

ELECTROCONVULSIVE THERAPY, SECLUSION, RESTRAINT AND PSYCHO-SOCIAL INTERVENTIONS

EXPLORING THE EXPERIENCES IN MBARARA AND GULU
REGIONAL REFERRAL HOSPITALS

**A Fact Finding commissioned by Mental Health Uganda and the Network of Public Interest
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ABBREVIATIONS

ECT	Electroconvulsive therapy
MHSU	Mental Health Services Users
MHU	Mental Health Uganda
NETPIL	Network of Public Interest Litigation
NGOs	Non-Governmental Organizations
OPDs	Organizations of Persons with Disabilities
SAGE	Social Assistance Grant for Empowerment
VHTs	Village Health Teams

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EXECUTIVE SUMMARY

1. Introduction

Mental health is a key policy priority in Uganda as evidenced by the recent legal and policy reforms instituted to improve mental health care delivery in the country. In spite of the policy and programmatic reforms, persons with mental disabilities still face a myriad of systemic, infrastructural, legal, cultural and material challenges in trying to navigate the mental health care ecosystem. Following an earlier desk study that revealed that the new Mental Health Act, 2019 allows the use of Electroconvulsive therapy (ECT), seclusion and body restraint under certain conditions, the Network of Public Interest Lawyers (NETPIL) commissioned this research study to explore the use of these treatment options, and ascertain the available alternatives in the two regional referral hospitals in northern and western Uganda.

2. Methodology

The present study adopted a qualitative case study research design of two regional referral hospitals located in northern and western Uganda. Data was collected from 30 participants using semi-structured interview guides that were separately designed for each of the three categories of participants: caregivers, mental health service users, and health workers. Data were analyzed using the thematic method of analysis. Data analysis started with taking field notes, transcribing interview data and coding using the NVIVO software. Recurrent patterns in the data were identified as themes and sub-themes, and the findings were reported with direct quotes to illustrate striking findings.

3. Findings

1. The study revealed that ECT and seclusion were seldom used in the two hospitals while body restraint was the most common mode of treatment used. Health workers and caregivers in the study regarded these modes of treatment as important components of the mental health care ecosystem. In contrast, the persons with mental disabilities in the study outrightly condemned the use of these techniques as a violation of their human rights.

2. Most of the study participants (58%) expressed preference for community and home-based mental health care compared to hospital based mental health care (42%).

3. There is a limited range of alternative mental health services available in the hospitals and in communities. Medical treatment (n =20) emerged as the dominant mental health service accessed by persons with mental disabilities, followed by counselling (n =10), faith healing (n =10) and traditional healing (n =6) services. Counselling and occupational therapy services are primarily received from hospital settings, suggesting the inadequacy of community-based mental health services in the two districts.

4. Informal mental health care (faith and traditional healers) emerged as a key component of the mental health ecosystem in western and northern Uganda. Persons with mental disabilities in the study areas tend to rotate between medical treatment, faith healing and traditional healing services in their search for recovery. Although relatively neglected, despised and unregulated, traditional healers are often the first course of treatment and/or the last resort after medical treatment has failed or when recovery is delayed.

5. Numerous barriers impede the effective provision of mental health services at regional and community levels. Shortage of drugs stood out as the biggest barrier reported by all the three categories of participants. Caregivers and their families endured stigma by association, that is, they suffered the same negative labels and discrimination as their family members with mental disabilities by virtue of their affiliation with them. Health workers expressed concerns about understaffing and the lack of facilitation to conduct community out-reaches.

6. The persons with mental disabilities who participated in this study observed that they had experienced human rights violations at multiple levels: at family, community or health facilities. At family and community levels, they reported having been locked up in houses for long durations and some subjected to torture in the form of beatings not only by the family but also other community members. They were sometimes tied up with ropes purportedly to restrain them from loitering around and stop them from causing physical harm to themselves and to others. In extreme cases, some of them were confined and starved without adequate food.

4. Lessons Learned

The findings from this study revealed that ECT and seclusion were occasionally used in Mbarara and Gulu Referral hospitals, while body restraint is commonly used both in the community and the two hospitals. Mental health service users who participated in the study were outrightly opposed to the use of these techniques on the ground that it violates their rights and subjects them to inhumane treatment.

It was evident that mental health caregivers shoulder a high burden of care owing to material hardships, lack of technical capacity on how to provide quality mental health care to family members with mental disabilities, as well as stigma, discrimination and negative community attitudes.

There is evidence of a strong need and support for community-based mental health care services. However, the district and regional referral hospitals lack the financial and human resource capacity to address this need.

Informal mental health care providers (faith and traditional healers) remain relevant and sought after by caregivers and mental healthcare users in the districts of Gulu and Mbarara

The outbreak of the COVID-19 pandemic negatively affected the availability and delivery of mental health care services owing to the nationwide lockdown measures. The

situation was compounded by the closure of mental health units to create space for COVID-19 isolation centers at regional referral hospitals.

5. Strategies to Improve Mental Health Care Service Delivery

Based on their lived experiences and challenges, the study participants proposed strategies for improving mental health care service delivery in their districts and nationally. These are elaborated here below:

1. To address the endemic problem of understaffing and the lack of specialized mental health staff in hospitals and lower health facilities.
2. In response to the demonstrated need for community based mental health care services, the study participants urged the government and non-state actors to prioritize and facilitate hospital staff to conduct community outreach services such as psychosocial support, home visits, and monitor drug adherence. One of the ways to improve community-based mental health care is to recruit more Village Health Teams (VHTs).
3. Ignorance and misconceptions about the nature, causes and diagnosis of mental health conditions is prevalent in all communities in both districts. Hence the need for increased community awareness on mental health as a way to promote early identification of symptoms and signs and encourage persons with mental health disabilities seek appropriate mental health care.
4. It is recommended that the Government of Uganda increases budgetary allocations to the mental health sub-sector from a paltry 1% to at least 10% of the overall health sector budget to ensure adequate supply of essential mental health drugs to hospitals and lower health facilities.
5. It was clearly evident that many caregivers lacked the financial capacity to meet the cost of care and medical treatment of their family members with mental disabilities. Most of the caregivers who participated in the study were unemployed or engaged in petty economic activities that do not generate adequate income to enable them dispense for both livelihood and medical treatment.
6. It was evident from the findings that the caregivers who participated in this study lacked the basic knowledge and skills on appropriate caregiving, a situation that sometimes resulted in unintended abuse and neglect of family members with mental disabilities. Participants proposed training, counseling, and supporting of caregivers and families of mental health service users to improve the quality of care they offer.
7. From the study, it was evident that all categories of participants demonstrated limited knowledge of mental health laws and policies. In addition, few mental health service users exhibited full understanding of their human rights. The Ministry of Health should therefore consider disseminating existing mental health

laws and policies and educating stakeholders on their rights and duties.

8. Finally, there is evidence of very few non-state actors focusing on mental health interventions in hospitals and communities, making public mental health services the only available options for most communities. There is need to promote public-private partnerships and deliberate engagement of NGOs and OPDs to support mental health care. These organizations could support activities like community awareness and advocacy for the rights of persons with mental disabilities, and contribute towards eliminating stigma, discrimination due to misconceptions and negative attitudes.

6. Conclusion

This study set out to ascertain the use of ECT, seclusion and body restraint and the alternatives to these modes of treatment in Gulu and Mbarara regional referral hospitals. The study found that these techniques are in use and were regarded by health workers and caregivers as relevant components of the mental health ecosystem in spite of the persons with mental disabilities holding a contrary view. The perception that persons with mental disabilities can be danger to themselves and to others is the major justification for the continuous use of these techniques. Even though these special treatments are supposed to be administered when all other treatment options are exhausted, there was no evidence that this legal requirement is adhered to.

Medical treatment remains the dominant mental health service with a limited range of psychosocial services in the two districts. The need for effective community mental health services evidently stood out as the complementary role of informal mental health providers in the mental health ecosystem. Mental health conditions remain a widely misunderstood phenomenon in communities, a situation that results in many unfounded negative stereotypes and mistreatment of the persons with mental disabilities. Families play an indispensable role in mental health care service delivery, but shoulder the greater burden of care compounded by the unavailability of drugs and the centralization of mental health care services to distant hospitals.

The findings of this study must be interpreted with caution in light of certain methodological shortfalls that limit the application of its findings beyond the sample. The study was conducted in only two regional referral hospitals and data was collected using only interviews. In future, widening the geographical scope, increasing the sample size and collecting data from multiple sources are recommended to improve the transferability of findings. Nevertheless, the study provides rich insights into the nature and range of mental health services provided in the two hospitals during a challenging time like the recent COVID-19 lockdown measures.

1. INTRODUCTION

Mental health is a key policy priority in Uganda and an important component of the National Minimum Health Care Package.¹ However, it constitutes only about 1% of Uganda's health sector annual budget.² The meagre budgetary allocation to the mental health domain is a major concern given that mental health conditions in the country are on the rise. Uganda is ranked among the top six countries with the high prevalence rates of depressive disorders in Africa.³ The Uganda Bureau of Statistics (UBOS) estimates the prevalence of psychosocial and intellectual disabilities at 5.6% and 7.6% in children aged 2-4 and 5-17 respectively, and 9.4% among adults.⁴ A study by Molodynski et al. estimates that 35% of Ugandans have mental health conditions, of which 15% require mental health treatment.⁵

In a bid to improve mental health service delivery, Uganda has made policy and programmatic reforms, including the enactment of the Persons with Disabilities Act 2020, the Mental Health Act, 2019, and the decentralization of mental health services to regional referral hospitals. The Mental Health Act, 2019 recognizes community mental health services as an important component of mental health service delivery and requires every district to appoint a Mental Health Focal Person to coordinate and oversee mental health services delivery at district level. Presently, every regional referral hospital has a mental health unit.⁶

The Mental Health Act, 2019 permits the administration of Electroconvulsive Therapy (ECT), seclusion and body restraint under strict standards and describes them as Special Treatment Modes. The Act requires that ECT be provided with written instruction of a Psychiatrist, and applied under the authorization and supervision of a Consultant Psychiatrist.⁷ To administer seclusion and body restraint, the Act sets a similar standard that requires prior authorization and supervision of a Consultant Psychiatrist, not to exceed seventy-two hours unless an application is made to the Board within that period for the seclusion or restraint for a longer period, and to be undertaken with intermittent

1 Kigozi, F., Ssebunnya, J., Kizza, D., et al (2010). An overview of Uganda's mental health care system: results from an assessment using the world health organization's assessment instrument for mental health systems (WHO-AIMS). 4(1) International Journal of Mental Health Systems.

2 Molodynski, A., Cusack, C., and Nixon, J. (2017). Mental healthcare in Uganda: Desperate challenges but real opportunities. 14(4) BJPsych International.

3 Miller, A. P., Kintu. M., and Kiene, S. M. (2020). Challenges in measuring depression among Ugandan fisherfolk: a psychometric assessment of the Luganda version of the Center for Epidemiologic Studies Depression Scale (CES-D). 20(45) BMC Psychiatry. Retrieved <https://doi.org/10.1186/s12888-020-2463-2>.

4 . Uganda Bureau of Statistics. 'Uganda Functioning Difficulties Survey 2017' (2018). Kampala, Uganda.

5 Molodynski, A., Cusack, C., & Nixon, J. (2017). Mental healthcare in Uganda: desperate challenges but real opportunities. 14(4) BJPsych international, pp. 98-100.

6 WHO and Ministry of Health (2006). WHO-AIMS Report on the Mental Health System in Uganda. A report of the assessment of the mental health system in Uganda using the World Health Organization - Assessment Instrument for Mental Health Systems (WHO-AIMS). Kampala, Uganda.

7 Mental Health Act 2019, Part IX, Article 27,1(a-b).

reviews.⁸ There is a limited body of knowledge in Uganda on the level of compliance of these special mental health treatment modes with the standards set in the Act, their health benefits to persons with mental disabilities, as well as their experiences and perceptions towards the use of these treatment modes.

Following an earlier desk study that revealed that the Mental Health Act, 2019 allows the use of ECT, seclusion and body restraint under certain conditions, the Network of Public Interest Litigation (NETPIL) commissioned the present research study to explore the experiences of applying these treatment options in the regional referral hospitals of Gulu and Mbarara, and to find out whether there are alternative mental health services in those facilities. It is hoped that the findings from this study will highlight the best practices to improve access to mental health services in Uganda, and to enforce the administration of these special mental health treatment modes in accordance with the standards set out in the Mental Health Act, 2019.

1.2. Objectives of the study

1. To explore the experiences of mental health service users of ECT, seclusion, and body restraint as a mode of treating persons with mental disabilities.
2. To establish the perceptions of caregivers, persons with mental disabilities and the medical practitioners towards the use of ECT, seclusion, and body restraint.
3. To identify the alternative mental health services available in Mbarara and Gulu regional referral hospitals and examine their perceived effectiveness and alignment with human rights standards.

8 Mental Health Act 2019, Part IX, Article 27 1(c-d).

2. METHODOLOGY

2.1. Research Design

This study adopted a purely qualitative case study research design. A case study of Gulu and Mbarara regional referral hospital in northern and western Uganda respectively was undertaken with the aim of eliciting in-depth first persons' stakeholders' perspectives on the use of ECT, seclusion and body restraint and alternative mental health services. The two regional referral hospitals were chosen because they have mental health care units serving several districts in their catchment.

2.2. Participants, Sampling and Recruitment

The participants for this study were sampled purposively to ensure that only those with information relevant to the subject under investigation took part in the study. A criteria to guide the selection of the participants was set out and included assessing one's role in the provision of mental health care services, knowledge of mental health, experiences in mental health service provision, and having a mental disability or a history of mental disability. During fieldwork, the research team visited the selected hospitals and met the hospital administrators to brief them about the study purpose and target participants. The hospital administrators helped the research team to identify the staff, mental health service users and their caregivers who were then invited to the hospital. The hospitals provided separate rooms where the research team could conduct interviews. The research team then met with the participants to explain to them the purpose of the study, obtained consent and conducted the interviews with those who expressed interest and willingness to participate. All the interviews took place within the hospitals in spaces provided by the hospital administration.

2.3. Data Collection Methods

This being primarily a qualitative study, data was collected using semi-structured interview guides. To elicit richer perspectives on the issues explored, separate semi-structured interview guide was designed for health workers, caregivers and persons with mental disabilities. In addition to demographics, the semi-structured interviews focused on the perspectives on the different types of mental health services, participants' knowledge and awareness of mental health rights and policies, approaches to mental health care, alternative mental health treatment and barriers to mental health care. All interviews were recorded using a voice recorder after getting the consent and permission of every participant. Interview sessions typically lasted between 30 to 60 minutes.

2.4. Data Analysis

Qualitative data was analyzed using the thematic⁹ method and template coding¹⁰ technique. It started with taking field notes and memos from the field, followed by verbatim transcription of all interview data. Interview transcripts were then coded using the NVIVO version 10 software. Template coding involved both deductive and inductive approaches. This means that a priori codes were derived initially from the study objectives and data collection tools in addition to data driven codes. During the coding process, emerging patterns were identified, categorized into themes and sub-themes, and summarized with supporting quotes. During report writing, the technique of thick description (or use of direct quotes from participants) was used to bring out the voices of different categories of participants on every theme.

2.5. Quality Control

To ensure quality in this study, the consultant infused a number of quality control mechanisms throughout the study process. These included but not limited to validating data collection tools, training of research assistants, conducting consistency checks to ensure accuracy of interview transcripts, inter-rater reliability (using more than one person to code the same interview data), and transparency in reporting of findings. Data collection tools were validated with inputs from NETPIL and Mental Health Uganda.

2.6. Ethical Considerations

During recruitment, all eligible individuals were contacted and given adequate information about the study and asked whether they would be interested and willing to take part in the study. Participation in the study was voluntary upon granting written informed consent by interested and willing individuals. Personally identifiable information was removed from all interview guides.

⁹ Gavin, H. (2008). Thematic analysis. *Understanding research methods and statistics in psychology*, pp. 273-282.

¹⁰ Crabtree, B. F., & Miller, W. F. (1992). "A template approach to text analysis: Developing and using codebooks." In B. F. Crabtree & W. L. Miller (Eds.), *Doing qualitative research in primary care: Multiple strategies*, Newbury Park, CA: Sage Publications, pp. 93-109.

3. FINDINGS

3.1. Participants' Characteristics

The primary target participants (N =45) for this study were mental health care workers, caregivers and mental health care service users or persons with mental disabilities from two regional referral hospitals. A slight majority (56%) of the participants who identified as persons with mental disabilities in the study were male. Whereas there were more male health workers and mental health care service users in the study, most (75%) of the caregivers in the study were female, implying that the caregiver role is still largely a women's duty. The findings revealed that caregiving were dominantly by close relatives (72%), but distant relatives (14%) and non-relatives (14%) also provided caregiving services. Meanwhile, many of the caregivers in the study (n =6) were self-employed while few (n =3) were unemployed. Most of the caregivers reported that they had provided caregiving services for between 1-5 years while 5 of them provided mental health care for more than 15 years. The demographic characteristics of the participants reveal that women shoulder a substantial mental health burden in terms of caregiving.

3.2. First Reaction to Diagnosis with Mental Disability

Mental health diagnosis can trigger a wide range of reactions for different people. To some people, a diagnosis can be a relief while for others a major blow resulting in fear, anger, shame, denial and sadness.¹¹ The study participants reported both negative and positive reactions after their first diagnosis with mental disability. The majority of the participants experienced a range of negative emotional reactions such as feeling bad, hopeless, demoralized, ashamed, stressed and terrified upon diagnosis with mental disability. The negative reactions were triggered by the fear of how their community would treat them and their experiences of how other persons with mental disabilities were mistreated. A primary school teacher revealed that some participants' reactions were prompted by the fear of being taken to a witchdoctor. A female mental health user was surprised and could not believe the diagnosis until they started on treatment: 'I did not believe it until I was given medicine and there was some change in how I was feeling.'

Some of the participants reported being misunderstood before their first diagnosis with mental disability. One of the female mental health service users from Mbarara revealed that she felt a huge relief after her diagnosis with mental disability because her behavior was unknowingly misunderstood by family members and the school before the determination of her mental disability. This is because the diagnosis exonerated her from the stigma and guilt of being an undisciplined school girl. She thus stated:

At 17 while in school, I had issues with everything routine, church, etc. I knew something was wrong but no one could help me or believe that I was ill. I got into trouble and got myself expelled from school. So, it was a huge relief when mental

11 Mental Health America, retrieved from <<https://www.mhanational.org/after-diagnosis>>.

*illness was confirmed.*¹²

Some of the participants did not know or understand whatever was taking place in their lives at the time of diagnosis. A female participant who was pregnant at the time of diagnosis explained how she was scared:

*I was pregnant when I was diagnosed, and I felt like somebody was holding my legs to separate me from my baby. With all the confusion, I have been having in my life. I felt I was being bewitched.*¹³

Another mental health user said she had many unanswered questions, and thus observed:

*Because I did not understand what I was going through. A lot was going in my life and I needed an answer to understand myself. The diagnosis awakened my curiosity in the mental health sector.*¹⁴

The persons with mental disabilities employed many tools and mechanisms to cope with their initial reactions to mental health diagnosis. The common coping mechanisms were seeking support from the family or close relatives, peer support from friends, avoiding triggers (such as noisy places), and turning to God in prayer, and fasting and seeking counseling services. One respondent noted:

*Over time, I came to know that I am sick and that the sickness can be managed by the hospital with drugs and I take the drugs properly.*¹⁵

Another respondent observed as follows:

*I met Paul, he encouraged me to join Mental Health Uganda, and I got involved in trainings in mental health and other programmes. This helped me to be focused, not to mind my situation and get a sense of direction.*¹⁶

Another male mental health user in Gulu spoke about how he copes as follows:

*I left teaching and I became a musician, and I wanted to join the band again, when you are in a band, life is good, we play music and they like you for a long time.*¹⁷

This study confirms that mental health diagnosis in most cases imposes an insurmountable emotional burden on individuals to whom close social networks like families and peers serve as invaluable first line of support. The negative reactions often stem from the individuals' anticipation of mistreatment from the community and/or the family.

12 Female mental health service user, Mbarara.

13 Female mental health service user.

14 Female mental health service user.

15 Male mental health service user, Mbarara.

16 Male mental health service user, Gulu

17 Male mental health service user, Gulu

3.3. Awareness of Mental Health Rights, Laws and Policies

The study sought to explore the participants' awareness of their mental health rights and knowledge of existing mental health laws and policies. Participants who are knowledgeable and/or aware of their rights and existing laws and policies are likely to seek services for treatment or protection from human rights abuses. Many of the participants in this study, including the health workers, were largely unaware of the Mental Health Act, 2019 and the Persons with Disabilities Act, 2020. Likewise, many of the mental health services users (MHSU) demonstrated limited knowledge on their rights as persons with mental disabilities. In most cases, the participants could hardly mention more than one human right correctly when asked to do so.

When asked to comment on the general state of mental health rights in Uganda, the participants were almost unanimous that there is a lot of room for improvement. As the following quotes illustrate, the participants felt that existing legal frameworks were not translated to commensurate action that can improve mental health services and/or protect the rights of persons with mental disabilities in Uganda.

...their rights are not being protected very much because I see most of them treated badly in their families, the homes and communities in which they stay, these people are considered to have no rights.¹⁸

When I look at the state of Uganda, I mental disabilities are not being protected. When you look at persons with mental problems, they are always stigmatized.

Nevertheless, the participants acknowledged the fact that decentralization of mental health services can improve access to mental health services. However, a caregiver from Gulu Regional Referral Hospital observed that mental health care is a largely neglected sub-sector:

For me the way I see it, the mental health unit is neglected by the Government. Although Mental Health Uganda is trying to help them... I think the Government should work on it too...For instance, sometimes you come to the hospital and there are no drugs...and yet mental illness cannot wait.¹⁹

3.4. Experiences of Human Rights Violations

The study findings confirm that the persons with mental disabilities who participated in this study experienced human rights violations at multiple levels whether at family, community or health facilities. At family and community levels, they reported being locked up in the house for long durations. Moreover, some of them were subjected to torture in form of beating not only by the family but also other community members. They were sometimes tied up with ropes purportedly to restrain them from loitering around and stop them from causing physical harm to themselves and to others. In extreme cases, some were confined and starved without adequate food. To place this in context, one respondent noted:

18 Male CG, Mbarara.

19 Male CG, Gulu.

So, the kind of restraint given to persons with mental disabilities is not like for human beings. It looks like torture because to a point of someone being tied with ropes and you see blood coming.

In the workplace setting, employees who were diagnosed with mental disabilities were unfairly laid off from work. A teacher at a private primary school testified that his school did not allocate him any subjects to teach after his mental diagnosis, a decision that was not reversed even after his recovery. He thus observed:

I was a teacher in Sacred Heart SS when I got ill. Eventually I was not given any lessons to teach anymore, and was told to return home.²⁰

The dismissal of an employee with mental disability whether done deliberately or in ignorance of the law violates the right to employment as stipulated in the Uganda's Employment Act, 2006 and the Persons with Disabilities Act, 2020 that prohibit discrimination of a person from employment solely or majorly on the grounds of one's disability. In particular, Section 9(3)(h) of the Act makes terminating the employment services of a person on the basis of disability an act of discrimination.

Persons with mental disabilities also suffered stigma and discrimination in communities. They are assigned derogatory labels such as "mad people", "insane", "bewitched" among others. In extreme cases, some of them were stopped from participating in family and community activities. As one respondent observed: "they just ignore me since they know I have mental illness. My ideas are not considered." Although the use of derogatory terms were outlawed in a recent constitutional court ruling²¹, their use is still common in communities.

The new MHA, 2019 requires obtaining consent from mental health service users prior to treatment, care or admission at a mental health unit or health facility. In case of involuntary treatment, the family member or concerned friend can provide the consent.²² The findings from the present study however revealed that health workers in the two hospitals rarely sought the consent of mental health service users in administering certain drugs. This means that mental health service users were hardly given the option to choose a preferred mode of treatment. As one respondent noted:

They don't give me the option because they are the ones that know what I should take, though sometimes I complain because of the sleepy mood when I am home,

²⁰ A respondent teacher who formerly had a mental disability.

²¹ Centre for Health, Human Rights and Development (CEHURD) and Iga Daniel v The Attorney General, Constitutional Petition No.64 of 2011.

²² A person who does not consent to voluntary admission or who due to incapacity to consent, cannot consent to voluntary admission, and who does not qualify for emergency treatment under this Act, shall not be admitted in a primary health centre but shall be referred to the nearest mental health unit (MHA 2019, Section 21(3)).

about the working hours, but they advise me accordingly and I keep on taking the drugs because you don't have an option when you are not a medical worker.

Meanwhile, some persons with mental disabilities reported being subjected to physical violence by health workers. As the following quote illustrates, some health workers tended to apply physical violence to restless patients as a way of restraining their violent behavior and/or administering medication. One patient from Mbarara regional referral hospital wondered "being beaten on the head using a stick by a health worker for failing to take my medicine."

The human rights abuses committed against persons with mental disabilities in this study generally stem from negative attitudes, lack of a clear reporting forum within the hospitals, ignorance of the law, poverty at family level that continues to increase the burden of care for MHSUs and limited knowledge of the rights and duties of medical practitioners, family members and the community.

3.5. Preferred Types of Mental Health Services

Evidently, a majority of the participants expressed more preference for community mental health services (58%) than hospital based mental health care (42%).

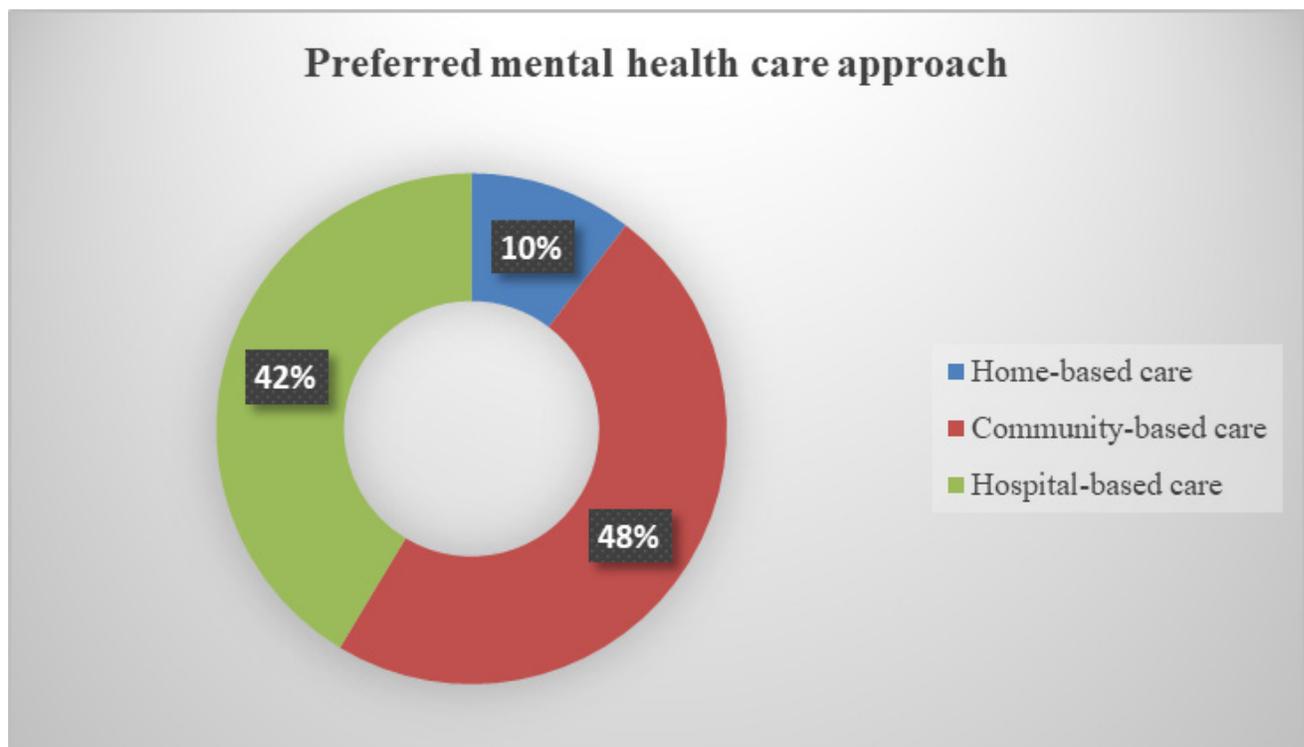


Figure 1: participants' preferences of mental health services

Source: Author's computation from primary data

The primary reasons the participants advanced in favor of community mental health services included the freedom to do other things while getting treatment, reduced burden of transport costs to hospital and reduced stigma as one continues to engage with the

community and deal with other social problems that trigger mental health conditions.

I prefer the community. In the Institution, you are locked up, you do not have something to add on to your life, but when you are in the community, you can do some work and get the treatment in the hospital, and continue going on.

On the other hand, the participants who expressed preference for hospital based mental health treatment argued that they trusted the doctors in hospitals more than the lower health facility workers like nurses. They complained about mismanagement, misdiagnosis, and mistreatment of mental health service users in communities. They argued that it is better to manage mental health service users in hospitals and only refer them to communities to recover. As some respondents noted:

I prefer hospital because there are trained health workers, unlike in the community where some people are just gambling.²³

In the hospital is okay, because you meet with health workers who guide you on your condition, and in the community, I may not have the health worker to help me.²⁴

...the hospitals are inclusive with people from different regions. You can even get stronger from seeing others in a worse off situation compared to you. This is an inclusion hospital...you can develop strength yet in the communities, people may be knowing me and can push me back.²⁵

Many of the health workers in the study preferred to use a blend of hospitalization and community- mental health services, arguing that the two approaches are complementary.

23 Mental health service user.

24 Mental health service user.

25 Mental health service user.

3.6. Experiences of Electroconvulsive Therapy, Body Restraint and Seclusion

Overall, the majority of the mental health service users²⁶ who participated in this study had no experience of the three mental health treatment modes investigated. The chart below indicates that only two mental health service users confirmed being subjected to ECT and seclusion, while one of the participants experienced body restraint.

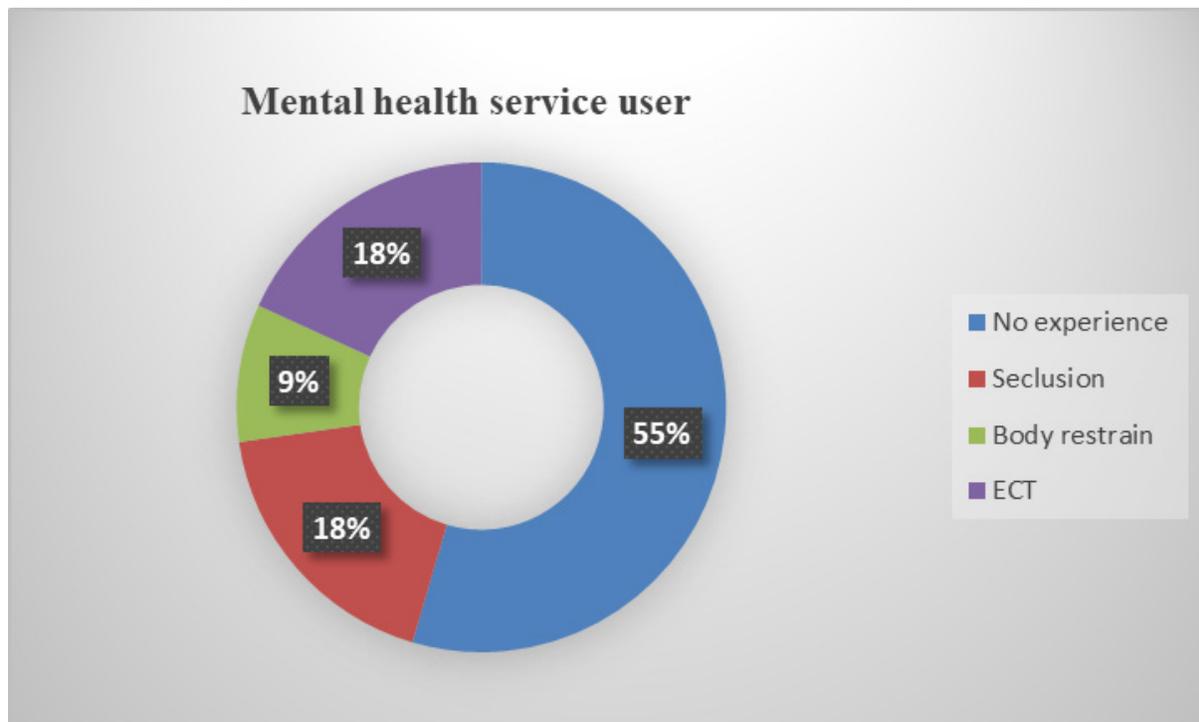


Figure 2: Mental health service users' experiences of ECT, seclusion and restrain

Source: Primary data from individual interviews

It was apparent that the mental health service users in the study had limited or no awareness of the three treatment approaches. Many of them said they had heard about the treatments from other people while very few of them experienced or witnessed someone being subjected to these treatments. Asked whether he was aware of ECT observed as follows: "that ECT, they told me about it, that they do it in Mulago, but I have not reached that state of using it."²⁷

Electroconvulsive Therapy (ECT)

The MHA, 2019 does not define ECT but prescribes the conditions and procedures for administering it. Section 48(1) states:

A mental health practitioner, where the mental health practitioner is not the psychiatrist who treats an involuntary patient shall not perform electroconvulsive therapy on an involuntary patient except where the electroconvulsive therapy is

²⁶ Section 2 of the Mental Health Act, 2019 defines mental health service user as a person receiving treatment, care, rehabilitation or palliation services or using a health service at a health facility aimed at enhancing the mental health status of a user regardless of age, gender, social or economic standing.

²⁷ Male mental health service user.

recommended by the psychiatrist who treats the patient or is recommended by a psychiatrist.

It should be noted that the MHA, 2019 prohibits the administration of ECT to children²⁸, and to voluntary patient except with their consent.²⁹ Administering ECT contrary to the provisions of the Act is an offense punishable by imprisonment and/or a fine of eighty currency points.³⁰

Typically, the use of ECT involves shocking the patients' brain with some amount of electrode that may stimulate seizures in the person. The ECT recipients go through anaesthesia just like any other patient in a theatre and get monthly injections instead of oral medication. The health workers clarified that the ECT equipment and technique they use were more advanced and friendlier than the traditional ones that could cause serious seizures.

At the time of this study, the ECT machine at Gulu hospital had been dysfunctional for the last 6 years. According to a health worker at the facility, "...for ECT we have the machine but people to work on the machine are not there, and the machine lacks some components."³¹

The health workers at Mbarara regional referral hospital admitted to using ECT but occasionally.

*Yes, we have ECT equipment here. But for the last 5 years I saw it being used only on two patients who were not responding to treatment. It is used when the situation is extreme.*³²

Generally, the study found a limited application of ECT in the two hospitals, and its application was limited to patients with severe conditions who did not respond to medication. The interviewed medical practitioners asserted that ECT lessens the time of recovery and hospital stay and is the best option for patients for whom medicine has totally failed to work. It was clear from the medical practitioners that they seldom used ECT and only for patients with severe conditions who were not responding to medication:

*We use ECT whenever necessary...in Mbarara we are lucky to have 2 ECT equipment and we reserve it for the sick who have failed on medication or for those who need to recover quickly and be more productive in the community. ECT would be the best option because they recover faster, get back to normal life and don't get side effects.*³³

A mental health service user who experienced ECT out rightly denounced it, claiming that it shocks the brain and causes unpleasant feelings. Some of the mental health service users who had never experienced ECT said they would never wish to be subjected to the procedure because of the perceived negative side effects associated to it. As stated by some respondents:

28 MHA 2019, section 47(5).

29 Ibid, section 47 (4).

30 Ibid, section 47(6).

31 Health worker, Gulu Regional Referral Hospital.

32 Health worker, Mbarara Regional Referral Hospital.

33 Interview with health worker, Mbarara Regional Referral hospital.

They raised me on the bed, I saw about five people here, and some was tying me. I had something and I don't know where it came from and it bunged me. They tied me very tight, so now I would ask Dr Scholar every day, but she said I was lucky. So those people were not there to fold and break my legs.³⁴

ECT and all are not good because they shock our brain with ECT, it makes you like a stupid person, you find that you are not thinking the way you used to...it is really bad.³⁵

ECT, I really thank God that I did not go through that experience, but I hear it is one of the services, which is provided in the treatment and care. But it has some experience that some people I work with describe it as very dangerous.³⁶

Since many of the mental health service users had not experienced ECT, some of them expressed reservations about this mode of treatment partly due to limited knowledge about the procedure and partly because of what they were told about it, or seen other people go through.

Body Restraint

The findings from this study confirm that body restraint is a common practice in communities but seldom used in hospitals. Body restraint seemed to be rare in hospitals because of health workers' preference for sedation. In the exceptional cases that body restraint was used in hospital, it served the purpose of enforcing adherence to medication. Whether in hospital or in the community, it was clear that body restraint was applied as a response to violent behavior toward caregivers and/or health workers. A female caregiver from Gulu narrates how she resorted to restraining a patient who was violent and resisting to go to hospital:

I have ever restrained him. He was rude and wanted to fight the sisters. He even beat me. We wanted to bring him to the hospital because we felt it was like a new disease. So we put him in the vehicle and we brought him to the hospital because he was refusing. We untied him and they gave him treatment, up to now we have never done it, we did it just that once.³⁷

The study confirms that all the categories of participants do not approve of the use of body restraint in as much as they justify it on exceptional grounds. The participants were unanimous that the use of body restraint violates the rights of persons with mental disabilities to personal liberty. Health workers equally recognize that it violates patients' rights but uphold its use for aggressive patients taking into consideration or applying their medical ethics. As respondents stated:

Body restraint is not good, but sometimes there is nothing to do, because you don't know and you may injure people since you don't know what you are doing.

34 Interview with mental health service user.

35 Female mental health service user, Mbarara.

36 Female mental health service user, Mbarara.

37 Female caregiver, Gulu.

It is good if they can do that to you and when you recover, they treat you like a human being.³⁸

Body restraint violates the patient's rights, but in a scenario where the patient is very aggressive, if you are trained to handle them well, it is good because we are trained and know the organs we are not supposed to hold, step on, and when we put the patient down, we know what to do. Then we sedate them with diazepam.³⁹

Body restraint is not good, because it does not help anything. I think injections and tablets are the most important thing to use, to cool body down and then you treat...yes you come out weak from the medicines but you get used.⁴⁰

In spite of its disapproval, it is apparent that caregivers and health workers continue to use body restraint in the pretext of countering aggressive and violent behaviors that are perceived to harm others. The lack of better alternative management mechanism appears to reinforce the use of body restraint. Some participants recommended the use of chemical restraint methods such as sedation and injections to calm violent patients instead of physical restraint.

The Use of Seclusion

According to the MHA 2019, seclusion means the sole confinement of a patient in a room, where it is not within the control of that patient who is confined, to leave that room. The Act restricts the administration of seclusion⁴¹ to only mental health units and to not more than 24 hours consecutively.⁴² The study findings reveal that seclusion was the most common practice in the two hospitals used to calm down patients deemed to be restless and/or dangerous to themselves and/or others. Health workers said they used seclusion for patients with a record of abusing drugs and those on whom medicines could not work effectively. The hospitals had a designated room for seclusion. The rooms were dark, cold and had no beds, and reportedly free of any objects that patients could use to hurt themselves. There were no sanitary facilities in the seclusion room, forcing patients to excrete urine in the rooms. The maximum time patients spent in seclusion rooms was four hours. Prior to seclusion, patients were sedated to calm them down, and if that failed they were sent to seclusion rooms. As one respondent observed:

...we seclude but not quite often, we seclude for a patient who seems restless but with maximum observation, and seclusion does not take more than four hours, we can seclude for about one or 2 hours. Sometimes held until someone's behaviour goes better.

38 Male mental health service user, Gulu.

39 Female health worker, Gulu.

40 Male mental health user, Mbarara.

41 Under section 46(2) of the MHA Act, only a psychiatrist can authorize seclusion. According to section 48(6) of the Act, a person who illegally keeps a patient in seclusion commits an offence and is liable on conviction to a fine not exceeding one hundred eighty currency points or to a term of imprisonment not exceeding eighteen months or both.

42 See section 48 of the MHA, 2019.

Whereas medical practitioners acknowledged that seclusion was a double torture to patients, they still justified its use on the ground that it helps to calm down violent patients who perceived to be a danger to themselves and others, and to restrain some patients from escaping from the hospital.

Seclusion is okay because it makes you as a caretaker relax, and if he is reckless and the movement too much, I can do other things. If the room is clean there is no problem with it.⁴³

Interestingly, seclusion was also done at home and communities by the caregivers. Caregivers argued that seclusion was a necessary procedure because it relieves them to attend to other equally important domestic chores. At home, the patient is usually isolated and locking up in a house usually to prevent them from roaming the community and disappearing, or to relive the caregiver for some time. As observed by some respondent caregivers:

Even me I do it at home to avoid her from disappearing, at least you lock the house. Her problem is seasonal, so when I see her becoming like that, I can lock the main door and she is free to walk anywhere in the house or go to her bedroom and sleep.⁴⁴

The other day I locked her in the balcony to go to the garden for 30minutes to get potatoes. When I returned, she had climbed the balcony and run away.⁴⁵

Seclusion is okay, because it makes you as a caregiver relax, and if he is reckless and the movement too much, I can do other things. If the room is clean there is no problem with it.⁴⁶

Unlike the caregivers and health workers who supported seclusion, the mental health service users decried the practice calling it an infringement of their human rights. They disliked the experience of being locked up alone in a cold dark room while naked for hours. They strongly condemned the administration of seclusion as an indecent care approach that subjects them to double torture.

3.7. Availability of Psychosocial Services

The study sought to find out the types of psychosocial services available and accessed by persons with mental disabilities in the two districts besides ECT, seclusion and body restrain. As the pie chart below shows, medical treatment (n =20) emerged as the most dominant type of mental health care accessed by persons with mental disabilities, followed by counselling (n =10), faith healing (n =10) and traditional healing (n =6) services.

43 Female caregiver, Gulu.

44 Interview with a caregiver.

45 Female caregiver, Gulu.

46 Female caregiver, Gulu.

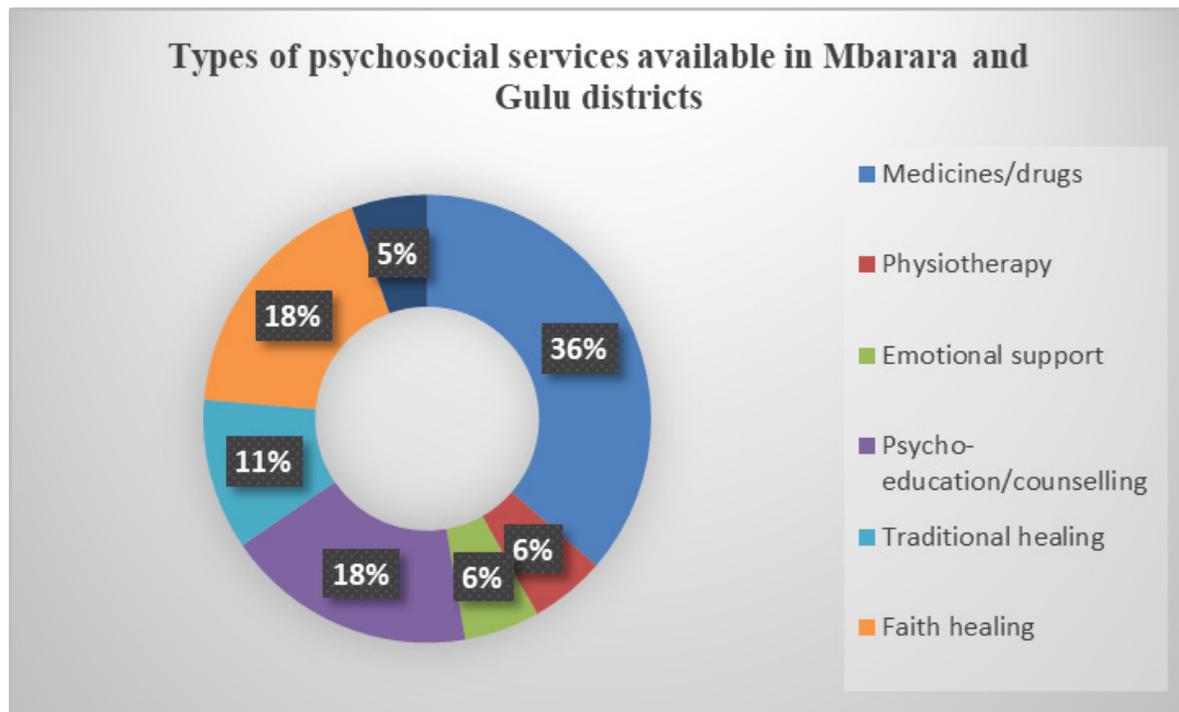


Figure 3: Alternative types of mental health services accessed by mental health service users
Source: Author's computation from individual interview data

The findings point to the primacy of informal mental health care services, as persons with mental disabilities tend to rotate between medical treatment, faith healing and traditional healing services in search for recovery. Informal mental health providers such as church leaders and traditional healers are often the first course of treatment, or the last resort after medical treatment has failed and recovery is not forthcoming. The following observations by the respondents illustrate that some persons with mental disabilities receive medical treatment simultaneously with traditional and faith healing services in the expectation of recovery:

Other people in the communities go to witchdoctors, others go to church. Okay going to church is not bad. For me I get medicine from the hospital and go to church.⁴⁷

In the communities they first go to the witchdoctors, it is not until they fail from there that they come to the hospital.⁴⁸

From the study, it was revealed that prayer turned out to be instrumental in mental health recovery, at least at the psychological level. Coupled with the socializing benefit from meeting people in churches, the participants believe the intercessional power of pastors and engaging in deep prayer contribute to mental health healing. This is illustrated in the observations made by some respondents:

I know prayer. When you go for prayers, then the person preaching helps you, when you are with people you be okay when you pray.⁴⁹

I have used prayer. It is helping. I think God is doing something.⁵⁰

In the community, some people go to the Balokole church, they say that they can pray for them and

47 Female mental health service user, Mbarara.

48 Male caregiver, Mbarara.

49 Female mental health user, Mbarara.

50 Female mental health service user, Mbarara.

they get better. Some go to the traditionalist and they think they can cure the condition.

Counselling and occupational therapy services were primarily received from hospital settings, suggesting the inadequacy of community-based mental health services in the two districts. Counseling and other forms of psychosocial support are particularly useful in dealing with extreme emotional stress and suicidal tendencies and restoring hope in patients. A male mental health service user from Gulu testified how counselling saved him from suicide:

Before I attended to the counselor, I was thinking of suicide, but when the counselor talked to me, he gave me some alternatives in life and from there, I changed my mind.

The family plays a crucial role in the provision of the continuum of mental health care services, regardless of the types of services. The following emerged as the key roles that families play in the provision of mental health care services:

- Provide love and care to the patient
- Provide transport to hospitals
- Monitor medication by the patient
- Provide social support to the user
- Attending to patients when admitted
- Financial support
- Escorting the users to pick medicine
- Praying for the user to recover
- Buy medication during stock out
- Managing the property of the user
- Provide psychosocial support to persons with mental disabilities

The family plays the role of a primary caregiver and the sandwich role of bridging the service gaps between regional referral hospitals and lower health facilities, family and informal health care and hospital and informal mental health care. They are the link to the services that mental health service users receive. In addition, families shoulder the greatest mental health burden as primary caregivers.

3.8. Alternatives to ECT, Seclusion and Body Restrain

As stated previously, in Uganda, ECT, seclusion and body restrain are recognized under the MHA, 2019 as special treatment modes to be administered in a regulated manner.⁵¹

⁵¹ Section 46.

This is in line with the WHO's guidance that restraint and seclusion may be allowed when they are the only means available to prevent immediate imminent harm to self or others, and then used for the shortest period of time necessary. They may only be authorized by an accredited mental health practitioner, and if used, there needs to be ongoing active and personal contact with the person subjected to seclusion and restraint, which goes beyond passive monitoring.⁵² Unfortunately, it is hardly the case that the administration of these treatments adhere to the WHO's guidelines or the conditions under which they are to be administered as stipulated in the MHA, 2019. Twinomugisha argues that involuntary ECT, seclusion, mechanical and bodily restraint impinge on the personal liberty of the patient and places persons with mental disabilities at the risk of abuse.⁵³ This section proposes alternative modes of mental health treatment that can be utilized in the place of ECT, seclusion and body restraint.

Community mental health services

The establishment of community mental health services under the MHA, 2019 and the decentralization of mental health services to regional referral hospitals is a step in the right direction toward strengthening community mental health services. The WHO promotes community mental health care as a strategy to reduce institutionalization of persons with mental disabilities.⁵⁴ Kabaale, a mental health advocate with a lived experience of mental disability, asserts that "recovery is not in the hospitals or institutions but rather in the communities, where persons with mental disabilities can access services, live with their family members and enjoy support from both the family and the well sensitized community".⁵⁵ With the provision of community-based mental health care and individualized support services, persons with mental disabilities can enjoy a person-centred recovery process that may not require the use of ECT, seclusion and body restraint. The WHO notes that recovery-oriented mental health [care] and social services provide messages of hope and support to overcome barriers and to foster empowerment, personal growth, inclusion and independence. Such services respect people's choices, allowing them to drive their own care and recovery journey and to live the life they want.⁵⁶

Early detection of mental breakdown or relapses

When dealing with persons with mental disabilities, it is important to avoid coercive, tense and conflicting situations that can cause distress and trigger a mental health break down or relapse or violent behavior. This can be done by keenly observing the person with mental disability for early detection of mental break down, quickly addressing their requests or need to avert stress related to delayed action; by having an individualized treatment or management plan that explores sensitivities and signs as distress for a

52 WHO (2005), 'Resource Book on Mental Health, Human Rights and Legislation', WHO: Geneva, pp. 122.

53 Twinomugisha, B. A Health and Human Rights Critique of the Mental Health Act 2019, NETPIL Paper (2020).

54 WHO Optimal mix of services for mental health care: WHO Pyramid Framework, pp2.

55 Interview with Kabaale Benon, January 2021.

56 WHO (2019), 'Strategy to end Seclusion and Restraint: WHO Quality Rights Specialised Training', pp. 2.

specific persons with a mental disability.⁵⁷ However, effective early and keen detection and monitoring of such conditions requires that government to ensure sufficient staffing and financing of the regional and community mental health facilities, as well as provision of adequate and individualized community based mental health care support services.

De-escalation Techniques

De-escalation is a technique for managing situations in which people are feeling extremely distressed or upset, leading them to act in a manner that may negatively affect them or others emotionally or physically.⁵⁸ De-escalation tips involve: respecting the persons personal space; avoiding enclosed spaces so that the persons with a mental disability does not feel trapped; interacting/engaging with the person with a mental disability; using appropriate language that cannot be perceived as provocative, humiliating or rude; talking to the person with appropriate degree of formality; give the person time to process what is being said to them without rushing them and enabling the person with a mental disability to access the people s/he knows and trusts.⁵⁹ This may also require some specialized training of both medical and support staff, as well as family members on de-escalation techniques. De-escalation technique is not emphasized in the MHA, 2019 although it is being utilized in Mbarara Regional Referral Hospital together with limited provision of community mental health care.⁶⁰

Individualized Plans to understand sensitivities and signs of distress

According to the WHO, an individualized plan outlines actions that can help a person calm down and relax in times of escalating anxiety, distress, frustration or anger depending on the person's sensitivities and common patterns of reaction. It is unique to each person, and focuses on the needs of the individual. Developing the plan with the person provides an opportunity for others to understand what the emotions and feelings of the person are in certain situations and to discuss effective ways to meet the person's need when these situations occur and in the longer term.⁶¹

Comfort rooms

These are private rooms that have a supportive environment for recovery and reduction of anxiety and distress and are different from seclusion rooms that have an element of coercion and punishment.⁶² These rooms should be kept clean and available for all persons including staff who may require moments of privacy and peaceful space to relax. Where affordable, government should build court rooms especially in the major and regional hospitals.⁶³ Studies have revealed that most of the mental health facilities in Uganda simply have filthy seclusion rooms, in which persons with mental disabilities face torture and other forms of abuse.⁶⁴

57 Ibid, pp. 26-27.

58 Ibid, p. 40.

59 Ibid, p. 41.

60 Twinomugisha, supra note 53, p. 40-41.

61 WHO, supra note 56, p. 31.

62 Ibid, p. 37.

63 S. Musisi et al (1989), 'A Psychiatric intensive care unit in a Psychiatric hospital', 34(3) Can. J. of Psychiatry, pp. 200-204, cited by Twinomugisha, supra note 53, p. 40.

64 MDAC and MHU (2014), "Psychiatric Hospitals in Uganda: A Human Rights Investigation", Kampala: Uganda. See also, MDAC

Strengthen Family support and involvement

The family remains core in providing support, necessities and care for persons with mental disabilities.⁶⁵ Although the MHA, 2019 provides for the involvement or participation of the relatives, concerned friends and parents of the persons with mental disabilities especially at the point or in situations of involuntary admission and the monitoring of the administering of treatment by medical practitioner.⁶⁶ However, there is no corresponding provision placing a duty on the government to provide families of persons with mental disabilities with information and knowledge about the mental health condition of their family members and how to cope or manage it, or provision of material, financial, social services and psychosocial support. As a result, these families become overstrained and burdened by the provision of care and resort to seclusion and body restraint, and in some cases abandoning their family members in mental health facilities.⁶⁷

Peer-to-Peer support programs

Peer-to-Peer mental health services ought to be adopted and fully supported by the government so that they reach a bigger number of beneficiaries who need them.⁶⁸ These programmes must be well monitored and the peer support persons well trained and facilitated by the State with support from DPOs/ CSOs.

3.9. Barriers to Mental Health Care Delivery

3.9.1 Barriers Faced by Mental health service users

Mental health service users recounted several barriers they encounter in accessing mental health care services, which include shortage of drugs, ignorance of the drugs/ medication they receive, limited availability of counseling services, mistreatment by some health workers, as well as stigma and discrimination from communities. The most outstanding challenge cited was about drugs and medication. The participants did not only complain about the shortage of drugs but also their poor quality, side effects and high costs. Participants reported that they are compelled to buy drugs even when they cannot afford. As one respondent noted: “at times there are no drugs in the hospital and we are required to buy, yet the drugs are costly”. Mental health service users also lacked knowledge of the type of drugs they received, something that affected their adherence to medication. Another challenge related to medication is unprofessional treatment by some health workers. Some mental health service users complained of disrespect and not being valued.

There were limited counseling services both at the community level and in the hospital setting offered to both the patient and their family members about mental illness. This

and MHU, “They do not consider me a person: Mental and Human Rights in Ugandan Communities”, Kampala: Uganda. Also see, CE-HURD and Kabaale Benon v. Attorney General, Civil suit No.094 of 2015.

⁶⁵ Inclusion International (2012), “Inclusive Communities=Stronger Communities: A Global Report on Article 19: The Right to Live and be Included in the Community Inclusion International Campaign on Article 19: pp 24- 27.

⁶⁷ Cappo. D; Mutamba. B. et al (2020), Belonging Home: capabilities, belonging and mental health recovery in low resources settings, Oxford University Press, pp 59.

⁶⁸ WHO, ‘Peer support mental health services: Promoting Person-centred and Rights-based Approaches’, (2021); Kabale. Kitafuna (2022), ‘A Critical Overview of Mental Health Related Beliefs, Services and Systems in Uganda and Recent Activist and Legal Challenges’, Community Mental Health Journal, p. 5.

was particularly so with regard to early warning signs and the prospects of attending to medical care. As such, there were few voluntary admissions as most patients reported being taken to hospitals by their families when the conditions escalated. Even while on medication, no adequate psychosocial support is offered to both the patients and their caregivers.

Participants also reported instances of stigma and discrimination resulting from misconceptions and negative attitudes towards mental disabilities. Due to stigma, some persons with mental disabilities are forced to live in isolation and fear of identifying with mental disability because it attracts maltreatment from the community. A mental health service user from Mbarara explained that some people in the community do not want to talk to persons with mental disabilities because they regard them as mentally sick.

3.9.2 Barriers Encountered by Health Workers

Mental health workers encountered numerous barriers in the process of delivering mental health services both in the regional referral hospitals and lower health facilities. Although the Mental Health Act, 2019 requires mental health facilities to provide a qualified psychiatrist or a mental health practitioner and other appropriate professional staff as a minimum,⁶⁹ understaffing emerged as a cardinal barrier to effective delivery of mental health services in the two hospitals. The mental health units in the two regional referral hospitals were understaffed and the few available staff overwhelmed by the high staff to patient ratio. According to a female health worker in Gulu:

Clinicians, we are only 3 catering for over 10,000 clients, and at the moment, one is sick and we are only two who are operating. So nursing, qualified nurses are five and you find 5 nurses working in 3 shifts, something that is difficult to plan.⁷⁰

Coupled with understaffing, the health workers complained about frequent shortage of essential drugs. It emerged that the hospitals did not often have enough drugs, compelling patients to buy some whose prices are out of range for ordinary patients and caregivers to afford. According to a respondent:

The first thing is that the hospitals don't have enough drugs for the patients and if the patient is not capable of buying drugs, he might get relapse, and thus violating his rights as a mental person.⁷¹

Health workers also reported the challenge of poor facilitation to conduct community mental health services such as home visits, counseling and peer-to-peer programs. This means that they could not conduct outreach activities to facilitate community recovery and reunion with the family. The limited number of NGOs and OPDs working in the field of mental health also exacerbates the situation, further limiting access to mental health care services. Even though health workers clearly recognize the need for community-based mental health care, they were hardly funded to go to the community.

A problem associated with the lack of facilitation to conduct community mental health services is the late identification, screening and diagnosis of mental health conditions

69 Mental Health Act 2019, Part IV, Article 21(a).

70 Female health worker, Gulu.

71 Male mental health user, Mbarara.

from the communities. To some extent, late identification results from the community's tendencies to first seek diagnostic and treatment solutions from traditional healers before medical care.

Health workers also reported the problem of abandoning patients when admitted to hospitals. Some caregivers reportedly dumped patients at health facilities without checking on them or giving any support. The health workers attributed this problem to negative attitudes, material and financial hardships, lack of knowledge of how to care for persons with different mental health conditions, among others. This situation mirrors what exists in the community where many persons with mental disabilities reportedly loiter unaccompanied and without appropriate care.⁷²

3.9.3 Barriers Faced by Mental Health Caregivers

The caregivers in this study recounted several challenges they encounter in providing care to their relatives and family members with mental disabilities. Caregivers also reported the shortage of drugs as a major barrier to mental health service delivery. Many caregivers said they do not get adequate stocks of drugs for their relatives, and in other cases fail to buy some of the prescribed drugs due to lack of financial capacity.

Caregivers also grappled with monitoring and enforcing adherence to medication. Some mental health service users reportedly refuse to take their drugs when they start to feel a little better, a behavior that slows their recovery and causes relapse in some cases. Moreover, some patients reportedly turned violent to caregivers in the course of enforcing adherence to medication. Understandably, the threat of violence to caregivers and community members was cited as a major reason for using body restraint and confinement of persons with mental disabilities in homes and communities.

Further, the COVID-19 lockdown measures exerted huge challenges to caregivers. The restriction of private transport during the lockdown meant that caregivers could not freely move to health facilities to pick or refill the prescribed medicines for their family members with mental disabilities on schedule. The situation was aggravated by the doubling of fares when public transport was eased at half capacity.

Caregivers and their entire families endured what one would call stigma by association. This means that caregivers suffered the same negative labels, discrimination, and marginalization as their family members with mental disabilities by virtue of their association with them as relatives or caregivers. The negative attitudes by the community stemmed from ignorance about mental health causes and diagnosis, and how or where to get appropriate treatment and care.

72 Mental health user, Mbarara.

4. LESSONS LEARNED AND IMPLICATIONS FOR POLICY

The findings from this study confirm that ECT and seclusion were occasionally used in the two hospitals, and are regarded as relevant constituents of mental health care ecosystem in spite of the negative rating about their use by mental health service users. Body restrain and seclusion are used in both community/home and hospital settings purportedly to enforce medical treatment, relieve caregivers to do other work, restrain aggressive patients and to protect health workers and caregivers from potential harm by violent patients. It is apparent that the use of seclusion, ECT and body restrain is reinforced by the perception among some health workers and caregivers that mental health service users can be a danger to themselves and to others. Mental health service users opposed the use of these treatment modes on the ground that it subjected them to inhumane treatment.

Mental health caregivers shoulder a high burden of care owing to material hardships, lack of technical capacity on how to provide quality mental health care to family members with mental disabilities as well as stigma, discrimination and negative community attitudes. Caregivers lack access to mainstream livelihood and social empowerment programs. The unavailability of drugs in public hospitals compounds the mental health burdens of caregivers by imposing on them the imperative to buy drugs for their family members with mental disabilities. Moreover, caregivers incur extra costs associated with seeking formal and informal mental health care services.

There is evidence of a strong need and support for community-based mental health care services. However, the district and regional referral hospitals lack the financial and human resource capacity to provide effective community-based mental health care services. Consequently, mental health services are still largely centralized to district and regional referral hospitals which are distant to many caregivers and mental health service users. They have to incur extra costs to travel long distances to seek treatment and attend to their hospitalized relatives.

The closure of mental health units at regional referral hospitals to utilize them as COVID-19 isolation centers countrywide amplified the relevance for, and the need to strengthen community mental health services. The mental health service users who were unable to access mental health units at regional referral hospitals would get such services at district hospitals, health center IIIs and IVs that are closer to them than the regional referral hospitals.

Informal mental health care providers (faith and traditional healers) remain relevant and sought after by caregivers and mental healthcare users in the two districts. It was apparent that the need for informal mental health care is reinforced by several factors among which are: (a) the unavailability of formal mental healthcare services in communities and lower health facilities, (b) community misconceptions and beliefs

about mental health care causes and diagnosis, and (c) delayed healing/recovery forcing caregivers and mental health service users to pursue alternative/additional care options. In regard to the relevance and inevitability of informal mental health care, it is in the best interest of the public and the Ministry of Health to reexamine and improve collaboration, technical support and regulating what they provide for the betterment of mental health service users.

The outbreak of the COVID-19 pandemic negatively affected the availability and delivery of mental health care services owing to the two times nationwide lockdown measures. The situation was compounded by the closure of mental health units to create space for COVID-19 isolation centers at regional referral hospitals. The closing of mental health units resulted in the premature discharging of mental health patients and the unnecessary referral of patients to Butabika, the national mental health referral hospital.⁷³ Some regional referral hospitals went as far as suspending all outpatient clinics in a bid to prevent the surge of COVID-19⁷⁴.

73 The Independent (July 16, 2020). Mbale mental health patients struggling to get treatment. Retrieved from: <https://www.independent.co.ug/mbale-mental-health-patients-struggling-to-get-treatment/>

74 New Vision, (June 11, 2021). Masaka Regional Referral Hospital Suspends Outpatient Clinics. Retrieved from: <https://www.newvision.co.ug/articledetails/105800>

5. STRATEGIES TO IMPROVE MENTAL HEALTH SERVICE DELIVERY

On the basis of the experiences and challenges they experienced in homes, communities and health facilities, participants suggested numerous actionable strategies for improving mental health care service delivery in their districts and nationally.

1. To address the endemic problem of understaffing and lack of specialized mental health staff in hospitals and lower health facilities, all the participants urged the government through the Ministry of Health to train, recruit and deploy adequate number of general and specialized health personnel to match the demand for mental health care services in the country.
2. In response to the demonstrated need for community based mental health care services, the participants recommended the government and non-state actors to prioritize and provide facilitation to hospital staff to conduct community outreach services such as psychosocial support, home visits, monitoring drug adherence. One of the ways to improve community based care more VHTs as well as retool existing ones to bridge the service gaps created by understaffing in hospitals. When empowered, VHTs can identify persons with mental health conditions, make appropriate referrals and offer psychosocial support to both the patient and the caregivers.
3. Ignorance and misconceptions about the nature, causes and diagnosis of mental health conditions is prevalent in all communities in both districts. To address this, participants recommend increased community awareness on mental health, as one way to promote early identification of symptoms and signs and seeking appropriate mental health care. Increased mental health awareness creation will also go a long way to address stigma and discrimination of persons with mental disabilities in homes and communities.
4. The Government of Uganda was recommended to increase its national spending on the mental health sub-sector as a proportion of the budget allocation to the Health Sector from under 1% to at least 10% to ensure adequate supply of essential mental health drugs to hospitals and lower health facilities. Increasing the mental health budget can reduce drug shortage and the burden of buying drugs that is shifted to caregivers due to drug stock outs.
5. It was abundantly evident that many caregivers lacked the financial capacity to meet the cost of care and medical treatment of their family members with mental disabilities. The caregivers in the study were unemployed or engaged in petty income generating activities that do not generate adequate income they can dispense for both livelihood and medical treatment. It also emerged that some caregivers and mental health service users lose their jobs at the onset of mental disabilities but hardly retain

their jobs after recovery. To this end, the participants requested the government to expand access to existing livelihoods and social protection schemes to families with persons with mental disabilities. This can be done through establishing targeted livelihoods programs but also ensure access to mainstream programs such as the Youth Livelihood Program, Uganda Women's Entrepreneurship Program and Social Assistance Grant for Empowerment, Disability Grant; National Special Disability grant and the recently adopted Emyooga and Parish Development Model.

6. Caregivers in this study lacked basic knowledge and skills on appropriate caregiving, a situation that sometimes resulted in unintended abuse and neglect. Participants proposed training, counseling, and supporting of caregivers and families of mental health service users to improve the quality care they offer. One of the participants recommended provision of support persons/personal assistants to those who may not have caregivers or abandoned by the family or who prefer to have support persons.
7. Evidently, all categories of participants demonstrate limited knowledge of mental health laws and policies. In addition, few mental health service users exhibited full understanding of their human rights. The Ministry of Health should therefore consider disseminating exiting mental health laws and policies and educating stakeholders on their rights and duties.
8. Finally, there is evidence of very few non-state actors focusing on mental health interventions in hospitals and communities, making public mental health services the only available options for most communities. There is need to promote public-private partnership and deliberate engage NGOs, and OPDs to support mental health are. These organizations could support activities like community awareness and advocacy for the rights of persons with mental disabilities, and contribute towards stigma, discrimination, due to misconceptions and negative attitudes.

6. CONCLUSION

The present study set out to ascertain the use of ECT, seclusion and body restraint and the alternatives to these modes of treatment in Gulu and Mbarara regional referral hospitals. The study found that these techniques are in use and were regarded by health workers and caregivers as relevant components of the mental health ecosystem in spite of their negative perceptions by persons with mental disabilities. The assumption that persons with mental disabilities can be danger to themselves and to others is the major justification for the continuous use of these techniques. Medical treatment remains the dominant mental health service with a limited range of psychosocial services in the two districts. The need for an effective community mental health services evidently stood out in the same way as the complementary role of informal mental health providers in the mental health ecosystem. Mental health conditions remain a widely misunderstood phenomenon in communities, a situation that results in many unfounded negative stereotypes and mistreatment of the persons with mental disabilities. Families play an indispensable role in mental health care service delivery, but shoulder the greater burden of care compounded by the unavailability of drugs and the centralization of mental health care services to distant hospitals.

The findings of this study must be interpreted with caution in light of certain methodological shortfalls that limit the application of its findings beyond the sample. The study was conducted in only two regional referral hospitals and data was collected using only interviews. In future, widening the geographical scope, increasing the sample size and collecting data from multiple sources are recommended to improve the transferability of findings. Nevertheless, the study provides rich insights into the nature and range of mental health services provided in the two hospitals during a challenging time like the recent COVID-19 lockdown measures.

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