; was if he was conducting a job interview and an individual came in drunk, would he proceed with an interview?

The second question was, are there standard definitions of mental illnesses? If one sacked from work can he/she easily go on and say that he/she suffers from depression or from a certain acceptable related mental illness.

I have a question on the Mental Health Act, is this in draft or has it gone through the official steps? Is it now an official document? Can one obtain a copy?

Listening to Dr. Lukwata and Dr. Basangwa, the Mental Health Act, is more of addressing existing health problems and ways of mitigating it, but how about some of the policies that look into prevention? Is that something to think about? Or done already? For instance, increasing suicide issues in universities and schools. Is there something that we can do to prevent other than looking at the real problem?

Dr. Lukwata was asked to clarify whether the mental health act or law provides for an interjection to the existing criminal and civil laws. A case in point, there are women who have been traumatized throughout pregnancy. By the time they give birth they throw away these children. Now the public responds by trying to stone them to death. If they are sued once taken to police, the officers in charge come to camera and say they are going to charge with cases related to intentions to loss of life. Where a mother conceives, goes through pregnancy and gives birth, and later decides at that last hour to throw away the baby that person should be taken as mental health client.

Secondly, does the law cover the abusers or the inducers of the mental health client? For example, given the above they could first ask if the father of the pregnancy was the one responsible for this stress and trauma - of what has happened. In most cases nobody asks about the man. Does the law provide to investigate the mental health problems and what course to be taken?

The first question was how can participants access the Mental Health Act?

The second was whether there is a provision for protection of employers, as far as retirement is concerned? This is because there are some professions where one might not have to compromise such as in the armed forces, where they handle firearms, where would they shift such people?

Knowing that there is always effectiveness and efficiency that depends on the mental status of a person. An institution or the government such Uganda Peoples' Defense Forces (UPDF) can only have 50,000 people and these are supposed to be effective. When not protected and the law leaves it open at the end of the day, it can overgrow but remain with only less than 10% of the people who cannot protect the country as required by the constitution.

The third issue is about linkage of this Act with other Acts. Whereas people can get physical injuries, they can also get mental injuries. Does this Act relate to say the workers' compensation Act? Assuming one gets mental problems at a place of work and it is work related does this act cover it? Unfortunately, most Acts concentrate on compensating the physically injured and leave out the mentally injured.

4.2.2 Responses

This law protects the rights of people. I think there are other laws on work environment that should deal with responsibilities in order to balance the rights and responsibilities. Where someone is really a drunkard, for that matter, then one is not conforming up their responsibility or for the standard of that organization he/she is working for. This means that one is breaking some law somewhere but as far as protecting their rights, this law says one may not have to lose their jobs simple because he/she is mentally unwell. Not all drunkards have actually mental illness. It is just a small portion of them who actually are addicted in that problem and in that case it is important to treat people even if you have to retire them as provided by the law. They should be taken to any facility because this law provides for their treatment even within PHC, even within the community for as long as long as there is a community order that has been written by the provider.

The mental health Act is still a draft. This law is not yet gazetted because there are some issues that the First Parliamentary Council found to be contrary to other laws. It was purposed to be that way because a policy spells out a little more than what the law actually writes. There are things that cannot be put in a law, like prevention. You cannot write a law around prevention, the law tries to put right something that could go wrong, or that is actually wrong.

Actually, most of the things in here are around treatment because that is where it was going wrong. The law of mental health is actually guided by the policy on Mental, Neurological and Substance Abuse. The policy is actually very comprehensive and covers epilepsy, drug abuse and many other things and not only mental disorders as it was before.

The law does not provide for a mother who dumps her new born baby or even murder may not be charged criminally as long as she has a diagnosis of mental disorder, she may be treated in another way. Just like all those who commit suicide or homicide, as long as they have mental illness their charge is different. That is why there is a provision for prisoners who have mental illness.

The UPDF Act and the Police Act and so many other Acts where they require people who may be mentally unwell are protected in there. The Mental Health Act takes care of the general public. Like if someone is working in the Ministry of Health or Public Service instead of retiring they may be requisitioned in another place where they can work best. That is the first principle. People should be put where they can work best. If they feel they cannot be employed anymore I think that is where the board has also to help with some of these complaints.

There are so many linkages with this law and other laws. It has actually been found out that quite a number of other laws may have to be amended. This could be one of the issues that the Parliamentary Council is having issues with. This law is most recent then it changes the way the other laws were being implemented and I think they have to adopt this new change since it is a national requirement and that is likely happen to some of the laws in Uganda.

5.0 Primary Health Care: Knowledge and Practices

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| Sub-Theme: | Mental Health Services (Primary Health Care) |
| Topic: | Integrating mental health into primary care in a low income country: evaluating impacts of a district-level mental health care plan on treatment coverage, detection and individual outcomes in Uganda. |
| Session Chair: | Prof. Peter Olupot-Olupot, Mbale Clinical Research Institute (Mbale Regional Referral Hospital), MoH |
| Presenter: | Dr. Juliet Nakku, Deputy Executive Director, Butabika National Referral Hospital |

Dr. Juliet Nakku, presented research work on *‘Integrating mental health into primary care in a low income country: evaluating impacts of a district-level mental health care plan on treatment coverage, detection and individual outcomes in Uganda’*. She reported that Butabika Hospital has been working towards integrating mental health into Primary Health Care (PHC) to address rising mental illness and the wide treatment gap (difference between those that need care and don’t get it) as well as the WHO recommendation of integrating mental health care in primary care. The study was supported by the MoH, WHO and other partners to look at how this can be done, and the likely impact.

She reported that the MoH included mental health services in the minimum healthcare package having realized that it needs to be provided at all levels of care. However, what was not known both at the national and district levels was exactly how this integration was to be done and whether it can even happen.

They developed an intervention called minimum mental healthcare plan. The districts through a theory of change process, held workshops with all stakeholders to determine what the problems were and what needed to be done, what strategies could be employed, what to focus on, how to evaluate and indicators that need to be used. The district mental healthcare plan addressed 3 levels of care of the health system; the health organizational level, the health facility level, and the community level. Specifically, at the facility level, training using WHO mhGAP for PHC workers was conducted to help them learn how to assess, diagnose and treat common mental disorders. They were allowed to detect, treat and later an assessment made known the outcome. At the community level, the focus was on sensitization and prevention of stigma programs as well as providing support in the community through support groups.

When the study was completed, an impact evaluation of the mental healthcare plan on change called ‘contact coverage’ was carried out to ascertain how many of the people diagnosed with a mental illness should go ahead to contact PHC providers. Evaluation of change in detection of priority mental disorders was also undertaken. In other words, for those PHC workers trained in mhGAP guidelines to identify mental disorder, detected what was the change over time in detection.

An evaluation of change in individual symptom severity and functional disability in the patients who were treated was also carried out. Using surveys: Community baseline and end line surveys 3 months apart were conducted to identify patients with depression and alcohol use disorder. Using selected disorders common in the community an assessment was conducted at the end of the study to see how many of those at baseline also contacted a PHC worker and then at end line, how many of those contacted a PHC worker.

The facility was surveyed to see how many of those patients could be detected with depression and alcohol use disorder by the trained PHC workers at baseline 3 months after training and then at end line. She also reported that a study with different cohorts for depression, psychosis and epilepsy was conducted to see what happens to the patients who are detected and treated by the PHC workers. The issues to address were: What happens? Do they improve? In all cases, the study was dealing with only adults.

She said that findings showed that contact coverage at baseline was 16.5% of those diagnosed with depression and contacted a PHC worker while at end line, proportion had gone up slightly to 19.4%, a change of about 4 points that was not statistically significant.

For alcohol use disorder, nobody was diagnosed with alcohol use disorder contacted a PHC worker at baseline, at end line, there was only a small percentage of 1.3%. And again, there was no one who contacted a PHC worker.

At the facility level through the facility detection baseline survey, PHC workers detected only 4.2% of those that had been diagnosed as having depression. The 4.2% was before training and 3 months after training they detected 12.7%.

The identified patients were recruited into treatment cohorts in order for the PHC to start treating them. The patients were assessed at baseline, midline 3-6 months depending on the disorder; (depression for 3 months, psychosis was 6 months) and at end line. At baseline the average score PH score for depression was 16.3 quite high, dropped significantly to 6.4, but at end line. Even functional disability, psychosis as well as that of epilepsy was significant.

She reported that the impact of implementing the mental healthcare plan on population with contact coverage was small for depression and alcohol use disorder, the common mental disorders. This she said were most likely affected by very many reasons that are personal or systemic. It could depend on the illness, the severity of the illness, why one decides to go to a facility or to pursue suitability of the care provided. She noted that people who have mental disorders always tend to seek services at a health facility other than a health worker near them which affects contact with such provider. Other sources of support such as traditional healers who were very many preferences for individual patients in the study are affects contact coverage. However mental healthcare plan is feasible framework to work within the districts when supported with regular supervision and ongoing training because of high rates of attrition

The care units in clinical detection were also not sustained due to decay of knowledge and skills, attrition within the health facility where trained people are transferred, patients move quite a lot. There is also much change in the PHC environment that is extremely dynamic such that what is done today is unlikely to be available 3 months down the road.

The alcohol disorder is not viewed as a health condition in the population to require medical treatment such that they patients don't turn up to the health facility. The question then is since people who mainly have alcohol disorders do not turn up at the health facility, is it possible to achieve coverage for treatment of alcohol disorders in a PHC facility?

Dr Nakku enumerated a number of challenges. The system readiness was constrained by low staffing levels a common problem well known to most of you. Mental health is quite intense and that health workers dedicate time, where you have very few staff who are seeing mothers who are pregnant it also becomes problematic. Others are high attrition from the health facility, heavy workloads, interest and poor attitude even for trained health workers not interested and irregular supply of medication as well as mental health illiteracy.

Last but not least, there are no set of national targets and outcomes being monitored for mental health. There is need to look at these because if they are not there people will not collect any data because no one is going to give it.

In conclusion, Dr. Nakku said that there is evidence that mental conditions can be successfully treated by trained PHC workers, as seen in the cohorts. However, training and consistent supervision are required to sustain the skills, protection of patients and treatment.

Dr. Nakku said the study recommended that:

- There is a need to review the health system to accommodate integration especially for chronic mental disorders.
- There is a need to scale up of integration of mental health within primary healthcare and other districts take it up.
- There is a need to deal with mental health literacy in the community to increase demand and therefore improve contact coverage.
- Systemic issues need to be worked to address low staffing levels and heavy workloads among others.
- Specific national indicators need to be developed to monitor the mental health of populations.

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| Sub-Theme: | Mental Health Services (Primary Health Care) |
| Topic: | Effectiveness and cost-effectiveness of group support psychotherapy delivered by Trained Lay Health Workers for Depression treatment among people with HIV in Uganda. |
| Session Chair: | Prof. Peter Olupot-Olupot, Mbale Clinical Research Institute (Mbale Regional Referral Hospital), MoH |
| Presenter: | Dr. Etheldreda Nakimuli-Mpungu, Senior Lecturer, Department of Psychiatry, School of Medicine, Makerere University |

Dr. Etheldreda Nakimuli-Mpungu presented the *innovative, culture and sensitive support group psychotherapy* that was developed to be used as a first line of treatment to manage mild depression. She reported that depression affects over 350 million people worldwide and 8 out of 10 affected people are living in resource poor countries like Uganda.

The goal of the intervention was to address depression as early as possible so as prevent certain individuals progressing into severe depression which has several complications.

Dr. Nakimuli, said she was presenting results from a large trial that was conducted in northern Uganda in the districts of Pader, Gulu and Kitgum. The focus was on assessing the effectiveness and cost-effectiveness of group support psychotherapy delivered by lay health workers to address depression which is the commonest mental health problem. The target population for this trial were special populations like persons living with HIV/AIDS, where 1 in 3 persons have been found to have significant depression which appears with the HIV outcome.

Dr. Nakimuli elaborated that depression has negative public health implications. For example, in HIV care it leads to a reduction in engagement with HIV care services, leads to poor adherence to treatment, poor response to HIV therapy and therefore increases the likelihood of transmitting the HIV virus. She noted that HIV care has an elaborate system of care, however it did neglect mental health of persons living with HIV/AIDS.

The group support psychotherapy was developed basically for counseling. Why a group approach? Because the patients are so many and the mental health counselors are so few. In order for people to access this service a group approach was seen to be better than an individual approach. In short she explained that group support psychotherapy treat depression by enhancing social and emotional support, ability to practice positive coping skills as well as income generating skills. She emphasized that property is a potent risk factor for depression.

She reported that the therapy was composed of 8 sessions delivered once a week for 8 weeks. In the first session the group members get to know each other. The second week they learn what depression is and the relationship with HIV/AIDS. In the third and fourth session they share their personal problems things that they had never spoken to anyone about while, in sessions 5 and 6 they are taught various coping skills. Finally, in the 7 and 8 session they are taught income generating skills.

In order to deliver the therapy to people who need it, health workers to train at the health centers were trained. This started by identifying health centers which have HIV clinics and then requested center managers to nominate 4 health workers; 2 males and 2 females who will be trained on how to deliver this intervention.

Step 1 was where health workers, working in the HIV clinic were trained. After training they go back to their centers and identify the lay health workers sometime known as community health extension workers or VHTs who are affiliated to that health center. They in turn train these lay health workers who thereafter are able to give the group psychotherapy in the villages.

The intervention covered a total of 30 health centers. In the evaluation 15 centers delivered group psychotherapy and 15 centers delivered control intervention which was group HIV education. Since the evaluation ended, every health center has been trained to deliver group psychotherapy. There are now health workers in the villages who convene these groups and are able to treat people with mild depression.

Dr Nakimuli said there have been lessons learned based on feedback on every session by group facilitators and focus group discussions conducted with the participants after the sessions. It was learnt that participants acquired the knowledge and the skills given to them and start to practice in their daily life.

More interesting, most of them said they were going back to their villages to help the other people who had the same problem. This is connecting with each other, drawing from the experience when they were brought together when they didn't know each other but were able to connect and work together. They formed social connections, their social support increased, they know how to cope with problems and they learnt income generating skills. All these lead to reduction in depression, their economic well being improved, adherence to medication is better, and so was reduction in their alcohol intake.

Dr Nakimuli, elaborating the results of the trial using photos and graphs reported that the group psychotherapy had a greater reduction in their depression and was maintained over 12 months. While the control group much as they seem to appear to improve their functioning goes down in the long term. The completion rates for these 2 group sessions is almost 80%. So this shows that this is an integration that resonates with the community.

The attrition rates for the group therapies were much lower compared to the control group. The secondary outcomes, were pleasantly surprising with post traumatic stress symptoms improved in these participants; but greater in persons who were receiving group psychotherapy. Stigma appears to go down during the interventions for both groups but in the long term, stigma is sustained in those who received group psychotherapy. The impact on ART adherence, show improvement in both groups with the psychotherapy group having an upper hand. There was also improvement in the viral suppression in both groups, with the improvement greater in the group therapy, however the difference between the 2 groups was not statistically significant.

The assessment of the cost effectiveness of the intervention revealed the most important outcome, effectiveness ratio at 11.4\$. This means in layman's language that to avert one year of disability you have to spend 11.4\$ using the group therapy. Whereas if you use the control group, you need 22.8\$, double of the group therapy making the group therapy more cost effective.

Turning to the implications for the group therapy; Dr. Nakimuli reported that first of all other than reducing the depression and other emotions, it is having an impact on the social economic status (SES) index of this population into 5 categories.

Enumerating the 5 categories, Dr Nakimuli said at baseline the proportion in the lowest SES was almost comparable, but 12 months later, those who received therapy, are very few people in that category. Whereas in the control group people in that low SES increased. This means that the group therapy is able to push people out of the low social economic status into the higher categories.

In conclusion, Dr. Nakimuli said that it is possible to integrate Group Therapy for depression treatment into existing HIV care platforms. It is also possible to engage men in HIV treatment services; the intervention happens to be the first trial to have the largest number of males, attending counselling intervention. It means it can bring in more men into the HIV treatment services, since it is known that attendance for males is quite low.

On the way forward, she said, there was need to extend the group therapy among others, especially young people. This is because in the study of health centres, 60% of young people initiating ART are failing to suppress the virus. As a result, we have attracted funding for doing that in the near future.

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| Sub-Theme: | Mental Health Services (Primary Health Care) |
| Topic: | Service user involvement in global mental health: what have we learned from recent research in low and middle-income countries? |
| Session Chair: | Prof. Peter Olupot-Olupot, Mbale Clinical Research Institute (Mbale Regional Referral Hospital), MoH |
| Presenter: | Dr. Richard Mpango, Clinical Psychologist/Research scientist/Post Doctorate Fellow, Butabika national Psychiatric hospital, MRC/UVRI and LSHTM, Uganda Research Unit |

Dr. Richard Mpango presented research results on *Service User involvement in global mental health in low and middle-income countries*. He reported that Global mental health is undergoing a 'transformational shift' and have an ethos of 'nothing about us without us' in 2016 Lancet commission on global mental health and sustainable development. There is an apparent contradiction between the transformational shift, nothing about us without us, with what professionals do in most of their work where users are less involved. Service-user involvement, he said is a 'fundamental, rights-based component of the ethos of mental health-care provision and research.

The field of global mental health is under scrutiny for a relative lack of involvement of people with lived experience of mental health conditions in low and middle-income countries (LMICs), compared to efforts made in high-income countries. This he said leads to a question, *to what extent the principle of 'nothing about us without us' is reflected in the literature on global mental health in low and middle income countries?*

Dr. Mpango said that a systematic review published in 2016 as part of the Emerald Project *Emerging Mental Health Systems in Lmics Programme* identified 20 articles reporting on user experiences of involving service users and caregivers in mental health systems strengthening in low and middle income countries. However, most articles reported on the involvement of service users and caregivers as research subjects, not as direct participants, not as equal partners in policy or service development, delivery of services or training of service providers, or the actual conduct of research.

A rapid review was conducted of the academic literature published between June 2017 and December 2018, applying search terms from Emerald's 2016 review across eight electronic databases: Medline, Embase, PsycINFO, Web of Science, LILACS, ScIELO, Global Health and the Cochrane Database of Systematic Reviews. All these included primary research conducted in LMICs using any kind of study design, as long as it reported on the involvement of people with mental, neurological, or substance use conditions in mental health policy, services or research

Out of the 765 identified texts, removed 677 texts, not from LMICs, more had to be removed; those which were not focusing on mental health ending up with 10 texts in this rapid review.

The rapid review search returned 10 studies from nine countries across Asia (China, India, Malaysia, and Nepal), Africa (Ethiopia, Nigeria, South Africa, Uganda) and Europe (Lithuania). The majority of included studies were qualitative and conducted as part of a situational analysis or part of the pilot study or other formative research. The three of the studies reported on user involvement in mental health policy and planning; three on user involvement in mental health services or capacity-building of service providers and three on user involvement in treatment decisions. One study involved users in data collection.

He further said that Emerald consortium research in six LMICs (Ethiopia, India, Nepal, Nigeria, South Africa and Uganda) recently published country specific and cross-country qualitative studies reporting on the state of user and caregiver involvement in mental health system strengthening. The team reviewed those which were involved in mental health policy and planning. These studies were qualitative, some were specifics, some were broad and had to look at additional labels like at what time were they involved; coverage (national, regional or district-level) and were users in mental health policy or planning.

Turning to the results, Dr. Mpango reported that with exception of India, there was lack of involvement of some issues, across all the countries. Lack of service user participation was identified across all six countries, with the general uncertainty on how to engage and involve service users? While many stakeholders in Ethiopia, Nepal and Nigeria recognise its importance, user involvement remains extremely limited and often appears tokenistic. It was found out that they talk about it in books and/or write about it. They talk about task sharing and task shifting but in the actual practice do not focus on it.

For example, he said that in Ethiopia, district health officials and heads of government recognise mental health facilities and more receptive to the idea of user involvement in less strategic activities, such as awareness-raising and service development, but not ready to involve them in policy or planning.

They also looked at an innovative peer support programme in China which is the first formal peer support program, recruited users as peer providers; these peer providers lead group sessions with service users focused on developing key skills (daily life skills, social skills and fine motor skills), promoting emotional well being (emotional support, self-image) and providing health education (mental health literacy and healthy lifestyle) as well as entertainment. Peer providers were recruited, trained and supervised by mental healthcare providers, and sessions were held in community-based health facilities such as rehabilitation centres and health centres. This is one of very few examples of formal peer support being delivered in a LMIC

He reported that the limitations for this study were; outcomes were self-evaluated at a single time-point, with no comparison group, in response to a series of yes/no questions that leave little room for nuance in participants' responses. More rigorous evaluation is needed.

A cluster-randomized trial focused on reducing stigma co-facilitated training delivered alongside other mhGAP (mental health Gap Action Programme) training modules in Nepal as part of the reducing stigma among healthcare providers to improve mental health services (RESHAPE) pilot study. RESHAPE used participatory research methods such as Photovoice, which helped participants shape a personal narrative through photography, to address stigmatising attitudes of care providers. This was a successful program focused on capacity building.

Caregiver involvement were adopted as best practice in the conduct of any anti-stigma interventions involving users in this setting; in Ethiopia, focus was upon the roles of caregivers in facilitating users' involvement in RESHAPE.

Three qualitative studies in Malaysia, Ethiopia and Lithuania reported on user involvement in decision-making regarding their treatment. All three studies describe hierarchical relationships between service providers and users in which providers' expert opinions generally prevail. These studies recommended providing more accessible information on treatment options to improve user involvement in decision-making.

He said, some countries were in the process of transition 'from a traditional 'paternalistic' model of clinical decision making into a current 'informed' decision making model; In Malaysia, there was formative research informing the development of a tool for shared decision-making in the treatment of major depression. In Ethiopia, there was a prevailing culture of collectivist decision-making that results in caregivers often taking responsibility for treatment decisions.

However, Users' roles in decision-making are limited and may also be mediated by social and economic factors, such as sex and poverty.

In Lithuania, a scarcity of human resources for mental health has translated into a predominantly biomedical approach to care. Psychotherapy is rarely available and therefore not presented as a treatment option. Those who can afford it may turn to the private sector for psychotherapy. Those who cannot, must make do with medication alone.

Overreliance on medication contributes to the 'passive position of the patient', due in part to the potentially debilitating effects of over-medication. Psychotherapy requires the user to take a more active role in the treatment process. In this context, the limited number of treatment options available not only diminishes the user's opportunity to exercise choice, but also reinforces the user's 'passive position. Overmedication and potentially debilitating side-effects of some psychotropic drugs can impede meaningful participation.

Providing a wider variety of treatment options, including non-pharmaceutical options, and more information about these options, for example by using a shared decision-making tool, as in Malaysia or engaging community-based rehabilitation workers in treatment planning, as in Ethiopia may be steps in the right direction. However, these interventions are still at the early stages of development and piloting; their effectiveness in improving involvement in decision-making has not yet been demonstrated. None of the studies included in this review clearly reported involvement of service users in any capacity building other than as research subjects.

Three of 11 data collectors involved in a survey on psychosocial disabilities and barriers to participation in North India were identified as people with disabilities. Some of these data collectors had psychosocial disabilities, although this was not apparent from the study text.

For many years, the field of global mental health has focused on narrowing the 'treatment gap' in LMICs as one of its central concerns.

Although studies from Ethiopia, Nepal and Nigeria mention improving access to affordable treatment as an important strategy to help lift barriers to involvement, the case of Lithuania reminds us that the kind of treatment matters. Psychosocial interventions like self-help groups in India and peer support in China can help empower users to take charge of their own recovery, while supporting others. However, the potentially transformative effects of this shift are not yet being felt by most users in LMICs.

Dr. Mpango noted that most of the studies included in this review highlight the importance of resource limitations as crucial barriers to meaningful participation. What does shared decision-making really mean in a community in which there are virtually no affordable treatment options available he asked?

Dr. Mpango concluded that if the field of global mental health is going to make the principle of 'nothing about us without us' a fundamental component of its ethos, then this principle must be extended to request governments and development partners to increase the resources for mental health in LMICs.

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| Sub-Theme: | Mental Health Services (Primary Health Care) |
| Topic: | Assessment of Alzheimer's Disease and its Related Dementias (ADRD): perceived training needs of Primary Healthcare Providers in Rural South Western Uganda |
| Session Chair: | Prof. Peter Olupot-Olupot, Mbale Clinical Research Institute (Mbale Regional Referral Hospital), MoH |
| Presenter: | Ms Clara Atuhaire, Research Fellow, Mbarara Alzheimers and Related Dementias (ARD) Research Initiative Mbarara University |

Ms Clara Atuhaire presented partial results of a descriptive study which set out to ascertain what propaedeutics health workers know about Alzheimers disease. The study collected data from PHC providers using a qualitative tool of the needs assessment.

Ms Clara Atuhaire said that Alzheimers disease is leading for years among the aged linked with disability. She reported that Worldwide, around 47 million people have alzheimers disease and dementias of which 58% are living in low and middle income countries. She lamented that 58% is likely to multiply in the next 20 years, where most healthcare systems are not prepared to handle the burden that comes with caring for the elderly.

In the African setting dementias is regarded as the normal aging process where as part of aging all grow old and all forget once in a while. Consequently, there is no preparation, there is scanty information available for the healthcare system to be able to handle the aged when they go to health facilities more particularly in Primary Health Care (PHC) setting.

Ms Clara Atuhaire reported that the study set out to conduct an assessment of the capacity of primary healthcare workers' ability to recognize, manage and diagnose alzheimers disease. Secondly assess the training needs of PHC providers in recognizing, managing and referring people with ADRD and then pilot a tailored short course to address the identified gaps.

She enumerated the study specific objectives as:

- 1 a) To identify the knowledge gaps faced by PHC providers in recognizing, managing and referring people with ADRD
- b) To analyse the specific areas in which more knowledge is required by the PHC providers in relation to recognizing, managing and referring people with ADRD
- 2) To develop and pilot a tailored short course to address the PHC provider gaps in recognizing, managing and referring people with ADRD. This was a pilot training module for the health workers to account for a difference between before and after the training.

The study conducted a total of 49 In-depth Interviews from 7 HCIIIs and 7 HC IVs. This covered 2 Medical Officers, 9 Nursing Officers, 10 Medical Clinical Officers, 3 Psychiatric Nurses, 8 Midwives, and 17 Enrolled Nurses.

She reported that the first part of the study has been completed and was in the process of working in partnership with the psychiatrists to develop the training manual based on the identified gaps. Consequently, she said her presentation was based on the results of first aspects of the study, the knowledge gaps in relation to recognizing, managing and referring people with ADRD that existed among study PHC workers.

The study results showed that one of the major issue was limited awareness about dementia. For example one of the clinical officers when asked whether she was able to identify someone who has alzheimers disease. She answered, 'do I even know alzheimers disease? The Clinical Officer further said that when patients come, they treat other problems including; neuropathy, high blood pressure but not dementia.

The other element was the fact that there was inadequate knowledge about dementia. In the healthcare setting they indicated that they were 25 diseases that require focusing on and dementia is not one of them. They also reported that when trained and retrained, it is not something that comes up, and if something does not come up consistently, he said they don't focus on it. They reasoned that, the inadequate knowledge is not failure to focus on it but because of the systems in which they work continually focuses on other ailments means the knowledge and skill they would otherwise accumulate on dementia just doesn't hold.

She reported that another health worker said that, 'generally, they take dementia to be a simple disease, they don't take it as a serious problem. But if people could get to know more about it, perhaps we can take it seriously. And if they can get to know where to refer, it would help, because as PHC health workers, we think that a psychiatric disease is referred when someone is boxing people or when they have to be tied with ropes (restrained), but for someone who is just forgetting things and you refer them (says this laughing), they do not take you seriously when they see such a referral.

Ms Clara Atuhaire reported that there was also the element of lack of diagnostic skills. The PHC health workers were unable to diagnose dementia from the other illnesses. This has to do with the fact that there is no provision for handling the elderly at the health center IIIs and HC IVs. In this regard the health workers are not confident of their ability to diagnose dementia in the elderly, because it is not a disease they focus on in the PHC setting.

The issue of lack of sufficient knowledge on diagnosis of dementia cuts across many settings. Referring to an Italian study, she said it is something that is recurring amongst the general practitioners, an equivalent to Uganda's private care system here. She also realized that even the referral system was not streamlined as most of the patients were reported to be lost at OPD simply because of the screening and triage. In the event that a patient is thought not to have alzheimer's, he/she will be withdrawn at that level and asked to go back to the community and eventually get stigmatized by the system.

Ms Clara Atuhaire, based on the partial results of the study recommended that:

- Professional training for PHC workers to manage dementia should be organized and delivered.
- IEC materials and information desks to raise awareness best set up at PHC facilities
- Create space at our HCIIIs and HC IVs for meeting medical needs of the elderly
- Set up a referral system for managing dementia.
- Explore the possibility of establishing a community-based dementia management team that includes specialists and community health workers (CHWs) identify right in homes and communities outside a healthcare setting.

Ms Clara Atuhaire acknowledged that the research was conducted in PHC system whose one of the limitations, is that it may not be applicable to private hospitals where they may have more resources and focus on the care for the elderly. Their practices and ability to recognize manage and refer people with Alzheimer's disease and related dementia and their capacity to assess and give a right diagnosis might be better than in the public health system.

5.1 Plenary on Mental Health Care Knowledge and Practices

5.1.1 Questions and comments

Dr. Nakimuli on findings of the randomized trial. First of all, how did you control for extreme variables or contamination in your randomized trial? Secondly, why did you choose to use lay health workers, and not psychotherapists or trained counselors and what impact did this have on your findings?

It was a commendable study, very interesting with high level of evidence for an RCT. Dr Nakimuli was asked if she ever thought of how to integrate this teaching in clinical care, despite the question about extreme variable.

The question to Dr. Nakimuli was on the composition of the group. Was it strictly for HIV positive or it also caters for those who are not positive but they are close like a spouse, caregivers? Because they could have a strong influence on the mental life of the patient and themselves can also be depressed by the treatment.

Referring to the New Vision, like a week ago there was a testimony by somebody who is HIV positive called Barbara Kemigisa. She reported that she was sexually abused when she was young, and because of the trauma, she had grown up to become a sex addict which is a testimony similar to so many sex workers. They are people who are traumatized as children they grow up to have risk behavior.

Dr. Nakimuli's presentation, hinted on the findings which are positive even for clients who had post traumatic stress disorders. Can you give statistics how significant this was? That people with post traumatic stress disorders were helped?

5.1.2 Responses

The question on the control for contamination by conducting a cluster randomized trial. A cluster of health centers deliver the group therapy and another cluster of health centers deliver a control group. These health centers were quite a distance from each other such that participants were unable to discuss what was going on. Using a cluster randomized trial, such that if you are in a given health center, you are getting one intervention and because of the distance between the health centers the people in the GHE don't know what takes place in these other centers.

The next question is; how do we control extraneous factors that could explain the outcome. The control group is designed the same way as the intervention. Meaning that it was also a group intervention, where people met once a week for 8 weeks, but they were being taught HIV education. That means that in both arms the group dynamics that came out during the group meeting were taking place in both arms. Both arms were enjoying the facilities of a group facilitator. Therefore, the effect seen is due to the active ingredients of the group therapy, which is enhancing emotional support, teaching positive coping skills and income generating skills.

The next question on why use lay health workers not psychologists. Again this goes back to the human resource; there are very few mental health professionals. Imagine these were over 60 groups for intervention and 60 for control. Are there many psychologists in Pader, Kitgum and Gulu? No, actually the global mental health movement, is advocating for this type of task shifting so that people can access care.

One should be able to access care in the locality when your depression symptoms are still mild so that they can be averted and avoid development of severe depression. Whereby training the lay health workers, they actually deliver this counseling in their local language. They actually resonate more with the people in the community because they live among them and they are able to see that it has a positive effect.

The integrating support psychotherapy to our teaching, is going to happen in the near future once they are convinced and the evidence is available since this is a viable counseling in a sensitive way which can push back depression.

This trial involved only HIV positive individuals. We decided to go for the HIV positive individuals because it is the most vulnerable population. Where there is an elaborate service but which is lacking in integration of mental health care. So we didn't include persons who do not have HIV/ AIDS.

The question about the young lady who appeared in the New Vision newspaper who is HIV positive with the history of sexual abuse. Yes, child sexual trauma is associated with an onset of mental health problems especially depression and untreated depression leads to HIV risk behaviors.

The group therapy, session 3&4 focuses on people sharing the most difficult personal things that have happened to them which they don't have a chance to talk about. These were the 2 popular sessions in this therapy where people find that they now have a chance to say something they had never been able to say. This was very much resonated with the group participants and wanted to go on and on even at session 5&6, expressing what their problems were. When followed up you able to see that actually this is a therapeutic thing to be able to bring out those difficult things that happened to you instead of holding it within which is a positive impact.

6.0 Secondary/Tertiary Health Care: Knowledge and Practices

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| Sub-Theme: | Mental Health Services (Secondary/Tertiary Health Care) |
| Topic: | Rates, types and co-occurrence of psychiatric disorders among HIV infected youth in Uganda: Implications for service development |
| Session Chair: | Dr. Sam Okware, Director General, UNHRO |
| Presenter: | Prof. Eugene Kinyanda, Researcher, MRC/UVRI, London School of Hygiene and Tropical Medicine UK |

Prof. Eugene Kinyanda presented *Rates, types and co-occurrence of psychiatric disorders among HIV infected youth in Uganda: Implications for service development*. He said that 5.8 million children and young people (aged 0-24 years) live with HIV in sub-Saharan Africa, and these children and adolescents with HIV (CA-HIV) are at risk of developing emotional and behavioral problems. In 2015, the WHO called for the integration of mental health into HIV care, and despite this, majority of HIV care services in sub-Saharan Africa still lack mental health care, partly due to the lack of contextually relevant data to inform policy. Western studies have reported rates of emotional and behavioral problems of 25 to 38%, rates of psychiatric disorders between 17 to 60.2%. African studies reported rates of emotional and behavioral problems of 9 to 63%. A study done in Nairobi, Kenya and the only one African study to report on psychiatric disorders among Children Associated with HIV reported a rate of 48.8%.

This study reported by Prof. Kinyanda was done together with Prof. Musisi, had its objectives as:

- Prevalence of emotional and behavioral problems (EBP) (including psychiatric disorder) among HIV infected children and adolescents attending CHAKA study sites,
- Social and clinical determinants of EBP among HIV infected children and adolescents attending CHAKA study sites, and
- Comorbidity between emotional and behavioral problems among HIV infected children and adolescents attending CHAKA study sites.

This study was undertaken in 2014-2016, under the MRC/DFID African Leadership Award funded study entitled, 'Mental health among HIV infected Children and Adolescents in Kampala and Masaka, Uganda' under the CHAKA study. This was a longitudinal cohort study involving 1,339 children and adolescents caregivers, who were recruited from 5 HIV care facilities 2 urban, 3 rural, and today this is the biggest study in this area. It was undertaken over 12 months follow up, had 3 assessments: baseline, 6-months and 12 months. The Psychiatric disorders were assessed using, a caregiver reported Child and Adolescent Symptom Inventory-5 (CASI-5) and the youth self-reported, Youth Inventory-4R (YI-4R)

The characteristics of the respondents were; almost 3 or 4 proportions from both urban and rural areas, and females were slightly more 52.2%, majority among religions are Christians at 79%. What is important to note is that only ¼ of children live with both parents, the rest were living with either single parents or grandparents. Then also, ½ of the children were either single parent or double parent orphans.

The highest level of education 71% were in primary level and the majority around 90% of the children were in reasonable physical health, they had CD4 counts 350 and above. And in line with the policy of the ministry 95% of these children were on ART.

Looking at psychiatric disorders about 17.4% had at least one psychiatric disorder by GS5 criteria. And these psychiatric disorders can broadly be sub-divided into 2 groups; behavioral and emotional disorders. 9.6% had at least one behavioral disorder and the most prevalence behavioral disorder was attention deficit hyperactivity disorder. 11.5% had at least one emotional disorder and most prevalent was the anxiety disorder at 9%.

Looking at the risk factors, there were study sites, sex of a child, age group, and tribe of a child. For behavioral disorders only the sex of a child and age group were significant among these variables and more disorders were reported among the males and adolescents than the other categories. Among the emotional disorders it was only age with more disorders and higher rates among the adolescents and children. And by adolescents, these are children who are between 11 – 17 years. And children refers to those who are between 5 and 11 years.

On who the child was living with, orphan-hood, education level, none of these factors was associated with either behavioral or emotional disorders. For the social development status, CD4 counts of the children on ART and caregiver education, it was only caregiver education which was significant among the emotional disorders and not in the behavioral disorders.

The study also looked at the psychiatric comorbidity and among the children who had at least one behavioral disorder 33% they also had comorbidity emotional disorder. And among children who had any emotional disorder, 24% had comorbidity behavioral disorder.

In summary the children and adolescents in this study had suffered considerable family loss, with about half of them being orphaned and only a quarter living with both biological parents.

Children and Adolescents affected with HIV were in relatively good physical health with the majority with CD4 counts greater than 350 cells/ μ L. In line with WHO guidelines, majority (95%) were already initiated on ART. About a fifth (17.4%) of the Children and adolescents in this study had a psychiatric disorder, and psychiatric symptomatology.

Apart from age (both emotional and behavioral disorders), sex (only behavioral disorders) and caregiver educational attainment (only significant for emotional disorders), all other investigated social and clinical factors were not associated with emotional or behavioral problems. There was significant comorbidity between emotional and behavioral problems in this study. Anxiety problems were the most prevalent diagnostic category and most reported emotional disorder in this study with a similar preponderance reported by other authors in Kenya by Kamau and in the USA by Mellins.

The most frequently reported behavioral problem was ADHD with a similar patterns having previously been reported in both Kenya by Kamau and in the USA by Gadow. About 4% of the participants in this study had a major depressive disorder (MDD). In the USA study where similar assessment instruments were used, a rate of MDD of 2% was reported (Gadow). African studies have reported varied rates of MDD ranging between 2% to 17.8% (Vreeman et al, 2015; Kamau).

The observation of lower rates of behavioral problems among females compared to males has previously been reported by Mellins and colleagues in their USA study and observed higher rates of both behavioral and emotional disorders among adolescents than among children has previously been reported by Mellins and colleagues who reported that older youth were more likely to report mood and behavioral disorders compared to younger youth.

In this study, there is no ready explanation why Children and Adolescents affected with-HIV whose caregivers has higher educational attainment should report higher rates of emotional disorders than those Children and Adolescents with caregiver of lower educational attainment. One possible explanation would be that more educated caregivers were better able to recognise psychiatric symptomatology among their Children and adolescents than less educated caregivers.

In this study, all other investigated socio-demographic and clinical factors were not significantly associated with any disorder category, similar results were reported by Mellins and colleagues (2012) in their study in the USA. In this study, about a quarter of CA-HIV with 'at least one emotional disorder' also had a comorbid behavioral disorders with slightly higher rates reported among children than among adolescents. Similarly, about a third of the CA-HIV with 'at least one behavioral disorder' had a comorbid emotional disorder with higher rates reported among adolescents than among children. Studies undertaken in both Kenya (Kamau) and the USA (Mellins) have reported rates of psychiatric comorbidity among CA-HIV of between 26-44%.

Given considerable burden, there is an urgent need to integrate mental health services into routine HIV care of CA-HIV in sub-Saharan Africa. Children and adolescents have a broad spectrum of psychopathology which spanned both emotional and behavioural problems, and therefore interventions should be broad based.

Since most of the investigated risk factors were not significant, it is difficult to build an 'at risk profile for Emotional and Behavioral Problems, case identification should be based on screening for specific emotional and behavioral problems.

And high levels of comorbidity between emotional and behavioral problems mean that the selected intervention should be comprehensive and able to address both emotional and behavioral problems.

Prof. Kiyanda, lastly reported that to make most efficient use of the limited mental health human resource in many of the LMIC and to address variation in severity of psychopathology, a transdiagnostic approach combined with a stepped care delivery model should be employed.

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| Sub-Theme: | Mental Health Services (Secondary/Tertiary Health Care) |
| Topic: | Prevalence and Factors Associated with Suicidal Behavior among Adolescents with Epilepsy at Butabika and Mulago National Referral Hospitals |
| Session Chair: | Dr. Sam Okware, Director General, UNHRO |
| Presenter: | Dr. Hillary Kuteesa, Psychiatrist, Butabika National Referral Hospital |

Dr. Hillary Kuteesa presented *Prevalence and Factors Associated with Suicidal Behavior among Adolescents with Epilepsy at Butabika and Mulago National Referral Hospitals*. In this study, he said suicidal Behavior was defined as a continuum ranging from passive suicide ideation, plans and attempts. On the other hand, Epilepsy is at least two unprovoked seizures occurring more than 24 hours apart. While adolescent as a period of human growth was considered from 10 to 19 years of age (WHO 2002), however 10-17 years was used for this study.

He said that it is well known that committing suicide is one of the three leading causes of death among adolescents and in the general population globally. In 21 studies, the average prevalence of suicide in epilepsy was about 11.5% compared to 1.2% in general population. The study found out that suicidal ideation among 5 to 16 year olds was 20% higher in those with epilepsy than in the normal group. The other factors that come into blame are psychiatric comorbidity, adherence to medication, seizure related variables and social support among others.

Despite the situation, suicidal behavior is still given low priority by policy-makers and government. In Uganda suicidal behavior is increasingly criminalized and stigmatized. There is also paucity of information on the matter in Uganda and Africa in general.

He reported that the study objectives were:

- to determine the prevalence of suicidal behavior among adolescents with epilepsy at Butabika and Mulago Hospitals,
- to determine the factors associated with suicidal behavior among adolescents with epilepsy at Butabika Hospital and Mulago Hospitals

This was a cross sectional study design, carried out in Butabika and Mulago Hospitals between 1st August 2017 and 1st February 2018. A total of 255 adolescents aged 10-17 with epilepsy who met inclusion criteria were interviewed using a socio-demographic questionnaire, MINI-KID, BRIEF COPE, MSPSS, and added Seizure related characteristics 8 end questions. Of the total respondents, 223 met the inclusion criteria and 32 were excluded for reasons of being unable to understand the questions or not being able to go on with the interview. The majority of the participants were male by 65% and majority were aged 14-17. Most were from an urban setting and Baganda in tribe. The highest level of education of respondents was at least primary education and both parents were primary care giver for most of the respondents. Most of the Caregivers were married and living in an owned house, and had at least secondary education.

The EpiData 3.1 was used to enter the Data and statistical analysis was with STATA v14 to generate frequencies that described the sample demographic characteristics.

The study used Bi-variate analysis to find variables associated with the suicidal behavior, and Multi-variate analysis to find out factors independently associated with suicidal behavior.

There was poor seizure control among most of the respondents as well as poor adherence to the medication. For psychiatric comorbidity, major depression was at 27% and generalized anxiety at 21%. In coping with epilepsy which is still stigmatizing the adolescents used strategies of emotional support, instrumental support and religion.

The prevalence of suicidal behavior was at 30.5% among adolescents with epilepsy. When broken down into characteristics of suicidal behavior of passive suicidal ideation that is having the thought of wanting to be dead or wishing you were dead, this was at 60% while active suicidal ideation was at 10%. These findings were current in that at the time of interviewing these thoughts were present.

This prevalence of 30% is considered big. This means almost 1 in every 3 is having or has had these thoughts. This was found to be higher than most studies globally. One study in Africa was not meeting age criteria. The studies in Brazil and US had wider gaps of age either having 2 children or crossing to adulthood which make this study quite unique.

In the life time having had these thoughts in the past were at 64%, and 7.4% respectively. Suicidal attempts in the past month, were at 8.8 among those who reported having has suicidal thought while suicidal attempt in a lifetime was at 11.8%.

Using a multi-variate analysis, it significantly showed that those who had post primary education doubled for all that had suicidal behavior. It was also found out that having a major depression disorder was significantly also associated with having suicidal behavior. The risk is highest with psychiatric comorbidity where it was found that it was 9 times increasing likelihood of more suicidal behavior. The higher rates were found in older adolescents with epilepsy which explains the increased suicide rates. On the other hand, the perceived family social support and active coping were protective against suicidal behavior.

He recalled what Prof. Kinyanda earlier hinted on higher levels of education. He said that though it was still difficult to explain, indication show that mainly the perfection of one's problems increases with higher education. While the study did not permit to explain that to the dot, it was apparent that the more educated the respondents were the more they had suicidal behavior. Seizure related variables were not significantly associated with suicidal behavior and this was also found in another study by Hecimovic et. al., 2012.

Literature on coping strategies associations with suicidal behavior in epilepsy was scanty and findings greatly varied. Family was found to be the major source of social support in a study in Brazil (Oliveira, et, al., 2014)

Dr. Kuteesa, acknowledged the limitations of the study. The study being hospital based had limited generalizability and meant that probably there were very sticky people coming in which most likely explains the higher prevalence. The study design used may not establish temporality between adolescent epilepsy and suicidal behavior. There was also recall bias caused by differences in the accuracy or completeness of the recollections.

In conclusion, Dr. Kuteesa said that in Uganda, the prevalence of suicidal behavior in adolescents with epilepsy is quite high with major depression the most strongly associated factor with suicidal behavior. On the other hand, perceived social support as well as using active coping strategies are protective against suicidal behavior.

He recommends developing policies that integrate mental health in management of epilepsy. In the service delivery, he recommends screening for suicidal behavior and major depression among adolescents with epilepsy to be part of the routine care.

He asserts that further research is needed to design interventions that enhance coping and social support among adolescents with epilepsy.

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| Sub-Theme: | Mental Health Services (Secondary/Tertiary Health Care) |
| Topic: | Implementing formal peer support in a low-income setting: Preliminary results of UPSIDES qualitative research in Uganda |
| Session Chair: | Dr. Sam Okware, Director General, UNHRO |
| Presenter: | Dr. Richard Mpango, Clinical Psychologist/Research scientist/Post Doctorate Fellow, Butabika national Psychiatric hospital, MRC/UVRI and LSHTM, URU |

Dr. Richard Mpango presented *Implementing formal peer support in a low-income setting: Preliminary results of UPSIDES qualitative research in Uganda*. He explained that UPSIDES (Using Peer Support in Developing Empowering Mental Health Services) is a consortium that covers 6 countries implementing a multi-stage study, starting with qualitative work in form of a bigger study and then developing conceptual framework to measure specific outcome peer support across high resource, middle income and low resources countries. He said that key questions include: Where does it impact more? How can we inform policy? How can it improve health? And what is the best way forward?

He elaborated that Peer support is an evidence based intervention that improves upon the lives of people with severe mental illness and it is delivered by a person with a serious mental illness to a person with a serious mental disorder. Peer support workers (PSWs) are people who have progressed in their recovery to the stage where they can manage their illness, pursue fulfilling lives and support the recovery of other mentally sick people.

He reported that Brain Gain I and II projects initiated by the Butabika East London Link (BELL) established the first formal peer support programme for people with lived experience of mental health conditions in Kampala, Uganda (low-income country). The focus was to identify factors that hinder or facilitate implementation of peer support based on the Ugandan experiences, to help inform an international programme of implementation research on peer support called UPSIDES.

This was qualitative research conducted using Focus group discussions and key informant interviews with key stakeholders at Butabika National Referral Hospital in Uganda. Four focus group discussions (FGDs) were held, with eleven participants each; two with PSWs, one with Psychiatric Nurses and one with Psychiatric Clinical Officers (PCOs) (n=11). Two hospital managers and one policy maker also participated in key informant interviews. Both focus group discussions and interviews were conducted in English, audio-recorded, transcribed, and coded by hand for thematic analysis.

He reported that study results reveal a number of key themes and sub-themes identified across institutional readiness; economic constraints; knowledge base; attitudes and practices. He enumerated institutional readiness issues as: Organizational structure, staffing structure, community facility and Organizational culture. He said there is already an established culture of training, supervision and the Butabika Recovery College (BREC), the first of its own in Africa as well as support from senior management team of Butabika Hospital. For access to mental health services, there are outreach programs that are being aligned to work alongside existing community outreach programs.

He said that there are a host of economic constraints including meager hospital budget. He reported that whenever there is a budget cut, mental health is not excluded. Do we talk about constraints for peer support when there are constraints at a national level?

There are also poverty levels, unemployment, homelessness/inadequate accommodation. He said that some of these peers need support but some of them have nowhere to stay. There are financial constraints as well. The privately owned transport system and increasing transport costs where peers pay the same amount of money in taxis when they want to access these services or moving to certain places pose a financial constraint.

The knowledge base of transformational shift 'nothing about us without us'. He noted that Global mental health is not in a position to scale up services and wondered what can be done so as to be able to sing the same slogan all over the world?

He said that the implementation of PSW programs is associated with unique challenges but also opportunities for development of mental health services in low resource settings. There is need to further explore the application, efficacy and effectiveness of PSW programs since this could be part of the global care strategy that calls for 'servicer-user involvement'

In his concluding remarks Dr. Mpango re-emphasized the role of Peer support as a recovery-oriented intervention that focuses upon empowerment of people with lived experience - described by many as strength, but also a potential source of conflict between PSWs and the clinical staff responsible for mental health care. He noted that participants generally expressed enthusiasm for peer support, preferred continuity at Butabika, but also raised practical concerns regarding sustainability in a low-resource setting.

In further development PSW programme, the Ugandan experience, Dr. Mpango recommended that it is important to address issues of Organizational culture, attitudes of staff and support for peer support workers through training, clarifying roles and ensuring adequate resourcing as well as developing peer network.

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| Sub-Theme: | Mental Health Services (Secondary/Tertiary Health Care) |
| Topic: | Exploring Pathways to Hospital Care for Patients with Alzheimer's Disease and Related Dementias in Rural South Western Uganda |
| Session Chair: | Dr. Sam Okware, Director General, UNHRO |
| Presenter: | Mr Nathan Kakongi, Lecturer, Department of Biochemistry, Mbarara University of Science and Technology |

Mr Nathan Kakongi presented *Exploring Pathways to Hospital Care for Patients with Alzheimer's disease and Related Dementias (ADRD) in Rural South Western Uganda*. He began with a brief background to challenges related with pathways to hospital care for patients with Alzheimer's disease and Related Dementias. He said that the mortality risk of people with dementias is two times compared to their counterparts and dementia burden of care doubles every 20 years in the developed world but it doubles in every 7.2 years in sub-Saharan Africa, presenting a very big gap between the worlds.

In Uganda, he said data about dementia burden is scanty with very few studies done at Mulago National Referral hospital. In Korea, dementia is known to be the second to depression as alluded to by the former presenter, hence a very big need to go deeper into cases of dementia.

The people with dementia seek health care in different ways and meet different challenges that affect their health seeking behavior. The patients often present late to the health care facilities so there is need to understand the pathways these patients go through while seeking care.

He reported that the study was guided by two major objectives:

- To explore pathways to hospital care undertaken for patients with Alzheimer's disease and related dementias.
- To describe the challenges experienced by patients with ADRDs and their families while seeking health care.

He said that this was a cross-sectional study carried out in 2 government and 1 private hospitals of Mbarara Regional Referral Hospital, Kabale Regional Referral Hospital and Kampala International University Hospital respectively all in south western Uganda.

The study population were Caregivers of elderly patients of 60 years and above diagnosed with dementia. The study included adults 18years and above, but who had stayed with the patients for at least 6 months, those who are able to tell more about the patients. It excluded caregivers who were unable to give adequate information. The medical records in the psychiatry wards were reviewed for contacts of caregivers of patients who had been diagnosed with dementia from which a sample was drawn. These were then followed up to their homes for interview.

A total of 33 in-depth interviews using interview guides were conducted. This was followed by data analysis that started during data collection process. The recorded data was transcribed and analyzed using ATLAS.TI software for analyzing qualitative data. The data was interpreted and theorized basing on recurring patterns or themes and objectives of the study.

The study found out that there was variability in pathways to hospital care from individual to individual. The encounters for healthcare varied. They were 1-6 under four types namely hospitals, clinics, religious prayers and traditional healers.

There were two broader themes captured. The first is on the points of care choice and perceived care outcomes and the second on challenges encountered at various points of care.

It was found out from respondents that patients visited hospitals at 1st and 2nd encounters, thereafter the number of patients visiting the hospital reduced.

| Encounter | 1st | 2nd | 3rd | 4th | 5th | 6th |
|---------------------|-----|-----|------|-----|-----|-----|
| Hospital % | 65 | 69 | 28.5 | 20 | 0 | 0 |
| Religious prayers % | - | - | 12.5 | 40 | 50 | 100 |

Source: Author

From the 1st to 2nd it is still high but from 3rd to 4th the number was reducing and surprisingly at the 5th and 6th encounters, nobody went to the hospital. The religious prayers received big number of patients from 3rd encounter upwards - 5.9%, 12.5%, 40%, 50% and 100%. This means that when patients go to formal points of care and don't get what they expect, they resolve to look for other means of care including religious prayers.

Why do people shift from the formal care to informal sector? There are wide range of challenges involved in the formal pathways. There are drug stock outs at health facilities. The financial implications such as selling property to seek treatment and lack of improvement in quality of life as expected at health facilities. He explained that patients go to health facilities expecting cure and when they do not get what they expect since dementia cannot be easily treated and presentation of symptoms of dementia look like demonic attacks as well as people's belief in spiritual healing leads them resort to none formal means.

He reported that challenges persist in both formal and informal sectors they include drug stock outs, patients' expectations for admissions at hospital are sent home when still very sick, and inability of some health workers to manage the condition and the fact that mental health is usually managed at hospitals and not lower health centers. In the informal sector patients go to herbalists for inexpensive drugs which are still not effective and most of the times treatment is full of lies. Others get unimpressive situations or care to the patients particularly from witchdoctors. Surprisingly, there were no challenges reported by the respondents with religious prayers an indication that people are devoted.

In conclusion Mr. Kakongi said that Caregivers and or families of patients with dementia go to different formal and informal care settings. The hospital point of care was more frequent at first and second encounters for most patients while Religious prayers took the lead at subsequent encounters with points of care. Although no specific pathway pattern reported, most of patients begin with hospital (formal sector) and end with non-formal ones.

Mr. Kakongi recommends that Public awareness of dementia is critically needed. Like the religious people preach, health systems should also go out raise awareness on dementia given that majority of people think it as part of normal aging or witchcraft and not a disease.

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| Sub-Theme: | Mental Health Services (Secondary/Tertiary Health Care) |
| Topic: | Peer support worker program at Butabika National Referral Hospital – Lessons learned |
| Session Chair: | Dr. Sam Okware, Director General, UNHRO |
| Presenter: | Ms Mauricia Kamuhirwa, Social worker, Clinical department, Butabika National Referral Hospital |

Ms Mauricia Kamuhirwa presented the *Peer Support Worker program (PSW) at Butabika National Referral Hospital focusing on Lessons learned*. She referred to WHO; recommendation that the world needs to recruit and to train 13 million health workers to cater for the gap in health generally. She acknowledged that different interventions have been put across to address the issue of the human resource gap.

She first clarified on the concepts used in her presentation. She said peers are people with a similar lived experience or attributes. The Peer support work is a novel intervention where peer support workers offer support to fellow peers to overcome or to come out of a crisis in this case mental health crisis where a large proportion of people living with severe mental illness in LMICs receive no care.

The Peer support work as an intervention is whereby people with a lived experience of mental illness are trained to work alongside hospital staff to compliment and offer support to people coming out of a mental health crisis or a recent admission.

She reported that the Peer Support Worker program come out of Brain Gain projects which sponsored by East London Foundation Trust. There was Brain Gain I, 2012 -2013, a collaborative project of Butabika Referral hospital, East London Link (BELL), East London Foundation Trust (ELFT), Lancaster University, Real-lives UK and Heart sounds Uganda - a community based organization which was led by service users here in Kampala. The purpose of Brain Gains I was to develop a peer support worker (PSW) programme to deliver formal peer support in and around Kampala and Entebbe, with the aim of filling the human resource gap.

The Brain Gain II of 2015-2017, purpose was to build upon the foundation laid by Brain Gain I. In this round, other collaborators came on board namely the London School of Hygiene and Tropical Medicine (LSHTM) and Makerere University, Kampala (Mak).

The aim was to provide a two recovery-oriented intervention aimed at primarily serving people with severe mental disorders and epilepsy.

She said that the objectives for brain gain II were:

- To deliver a formal PSW intervention to ‘revolving door’ service users around Kampala, Wakiso, Mukono and Jinja.
- To establish t Butabika Recovery College (BREC) at Butabika hospital
- To assess the effeectiveness of PSW and Recovery College activities delivered through Butabika National Referral Hospital

The Brain Gain Impact of 2018 from January to December was to build on the work carried out in Brain Gain I and II. The purpose was scalability, scaling up PSW training capacity by having PSW Train of Trainers and sustainability, embedding PSW and Recovery trainings into routine hospital work, offering group PSW to patients attending outreach services run by Butabika Hospital Community Recovery Team. All the 3 projects were funded by the Tropical Health Education Trust under the UKAID.

During Brain Gain II, the theory of change workshops were carried out during which PSWs, hospital staff and link leadership from East London were convened in order to develop a TOC path way of change to inform the evaluation design. Mixed methods qualitative and quantitative study designs were employed during the Brain Gain projects. Multi-variate analysis was done using linear regression models adjusting for potential confounders.

ME” (Mental health information, monitoring and Evaluation were a package of tools that were used in routine Monitoring and evaluation. The qualitative methods included: Focus Group Discussions (FGDs), and Key Informant Interviews (KII) with PSWs, staff and service users.

Tools used included Standardized questionnaires, FGD guides, KII guides, WHODAS, Coding was done and thematic analysis was employed. She reported that under Brain Gain I, 27 PSWs were trained. First formal PSW programme was established to deliver formal peer support in the communities in Kampala and Entebbe in Uganda. The Brain Gain I laid a foundation for recovery and created capacity for PSW at Butabika hospital, though it was not formally evaluated and had minimal formal supervision.

The Brain Gain II project delivered a formal PSW intervention to ‘revolving door’ service users around Kampala, wakiso, Mukono and Jinja and led to the establishment of Butabika Recovery College. Brain Gain II also introduced formal PSW supervision and evaluation, mutual support group meetings, peer to peer supervision, community recovery team and training of an additional 20 PSWs. Brain Gain II led to an enhanced evaluation, co-production and established staff were brought on board. PSW were using experience as professionals, including BREC trainings, service user library and vocational work, economically evaluated the hospital services and had a strong component of empowerment to both staff and service users.

Brain Gain Impact scaled up peer support work training capacity through peer support work and Trainer of Trainers (TOT). It offered group peer support to patients attending outreach services run by Butabika hospital community recovery team.

She reported that PSW can be viewed as an appropriate intervention to serve as a form of 'task shifting' to address the human resource gaps and help support service delivery of the already strained mental health system. She recalled that TASO, has been successful in the PSW model in fighting HIV stigma and creating awareness and saw a need to explore more on their success to integrate peer support work in the health system to cater for the scarce resource.

However, Peer support work was associated with lack of role clarity, power struggle, complaints about inadequate pay based on the workload, difficulties in managing relationships, litigation, difficulties related to sustainability of PSW programme and managing the transitions.

Ms Mauricia Kamuhirwa concluded that implementing PSW programmes results into valuable and communal benefits, mental health service receptiveness and wellbeing as well as usefulness person centeredness services. It also has equal outcomes compared to experts employed in similar jobs.

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| Sub-Theme: | Mental Health Services (Secondary/Tertiary Health Care) |
| Topic: | Alzheimer's disease and related dementias in rural Uganda, prevalence and associated factors: A cross-sectional population based quantitative study |
| Session Chair: | Dr. Sam Okware, Director General, UNHRO |
| Presenter: | Dr. Vincent Mubangizi, Research Fellow, Mbarara Alzheimers and Related Dementias Research Initiative (MARDI), Mbarara University |

Dr. Vincent Mubangizi presented part of the study *Alzheimer's disease and related dementias in rural South Western Uganda*. He said that his presentation shares the background with the one earlier presented by Ms Clara Atuhaire. He reported that alzheimer's disease remains unclear but it is related to genetic and environmental factors. As such it continues to be rejected saying that dementia doesn't occur. This was the main reason as to why a study on Dementia was undertaken in South Western Uganda in December 2018 to prove the case.

The objectives were:

- To determine the prevalence of AD/RD in rural South Western Uganda.
- To examine the associated risk factors for AD/RD in the rural South Western Uganda

This was a cross-sectional population-based study using quantitative methods, and it was conducted in rural South Western Uganda. The study employed a multi-stage area probability sampling of one parish in eight districts by first choosing 8 districts out of 16. From 8 districts, sub counties were chosen and from each sub county the parishes were listed and one parish in the 8 districts was selected.

A brief Committee Screening instruments for Dementia to assess 400 people for dementia was used. This instrument is easy to use and takes about 5 minutes. A total of 400 people aged 60 years and above were screened for dementia and their care givers were interviewed too. Of the 400 respondents, 45% had no education at all while 43% had 1-7 years of education, any class of primary education, not necessarily that they completed. Females were 60% of the sample. Their caregivers were either their children or grandchildren 65% and most of them were females. A questionnaire was used to look for the independent association of known risk factors of dementia. The mean age of older people was 72.4 (Standard Deviation of about 9.5)

People were screened positive for dementia, screened positive because the study did not make a clinical diagnosis due to some limitation of resources. Using the tool people who were screened positive overall were 19% noting that as age groups increase prevalence also increases.

The prevalence of dementia in Uganda tends to be higher than in other countries. However when considering age specific, the age was lower than South Africa where they go above 75. It was also noted that inability to detect an association with none risk factors could have been due to the small sample size since some studies look at 1000 people compared to 400.

Dr. Mubangizi recommended the need to find out if prevalence reflects a better case finding, or there is a temporal trend due to potential aging. In spite of the knowledge that dementia in developing countries is mainly due to transitional and forthcoming aged there is need to do more studies in Uganda.

Sub-theme: Mental Health Services (Secondary/Tertiary Health Care)

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| Sub-Theme: | Mental Health Services (Secondary/Tertiary Health Care) |
| Topic: | Alcohol use in a rural district in Uganda |
| Session Chair: | Dr. Sam Okware, Director General, UNHRO |
| Presenter: | Ms.Olivia Nalwada, Research Officer, Research Department, Butabika National Referral Hospital |

Ms.Olivia Nalwada presented part of the PRIME study undertaken in Eastern Uganda where Dr. Kigozi, former Director, Butabika National Referral Hospital was the principal investigator.

Beginning with the contextual analysis, she reported that Uganda has one of the highest per capita alcohol consumption rates in sub-Saharan Africa. Alcohol use disorders (AUD) are characterized by harmful, hazardous or dependent patterns of alcohol consumption that result in adverse physical and mental health consequences. She said some of the consequences are not only immediate, but they can be long term with lifelong effects.

Referring to various studies that have been conducted in Uganda, she said that alcohol dependence is one of the main causes of psychiatric morbidity in Uganda, with the men estimated to have one of the higher alcohol per capita consumption levels than women.

In Uganda's rural communities the majority of alcohol which is consumed is actually crude alcohol and because of this it was difficult to quantify or measure the alcohol being taken in the rural communities. Most people take local brew of tonto and crude waragi which was really hard to quantify during the study.

The study was conducted in Kamuli District, which has a population of 490,255 of whom 48% are males and about 96% of the population of Kamuli resides in rural areas and 58% live in abject poverty. At the time of the study, the district had one government hospital, one Non-for--Profit hospital and 24 government health centers at various levels. However mental health services including counseling and medication were only available at the government hospital - Kamuli District hospital. A situational analysis which was also conducted in Kamuli district showed that the majority of people with mental illness including those with alcohol related disorders prefer to seek care from the regional referral hospital of Jinja, or national referral hospital, Butabika as opposed to getting treatment from Kamuli district hospital.

The eligibility criteria for participation in the study included being adult 18 years and above, fluent in English or the local languages (Luganda/Lusoga) and those willing/able to complete the full interview, both a Community Survey, a facility based survey. A random selection of 25–60 households in each village across 30 villages was carried out, of which a total of 1291 adults were approached and 1290 (99.9%) consented to participate in the study.

In the facility survey, participants were consecutively recruited from 13 primary care clinics within Kamuli District, and a total of 1922 adults were approached and 1893 (98.5%) consented to participate. Patients were ineligible if they had acute medical condition.

A 10-item study questionnaire was used assessed alcohol to screen for Alcohol Use Disorders Identification Test (AUDIT). The AUDIT is a 10 item tool which scores from 0 (Never occurs) to 4 (Daily) = hazardous (score 8–15), harmful (score 16–19) or dependent (score ≥ 20). The total score tells us if someone belongs to harmful alcohol use dependent or a glass drinking.

To assess for depression, the 9-item Patient's Health Questionnaire (PHQ-9) was used, and to assess internalized stigma among AUDIT-positive men, the Internalized Stigma of Mental Illness scale was used. Then to assess the attitudes and barriers to health care seeking were examined using the Barriers to Access to Care Evaluation scale (BACE)

Reporting on the findings, she said 21.8% of men had consumed alcohol in the past year. There was 4.1% of all men were AUDIT positive which means they scored 8 and above the AUDIT test. Of these 2.9% had AUDIT scores consistent with hazardous drinking, 0.7% with harmful drinking and 0.5% with dependent drinking. Using the facility survey, 39.6% of men had consumed alcohol, 5.7% of all men were AUDIT positive.

She reported that there was an association between age and alcohol use or the AUDIT score. Older men aged between 45–59 years had the highest likelihood of AUDIT-positive status score (27.5%) while only 9.4% of men aged 18–29 years had a positive AUDIT score.

In the binary analysis, there was an association between depression severity and AUDIT-positive status score as well as internalized stigma and AUDIT score. Men with severe depression had the highest AUDIT-positive where over 8 in every 10 men (83.3%) had a positive AUDIT score. Almost half (47.5%) of the AUDIT-positive men reported that alcohol use has ruined their lives. That means that alcohol had negative impact on their lives. 47% of those with alcohol use problem agreed that they need others to make decisions for them. Four out of every 10 men (42.5%) felt embarrassed or ashamed in themselves due to alcohol problems. 28.4% were afraid of discrimination by their loved ones.

The most interesting part is that in the study, none of the men had sought care for alcohol problems. The majority (55.0%) of the men did not seek care because they did not think alcohol use disorders was a disease that could be treated. 4 out of every 10 men did not seek care because they thought they would get better without treatment so they did not need to seek professional care. 35.0% were not bothered or inconvenienced by their alcohol use. A quarter (25.0%) of the men did not seek health care because they were unsure about where to go or who to seek professional help. A few (10.0%) of the respondents reported that they were embarrassed to seek care for alcohol use effects and did not know how approach a provider to seek help. 5.0% did not seek help because they were not satisfied with available services. 5% of the men did not seek care due to concern of treatment cost.

She said the results show the dire need to sensitize communities. As reported earlier, take the religious leaders approach of going to communities and shouting about mental illness, shout about alcohol disorders, shout about the availability of treatment and integrate mental illness services at Primary Health Care level. There is need to consider the role of primary healthcare workers in implementing screening and brief intervention programs. Example is AUDIT tool, takes 5-10 minutes to screen somebody with alcohol disorders. If anyone goes to a lower level unit seeking treatment even if she is pregnant just help her for 5 minutes. It is known that some women take alcohol while pregnant because they think that the baby's eyes will be white.

In short, Ms. Nalwada said that there is need for change from clinical to public health, that is community-level practice so as to boost demand for Alcohol Use Disorders (AUD) treatment. The link between internalized stigma beliefs and failure to seek professional care further suggests that clinicians and District Health officials should integrate stigma reduction into public health efforts to promote alcohol treatment. She proposed that future studies need to explore if men who do not seek treatment have special needs which are not met in primary health care settings.

Given the increased likelihood of AUD among elderly men and women with depressive disorders, she called upon, the Ministry of Health officials and mental health professionals to design intervention targeted at these particular high-risk subgroups of the drinking population so as to reduce the public health burden of alcohol misuse.

In conclusion, she pointed out that internalized stigma beliefs among AUDIT-positive men impede treatment-seeking. She therefore proposed that as part of any efforts to increase detection and treatment services for alcohol use problems, routine Screening and Brief Interventions (SBI) for internalized stigma must be incorporated within the normal clinical routine of primary health care.

Question

Ms Olivia Nalwada you mentioned that while in Kamuli there was only one health facility which was providing mental health services. I just want to know if that was before PRIME started.

Response

PRIME is a study and overtime one of our biggest point of advocacy has been integration of mental health into primary healthcare. In 2013 when the baseline study was conducted, it was mainly Kamuli general hospital which was providing mental healthcare services.

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| Sub-Theme: | Mental Health Services (Secondary/Tertiary Health Care) |
| Topic: | Medical plants used for management of mental disorders in the districts Luwero and Mukono in Central Uganda. |
| Session Chair: | Dr. Sam Okware, Director General, UNHRO |
| Presenter: | Dr Francis Omujal, Senior Research Officer, Natural Chemotherapeutics Research Institute (NCRI) |

Dr. Francis Omujal, presented a study on Medical plants used for management of mental disorders in the districts of Luwero and Mukono in Central Uganda conducted by Natural Chemotherapeutics Research Institute (NCRI); is an institution with mandate of the government of Uganda for conducting research in traditional health products and methods.

He started by defining mental disorder as, any behavioral pattern that causes distress or personal mental functioning or any human experience that is unpleasant or disease of the mind. He said that mental health is something very unique because sometimes individuals change the behavior. Functional Psychosis is any form of mental disorder which has not occurred as a result of any physical disease anywhere in the body.

He reported that in the past few decades, the problem of mental health has become a serious health problem. Mental disorders in most communities are often perceived as a source of misfortune; ancestors and witches. Such disorders are usually viewed in terms of magical, social, physical and religious causes, but rarely as diseases.

He said talking about mental health compels him to talk about traditional medicine because it is the traditional healers and to an extent the clergy that are currently helping most people with mental health illness at the community level. Since mental disorder is still believed to be caused by witchcraft, it is avoided, feared, stigmatized and it is regarded an area of Traditional Health Practitioners (THPs) and the Clergy. It tends to cause fear even among health workers, because in the communities there is a belief that mental health is not a disease

In most developing countries, primary care is provided by THPs because they are generally more accessible, show concern or respect for their patients, and have strong influence in society they serve. The patients sometimes do make payments in cash or in kind in some rural communities. He said in Tanzania, the prevalence of patients seeking care for common mental disorders among Traditional health practitioners' clinics patients was double that of biomedical health clinics. He said that he was very sure there are more people that need help from Butabika National Referral Hospital but, how many psychiatrists are in Uganda?

In Uganda, indigenous knowledge on the use of medicinal plants for common mental disorders is limited and not documented. This information is crucial in the development of drugs, since current drugs for mental disorder have shown poor response, slow onset of action, poor tolerability, persistent adverse effects and others. Currently Scientist are searching for new drugs for different mental disorders. They are looking up the drugs which might be the future for psychiatric cases.

The objective of the study was to document indigenous knowledge of medicinal plants used by THPs to manage mental disorder (Schizophrenia) in Luwero and Mukono districts in Uganda.

The study looked at traditional medicine, based on multiple mental disorders such as dementia, those cases which make people unique. This was a national study represented by Mukono and Luwero districts.

A survey was conducted among 86 and 117 THPs in Luwero and Mukono respectively. The study focused on those that claim to treat any form of mental disorder or functional psychosis. Data was collected using semi-structured questionnaire on the medicinal plants and parts used; methods of preparation and method of administration of medicine. The scientific names of plants were authenticated by a Botanist. Most plants species reported to be used to treat mental disorder have antipsychotic properties that have potential to improve patient's condition. They contain several phytochemicals including alkaloids and polyphenolic compounds (flavonoids) with pharmacological effects.

In conclusion, Dr. Francis Omujal said, the study provided indigenous knowledge on plants used to manage functional psychosis and there are plans to follow them up and providing a basis for further studies. It also provided a basis for further phytochemical and pharmacological studies of the plants as sources of potential lead compounds for antipsychotic drugs including; Mode of action, optimal dosages, drug interactions and side effects.

7.0 Closing Remarks

Prof. George Kirya, Chairman, Management Board, Butabika National Referral Hospital delivered the closing remarks on the Mental Health Symposium. He thanked the Session Chair for the opportunity extended to him to deliver the remarks. He extended greetings from the members of the Management Board of Butabika National Referral Hospital.

He thanked the clinicians, academicians, researchers, policymakers, and civil society practitioners for deciding to be here today despite other important responsibilities in order to discuss, share experiences and hopefully come up with policy and program proposals, and actions to promote mental health research and better services for this country.

Ladies and gentlemen talking about research, it is a fact that most developing countries, including Uganda, give limited or hardly any investment support to research. Yet it has been demonstrated that it is through research that we can continue advancing to a better future. A future where most medical conditions have either a cure or a vaccine to at least provide treatment that allows people to leave to their last days in a dignified manner.

He said, research does not only offer innovations like drones for transporting medicines, faster and to far hard to reach parts of the country, but may also contribute greatly to the wealth of a country. I am therefore pleased that you have taken time to discuss research.

He said that he been observing the burden of mental disorders through the boardroom of the Butabika National Referral Hospital during management board meetings where he is a Chairperson and by visiting wards and patients in departments of the hospital.

In this connection, he said he has realized that the burden of mental health in this country is very much on the rise and expressed fear that this is steadily becoming bigger. Again talking about Butabika hospital, it's currently accommodating over 150% of the beds that it should have had meaning that patients don't have much space. What is worrying, he said is to see that 40% of the admissions are cases of drug and alcohol abuse, which is extremely sad. He hoped that all out there appreciate that it is very worrying and most likely a reflection of what is happening in the country generally. The outpatient attendance in Butabika again is very high, showing that a good number of people out there are suffering from mental illness. He said, it was in 2006 when WHO ranked Uganda among the top 6 countries in Africa with highest cases of mental disorders and he does not think over the period since that was announced there has been much change.

He called upon ladies and gentlemen to watch out because the situation is not at all rosy. You may have been told about the problem of depression which seems to be engulfing many of us. The other most worrying is suicide. Suicide and suicidal tendencies have been found to be on the increase in Uganda. Because of the increasing prevalence of mental health problems, the government through the MOH found it essential to have a Mental Health Policy.

Ladies and gentlemen, Uganda is well known for coming up with very good policies but the problem is always and has always been failure to fully to implement them. Now that today you have been discussing this policy, kindly find a way of helping ourselves to implement it. The policy's vision is a country free of mental, neurological and psychological disorders which is quite a hefty vision but that is a vision to take and implement.

Prof. Kirya mentioned a few areas; empowerment of patients, community and other stakeholders which he felt could have room in this policy.

The proposed increased access to care of patients through integration of mental health services in PHC needs cautious approach in that Uganda seems to be weak as far as PHC is concerned. In the past, there was no known emphasis of PHC to be taught in medical schools as a major source of healthcare. He said that this is a problem which needs to be addressed.

In terms of empowerment, there is a core of well trained human resources for mental health to a certain extent. Though there is improvement, there is still lack of enough psychiatrists, and other mental health personnel. This is a matter that should be taken seriously by government especially now that the mental health burden is increasing, more of these are needed. Regarding observance of human rights for people with mental illness; one could say that this has also improved to a certain extent, but again there is room for improvement especially in the rural areas.

Encouraging partnerships between families, partnerships between service users and health workers. He expressed his happiness that Butabika hospital is trying its best to perfect this empowerment, through opening a general outpatient department which provides not only mental health services but also general medical care, dentistry, STDs, eye clinic, and so on.

This arrangement he said has been welcomed by public from near and far. First of all, the services have been rendered and have also noticed that it helped to reduce office stigma worth of mental health and mental health patients. There is therefore no reason why other facilities out there cannot borrow a leaf from Butabika hospital to do exactly that.

In addition, Butabika Hospital gives sensitization programs to the community. They also have sensitizing programs dealing with mental health carried out on radio, television, and print media. He appealed to all to join Butabika Hospital on this area. The hospital also has a mental health film showing at the national theatre monthly, he encouraged all once in a while to go and have a look at it.

He reported that it has been found out by Gabecho that many victims with mental conflicts, stay in the village without care. And it is further found out that many who require service only 50% of them are able to get it. The other 50% are left without that service. This again is an area which he hoped the symposium has discussed that need serious attention.

In Uganda, he said, all the 14 regional referral hospitals have mental health clinic of 30 beds each. One would therefore expect that these units are able to handle mental health care in their areas. However, this is not always the case because of shortage of qualified staff, most of the units cannot provide meals to patients and given importance of meals for mentally ill patients most shy away from these units and end up at Butabika National Referral hospital.

He was pleased to report that Butabika hospital senior staff provide outreach services in mental health and support supervision in Kampala district and regional referral hospitals; this practice helps to maintain and improve quality of service.

He reported that it was not so long ago Butabika national referral hospital was fully rehabilitated and refurbished to make it a state of art mental health hospital. He extended his gratitude to all those who assisted us because once the head which is Butabika in this case, the national referral hospital is properly facilitated, it helps others to also get something out of it. He further reported that Butabika hospital has also opened up super specialized services which include alcohol and drug abuse treatment, and more recently completed a new modern wing to deal with increase on the numbers and provide other facilities. However, his fear was with the quantity of alcohol and drugs Ugandans take in these days, that sooner than later this extension might not be enough for those people who indulge into drug and alcohol abuse.

They have also come up with child and adolescent mental health service; they have psychological treatment, and also forensic mental health service. I wanted to mention this because some of you may not know that it really exists, but I think these are areas which are going to improve our mental health services.

He commended Butabika hospital for setting a good example as far as maintaining buildings very well and making sure that the surroundings of the hospital have the relaxed ambience to the patients something that need to be emulate elsewhere.

He called upon the ladies and gentlemen to recognize Butabika National Referral Hospital as a center of excellence in mental health of Uganda. The recognition is expected to appeal to others to also move towards being recognized. He was of the view that such a center of excellence in mental health in Uganda should be emulated in the East African Community (EAC), and the entire Africa continent.

Prof. Kirya, acknowledged that there still a number of key challenges. The increasing number of people with mental health such as those due to drug and alcohol abuse. The lack of psychiatrists in different specialties, and stigmatization of mental illness as well as poor social support for people with mental illness, high in communities are surmountable challenges.

Prof. George Kirya once again extend his sincere thanks to the organizers of this symposium. He also thanked all the participants for sparing time to discuss issues that are pertinent to the lives of most Ugandans. He appealed to participants, as they leave symposium venue to remember that research is the only way to innovations, the only way to continue to advancing to a better future. It is the way fulfill mental health policy with its vision of the 'country free of mental, neurological, and psychological disease'.

He finally, with much pleasure declared the symposium closed.



THE UGANDA NATIONAL HEALTH RESEARCH SYMPOSIUM

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