

Annex 1: Development of the mental health support group in rural Vietnam

The development of the mental health support group in rural Vietnam was conducted as a formative research with two steps.

Step 1: Identifying the gap in care for people with SMI

Method

Sample size: Qualitative methods were used to explore the treatment gap and the quality of care for people with severe mental illness (SMI) in Tien Ngoai commune. In-depth interviews were conducted with relevant stakeholders including commune health station; the local authority; communal department of Labour, Invalids, and Social Affairs; and social organizations. In addition, main caregivers of people with SMI were randomly selected from the list managed by the commune health station to undertake in-depth interviews.

Data collection tools: The guiding questions for in-depth interviews were based on a previous research study on mental health system Vietnam [1]. The questions included main activities to support people with SMI, challenges of these activities, and recommendations. The structured interview with the main caregivers consisted of the living standard, self-care, and family care of people with SMI.

Procedure: An official meeting was conducted with Hanam provincial Department of Health to get their approval to conduct the project activities in Tien Ngoai commune. A letter was sent by the Department to the local authority of Tien Ngoai commune to introduce the project. The research team had an official meeting with the Tien Ngoai authorities, including representatives of health, labour sectors and other social organizations to describe the project's aims and activities. The explanatory statement in plain language was given to the in-depth interviewees one week before the interview. All in-depth interviews were implemented in private rooms at the building of the local authority or commune health station.

Regarding the structured interview, a letter of invitation was sent by the local authority to the main caregivers of selected people with SMI to a meeting facilitated by the research team. Explanatory forms and any questions related to the project were provided to the participants in the meeting. At the day of the interview, consent forms were given to the main caregivers for obtaining their permissions to collection information of people with SMI.

Data management and analysis: Information of all in-depth and structured interviews was taken note. The notes were read carefully and transcribed by the researcher who conducted the interview. Deductive approach was used to analyse the qualitative data. Information was allocated into main themes. Information of the structured interview was analysed in terms of living condition, self-care and family-care of people with SMI.

Results

Theme 1 - Gap in treatment in the health and social systems

In the health sector, there was one commune health station staff member who was in charge of implementing the community mental health program. Her main mental health responsibility was to collect medications from the provincial psychiatric hospital, and to distribute them free of charge to people who had been diagnosed as having schizophrenia or bipolar disorders and were registered with the program. Thirty people were managed by the commune health station in this program. However, it was reported by the mental health staff and caregivers of

people with SMI that the medications were old generation, with adverse side effects and limited effectiveness. Adherence to pharmaceutical treatment was low. For those living in more economically advantaged households, it was common for out-of-pocket payments to have been made to purchase newer generation medications for people with SMI. *"I know that the medications provided by the program have side effects because they are cheap. In addition, the medications are distributed from the provincial psychiatric hospital, we are in charge of providing it to people with SMI in the community only"* (A mental health staff of the commune health station).

There was one social work staff in the commune who was responsible for providing monthly financial support and health insurance cards from the government to people with SMI. The financial support was around 270 thousand Vietnam dong in 2013 (approximately US\$13,5) per month. Due to the regulation of the Ministry of Labour, Invalids and Social Affairs, only people with SMI diagnosed at the public psychiatric hospitals could receive the social support. It was estimated that there were around 50% of people with SMI who were unable to receive this financial support due to lack of formal diagnosis of having SMI. The social work staff member was experiencing an overload of administrative work, and was not conducting any additional activities for people with SMI. *"I am so busy with administrative work to provide financial supports to disadvantage groups in the community, so that I cannot help families having members with SMI"* (Social work staff of the communal Department of Labour, Invalids, and Social Affairs).

In general, there was no comprehensive care for people with SMI in the community such as rehabilitation, or reintegration into the community. There was severe stigma and discrimination against people with SMI due to limited mental health literacy and no public communications in mental health. *"In our commune, the community members do not understand much about severe mental illness. We all think they are crazy and dangerous. Therefore, families having people with SMI do not receive support from the community"* (Deputy Head of the local authority).

Theme 2 – Gap in community, family and self-care

Totally five main caregivers of people with SMI were selected for the structured interview. All of them were cared for by their families. The quality of the family care was low and did not respect to the human rights. Most of them did not have private and clean room. They were cared for with traditional experience in the community without scientific evidence. Two out of five selected people with SMI were wandering around the commune for food and slept in the rice field at the time of the interview. In order to prevent people with SMI from wandering, most of them were locked or confined in a room. They were not allowed to participate the festivals or common events in the village or commune.

All interviewed caregivers were female. They are wives, mothers, sisters or daughters of people with SMI. According to Vietnam tradition, the role of a woman in the family is to taking care of the whole family members. Therefore, if there is a mentally ill member, it will be the responsibility of the woman.

Theme 3 – Delayed duration of diagnosis and treatment

It was reported by both the mental health and social work staff that the government support could not reach all people with SMI. Due to limited mental health knowledge of caregivers of people with SMI, stigma of the community, and disadvantaged household economic status, families did not disclose if they observed psychotic symptoms of a member. Therefore, it is estimated by the mental health staff that there was at least 30% of people with SMI did not receive any formal diagnosis and treatment in the commune or had long delays to diagnosis.

Step 2 – Developing intervention framework

Method

The research team conducted a group discussion with four national experts in community mental health and community development in both the government and non-government sectors to explore common strategies used in community-based mental health projects.

In order to improve the quality of life of people with SMI in the community, their basic rights must be respected. However, there is no mental health law in Vietnam. The rights of people with mental disorders are mentioned separately in some related laws such as the law on health examination and treatment (2009), the law on the elderly, and the law on health insurance (2014). Therefore, after reviewing existing international human rights, the research team decided to use the Convention on the Rights of Persons with Disabilities developed by the United Nations to identify the key basic rights of people with SMI for the intervention. The convention was published by UN in 2006, and has been signed by 161 countries. It included of 50 articles which aimed to promote, protect and ensure the human rights and freedom of people with disabilities [2]. Among 50 articles, key human rights were selected using two criteria: Feasibility and necessity. Each research team member worked independently to select the key rights for the intervention. Then a discussion was organized to get the consensus among the team members. Combination of the two steps helped the research team to develop the intervention. The gaps in care and results of the focus group discussions informed the implementation mechanism of the intervention. The key human rights suggested the key content of the intervention in the community.

Results

A positive deviance approach was adopted by the research team after consultation with local experts. Positive deviance is defined that in a resource-constrained community facing a common health problem, there are several individuals or families initiating “uncommon” behaviours or practices that allow them to overcome the health problem to achieve a better health outcome when comparing to their neighbours [3]. It means that using the same resources and facing the same health problems, some people can find a “creative solution”. This approach was used successfully in dealing with malnutrition among children in low and middle income countries, including Vietnam [4, 5]. There are four main steps (four Ds) in the positive deviance design including: Define (problem or desired outcomes), determine (positive practice), discover (positive practice), and develop (implement the positive initiatives) [6].

After reviewing the rights of people with disability, the research team decided to select the following core themes to be addressed in the intervention: access to mental and physical health care and treatment; the right of having appropriate care in terms of sufficient food and access to hygiene; the right of being integrated into community activities; and the right to have rehabilitation. In addition, previous studies reported that the caring burden on caregivers affected their mental health seriously [7]. As a result, it would affect directly to the quality of family-care. A session of caregivers' stress was added into the intervention. Finally, eight topics were selected for the content of the intervention meetings: (1) personal hygiene; (2) nutrition; (3) other physical health care; (4) mental health care; (5) other rights and privileges of people with mental disorders; (6) rehabilitation; (7) returning to community life; and (8) decreasing stress for caregivers.

Women were the main caregivers of most people with SMI in Vietnam including in the intervention site. Therefore, the research team aimed to support those women by using the Women's Union as facilitators of the mental health support group. The Women's Union is a structured social organization and more than 90% of

women in Vietnam are members. Its commitment to national interest is expressed in its aims to assist women both in “building prosperous, equal, progressive and happy families” and in income generation by increasing their “knowledge and capacities” [8]. In fact, Women's Union staff function as subsidiary social workers in the community when professional social work was newly introduced to Vietnam.

Mental health support group intervention is a structured program that combines eight topics, seven of which address the key human rights of people living with SMI (personal hygiene, nutrition, physical health care, mental health care, other rights and privileges of people with SMI, rehabilitation, and community integration) and one topic focuses on reducing stress of caregivers. Each topic was implemented using four steps (four Ds): (1) Define the topic and the context of implementation in the community; (2) determine the positive practice in the commune or village; (3) discover the positive practice by introducing and sharing it in the mental health support group; (4) develop and implement the positive initiative among intervention participants.

The intervention meetings were facilitated by Women's Union staff trained in group facilitation, basic counselling skills and basic knowledge of mental health care. There was one mental health support group per village. The meetings were conducted every two weeks at the Women's Union staff's houses or participant's houses. Each meeting included people with SMI, and their caregivers. Each topic was delivered with two meetings and one home visit. The first meeting of the topic was to share the positive practice. It was followed by a 30-minute home visit conducted by the facilitator to reinforce the application of the positive practice. The second meeting focused on sharing any difficulties that participants may have encountered when implementing the initiative and discussing solutions with other participants. Each meeting took 60 to 90 minutes.

In addition to the group meeting, the Women's Union staff also conducted several activities to reduce the stigma against people with SMI in the community. These activities included: (1) a summer program for primary and secondary students to visit people with SMI in their village and help them with simple housework; (2) loudspeaker communication every week for 30 minutes to provide basic mental health knowledge and real stories of people living with SMI; and (3) a talent show with the performance of all intervention participants. Regarding the rehabilitation, each village had their own common garden for intervention participants to grow vegetables to support their daily nutritional needs. The seeds were provided by the Farmer's Union.

As a whole, the intervention aimed to improve the psychotic symptoms and personal functioning of people with SMI and to support rehabilitation and reintegration into the community. The draft of the intervention framework was presented to the local authority, representatives of the community and social organizations in Tien Ngoai commune to collect feedback and permissions for implementation.

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