“Access to health is my right” - a model to improve life for women with Psychosocial Disabilities in the streets of Kampala

A description of a practical model for improving homeless women’s life

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Klara Thorsen

Else Lillebæk

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SIND Mental Health, Denmark

Introduction

This article has been written to bring focus on and open a window into the complexity around homelessness and more specifically homelessness among women with a psychosocial disability and how it is possible to improve these women's life when living in the street or even better by reintegrating them in their families and communities.

The article is based on the experiences and results from a model developed by Mental Health Uganda (MHU) in cooperation with their partner SIND Mental Health Denmark (SMH). The experience is from a common project with the goal to reach out to homeless women in the streets of Kampala as it was found that this group of women was the most vulnerable in the context of people with a psychosocial disability.

MHU and SMH have cooperated for two decades and MHU located in Kampala has observed the women in the streets and SMH had likewise interest in reaching out to these women to try to improve their life.

The model was developed as a pilot project in 2018 and the results reached in 2022 are so convincing that the model should be accessible and published to benefit other civil society organizations or health government authorities in neighboring countries. The article is a description or presentation of a practical model that has shown to be useful in rehabilitation of these vulnerable women. It has not been the intention to write a scientific contribution to the discussion of women's homelessness worldwide, and it should not be considered as such. The few articles found on this objective (A. Fekadu 2014, Benedict Osei Asibey, 2020 and V. Gopikumar 2014) all support MHU and SMHs experienced evidence. But why has it been important for MHU to reach out to the homeless women living in the streets and in which context has the model been developed by MHU to reach this specific target group?

Context

In Uganda the escalating level of urban poverty has reduced the capacity of the family systems to access the basic needs of life to take care of their families. As a result, many people end up on the streets of Kampala for casual labor, experiencing alcohol and drug abuse etc. where if not already having a psychosocial disability, may get it from living under the severe conditions on the streets.

Women and men with mental health challenges in the streets are met with stigma, malpractice and exclusion. They are removed from the streets by the police, beaten and taken to police stations and accused of crimes like idling and disorderly. They are rarely brought to justice or gain access to psychiatric treatment while incarcerated. They live in severe poverty; go hungry or feed from the dustbins. They usually sleep in the slums and they are at risk of being misused and forced to engage in criminal behavior. They have no contact with mental health or public clinics and are excluded from their communities. They

have nobody to share information about suffering from mental illness and apart from suffering from psychosocial challenges they often end up in substance abuse to relieve their internal pain. The complex mix of poverty, mental health challenges and homelessness - as not being amenable to simple explanations - is thoroughly elaborated in the article “Understanding the Mental Health - poverty - homelessness Nexus in India '' of Vandana Gopikumar in 2014. Poverty coupled with inadequate and inaccessible health care and support systems can render persons with mental disorders homeless and susceptible to rapid deterioration, placing them in an environment of conflict, distress and heightened vulnerability,

Even the needs of homeless people with mental illness on the streets might look similar, they are not quite the same. They vary from age group and gender. Homeless women with mental illness have a wide range of needs. They hardly bathe, do not have access to sanitary pads, and if they get pregnant, they are unable to get help giving birth to the child and to take good care of the child. Sexual and reproductive needs of homeless women with mental health challenges are a very urgent concern as it also involves their children. Stigma and discrimination by the society may be followed of abandonment and expose the women to both physical and sexual abuse.

An Ethiopian study from 2014, “Burden of mental disorders and unmet needs among street homeless people in Addis Ababa” of Abebaw Fekadu etc., found that despite comprising only 10% of participants, women appeared to be much more vulnerable to exploitation, for example 50% women who reported sexual abuse. The study suggests those at higher risk of exploitation, particularly women, have to be prioritized in any intervention planning.

When women end up living in the street without money and with all their belongings in a plastic bag they have no human resources to help themselves coming back to family and community. Most of the women living on the streets have been abandoned from the family, due to no or very little knowledge of how psychosocial disability affects them and changes their behavior in the family. The affected women will need an outstretched hand to get them into treatment.

The model

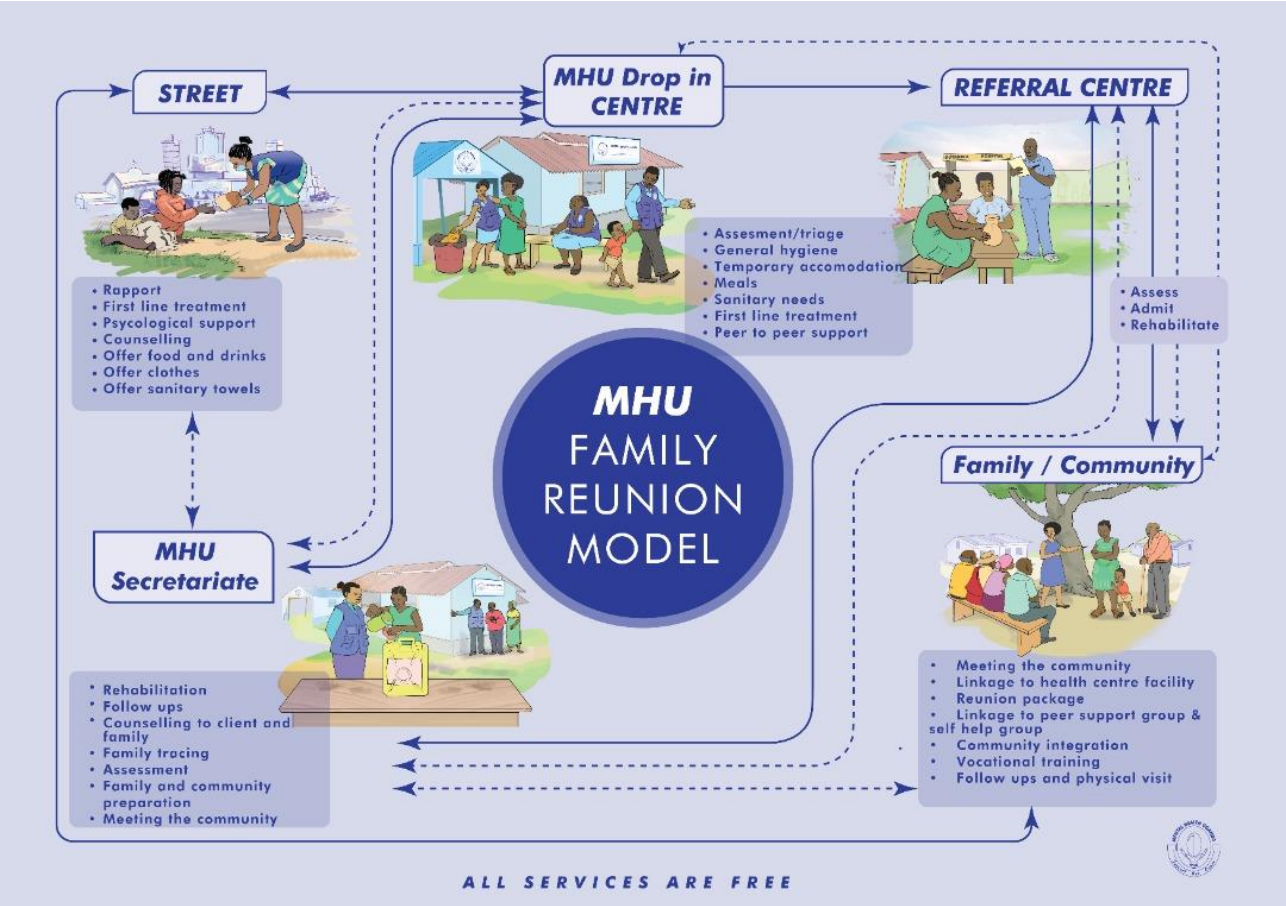
MHU has learnt that traumatic events in the lives of women and children feed into a sense of economic and emotional powerlessness. A matrix of poverty, victimization, early physical and sexual abuse, substance abuse and mental illness experienced by homeless women is mirrored by evidence of depression, low self-esteem, mal-adaptation, health problems and social disaffiliation. This is expressed in the article “Rehabilitation of mentally ill women” by Rajni Chatterjee and Uzma Hazim in Indian Journal of Psychiatry, 2015. Studies indicate a more gender specific focus is being recognized as appropriate to address the special needs of women. To get the women into treatment with the correct diagnosis is crucial for MHU and for the model to work.

This model highlights some barriers in the mental health and social sectors in Kampala and how these challenges can be addressed more effectively. It also aims to improve the understanding of the distress experienced by homeless women with mental health concerns.

Many of the insights are the result of, MHUs, work to promote community based mental health care. The model is integrated in the community based approach which is the brand for all of MHUs interventions.

The model is also to follow The Safe Haven opinion on this: *"A non-institutional approach to homeless services has been found to be the most successful in engaging and changing lives of homeless women. They also rely on self-help and self-empowerment and aim to ameliorate the pervasive social isolation of homelessness to promote a learning of social skills and to build self-efficacy and self-esteem. A supportive environment, a caring staff and flexible structure will engage the women and encourage involvement of communities".* (Safe Haven - For women only continued…)

The model shown in a flow diagram illustrating the rehabilitation Process



Outreach at the streets

The first step in this model is to find and contact homeless women in the street where they stay, - often in slum areas close to a marked place. But how to find the women?

In three divisions a Team, hereafter referred to as the Team, of two female psychosocial workers and a driver have developed a gentle and respectful approach to making contact with the women. The Team has a particular eye for the homeless women and has no difficulty in spotting them on attitude, hair and appearance when the Team seeks out the women on the streets. Sometimes the women only agree to accept e.g. something to drink, first aid or painkillers on the street. And they feel better. Other times they accept to go to the Centers for counseling, first line treatment, care for sanitary needs, clothing, food and rest. After this care the women feel comfortable and have trust in the Team. Often the women are approached several times before they are willing to get into contact with the Team and agree to follow them to the Center.

Outreach thus means in this context to find the women, to get in touch with them and to find and see their needs.

Through the project period of 18 months the Team contacted 304 women on the streets . Of the 304 women 275 came to the Center and received service.

During the outreach the Team performs much advocacy and teaching in the communities about women's harsh lives on the street and about mental health challenges to the onslaught of people that always occurs when women are contacted on the street. Homeless women are very lonely and alone because of ignorance and stigma in the population.

Also in TV and radio awareness rising about the life of the homeless women and their harsh lives is regularly carried out by MHU during the project period. To generally draw attention and knowledge to the lives of mentally challenged women on the streets.

Another element in the outreach program is training of the police. The police training is held to sensitize the police in its role in the protection and promotion of the rights of women living on the streets where the police play a key role. Many times women are reported as criminal suspects by the community due to stigma. At the forefront the police are trained in how to deal with a situation where the women are mentally ill.

Outreach and referrals in the Drop-in Centers

The design of the Centers is very simple in this model. A sturdy tent with little furniture, a separate resting place along with a counseling area, as well as equipment for sanitary needs; clothes, food and drink, some volunteers, a psychosocial worker with a computer and safety. One Center is located at Mental Health Uganda's administration office. The other two so-called Drop-in Centers are located and connected to two Health Centers in slums close to where the women stay and move around. The Drop-in Centers share some of the facilities of the Health Centers e.g. bathing facility. The Team have built up a close collaboration with the staff of the Health Centers, in particular with their psychiatric nurse. They share knowledge and education in mental health care, and they exchange knowledge about outreach in the Health Center on how they see the needs of the women and how they treat them.

MHU is fundraising from private companies to donate equipment used at the street and in the Center to care for the women. A part of the local fundraising strategy is to educate the private companies of homeless women living on the street and mental health challenges.

But how do women gain access to the necessary treatment sites ? In addition to personal care, attention and security the Dropj-in Centers offer counseling and referral for specialist treatment at a psychiatric hospital or other treatment depending on the individual needs. After having a bath, a haircut, some clean clothing and counseling the women have more confidence, and now they also get access to the necessary treatment sites with whom the Team also has established a good collaboration about the women. Often the Team follows the women to the treatment institution.

How do children cope in the model

Some homeless women live with their children on the streets. Homeless women with children often report cases of child neglect by the fathers of the children and yet the mothers are not able to provide for their children also. MHU recognized the need for a legal aid desk to provide services like legal aid counseling to mothers, but also authorities are consulted if it is not possible to reach any agreement, and the Team makes follow up to those kinds of challenges where children are neglected and malnourished. The Team collaborates with clinics that can help provision of medical services to homeless women and their children. The Team also collaborates with local NGOs for referring children when their mothers are hospitalized at the capital's psychiatric hospital or elsewhere as children cannot stay with their mothers during treatment.

Role of the families

Up to April 2022 a total of 32 of the 312 referred women had been discharged from psychiatric treatment and reunited with their families by the Team. Others have been discharged by the staff of the capital's psychiatric hospital. When being discharged from the psychiatric hospital the woman can choose between rehabilitation back into her family or back to the streets. If the women want to go back to her family the Team is preparing the family while the women is admitted. After she is discharged the Team brings her to her family. After this the hospital offers monthly follow up reviews as well as prescribes free medicine, when it is available. Although psychiatric treatment in principle is a free service for everyone, the mentally ill and homeless persons are not aware of the possibilities of treatment and are also unable to approach the health clinics in a manner where they can receive assistance. This fact is supported by Benedict Osei Asibey in her scoping review of healthcare services utilization amongst homeless adults in Africa from 2020. The fact that the MHU Team supports the women in the referral process is a decisive factor in securing the women access to treatment.

For the reunion the Team traces and contacts relevant relatives. Families and neighbors are prepared for reunion through awareness meetings and capacity building with respect to mental illness, the handling and effects of drugs, problem solving, and reintegration of women into the community. Awareness raising about mental illness helps the families to better understand and deal with the mentally challenged relative.

But why is it necessary to prepare and slightly push the family to receive and accept a woman coming home after perhaps up to years with a life as homeless? The stigma of people with a psychosocial disability is still a strong factor in the communities and even in the family, and through the preparation the Team makes it acceptable to include the women again. The family is supported in the care of the woman and how to help in taking the medication prescribed from the hospital. This preparation helps in the acceptance of the women and prevents them from ending up in the street again.

The local community

Peer to peer counseling and Vocational training

When the women are coming back to their families it means that there is another person to be fed in the household. How can it be prevented that the woman feels as a burden for her family and goes back to the street? To prevent this, a part of the model includes that the women are offered peer-to-peer counseling and vocational training. Both activities are important in building the women's self-esteem, well-being and life capabilities. Peer-to-peer counseling takes place on a weekly basis and involves both the women and their nearest relatives. Results are good and found to be important for both the women as well as the relatives as they meet people in the same position. The peer to peer meetings are held in the communities, where public space can be made available and with no expensive transport.

The vocational training both has a therapeutic and an income generating aspect. Vocational training in e.g. liquid soap making for women and their relatives are organized by the Team. The training is highly successful from a therapeutic point of view, in the sense that it has an impact on the participants' skills, social competences and self-respect. The learning from this has been that the training should also emphasize on the financial and marketing aspects in order to enable the women to market the product and generate an income. The resettled women are also guided into existing vocational training opportunities and self help groups organized by Village Health Teams (VHT) in their communities.

VHTs

The Village Health Teams (VHT) are informed about the return of the women in the families and support the reintegration. A successful resettlement depends in some cases on the woman's ability to contribute to the family income. A follow up program from the VHTs and some support to them have been given to strengthen cooperation with the VHT to make them ready to document the development of the individual client.

By the end of 2021 women, who had already been trained, are doing the training of new reunited women and their caretakers. If the women have the ability to save a small amount every week they can join loan and savings groups to start small Income Generating Activities (IGA). Rooting the efforts in the community is assumed to make the effort more sustainable. While promoting the inclusion of the targeted women into training in the community, it is also acknowledged that not all the women are in a state where they can benefit from such training in the community and that other options must be considered for those.

Some Results

In the same 18 months of the project 145 women were resting at the Center and 38 women opted to go back to the street. 250 women were referred to other specialized health service providers and 44 cases of abuse were documented and reported to the community police department. The number of children referred to special treatment in the period was 25. A Legal Aid Desk was set up to respect the rights of children and women and to deal with the challenges they face. 39 women have received support from Legal Aid Desk concerning sexual abuse, assault and destruction of property. The women are still victims of stigma and abuse, but are now able to report their cases to authorities and get justice. They have been empowered to report and authorities have been motivated to follow up on the cases.

A statement from a project report tells us that many of the women are neglected and discriminated against, so they usually find it difficult to make friends and also feel loved. The essential service given to them at the drop-in Centers such as clean clothes, sanitary towels, general hygiene, food and drinks makes them feel valued, loved and hopeful.

Kampala City Council Authority, KCCA, takes more and more responsibility for the rights of the women on the street and plays an active role in treatment. Also the police have increased the protection of women on the streets and promote the rights of the women like any other citizens.

Discussion

The model demonstrates a high level of activity in the outreach work. To find the women, to get in touch with them and to find and see their needs.The large number of women receiving help states a high burden of mental disorders among women on the streets. Up to now the outreach work and the advocacy on the streets is performed by paid and trained staff and is a newly cultivated work area developed by Mental Health Uganda. MHU says neither KCCA nor others will perform this kind of work. So how can it continue without funds and the trained staff?

MHU has during the years worked hard to influence the central health authorities on better conditions for the mentally ill. In 2018 a new Mental Health Act was passed in Uganda, which describes the rights in the mental health area for the people. The new law obliges the authorities to make efforts in the field of rehabilitation, in Uganda Community based Mental health, and also for mentally challenged women.

Unfortunately a rehabilitation process is not described in the Act where it is more about the right for treatment and care. In the article on India “Rehabilitation of mentally ill women” from 2015 the Delhi High Court gave some directives to their government among others that the central government was to release funds for the Urban Health Module so that rehabilitation work can be done at a faster pace. The government was also to constitute a committee consisting of the secretary of the social welfare department, principal secretary of family and child health development, and the head of Department of Psychiatry at the Institute for Behavioral Health Studies and Applied Sciences and asked it to submit a compliance report. Finally the government was to formulate guidelines so that people could help the mentally ill without any legal tangles. Would it be possible to use some of these ideas in the obligations of the Ugandan authorities to the mentally challenged women on the streets? Mental Health Uganda has recently called upon The Ministry of Health to give guidelines for the provision of Community Mental Health Care as provided for in The Mental Health Act in 2019. This will not only increase access to care but also support full integration of homeless women with mental disabilities back into their communities.

Or should one resort to more voluntary support to perform the various tasks in the outreach work? The outreach work requires extensive knowledge and skills in the field of mental health and in committing oneself in the field and in collaboration. Just as it requires stability and continuity. Training and resilience are a necessity. The police in Kampala, along with VHTs and Community Health workers has been trained in mental health issues and sensitization by the Team. Could these devices be able to take over the functions of the outreach work? And can volunteers receive the necessary training to perform outreach work? Will MHU be able to perform this training from now on?

Furthermore, for the sustainability of the model, more social workers and NGOs are attached to the hospitals to function as a constant bond between the professionals and family members so that the patient raps the maximum benefit. How to bridge between “what is” and “what ought to be”?

Conclusion

The complete success of this model to improve life of homeless women with a psychosocial disability would be when the Mental Health Acts is implemented and City Council Authorities would be able to take over the full responsibility for providing these women their rights and possibilities to access the health system as any other citizen and when the holistic and community mental health care can include these women and their special needs. All the stakeholders from the service providers to the consumers and their families and then society at large can and should be a part of the rehabilitation strategy to make it effective and meaningful.

But as homelessness is a growing concern worldwide and in the East African region it is a prevalent issue this might be a too optimistic view for the nearer future. As there has been very little research into the complexity around homelessness among women in the Global South the interest from international organizations to support homeless mentally ill individuals - women as men, has been at a minimum. (A. Fekadu and colleges, 2014).

The model was developed to improve life for homeless women with psychosocial disabilities in Kampala. The documentation and experiences has shown that the model has been capable of doing so to a certain extent. There was no expectation of getting all homeless women away from the street. Some just want to stay there even after rehabilitation and medication. It is their right to choose a life as homeless, but even this life has been improved by giving them access to the health system in their division in the city.

References

Health problems and healthcare service utilization amongst homeless adults in Africa - a scoping review by Benedict Osey Acibey with more in BMC Public Health vol.20, no:594(2020) https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-020-08648-y#main-content

Homelessnes in Addis Abeba. Burden of mental disorders and unmet needs among street homeless people in Addis Ababa, Ethiopia by Abebaw Fekadu with more in BMC Med. 2014; 12: 138. Published online 2014 Aug 20.doi: 10.1186/s12916-014-0138-x

Rehabilitation of mentally ill women by Rajni Chatterjee and Uzma Hashim, Department of Psychiatry, Bhopal, India. http://www.indianjpsychiatry.org 2017

Safe haven - for women only continued… Lotus House: Indian Journal of Psychiatry. 2015 Jul; 57(Suppl 2): s345-s353. lotushouse.org

Understanding the Mental Health - Poverty- Homelessness Nexus in India by Vandana Gopikumar, August 2014, The Banyan, Chennai, India.ihrn.org.in