YOU BELONG UGANDA

June 2021

"YOU MADE US STRONGER"

A MID TERM EVALUATION REPORT ON PROJECT 500

A 5 Weeks Pre and Post Discharge Intervention, under COVID-19 Conditions, to Resettle 500 Persons from the National Mental Hospital, Kampala, Uganda, to Family and Community Care

With generous Support from

standard chartered

Ambasáid na hÉireann
Embassy of Ireland

absa

Edith Kebirungi | Eric Odoki | David Cappo

‘You Made Us Stronger…’

said a mother of a 35 years old woman recovering from Bipolar Affective Disorder

A MID-TERM EVALUATION REPORT ON PROJECT 500

A 5 Weeks Pre and Post Discharge Intervention, under COVID-19 Conditions, to Resettle 500 Persons from Butabika, National Mental Hospital, Kampala, Uganda, to Family and Community Care

Edith Kebirungi (BA. SWASA), Eric Odoki (BA. SWASA)
David Cappo BA (Soc. Wk)

A Publication of YouBelong Uganda

‘You Made Us Stronger’; A Mid-Term Evaluation Report on Project 500

A 5 Weeks Pre and Post Discharge Intervention, under COVID-19 Conditions, to Resettle 500 Persons from Butabika, National Mental Hospital, Kampala, Uganda, to Family and Community Care

Cover Design and Layout: Philip Odoi

Published by
YouBelong Uganda
P.O Box 36510 Kampala, Uganda
www.YouBelongCommunity.org
ugoffice1@youbelongcommunity.org

The YouBelongHome Survey Team

Conducting the survey, analysis of data and preparation of this report, was undertaken by the following YouBelongHOME team members at YouBelong Uganda.

Kenneth Ayesiga - *Occupational Therapist and Team Leader*
Edith Kebirungi - *Senior Social Worker*
Eric Odoki - *Social Worker*
Philip Odoi - *Social Worker*
Ethel Birungi Nsangi - *Social Worker*
Isaac Mpairwe - *Community Mental Health Nurse*
Innocent Ntabazi - *Community Mental Health Nurse*
Winnie Wanyenze - *Community Mental Health Nurse*

Technical Director: Dr Byamah B. Mutamba.

Chief Executive: Monsignor David Cappo

Table of Contents

Table of figures

ACKNOWLEDGEMENTS

Project 500, an emergency response during COVID-19 times in Uganda, by YouBelong Uganda, is made possible by the generous support of:

- A grant from the Embassy of Ireland to Uganda
- A grant from Standard Chartered Bank of Uganda
- A donation of Personal Protective Equipment (PPE) from ABSA Bank Uganda

YouBelong Uganda acknowledges with deep gratitude your generous support, concern for vulnerable Ugandans and their families during the COVID-19 crisis, and your concern for the economic, social and mental wellbeing of the community of Uganda.

Monsignor David Cappo

Chief Executive, YouBelong Uganda

FOREWORD

The work of YouBelong Uganda is very unique. It is different from most other NGOs working in mental health in Uganda.

YouBelong wants to help build a responsive mental health system in Uganda, for children, youth, and adults, and its vision is that the system will have four pillars;

1. The person in recovery from severe mental illness, and their lived experience, need to be placed at the centre of mental health policy and programme development.
2. Families, must be seen as an essential part of community based mental health care. And they need to be provided with different types of support to help in the recovery of their family members' mental illness, at home and in the local community.
3. Health care workers trained in mental health care need to be spread throughout the range of Health Centres in Uganda. Community based mental health care needs to be integrated into the health care system.
4. A balance between short term hospital care for people in acute stages of severe mental illness and family/community mental health care.

YouBelong Uganda has a strategy to help build these four pillars, as it works closely with the national mental hospital, Butabika, and the Ministry of Health.

In this time of COVID-19, YouBelong is helping Uganda in the best way it can through PROJECT 500, as described in this report. Working closely with Butabika Hospital, and the Ministry of Health, PROJECT 500 will save lives, support many families, and help many people as they recover from mental illness.

The recommendations in this evaluation report need a serious response, and they are submitted for your attention. They are written by people who are proud of Uganda, and want to see it successfully respond to the devastation caused by COVID-19.

Dr. Nathan Kenya-Mugisha

Chair, Board of Management

YouBelong Uganda

June 17 2021

ADDENDUM

By early June 2021, the Government of Uganda announced that the country was experiencing a second wave of COVID-19, with a significant increase in infection rates and associated deaths. Notably, infection rates have increased amongst patients and health care personnel at Butabika National Referral Mental Hospital.

This has resulted in YouBelong Uganda needing to further scale up the return rates of patients out of the hospital, back to their families and local communities.

The new target of Project 500, evaluated in this mid-term report, is to increase the return rate of patients to a minimum of 50 patients a week, from the overcrowded national mental hospital to their families.

Further innovations will be made to the YouBelong Uganda 'pathway of care model', in order to reach this target while maintaining a low relapse rate, as service users recover from severe mental illness.

This revamped model of care, is an emergency response, adapted to achieve the 50 per week rate for return and support, and it will be evaluated and reported upon in approximately six months' time.

The findings noted in this mid-term evaluation report, will be invaluable in shaping the new Project 500 target.

EXECUTIVE SUMMARY

Between March 2021 and May 2021, the Ugandan registered NGO, YouBelong Uganda (YBU), undertook a phone survey of 76 persons (an additional 17 persons could not be contacted by phone), who were returned from hospital care to home care in the period July 2020 to December 2020. This survey was a mid-term evaluation of PROJECT 500, a project to move 500 people out of the overcrowded (often over 900 patients in a 550 beds facility), national mental hospital in Kampala, Uganda, in COVID-19 times, and return them to family care. To date, over 170 persons have been resettled. With the recent addition of a second YBU mini- bus, the rate of returns to family care will increase considerably over the next 6 months.

The project aims to increase the safety of these patients by resettling them with their families, and increasing the safety of remaining hospital patients, health care and ancillary personnel who work at the hospital, by helping to reduce the hospital's total population, during COVID-19 conditions.

This evaluation of Project 500 will inform further refinement of the YBU pre and post discharge program in order to increase its effectiveness in resettling its service users, facilitating community-based recovery from severe mental illness, and further reducing relapses (recurrence of illness symptoms) and readmissions to hospital and institutional care.

YBU streamlined its usual 16 weeks pre hospital discharge assessment and post discharge family empowerment programme to a 5 weeks programme. This was necessitated by the need for an emergency response to the threat of COVID-19 to the hospital, its patients and personnel. YBU developed a triage system to use the shortened 5 weeks' intervention with service users with less complex mental health conditions as distinct from the 16 weeks' intervention for the more complex conditions. Initial results show a high rate of efficacy of the 5 weeks pre and post intervention model.

Key survey results highlight a low number of relapses and readmissions in the survey group. As well, thirteen out of the fourteen relapses were able to be managed by family members at home, following mental health education, and skill and capabilities building by the YBU team of social workers, community mental health nurses, and occupational therapists. This is a significant finding, as relapses are more often than not accompanied by a return to hospital, when no post discharge family support is available.

Relationship building, developing a sense of belonging to family and local community, targeted psychosocial support, skill development and capabilities building in the family unit by the YBU team, were viewed by the survey group as essential components of successful relapse management at home. Survey results highlighted some key themes for further attention.

- The key role of psychosocial support in building resilience and capabilities in persons and their families in mental health recovery.
- The high correlation between young people (mainly males) in the survey group, and alcohol and substance use, and mental ill health. Survey respondents suggested that the availability and use of alcohol and various substances amongst young people, is high, particularly in Kampala.
- The vital importance of an uninterrupted supply of medication in the health system, noting that breakdowns in the supply chain for medications to health facilities are not uncommon. Of note, was the importance of monitoring the person's daily medication regime by their family, as well as assistance in coping with medication side effects. As well, the cost of transport to health facilities in order to obtain medication refills is a significant factor in the interruption in persons' medication regimes.
- The need to build mental health capabilities in local health centres, particularly for young people's mental health needs.
- The importance of maintaining an active and productive lifestyle for people recovering at home from severe mental illness is seen as an imperative, particularly activity that is income producing. Yet, survey results were clear that many barriers exist to achieving income generating activity, the main one being the lack of some finance to 'kick start' a particular activity.

The ongoing use of both the 16 weeks and the 5 weeks' model of intervention, within a triage strategy, in PROJECT 500 in COVID-19 conditions, is supported by this survey. A further phone survey will be conducted in 6 months' time to continue the evaluation process.

RECOMMENDATIONS

1. That the FAMILY UNIT as the ACTIVE AGENT of care and support for persons with disabilities, including mental illness, be recognized for their essential caring role and that the Government of Uganda, consider policy development to support these particular families. An income support programme might be considered with a monthly grant of basic food to families with disabilities. YouBelong Uganda to write to the Government and advocate for a policy discussion about this initiative.

2. That the Government of Uganda be requested to develop an INTEGRATED PLAN to respond to the economic, social, health, and mental wellbeing impact of COVID-19. And that this plan should particularly target the needs of people with disabilities such as mental illness. YouBelong Uganda to engage in discussion with the Government of Uganda about this recommendation.

3. In order to maximize the effectiveness of limited resources in the mental health system, that a priority focus be given to the development of policies and services for early diagnosis, early intervention, and prevention, particularly for children and adolescents.

4. That the mental wellbeing needs of children in Uganda, having increased in COVID-19 conditions (including the disruption of their schooling, isolation from their school community, and emotional upheaval and uncertainty in the future), be addressed through specific action as follows:
    A. The development and implementation of an IT'S TIME FOR HOPE seminar programme for both primary and secondary schools, and in religious institutions. And that these seminars particularly attend to emotional wellbeing, mental health, self-confidence building, a sense of security, and resilience, and prevention of alcohol and substance use. The use of the YouBelong Uganda FAMILY MAPPING AND RESOURCE MAPPING tools be recommended.

    B. Policy discussions to consider ways to integrate mental health services, specific to children and young people into the broader health system.

5. That a SCHOOL BASED EDUCATION AND RESILIENCE BUILDING PROGRAMME ABOUT THE DANGERS OF DRUGS be developed as a priority, considering the high-level access and use of substances, by young people, particularly in Kampala and neighboring districts.

6. That dialogue occurs with groups of traditional and faith healers to explore possibilities for cooperation and collaboration in a more holistic health response to mental illness in Uganda.

7. That advocacy to the Government of Uganda occur to request a review of the policy regarding the supply of mental health medications to the various levels of health centres, in order to ensure continuity of supply and training of health centre personnel in treatment, and prescribing of medications.

8. Noting the vital importance of productive activity, particularly INCOME GENERATING ACTIVITY (IGA) in the mental health recovery process, that discussions be held with financial institutions in Uganda, to develop a model for an IGA FINANCE FUND for mental health recovery, and a pilot study be commissioned.

9. That the COVID-19, 5 weeks' emergency 'hospital to home' programme developed by YouBelong Uganda, continues to be implemented and further validated in reducing relapses and return to mental hospital care. And that the 5 weeks pre and post discharge programme be inserted into more formal research grant applications by YouBelong Uganda.

1.0 INTRODUCTION

The COVID-19 pandemic has severely impacted on the social and economic life of families and individuals.[1] General health and mental health needs have increased amongst adults and children in the community. Fear, anxiety, and a sense of loss of control over one's life, continue to abound in Ugandan society. While this experience is not unique to Uganda, low-income countries such as Uganda magnify the impact, seen in increased levels of poverty, social stress, and high pressures on the health system. As a result, vulnerable people such as Ugandans with severe mental illness become even more vulnerable, as do their families.

YouBelong Uganda (YBU), was founded in 2016, to assist people with severe mental illness ready for discharge out of the national mental hospital and to empower, and support them and their families to recover from their illness at home and in their local community. Imbedded in this work is the YBU focus on helping to build a community based mental health system in Uganda to provide sustainable long-term care.

As an emergency response to the influx of persons with mental illness at Butabika National Referral Mental Hospital during COVID-19 times, YBU developed and implemented PROJECT 500 to quickly and efficiently transition up to 500 ready-to-discharge persons back to their families and communities (Project 500), while maintaining high standards of care and ensuring minimum relapses and readmissions to hospital. A 5 weeks pre and post discharge process for less complex illnesses was developed to increase patient outflow from the hospital, keeping the long standing YBU 16 weeks' process for more complex conditions.

Butabika National Referral Mental Hospital is a 550 beds facility but the inpatient population fluctuates between 900 to over 1000 patients, at any one time. The danger of Covid-19 to the hospital is high, noting the high population and overcrowded facility of patients, together with doctors, nurses, and other personnel.

A serious concern is that if COVID-19 enters the hospital, it could so severely impact on patients and hospital staff, as to cause a critical health crisis and the possible closure of the hospital. Avoiding these outcomes is an imperative for both the hospital and YBU.

Often, the YBU team of community mental health nurses, occupational therapists, and social workers needs to trace the families of patients, who display reluctance to have their family

[1] YouBelong Uganda, *A RAPID COVID-19 RELATED PHONE SURVEY of individuals and families who have been supported by the YouBelong Uganda community based mental health programme in Kampala and Wakiso Districts, Uganda, May 2020*

member returned home. This reluctance is often triggered by fear of destructive behavior, a lack of finances to feed an extra person, fear of the stigma associated with having a family member with mental illness, and cultural beliefs about the cause of mental illness.

Once contacted, a dialogue with the family begins to assist them to come to the decision to have their family member returned to home based care. The YBU team then prepares the family member to be returned home. YBU works with the person discharged and their family to minimize relapses and return to hospital. Without this latter emphasis, the emergency work of YBU would be futile as we would simply be 'turning a revolving door'!

It is important that we learn more about the progress of Project 500 and our emergency 5 weeks pre and post discharge intervention, and evaluate it to confirm its effectiveness in reducing relapses and readmissions to the national mental hospital, Consequently, the YBU team conducted a phone survey to evaluate outcomes of Project 500 among individuals and families with whom it has worked from July 2020 to December 2020.

This report presents key findings and lessons learned from the Project 500 programme. The evaluation report will be used to continuously refine and improve the programme, so that we can increase the rate of returns, and ensure a high level of recoveries within family and local community.

2.0 THE 3 GOALS OF PROJECT 500

2.1 Goal one

The first goal of Project 500 is to engage up to 500 people from the national mental hospital and return them to their families, as quickly as possible.

2.2 Goal two

The second goal is interconnected with the first. It is vital that hospital patients who are returned home, are provided, together with their families, with the supports to minimize the occasions of relapses. However, if relapses occur, the goal is to manage these relapses in the home and prevent as much return to the hospital as possible. This second goal, added to the first, maximizes the projects attention to the primary issues of care for the lived experience of the person in mental health recovery, their active role in their own recovery journey, and their human dignity and human rights. As well, the second goal accentuates the vital role of family support and care, as a key component of the mental health recovery process. In a low-income

country such as Uganda, the role of a supportive family is accentuated as essential, in a low resourced health system.

Without any consideration of goal number two, the movement out of hospital of patients would be faster and easier to accomplish, but the achievement would be very short term, as most patients without proper supports would be returned to hospital in a very short period of time. Project 500 could achieve superficial results and have seemingly impressive return rates, but the personal cost to service users and their families would be too high.

2.3 Goal three

The third goal of Project 500 is to learn from the persons with lived experience of severe mental illness, and from their families, so that YBU can continue to innovate in building mental health services in Uganda, particularly in the community.

3.0 METHODOLOGY

Using an interview guide developed by YBU (appendix 1), the team conducted a phone survey of service users and their primary carers, with whom the YBU team had worked and who had spent three months to six months in family home care, during the period July 2020 to December 2020.

Service users and their family members who fulfilled the above criteria were identified from YBU data. The YBU team contacted each identified service user and their family, by phone. The aim of this initial phone call was to inform the main family carer and service user about the planned survey, the purpose, process, invite them to participate, and discuss the need for informed consent to participate in the survey.

Following receipt of informed consent from the main carer and service user, the YBU team member proceeded to conduct an interview using the guideline document.

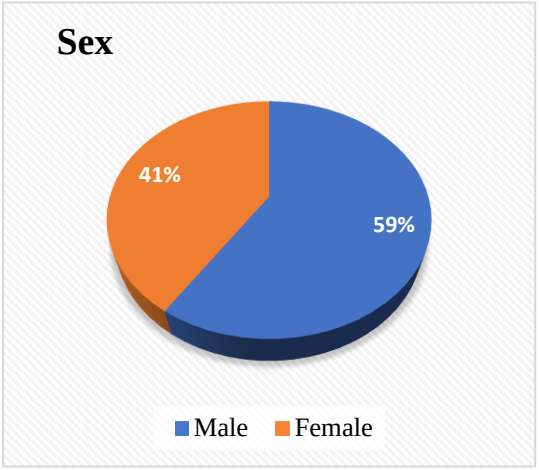
4.0 RESULTS

At the time of completing this survey (May 2021), Project 500 had resettled 159 persons living with severe mental illnesses back with their families and into their local communities. Of these, 146 persons have gone through the 5 weeks pre and post discharge programme and 13 persons with more complex needs have gone through the 16 weeks of the YBU pre and post discharge programme.

The innovation of the YBU 5 weeks programme for less complex needs of patients with severe mental illness has shown a breakthrough statistic, although the survey sample size is small. Further analysis will be required.

Survey data shows that post discharge, and between 3 to 6 months of family home care, only 1 out of the 14 relapses in the total of 76 surveyed persons, led to a re-admission to hospital care. This may appear to indicate that these families had developed the capability to manage the relapse at home, and the returned family member possessed the ability to function and move through relapse to continue recovery in the family home, and avoid returning to hospital. If this result can be verified in further evaluation, and can then be replicated and upscaled, a shift away from the near exclusivity of hospital based mental health care to family care might be able to be facilitated in Uganda.

4.1 Socio-demographics



The survey results come from 76 families successfully contacted out of a total of 93 families. More than half (59%) of the respondents were males (see figure 1), a statistic that is consistent with the inpatient populations at the hospital where more male than female patients are admitted. However, the proportion of females is notably high (41%) highlighting the burden of severe mental illness among women.

Figure 1: Sex distribution of survey respondents

Most respondents were in the younger age group (see figure 2). Severe mental illness typically affects persons in late adolescence and early adulthood, probably the most productive years of one's life, setting forth a negative life trajectory that impacts on individual, family and community wellbeing. YBU aims to mitigate this, promote recovery and give individuals and their families the skills and capabilities for a productive and fulfilling life.

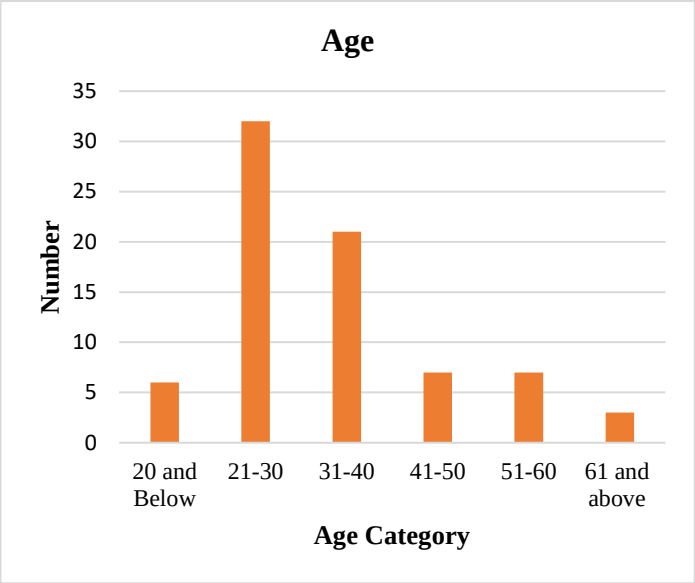


Figure 2: Age distribution of survey respondents

More than half of the survey respondents had been diagnosed with an alcohol and substance use related mental disorder (Figure 3), an indication of the prominent role played by psychoactive substances in mental ill health. This is discussed in more detail in subsequent sections.

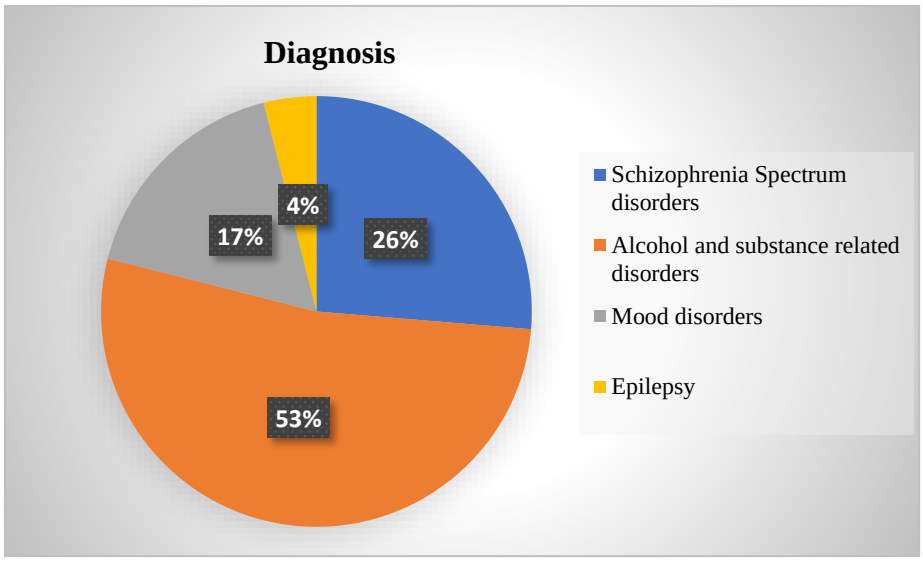
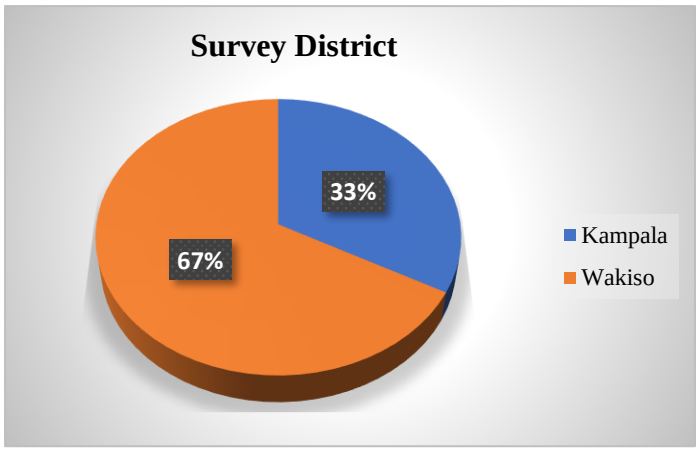


Figure 3: Illness diagnosis of survey respondents.



In keeping with the patient distribution at the national mental hospital, most of the respondents were from Wakiso district, in close proximity to the hospital (Figure 4).

Figure 4: Survey respondents' district of residence

4.2 Relapse and hospital readmissions

It is by monitoring the number of relapses of symptoms of severe mental illness, and readmissions to hospital for further treatment, that an analysis of the potential effectiveness of the YouBelong Uganda pre and post discharge tools, can be undertaken. This gives YBU further data to continue to refine its model of family/community-based care. In addition, this will give a strong indication of the current status of Project 500.

Sixty-two (82%) of the surveyed persons reported no relapse of the illness since they were returned home to their families by the YBU team, three to six months previously. This is a very high rate of successful recoveries without a relapse in the survey time, but further evaluation of this group, over a 12 months' period is required.

Fourteen (18.4%) service users of those returned to home care experienced a relapse of symptoms, and one person of this group of 14 persons required readmission to hospital for further treatment.

The one person who required hospital readmission received the 5 weeks programme.

In this small sample-size it would not be advisable to draw definitive conclusions, but the data could be indicative of 1. The benefit of triaging YBU service users as having either more or less complex mental health needs, and 2. The potential effectiveness of the 5 weeks pre and post discharge programme, produced as a result of emergency needs in COVID-19 times. 3. Once capabilities are increased in families, and with community-based support, the family's ability to manage relapses *in situ*, is enhanced.

Key themes emerged in the survey data

4.3 Alcohol and substance use

More than half of the respondents, (55%) had a diagnosis of alcohol and substance use related mental disorders and 64% of persons who relapsed were diagnosed with alcohol and substance use related mental disorders.

Results also indicated that 78% of young people aged 21yrs to 30yrs surveyed, had a mental illness associated to alcohol and substance use, and the majority (80%) were males.

Eight of the nine persons (89%) who resumed alcohol use after their return home, stated easy access to alcohol and substances in communities as the major cause of their relapse.

"*There are many youths who use drugs in our community; also, alcohol and substances are very easy to get. My son lost the motivation to stop using alcohol because of peer influence and easy accessibility,*" a mother of a 20 years old male from Wakiso district mentioned.

Sixteen of sixty-two survey respondents (26%) who did not register a relapse, attribute this partly to their own motivation, and their ability to reduce or stop alcohol or substance use following counselling and support.

"Substances of every kind are available in this community and many youth access them very easily and cheaply, marijuana is very available and no one is controlling people in this village from using it. I really don't know what the government is doing about this because it has become very common amongst youth," a carer of a young man in Wakiso reported.

Of concern is that families caring for persons recovering from alcohol and substance use related mental illness, often have a negative attitude towards being supportive. The affected persons are held solely responsible for their alcohol or drug related mental illness or addiction, and if they relapse, no further supports are provided to them. Just over a half (56%) of the young persons who resumed taking alcohol and substance use after discharge and return home, were not given any further family support.

"Currently, there is nothing we are doing to help him, we just watch him and make sure he doesn't hurt himself or another person," a carer of a 25 years old male in Wakiso commented.

"He was well for the first four months after working with the YouBelong team, he later started using substances again and mentally deteriorated, we also left him to do what he wants," a carer of a 29 years old male diagnosed with a substance use disorder mentioned.

However, although the scope of the survey did not allow further inquiry into potential solutions, it is clear from the survey, that:

- High motivation from the individuals concerned and their families,
- together with engagement with education and training about the support needs required for people recovering from alcohol and substance use,

can lead to a reduction or in some cases a stopping of alcohol/substance use. Family support and involvement in the recovery process is viewed as essential.

"*I have not consumed alcohol for three months following the education on the effects of alcohol consumption, it has helped me stay well and I hope to get better,"* said a 27 years old male recovering from severe mental illness in Wakiso district.

"YouBelong actually helped, he spent at least 5 months without using substances which had not happened for the three years he has been using, he also now works as a casual laborer which is good for him," a mother of a young adult recovering from mental illness said.

"When you people came and taught us the dangers of alcohol and other substances, it was something we knew about but you elaborated more and helped us understand how it can cause a mental problem, this education was very helpful to him and also other family members who use these things," said a father in Wakiso district.

4.4 Medication

4.4.1 The role of medication in the recovery of people living with severe mental illness

The social determinants of mental illness are well known and evidence based. Poverty, lack of adequate housing, family disruption, health issues, personal crises, stigma, unemployment, all play a role in the mental health status of persons, and responding to these factors is central to the work of YBU in assisting in the recovery process. Even so, the bio-medical component of treatment of severe mental illness, is normally an essential part of the treatment and recovery regime.

YouBelong worker and Hospital worker prepares medication for a Service user to be discharged

A large proportion (81%) of the families of the persons who did not register a relapse, stated that taking medication as prescribed by the health workers contributed to preventing a re-occurrence of signs and symptoms of mental illness.

"If you spend days without giving him medicine, he starts presenting with symptoms of mental illness but if he swallows it well, he maintains a good mental state," a carer of a 44 years old male from Wakiso mentioned.

"I think the medication has helped her a lot, she swallows it properly and doesn't miss to go for review, her sister-in-law helps her to go to the hospital and she even escorts her to get medication, she also takes the initiative to swallow the medication by herself," a main-carer from Kampala district replied.

Yet others struggle with incorporating medication into their recovery journey.

This study also shows that 64% of persons who relapsed attributed this to a failure to access medication when their monthly prescription supply finished. The national mental hospital distributes medication to persons in recovery who come for an outpatient review. However, reviews often do not take place as it is costly for most families to travel to the mental hospital every month. There are health facilities (particularly Health Centre II) that are close to most people, but these lower-level health facilities often do not have the range of mental health medications required. The distribution of medication according to the Ministry of Health places a broader range of mental health medicines at Health Centre IIIs and IVs, but these health centres are less numerous and at a further distance to travel for most people.

"*For the many times we have gone to the nearest health centre, we have not been able to get medication that was prescribed to manage my son's symptoms,"* a mother caring for her 23 years old son recovering from mental illness in Wakiso district mentioned.

"*If only we can be helped to bring epilepsy medication closer. It is very costly and tiresome to come all the way to the hospital for medication refill,*" a mother of a 19 years old male diagnosed with epilepsy commented.

"I wish you could help us get medication. We spend a lot of money on transport to the hospital to pick medication and remain with no money to buy the medicine in case we do not find it," a carer of a 36 years old female diagnosed with Bipolar Affective Disorder mentioned.

4.4.2. Outreach Clinics

The role played by Outreach Clinics conducted by mental health nurses from Butabika National Referral Mental Hospital.

Over half (56%) of persons who did not register a relapse indicated that they easily and consistently accessed medication at health centres where monthly outreach clinics were conducted by community mental health nurses from Butabika hospital. These clinics bring vital mental health services nearer to the families requiring regular medication. Families become aware when and where these outreach clinics operate and seek them out for medication and support. While these clinics are of small scale due to scarce resources, they indicate that:

- if large numbers of health personnel at health centres were trained in mental health diagnosis, prescribing medication, and treatment and,
- if primary health centres (HC IIs, IIIs and IVs) had the necessary mental health medication available with an uninterrupted supply,
- and organizational arrangements (both at a policy level and strategic planning level) were made at the district level of government to ensure mental health clinics were established in local health centres on a regular basis,
- and this plan was led by the Ugandan Ministry of Health, people and families in need of mental health support would make their way to access this local community service, and a regular community based mental health system, in

The YouBelong team visits Kira Health Centre III to inquire about the mental health services

addition to a mental hospital service, could emerge in Uganda. Currently, in Uganda and in most other African countries there is minimal community mental health service.

4.4.3. Medication side effects

Side effects that accompany certain mental health medications can influence a person's decision to take or not to take medication.

Educating persons in recovery about the management of side effects of medication is a crucial part of the YBU process of resettlement back with family. Almost two thirds (79%) of respondents reported that learning about the management of side effects was a contributing factor to proper medication adherence and a facilitating factor to living a functional life in the community.

"*You taught her how to deal with the side effects of the medication and this helped her a lot, she now takes her medication well, and she went back to live with her husband and take care of her children*," a mother of a 28 years old female from Wakiso district mentioned.

Medication adherence is also facilitated by monitoring medication intake by family members. More than half (57%) of persons in recovery who successfully managed a relapse at home, attributed it to supervising medication intake by their family, when they noticed signs of a relapse.

"*My sister had stopped taking her medication without our knowledge, we then started monitoring her medication intake, counselled her and she stabilized,"* a carer mentioned.

"She lost motivation to swallow medicine, this affected her because I realized she started talking uncoordinated words which forced me to find out if she was really swallowing medicine, I learnt that she used to throw it behind the fridge whenever I gave it to her," a mother from Kampala reported.

4.5 Psychosocial support in the family home

At the centre of effective recovery from severe mental illness and minimizing relapses and readmissions to hospital is:

- Engaging, and building a relationship of care and trust with persons recovering from severe mental illness, and their families,
- Empowering, skilling, and enabling persons and their families to learn how to live day to day with the mental illness, in a recovery process,

- Assisting them to increase their capabilities as individuals and as a 'whole of family' unit.

This involves teaching families about mental illness (signs and symptoms, possible causes, treatment, early warning signs of re-occurrence of symptoms and early intervention), mental health crisis management skills (supporting persons in a state of relapse), guidance on encouraging and developing productive activity including income generation possibilities, enhancing good relationships and mutual support for persons in recovery within their families and local communities, linking families to local community resources such as village elders, other families who have had experience in managing mental illness, and local health facilities. It also involves adopting a broad perspective in assessing the health and wellbeing of all family members.

Respondents identified helpful interventions that were carried out by the YBU team to support their family member in recovery. The most helpful interventions included:

YBH team members conducting a session at a family home as they return a Service User (YBH team members seated on a bench)

- Education about mental illness and its management, which was mentioned by more than two-thirds (79%) of survey respondents.
- Enhancing relationships and mutual support, which was mentioned by almost a half (40%) of the survey respondents.
- Motivating persons to stop the use of alcohol/substances which was mentioned by a quarter of respondents (27%).

Survey results affirmed the YBU focus on interventions that increased the capabilities of families in supporting a family member recovering from severe mental illness.

"*I have learnt all the changes in my lifestyle that I need to make to maintain recovery,"* a 29 years old male living with mental illness mentioned.

"*You taught us better ways of handling him when he has relapsed, not to put him in chains,"* a carer of a 55 years old male with severe mental illness mentioned.

Family members welcome back their relative (Service user being hugged) from hospital care

"*Encouraging us to be more involved in our father's care such as visiting home more often at his home made a difference in his life, he is happier now,"* a young adult caring for his father with a mental illness, in Wakiso district said.

"*When we took him to Butabika hospital, we thought he would come back completely healed, now we know that his illness requires taking medication for the rest of his life and that symptoms may re-occur, we shall therefore support him better,"* a father to a 26 years old male from Kampala district mentioned.

"Yo*ur efforts made us realize that my daughter would become stable and functional in the community,"* a father to a 24 years old female living with severe mental illness said.

"*The knowledge and skills we acquired from you made us stronger and enabled us to live with our family member with mental illness,"* said a carer of a 35 years old female recovering from mental illness.

"*Connecting us to the nearby community outreach helped us get medication in time and at a lower cost, we did not know about it,"* said a paternal aunt caring for her 19 years old nephew in Wakiso district.

"*You equipped us with counselling skills that enabled us to continue counselling him,"* a carer of a 27 years old male from Kampala district recovering from a substance use disorder mentioned.

"*You have taught us how to manage him without hurting him in case he gets a fit,"* a carer of a 25 years old male living with epilepsy said.

"*Educating my sister about her mental health condition and the importance of taking medication well was a very helpful intervention for us,"* a sister of a 31 years old female living with severe mental illness mentioned.

"*We acquired enough knowledge and skills to support him at home, that is why he is still well, currently,"* a carer mentioned.

"*We thank you for bringing him home, we had searched for him all over for three years. We had given up on him thinking that he had died,"* said a father caring for a 32 years old male diagnosed with schizophrenia, from Wakiso district.

As well as psychosocial support from the YBU team, the family as a whole, is an important focus. The YBU team identify and build on the strengths of family relationships, as well as skills training, information and education about mental health, so that the family has the resources to be an active agent in the recovery journey of its family member.

YouBelong worker educates a family about medication adherence using a discharge form (Service user in a black dress, her grandmother and her mother)

More than three quarters (77%) of the persons who did not register a relapse in the survey time frame mentioned that support from their families helped them prevent a relapse. This support was noted as:

- encouraging them to take the medication,
- helping them engage in income generating activity,
- supporting them to access medication from the hospital,
- counselling them,
- accepting them into their family and community,
- providing them with basic needs. As well, the importance of the local community providing support.

"The emotional support from the husband which wasn't there initially has helped her not fall sick quickly, and we also spend time with her so that she doesn't get bored," a resident of Wakiso reported.

"*The community appreciates me for the good work I am doing to support my son to get better because my son has greatly improved, this motivates me a lot,"* a carer of a 34 years old male with substance use problems said.

"*My mother and I go to Church every Sunday for counselling, this helps us keep well,"* a 30 years old male from Kampala mentioned.

"*His employer encourages him to keep away from the use of substances and has given him a job,*" a mother to a 28 years old male mentioned.

"*His colleagues at his work place are aware of his mental illness; they always take the initiative to monitor his behavior and they contact me in case of any changes that could indicate early warning signs of relapse,"* a carer mentioned.

4.6 Productive Activity, Including Income Generating Activity (IGA)

Motivating and supporting the returned family member to be productive at some level, during each day, is very important in the mental health recovery process. The ideal is that the person engages in some income generating work, or full employment. A sense of productivity and connection to community enhances wellbeing, self-confidence, self-respect, and self-esteem.

Less than half (39%) of persons surveyed were able to engage in income generating activities (IGA).

YBH team member interacts with a Service user at her grocery stall during a post discharge visit

For those who were able to engage in IGA, supporting factors included;

a) support from family or local community to engage in IGA, such as connecting them to opportunities, giving them start-up capital, encouraging them to engage in IGA,

b) possession of skills that enabled them to find jobs,

c) enabling the recovery process by stopping alcohol or substance use.

"*He already had skills in construction and that helped him to easily find employment when he returned from the hospital,"* a carer of a 30 years old male mentioned.

"*My sons gave me capital and have helped me maintain my grocery business,"* a 44 years old female recovering from mental illness reported.

"*Her employers who are also her friends called her to work as a gardener in a hotel,"* a mother of a 34 years old female recovering from Bipolar Affective disorder mentioned.

"*He makes and sells bricks, his previous experience and interest helped him engage in this activity,"* a father of a 31 years old male from Wakiso district mentioned.

Yet, most (60%) persons surveyed were unable to engage in income generating activities.

Factors viewed as barriers to productive activity can be low motivation of persons in recovery, low level functioning due to the nature of their illness, the side effects of medication, a lack of opportunities, and a lack of finance to begin an income producing activity. The social and economic impact of COVID-19 is a current factor.

"He is still very weak; I don't think he can do anything," a carer of a 32 years old female from Kampala district mentioned.

"*We plan to start for him for some work in the near future when his medication dosage is reduced,"* a brother of a 27 years old male recovering from mental illness mentioned.

"*She has been working as a sales person in a dairy however the challenge is that she experiences side effects of general body weakness while at work,'* a brother of a 29 years old female from Kampala district mentioned.

YouBelong social worker encourages a Service user to engage in household chores while at home during a post discharge visit (Discharged person washing utensils)

However, of particular importance, is that 52% of persons who were unable to engage in IGA mentioned a lack of financial support to start up an income generation activity, as the main factor impeding their engagement with IGA.

Productive activity and IGA are vital components to mental health recovery and wellbeing. Both the economic and social impact of COVID-19 on the Ugandan community, make the challenge of developing innovations to promote IGA, an imperative.

"He is still very weak; I don't think he can do anything," a carer of a 32 years old female from Kampala district mentioned.

"*COVID-19 affected us so much, there are no opportunities to engage in income generating activities,"* a 27 years old male recovering from several mental illness reported.

"*He is not able to engage in any work because his employer laid him off due to the COVID - 19 effects,*" a mother of a 19 years old male recovering from mental illness in Wakiso district mentioned.

Innovations that would provide some mechanism for loans or grants to assist in 'kick starting' IGA, would be a major asset to the recovery of and integration back into community life, of people with severe mental illness.

4.7 Cultural understanding of mental illness

In this phone survey, respondents spoke of their involvement with faith and traditional healers, as well as their involvement with the national mental hospital and YouBelong Uganda.

Results from this survey indicate that 64.4% of surveyed families used traditional/faith healers in a bid to find treatment for mental illness; all of the 49 families that used traditional healers or faith healers, used them as the first 'port of call' and only sought care from the national mental hospital when symptoms persisted.

In Uganda, and throughout Africa and many other regions of the world, mental illness is placed in a spiritual domain. Its cause is interpreted within this domain as well as its treatment. Cultural norms, values, meanings, developed over generations, become imbedded in the way communities respond to their versions of realities.

YouBelong van at a Church during a community visit

The cause of mental illness is most often viewed within culture in Africa as coming from 'outside,' such as a curse or some type of disruption in a relationship with an

ancestral spirit. The person 'cursed' is a passive receiver of this 'curse' and assistance is sort from help within culture.

"My clan members sent me these spirits because I am the heir to my father's property. I plan to have a clan meeting to resolve this. I am on medication but I think I need to do traditional ceremonies to completely be well," said by a 56 years old male from Wakiso district diagnosed with bipolar disorder and substance use.

"We shall combine both traditional healer's treatment and the use of modern medicine to reduce the cravings of my son," said by a father of a 32 years old male recovering from alcohol induced psychosis.

"I think that my uncles sent me spirits since they made traditional ceremonies to make me the heir of my father's property, I need to put things right with my uncles to get full healing," said a 48 years old male recovering from chronic psychosis.

Traditional healers and faith healers, who are imbedded within local villages, and are an important part of local culture and communities, and they provide a response that is culturally acceptable to their community.

Herbalists, and various forms of spiritualists and prayer focused interventions, are all a part of the traditional and faith healer context. Some, who move to a more extreme context would be classed as local witch doctors, some of whom would be involved in inappropriate, harmful, if not criminal practices.

Traditional and faith healers are highly accessible to village communities and become de facto advisors and counsellors for people with signs of mental illness, as well as their families. They play a powerful role in shaping community views and understandings of mental illness. They are an important part of the informal health system in Uganda and other African countries.

As such, it is important that an evidence-based health system does not dismiss the role of traditional and faith healers in local culture. Consequently, it is the policy of YouBelong Uganda to acknowledge and collaborate where appropriate, with such healers, within parameters of ethical behavior that supports human dignity and human rights, and that is not harmful to people. The use of the YBU Safeguarding policy underpins its dialogue with faith and traditional healers.

5.0 DISCUSSION

In low-income countries such as Uganda, health systems have very limited resources to meet the health needs of their populations. The situation is more dire for mental health services which are sparce and scarce. What resources are available are often centred on hospital-based mental health services, with scarce funding allocation for community based mental health care. Nevertheless, the imperative for Uganda, like most other African countries, is to accelerate the shift away from near exclusivity of hospital-based care for people with severe mental illness, to community-based care. Ease of access to mental health services based in local communities, and imbedded in health centres throughout the districts of Uganda, needs to be an important goal. A strategic step in achieving this goal, would be the mobilizing of families of people recovering from severe mental illness, to be active agents of care.

Persons with severe mental illness have much better prospects of long-term recovery when they are supported in a family and community environment. YBU works to facilitate this model of care in Uganda.[2] It is vital, that besides increasing the individual's level of awareness of their illness, and their skill development in managing their recovery process, it is just as important to increase the capabilities of families of care. YBU would go one step further to say that part of the process of increasing the capabilities of families, is to address 'whole of family' dynamics and needs.

Of note in the survey results is that 13 out of the 14 relapses were either successfully managed by the families in the family home. Further research is needed to explore if there were additional factors currently unidentified, that mitigated against a return to hospital care. However, this significant survey result might well reflect on the level and content of family education and capability building by the YBU team. But above all, it could demonstrate that families can be resilient, use their strengths, and be successful as active agents in the recovery process from severe mental illness.

Families need to be considered an essential resource in community mental health planning by governments, international development agencies, and community organisations, in low-income countries.

Integrating mental health care into the broad-based health system is viewed as essential, particularly in low-income countries. This survey suggests that if health centres have an

[2] Cappo, D., Mutamba, B., & Verity, F. (2021). Belonging home: capabilities, belonging and mental health recovery in low resourced settings. *Health promotion international*, *36*(1), 58-66.

adequate and uninterrupted supply of essential mental health medications, and that health centre personnel are trained in proper diagnosis, and treatment, including prescribing skills, and skills in psychosocial support, then the local population in need of mental health care, will access such health centres. This is a further important part of an emerging community based mental health system in Uganda, and must be advocated for, in dialogue with the government.

The importance of integration, must also take note of cultural issues. Cultural understanding of mental illness in Uganda, needs to be in dialogue with evidence-based medicine and health systems. Considering that families and individuals in need of mental health support, in the main, firstly consult faith and traditional healers, an imperative exists for a more holistic health system. Such a holistic approach might well establish dialogue, understanding, and cooperation (if not collaboration) between, what up to this point in time, has been two separate and somewhat oppositional streams of mental health support.

The experience of YBU team asserts that the recovery process for people with severe mental illness is enhanced through productive activity, and in low-income countries, this can be as basic as some domestic work or some laboring work to generate a little daily income. Further to this, motivating and supporting the person to engage in IGA perhaps at the level of a social enterprise, or a small business, can produce increased results in recovery. This gives the person a sense of purpose, of belonging, and of being respected and acknowledged in their local community. Productive activity, particularly IGA builds self- esteem and self-confidence.

But, as the survey showed, a barrier exists to bringing this level of engagement in IGA about, namely the lack of finance to kick start an enterprise. Initiatives, attached to available funds to assist in help start an enterprise, would be an excellent research field to further study the impact on recovery from severe mental illness.

Mindful of other barriers to mental health recovery is the extent of the use and addiction to alcohol and psychoactive substances. The ease of access to home-made and cheap alcohol, and other psychoactive substances in Uganda is a worrying trend. Strategically targeted school-based education of young people in Uganda about the harmful effects of alcohol and substance use, would be helpful initiatives.

6.0 CONCLUSION

In summary, the work of Project 500, through this recent survey, demonstrates the importance of the following factors, in reducing relapses, enabling most relapses to be managed by the family at home, and minimizing readmissions to hospital care:

- Psychosocial and psychoeducation interventions need to be relational, and built on the lived experience of the person recovering from severe mental illness.
- Respect for the human dignity and human rights of persons with mental illness, must underpin all support and engagement.
- A 'whole of family' approach to support, enhances the wellbeing of the person recovering from severe mental illness, at home.
- A mindset that sees the person's family of care, as ACTIVE AGENTS in mental health recovery, is important. This necessitates a focus on building capabilities and capacity both in families.
- Productive activity, particularly income generating activity, is seen as crucial in enhancing recovery from severe mental illness.
- It is important that bio-medical care not be disconnected from engagement with the social determinants of mental health, but integrated into a holistic care plan.
- An uninterrupted supply of prescribed medication for the person in recovery, is important in minimizing relapses. Issues of dosage, storage, adherence, and supervision issues, need to be a part of mental health education, preferably in a family setting.
- Long term sustainability of this model of care can be achieved when primary health care workers in community health centres have upscaled capacity and increased capabilities through training and other supports.

These factors, placed in a strategic plan, could see the emergence of a sustainable community based mental health system, imbedded in the country's health system.

The work of YouBelong Uganda, social workers, community mental health nurses, and occupational therapists in Project 500 is providing a successful response to the crisis conditions in COVID-19 times. Relapses of people recovering from severe mental illness, who have been returned home have been minimized, and if they have occurred, they have been mainly managed by the family at home. Further innovations in the work of YBU will come from the results from this survey. This survey has provided valuable data and lessons that can contribute to more targeted interventions and innovations to build and enhance the mental health system in Uganda.

APPENDICES

APPENDIX 1: Interview Guide

YouBelong Uganda

Evaluation of Project-500 Report

Introduction and Consent:

YouBelong Uganda is implementing an abridged version of the YouBelongHOME program called Project-500 which aims at reintegrating 500 service users to their families/communities within a period of 1 year.

We would like to request you to participate in a periodic survey which aims at collecting data for the project as part of its evaluation. You will be asked questions that provide the YBH team with information about the impact of project-500 and further guide in enhancement and improvement of the project process. Your responses will only be used for the purpose it is intended to. Your participation should take approximately 10 minutes and all responses you provide for this survey will remain confidential. Your participation is voluntary and you may withdraw from this survey anytime you wish or skip any questions you don't feel like answering. Your refusal to participate will not result in any penalty or loss of benefits to which you are otherwise entitled. The survey is not directly beneficial to the participants; however, it will be of value for the improvement of the project. You will receive no incentive or payment for your participation.

Do you consent? YES ☐ NO ☐

1. Demographic information of the service user:

   Name/Initials:

   Age:

   Sex:

   Village/district:

   Diagnosis:

   Nearby health facility:

   Other care sought (Religious, Traditional, etc.):

2. Feedback from the family (how they have been since termination visit/last meeting with the YBH team, and how they are doing currently/how are they maintaining recovery? have they registered any relapses/readmissions?)
3. Feedback from the service user (how he/she has been since termination visit/last meeting with the YBH team, and how he/she is doing currently?)

4. If they registered any relapse, what do they think were the reasons for relapse and how was it managed?

5. If no relapse was registered, what do they think helped them prevent relapse?

6. Has the service user been readmitted since the last meeting with YBH team? How many times? How long did the service user spend at home before readmission after the YBH interventions? For how long was the readmission and how did he/she return home?

7. Do they think the period of 5 weeks was adequate? YES/NO If no, what duration do they think would be adequate?

8. A) What interventions did the family/service user find helpful within the 5 weeks of YBH intervention?
   B) Do you think the knowledge and skills you acquired are adequate to support your family member with mental illness?
   C) What does the family/community think is their role in supporting the service user to recovery?
   D) What level of the intervention did you find most helpful and why?

9. What support for continued care do you think you (service user and family) need to sustain recovery?
10. What support services have they acquired from referrals made by YBH team?
11. A) Did the service user engage in any IGA/basic activities? YES/NO
    B) If yes, what activities has the service user engaged in? What has helped the service user engage in these activities? Have they faced any challenges while engaging in any IGA/basic activities?
    C) If No what challenges have hindered his/her engagement in an IGA/basic activity?
    D) Does the family have any plans in terms of IGA/basic activities for the service user?

Thank you for your participation!