

# SOCIAL, EMOTIONAL AND ECONOMIC EMPOWERMENT THROUGH KNOWLEDGE OF GROUP SUPPORT PSYCHOTHERAPY PROJECT, UGANDA

Using a culturally sensitive group support psychotherapeutic (GSP) intervention as first line treatment for depression among people living with HIV/AIDS in Uganda

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## ABBREVIATIONS

	:	
AIDS	:	Acquired Immunodeficiency Syndrome
CHW	:	Community Health Worker
COVID	:	Corona Virus Disease
GHE	:	Group HIV Education
GSP	:	Group Support Psychotherapy
HIV	:	Human Immunodeficiency Virus
MOH	:	Ministry of Health
PLHIV	:	People Living with HIV
SEEK	:	Social, Emotional and Economic empowerment through Knowledge
UNAIDS	:	The Joint United Nations Programme on HIV/AIDS
WHO	:	World Health Organization

## CASE INTRODUCTION

The Social, Emotional and Economic empowerment through Knowledge of Group Support Psychotherapy (SEEK-GSP) project is implemented by Makerere University in collaboration with the Ministry of Health. The project aims at narrowing the treatment gap for depression among people living HIV using group support psychotherapy delivered by trained lay health workers in Northern Uganda. Globally, the advent of antiretroviral therapy has led to improved quality of life of people living with HIV (Mugavero et al., 2009; Oguntibeju, 2012), reduced HIV related death (UNAIDS, 2018) and reduced new HIV infections (Bavinton et al., 2018; Cohen et al., 2016; Rodger et al., 2016). However, Other HIV/AIDS related challenges like depression still prevail. Previous studies have found that people living with HIV are two to four times more likely to suffer from depression compared to the general population (Ciesla and Roberts, 2001; Do et al., 2014; Remien et al., 2019). In Uganda, the prevalence of depression among people living with HIV/AIDS is estimated to be between 9 - 25% (Kinyanda et al., 2017; Nakimuli-Mpungu et al., 2011). Despite this, most of HIV treatment facilities in Sub Saharaan Africa including Uganda do not screen for depression among people living with HIV.

The world health organisation recommends psychotherapy as the first line treatment for depression. The SEEK GSP project involves group support psychotherapy sessions to treat depression among people living with HIV/AIDS, by enhancing emotional and social support networks, the ability to practice positive coping skills, and income-generating skills. Lay Community health workers and facility based health staff are recruited and trained by the project team. Eight group support psychotherapy sessions are facilitated by the trained community health workers who were supervised by the facility based health workers. Community advisory boards are formed community to monitor project activities and provide timely feedback to the project team. Makerere University in collaboration with the Ministry of Health developed the formal and informal training sessions. The group support psychotherapy sessions were implemented at 30 health facilities in Pader, Kitgum and Gulu districts.

This case study illustrates how task-shifting to lay community members and health workers to provide group psychotherapy sessions can effectively treat depression among people living with HIV/AIDS in Uganda. This intervention is appropriate for countries in Sub-Saharan Africa which have high prevalence of HIV and depression. It will be valuable to explore the potential for scaling this intervention to other regions in Uganda and to other Sub-Saharan African countries.

# 1. INNOVATION PROFILE AT A GLANCE

## Organisation Details

<b>Project name</b>	<b>Social, Emotional and Economic empowerment through Knowledge of Group Support Psychotherapy</b>
<b>Founding year</b>	2012
<b>Founder name</b>	Dr. Etheldreda Nakimuli-Mpungu
<b>Founder nationality</b>	Ugandan
<b>Organizations involved</b>	Makerere University College of Health Sciences, Department of Psychiatry; Ministry of Health; The AIDS Support Organization
<b>Organizational structure</b>	University (Not for profit)
<b>Team size</b>	8

## Innovation value

<b>Main value proposition</b>	
<b>Beneficiaries</b>	People living with HIV/AIDS
<b>Key components</b>	<ol style="list-style-type: none"> <li>1. Cultural appropriateness of the group sessions</li> <li>2. Task-shifting</li> <li>3. Training in income generating skills</li> </ol>

## Operation details

<b>Main income streams</b>	Grant funding
<b>Cost per person served</b>	UGX 24,000 (6 USD)

## Scale and transferability

<b>Scope of operations</b>	Uganda
<b>Local engagement</b>	Makerere University College of Health Sciences, Department of Psychiatry; Ministry of Health Uganda Local government
<b>Scalability</b>	<ul style="list-style-type: none"> <li>• The successful use of community health workers and existing public facility health workers makes scale and sustainability possible.</li> <li>• Similar settings with high HIV/AIDS, depression and poverty levels both within and beyond Uganda can benefit from this intervention.</li> </ul>
<b>Sustainability</b>	<ul style="list-style-type: none"> <li>• The existence of community health workers in every village in Uganda is an opportunity for sustaining the programme.</li> <li>• Income generation activities utilized in this project ensure sustainability of groups and improved economic status of participants.</li> </ul>

## 2. CHALLENGE

Globally, there has been a significant increase in access to antiretroviral therapy since its inception, with the number of people living with HIV accessing antiretroviral therapy tripling since 2010 (25 million in 2019 people compared to 7.4 million in 2010 ) (UNAIDS, 2020, 2011). This has resulted into 47% decrease in the annual number of new HIV infections since the peak in 1996 (UNAIDS, 2018) and 39% reduction in AIDS related death since 2010 (UNAIDS, 2020). Studies also suggest that antiretroviral therapy improves the quality of life of people living with HIV/AIDS, prolongs their life span (Mugavero et al., 2009; Oguntibeju, 2012), reduces progression of HIV to AIDS (May et al., 2010; Violari et al., 2008), and increases viral load suppression thereby reducing HIV infections (Bavinton et al., 2018; Cohen et al., 2016; Rodger et al., 2016). However, HIV still remains a worldwide challenge; the Joint United Nations Programme on HIV/AIDS (UNAIDS) estimated that in 2019 about 38 million people worldwide were living with HIV. The burden of HIV is most felt in Sub-Saharan African which accounts for around 70% of global HIV infections (UNAIDS, 2020).

Mental health disorders particularly depression is the leading cause of morbidity worldwide. Studies suggest that depression is more prevalent in people living with HIV, and they are two to four times more likely to suffer from depression compared to the general population (Ciesla and Roberts, 2001; Do et al., 2014; Remien et al., 2019). Evidence from SSA suggests that one in three people living with HIV have symptoms of depression whereas one in five of them have clinical syndrome of depression (Nakimuli-Mpungu et al., 2012). The prevalence of depression among people living with HIV/AIDS in SSA is estimated to be high, ranging from 8 to 32% (Abas et al., 2014; Bernard et al., 2017). Depression negatively affects HIV treatment outcomes. Studies suggest that depression is associated with poor adherent to antiretroviral therapy (Mayston et al., 2012; Meffert et al., 2019; Nakimuli-Mpungu et al., 2012), with the non-adherent persons having a 3-fold higher likelihood of presenting moderate to severe depressive symptoms compared to their counterparts (Nel and Kagee, 2013). Poor adherence to antiretroviral therapy is evidenced to result into treatment failure and advent of drug-resistant HIV strains (Hartzell et al., 2008; Rivera-Rivera et al., 2016). Evidence suggests that even when viral suppression is achieved, depression results into increased mortality among people living with HIV (Abas et al., 2014). It has also been shown that depression is associated with increased HIV infections (Antelman et al., 2007). Despite the high prevalence of depression

among people living with HIV and its associated negative effects, most of HIV treatment facilities in SSA do not screen for depression among people living with HIV.

In Uganda, antiretroviral therapy was made available to people living with HIV through the President's Emergency Fund for AIDS Relief (PEPFAR) in 2004. Thereafter, the MOH adopted UNAIDS 90:90:90 targets and implemented Option B+ (MOH, 2012) and the test and treat programs (MOH, 2018) so as to improve accessibility to antiretroviral therapy among people living with HIV and consequently improve their lives. As a result, accessibility to antiretroviral therapy in Uganda increased by more than 80% between 2015 and 2016 (Uganda AIDS Commission, 2016). Despite these great improvements, challenges still exist in ensuring people living with HIV live a quality life and adhere to treatment. Uganda, with the prevalence of HIV of 6.2% (MOH, 2019), it is estimated that the prevalence of depression among people living with HIV is high, ranging from 14 to 25% (Kinyanda et al., 2017; Nakimuli-Mpungu et al., 2011). Depression among people living with HIV has been evidenced to be prompted by loneliness, HIV-related stigma (Rivera-Rivera et al., 2016), side effects of the medication (Abas et al., 2014), lack of social support (Amiya et al., 2014; Kingori et al., 2015), and food insecurity (Bhatia and Munjal, 2014). Therefore interventions addressing these issues have been recommended.

This case study illustrates how a culturally sensitive group support psychotherapeutic (GSP) intervention is used as a first line treatment for depression among people living with HIV in Uganda.

### 3. INNOVATION IN INTERVENTION

Dr. Etheldreda Nakimuli-Mpungu, a psychiatric and senior lecturer in the Department of Psychiatric Makerere University and her colleagues started the Social, Emotional and Economic empowerment through Knowledge of Group Support Psychotherapy (SEEK-GSP) project. The project aims at narrowing the treatment gap for depression among people living HIV using group support psychotherapy delivered by trained lay health workers.

*“This project was formed after the successful developing and testing of group support psychotherapy, a culturally sensitive psychological treatment that we use as a first line treatment for depression among persons living with HIV/AIDS”* . (Dr. Etheldreda Nakimuli-Mpungu, Principal Investigator)

Based on the high rates of mental health disorders among people living with HIV admitted at Butabika national referral mental hospital coupled with limited mental health care services in HIV clinics in Uganda, Dr. Etheldreda saw an opportunity to address these issues.

*“We realised that patients were coming from the HIV clinics that were scattered all over the country and we realised there was no mental health care in those clinics. ...so they (patients) progressed to become severe and it is only when the person became overtly psychotic and they were shouting or they attempted suicide that the health workers were able to notice. And the action then was to refer to Butabika Hospital. Then I realised we need to research mental health in HIV centres that are scattered around the country”* . (Dr. Etheldreda Nakimuli-Mpungu, Principal Investigator)

The project team is comprised of persons with diverse health care professionals, including a psychiatric clinical officer, a psychiatric nurse, a social worker and psychologist. The project was first implemented in Northern Uganda and has also been scaled up to other areas in Uganda, both in rural and urban settings. The project involves group support psychotherapy sessions that treat depression among people living with HIV by enhancing emotional and social support networks, the ability to practice positive coping skills, and income-generating skills.



### 3.1 Cultural appropriateness of the group sessions

The psychotherapy groups are gender specific and facilitated by lay health workers of the same gender because problems faced by men and women differ. This enhances active participation and promotes problem sharing within the groups. These gender specific groups may explain the high level of engagement of participants completing all the eight GSP sessions, estimated at 80%.

### 3.2 Task-shifting

Task-shifting approaches, through use of non-specialist health workers in health facilities and community settings to deliver mental health services have been recommended by the world health organisation (WHO) (WHO, 2008) and mental health researchers (Patel et al., 2011). Standardization and simplifying these task-shifting approaches ensures that non-specialist health workers effectively offers the services. Every village in Uganda has lay health workers or Village health team (VHT) members who offer health promotion and education activities, mobilize communities for utilization of health services, distribute health commodities in the community and among others (MOH, 2010). Group support psychotherapy sessions are facilitated by trained lay health workers and supported by the trained health workers at the health facilities.

### 3.3 Training in income generating skills

Poverty and food insecurity in households of people living with HIV is reported to increase the likelihood of depression (Tsai et al., 2012). As a result, interventions aimed at improving the livelihoods of people living with HIV are recommended. The SEEK-GSP project enhances the livelihoods of people living with HIV in the Northern Ugandan districts by engaging them in income generating activities. The participants form livelihood groups and/or business activities such as planting food crops and selling the produce or baked goods. They are able to attain improved financial independence and access basic needs unlike before.

## 4. IMPLEMENTATION

### 4.1 Innovation in implementation

The SEEK-GSP project was first implemented in Kitgum district and then scaled to other two districts in Northern Uganda namely; Gulu and Pader. These districts experienced a civil war which lasted for two decades (1987-2007) and was characterised by murders, rape, loss of lives and property and breakdown of health care system. This instability led to high poverty rates, risky behaviors including excessive alcohol consumption, and sexual violence making the population highly vulnerable to depression and HIV/AIDS (Delavande and Cordeiro, 2012).

Lay health workers or VHTs play an important role in providing health care services to the population, as they are the first level of contact for health care delivery in communities in Uganda (MOH, 2010). These lay health workers are affiliated to the public health facilities.

The SEEK-GSP intervention does not require ongoing input from expert mental health practitioners. Instead, trained lay community health workers (CHWs) identify and treat individuals with depression through village-based weekly GSP sessions under the supervision of trained health workers. This empowers local communities to take control of their own mental health needs. The GSP training program consisting of both formal and informal training sessions was developed by Makerere University in collaboration with the Ministry of Health.

Community advisory boards are formed, that monitor community satisfaction with project operation activities and provided feedback to the project team in real time on any conflicts or dissatisfaction arising from project implementation activities. This ensures retention of participants in the project.

### 4.2 Recruitment and selection

#### Stakeholder engagements

At inception, the project team holds stakeholder meetings with the district health officials, health facility managers, religious leaders and community leaders in the participating districts. The purpose of these meetings is to explain the objectives, benefits and procedures of the project to the stakeholders.

Through engagements with district health official and health facility managers in the initial three districts, 10 public health facilities that were offering HIV care and treatment services

were selected. The eligible health facilities were randomly assigned (1:1) to have their lay health workers trained in the delivery of GSP (intervention) or group health education (GHE) (control) to people living with HIV with mild to moderate depression.

### **Training of trainers and lay community health workers**

The health facility managers of the selected health facilities the nominate health workers and lay community volunteers to participate in the project. These selected individuals have an interest in learning an additional skill, are respected in the community, and are willing to commit at least two hours of their time per week to lead the GSP sessions. The project team trains the health workers for 5 days on the following topics; introduction to the GSP model, introduction to depression and HIV/AIDS, basic counselling skills and effective coping strategies, basic livelihood skills (enterprise selection, basic financial skills, and resource mobilization) required to overcome poverty, and self-care strategies. The trained health workers then give health education to their clients at the HIV clinics and also identify persons with depression. These persons with depression are then enrolled to the groups.

The trained health workers on the other hand also trained the lay community health workers attached to their health facilities. The CHWs are then able to identify persons living with HIV with depression and treated them using the weekly GSP sessions.

### **Group support psychotherapy (GSP) sessions**

The GSP is delivered in 8 sessions, one per week lasting for about 2-3 hours. Participants are grouped into gender specific groups of 10-12 participants with a facilitators of the same gender.

The first session is introductory: it addresses issues relevant to group process ground rules and the therapists address participants' expectations. At the end of this session, the participants are paired and are asked to visit one another. They are required to share their experiences in the next session.

The second session is about psycho education where participants are educated about depression, how it is related to HIV and how it could be treated. At the end of the second session, participants are asked to educate any member in the community about what they have learnt.

Sessions 3-4 are about problem sharing: the participants share their problems in the group and they receive feedback from group members. These sessions are supervised by the trained health workers who assess the lay health workers' basic counselling skills using a supervision checklist.

*“It is after those two sessions when people have expressed their problems, (and) they have released their anger, their pain, that you see people changed physically”* . (Dr. Etheldreda Nakimuli-Mpungu, Principal Investigator).

In sessions 5 and 6, the participants are taught about coping skills. At the end of this session participants are asked to practice what they have learnt to the community. The last two sessions (7-8) focus on helping participants to acquire basic livelihood skills that would enable them to identify income generating activities and improve their income levels. These two sessions were requested for, by the community:

*“They told us, okay doctor, you want to help us with depression but don't you see the poverty in which we live. We are so poor and even that make us depressed. They said if you want people to come to this intervention for depression, then you must also teach us how to come out of poverty (···) we thought about teaching them skills and they come out with their own idea and they have been able to improve their income”* . (Dr. Etheldreda Nakimuli-Mpungu, Principal Investigator).

### 4.3 Organization and people

The project lead and principal investigator is Dr. Etheldreda. The project team includes a psychiatric clinical officer, psychiatric nurse, social worker and psychologist. An advisory committee also ensures that activities are being implemented appropriately.

Initially the project was implemented in Kitgum district, but it was later extended to other districts in Northern Uganda through funding from Grand Challenges Canada. Through this work, Dr. Etheldreda earned herself the 2016 Elsevier Foundation Award; a Presidential National Independence Medal of Honor in 2016 and she was recognised among the 100 most Influential & Inspiring Women of 2020 by British Broadcasting Corporation (BBC).

## 4.4 Cost considerations

This project was made possible through grant funding from Grand Challenges Canada and the MQ Mental Health Fellowship Award. In terms of participant expenses, every participant receives light refreshments and a transport facilitation equivalent to 6 USD.

## 5. OUTPUTS AND OUTCOMES

### 5.1 Impact on health care delivery

The project was evaluated using the most rigorous scientific study designs. The project team conducted a 109-person pilot randomized clinical trial (RCT) that evaluated group support psychotherapy for depression treatment in people with HIV/AIDS in northern Uganda. The findings showed that at 6 months after end of treatment, participants in the intervention (GSP) arm had lower mean depression scores compared to those in the control (group HIV education, GHE) arm (Nakimuli-Mpungu et al., 2015). Therefore GSP was more effective than the control intervention in reducing depression symptoms and increasing functioning levels.

The project team also conducted a 1140-person cluster randomized clinical trial which evaluated the effectiveness and cost-effectiveness of Group Support Psychotherapy delivered by trained lay health workers for depression treatment among PLHIV (Nakimuli-Mpungu et al., 2020). This evaluation of the programme included 30 health facilities which offer HIV care and treatment. These facilities were randomly allocated the trained lay health workers who delivered GSP sessions in intervention arm or GHE sessions in the control arm. Following the eight-week programme, with data from almost 1,500 participants, the researchers were able to assess the effectiveness of the intervention. Six months after the intervention, only 2 (<1%) participants in the GSP arm were diagnosed with major depression compared to 160 (28%) in the GHE arm. Therefore this indicated that GSP was effective in the treatment of mild to moderate depression, with almost everyone achieving remission within six months. In addition, the participants remained free from symptoms of depression up to 12 months later. Interestingly, a greater effect was observed among males than females. The group support sessions also reduced symptoms of post-traumatic stress, alcohol use, HIV-related stigma, and improved social support and self-esteem. The researchers also found that those who attended the sessions showed clinical health improvements, as well as mental health improvements, with

improved adherence to anti-viral treatments and suppression of the HIV viral load. This means that affected individuals were less likely to transmit HIV to others.

*“this evaluation we have done makes us confident that group support psychotherapy treats depression and in persons with HIV, it will not only treat depression but it will also improve their adherence and viral suppression and thus improving their overall outcomes and contributing to the prevention of the spread of the virus”* . (Dr. Etheldreda Nakimuli-Mpungu, Principal Investigator)

## 5.2 Community and patient experiences

The SEEK-GSP project has reached over 3000 people living with HIV/AIDS over the past 5 years. The experiences of the beneficiaries, the lay health workers, and the health workers are all positive. The beneficiaries express how GSP has made it possible for them to overcome symptoms of depression and improved their mental health, physical wellbeing and adherence to antiretroviral treatment. Beneficiaries also maintain their income generating groups for a long time and request for the intervention to be extended to all villages.

*“By the time I was enrolled into this counselling (GSP session) I was hopeless. I knew there was nothing left for me as an HIV positive person (but death). But when I enrolled into this program, it empowered me to gain confidence and started taking my medication. I also started investing each year in laying bricks and practicing agriculture and I now buy a cow every year. This project has helped me to realize that there is some importance in life.”* (Male beneficiary)

The project empowered the participants to become confident and they were able to overcome self-isolation practices.

*“This training (GSP sessions) came in and gave me confidence. I stopped isolating myself from others and I started mixing up freely with the community”* . (Female beneficiary)

The hospital administrations also expressed their satisfaction with the project’s impact of treating depression among their clients and supporting the hospital in following up the clients.

*“It helped the hospital a lot because patients (PLHIV) were able to support themselves. Patients who had psychosocial problems were able to counsel themselves with the support and training given by the SEEK-GSP staff. SEEK project supported the hospital in following up some of these patients in their homes and support them from there including referrals” . (Former Hospital administrator, Kitgum Hospital)*

The GSP training session have benefited communities in Northern Uganda. As a result, this has led to a strong relationship between SEEK-GSP project and the community. People expressed concerns of the project being extended to other villages. The beneficiaries of the project also showed interest for membership continuity even after the end of the project activities.

*“Many community members want SEEK-GSP to be extended to the other villages. Actually they want to be continuously in the groups because it is helping them. Even the people who have not benefited from the group they see that some of their friends they are living positively then they also want those groups to also help them. That is why sometimes they can call VHTs that SEEK-GSP should go deep to the villages” .*  
(Ouma Nelson, Coordinator SEEK GSP project)

## 6. SUSTAINABILITY AND SCALABILITY

The SEEK-GSP project has mainly depended on grants, but some aspects of the intervention have been demonstrated to be sustainable. The project actively engaged the MOH, health district officials and health facility managers in the study districts. This facilitated integration of project activities into the existing public health system in Northern Uganda. Further, the use of community health workers who already exist within the health system, to provide GSP is also a sustainable approach. Finally, the improved access to economic resources through group savings and new income generating skills learned by the participants, facilitates their retention in these groups beyond the psychotherapy intervention.

The GSP intervention was first implemented in Kitgum district in Northern Uganda, and was scaled up to Pader and Gulu districts. The project team has published nine research papers in peer-reviewed journals. These results have excited other organisation who are prompted to support scale up this intervention. The project team received funding in 2020 from the

Infectious disease institute (IDI) to train health workers to delivered GSP sessions among depressive PLHIV in health facilities in urban-poor settings of Kampala, central Uganda. The project team was also contacted to offer GSP training to eight health facilities in Mukono district, Eastern Uganda, however, this process was affected by the COVID-19 pandemic.

The project team has ambitions to scale up the intervention and reach more people, cover a wider geographical area and to increase the variety of service offered through a 'Freemium' model. They hope to achieve their goal of providing the service at no cost, or a greatly subsidized cost, to low income beneficiaries, while allowing others in higher socio-economic categories to access GSP techniques via an online platform and pay premium rates to meet the cost of providing the service.

## Implementation lessons

### 6.1 Implementation lessons

#### Responding to a need

The idea of this project began during Dr. Etheldreda's job as a young medical officer at Butabika national referral mental hospital. She realised that most of the patients with mental health problems referred at this hospital were people living with HIV/AIDS. In addition, there were no mental health clinics in HIV care and treatment centres in Uganda. Her next step was to master in mental health to gain more knowledge in this field. Her PHD study on depression and how it is associated with adherence to antiretroviral therapy among PLHIV, Dr. Etheldreda Nakimuli-Mpungu and her colleagues found that PLHIV with depression were less likely to take their antiretroviral treatment as prescribed.

As the WHO recommends psychotherapy as a first line treatment for depression among PLHIV, the project team set out to explore the effect of group support psychotherapy delivered for treatment of depression among people living with HIV /AIDS in Uganda.

#### Maintaining efforts

Establishing strong relationship with the MOH and local governments was crucial in the development and acceptance of the SEEK GSP project. For both sustainability and cost minimization, the project utilizes existing health workers at both the facility and community



level. Monitoring of the project activities was made easier by establishing community advisory boards.

### **Overcoming challenges**

*“There is a lot of stigma in mental health issues. People thinking that it is not something to address and people just feeling offended by the fact that you are suggesting that the cohort of patients they are taking care of have mental health issues”* . (Dr. Etheldreda Nakimuli-Mpunga, Principal Investigator)

One of the biggest challenges faced during initiation of the project was trying to convince some stakeholders, including HIV research programs in Uganda, to conduct studies on the mental health of the patients under their care. This is because mental health was not necessarily considered a priority. Eventually the project was successfully implemented in public health facilities which are accessed by most people living with HIV/AIDS in Uganda.

### **6.2 Personally lessons**

Dr. Nakimuli-Mpungu is an ambitious clinician who would like to extend depression related care to all people who need it. The effectiveness of the GSP intervention drives her work harder every day. However achieving these results comes at a cost of frequently spending time away from her family.

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