

Promoting Better Health Care Services for Mental Health Patients in Malaysia

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Abstract—The purpose of this research is to explore the mental health services provided by caregivers of a community based rehabilitation centre and the problems encountered by the mentally ill patients. It also sought to propose ways to further improve the psychological well being of the patients in the centre. A narrative inquiry approach and an in depth interview were chosen to get in touch with the social relationship of these patients with their caregivers. The findings revealed the need for more caring, understanding and trained caregivers in the recovery process of mentally ill patients.

Index Terms—Caregivers, community based rehabilitation centre, narrative inquires, caring, policy makers, mental illness.

I. INTRODUCTION

In the 1960's and 1970's people with mental health illness in Malaysia were commonly stigmatized and institutionalized. During the 1980's and 1990's with the development of the National Mental health policy in 1997, there was a shift where people with mental illness were de-institutionalized. With the introduction of the National Mental Health Act in 2001, many mental health service users were being discharged into the community where people with mental illness were preferably care for by family members with the support from community clinics and general hospitals [1]. This move was in response to the World Health Organization recommendation to provide opportunities for people with mental illness to continue living in their own environment. In Malaysia, the community mental health services are categorized into the formal and informal health services. Formal community mental health services include community based rehabilitation services, hospital diversion programs, mobile crisis team, residential supervised services and community support services. The informal mental health service incorporate community support group and non-governmental organizations. In Malaysia, due the lack of knowledge, coping skills and the prevalence of stigmatization some families preferred their mentally ill relatives to be institutionalized in hospital or community based rehabilitation centre. Studies have shown that family caregivers complain of the burden, anxiety, depression and economic strain in caring for their mentally ill family members [1]. Mental service users are regarded as dangerous, violent, unpredictable and beyond professional help [2]. In Malaysia, the multicultural belief systems remain a challenge

to family caregivers, mental health service providers as well as the users. The multidimensional experience of mental health services users remain unexplored in Malaysia. However, the studies regarding the process through which caregivers interact with patients and factors affecting the life of these mental ill patients in a community based centre is lacking. This present study aimed to investigate the problems encounter by mentally ill patients with regard to the services provided by caregivers in a community based rehabilitation centre. It also sought to propose ways to improve the caregiver services thus further improving the psychological well being of the patients living in the centre.

II. METHOD

This research adopted a narrative inquiry approach to directly listen to the service users' experience of the services provided by caregivers. Brown and Lloyd [3] regard this approach as appropriate in collecting subjective views as it adopts a participant centered approach. We obtained approval from the management of a non-governmental female community based rehabilitation centre which is managed by a committee of volunteers and assisted by 14 salaried female staff. Eight of the mental health service users living in this rehabilitation centre volunteered to participate in the study. These women participants' age ranged from 25 to 45 years. Before their mental illness these participants worked as sale promoters, customer service executive, office administrators, clerk and teachers. Informed consent was obtained from these participants who were briefed of the confidentiality and the purpose of the study. Semi structured questions were used to explore the experiences of the service users as they interact daily with the caregivers of the centre. Further in-depth interview were conducted with the research participants. The face-to face interviews were audio taped and the interview scripts further transcribed. The verbatim statement was quoted without any changes. Each transcript was read and coded by the two authors separately to identify emerging themes which were then categorized. The classification of emergent themes was agreed upon discussion between the two authors.

The thematic analysis process followed the principles proposed by Miles and Huberman [4], where emergent themes were extracted and constant comparison was performed across all the 8 cases to derive at common themes. The voices of the participants were further triangulated by randomly selected residents who were also residing in the same centre. Data analysis followed Chase's suggestion of multiple lenses and voices [5]. These included the voices of the participants. Two dominant themes were identified from

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the data analysis. They were the need for more caring, respectful and understanding caregivers. Secondly, the participants felt that the centre should provide them with more trained caregivers who might be able to provide them with better services. Thus, it is hoped that through these emerging narratives and interactions with the research participants, one is able to further understand the challenges faced by these mental health patients.

III. RESULT

A. Need for Caring, Respectful and Understanding Caregivers

As most of the staff and caregivers are not trained they viewed their work as a job and failed to understand the psychological well being of these patients. The participants viewed their caregivers as unkind, rude and unapproachable. As one participant commented,

"We need staff who are humble, who can treat us with respect. The centre should hire staff who will not judge us."

Due to the lack of understanding of the nature of managing these patients there were misunderstanding and tension among the patients. They felt that they were being exploited and discriminated when asked to assist in some light chores which are part of the rehabilitating activities. For example one participant lamented,

"What they want me to do I cannot do and they force me. I cannot take it. I am a patient. How can they force me?"

The participants also felt that the caregivers did not respect them and always disregard their views and request. For example a participant complained

"Before you can say anything, they have made judgment on you. If you voice out they said there is something wrong with you."

Furthermore the caregivers' lack of understanding of the mood swing and social functioning of these patients had resulted in the participants feeling depressed and frustrated. The experience of non acceptance through contact with the caregivers resulted in them having a feeling of a loss of self respect. As one participant who was frustrated and stressed, voiced out angrily *"I don't wish to see their faces. Every time they tell me to do this and that, they make me angry. They gave me too much stress that sometimes I feel like it is better to die."* The overuse of force, threat and verbal humiliation by the caregivers were very upsetting and hurtful for the patients and is well illustrated in the following example provided by the participant *"What happened to me was a staff asked me to sweep the floor and after having done the job, she commented. Is that what you can do?"*

Research [6] also concluded that perceived judgmental attitude, lack of respect and absence of listening to mental patient impeded rapport and trust between service providers and patient with mental illness (pg176). Participants also felt that the caregivers normally talk down and make assumption about their behaviors. As a participant lamented,

"The staffs need to get to know the patient, talk and listen to them."

The need to connect to others and self is an important facilitating factor for patient recovery. A study by Schon [7] found that social relationship with supportive caregivers was helpful in the recovery process rather than the medical treatment itself (pg 561). In their personal struggle to recover the participants need to talk to caregivers who could be trusted, able to listen and not to deprecate them as a person. These patients will identify supportive caregivers based on what they had been like rather than on what they had done [7]. All the participants felt that they should be treated "as normal" for they need a sense of respect as a person regardless of their illness. This desire of wanting to be treated as a respectful human being is clearly illustrated by the comment of a participant *"Because they look at us differently so we cannot act normal. If they treat us as normal we can act normal. Just don't keep scolding us."*

Friendly relationship and positive feedbacks from caregivers can influence the recovery process of people with mental illness. Previous research by Funakoshi, Miyamoto and Kayama (as cited in [8]) also support the importance of the provision of good relationship between caregivers and care receivers.

B. Need for Trained Caregivers

The lack of knowledge and experience of mental health illness among the untrained caregivers in the community based rehabilitation centre had created unhappiness among the patients. These caregivers commonly perceived these mentally ill patients as restless, violent and unpredictable even when they are only occasionally symptomatic [9]. The patients perceived the caregivers as unfriendly, unapproachable and are negative towards them. One of the participant lamented,

"The staff always kept themselves in the office. I don't talk to them unless it is urgent and important."

The counsellor is the only person the participants are able to share their feelings and problems. Unfortunately the counsellor who is employed by the government only visits the centre once a week. They viewed the counsellor as their teacher and social support. For example one of the participants demonstrated,

"The counsellor gives me a lot of support, where I can share with her deep feeling and hurt." Another participant commented,

"The counsellor assured us that whatever we do is right and then will point out our fault. So we will learn and will not do what is wrong."

Besides providing them with emotional and social support the counsellor helped the participants to identify their problems and provide them with problem solving skills. The participants opined that the counsellor listens to them and provide a channel for them to voice their frustration and anxiety.

According to Huang and colleagues [10], educating caregivers to use encouragement to communicate with patients and educating patients to communicate with

caregivers in proper way are essential in maintaining the relationship between the both parties. Earlier research has also shown that community caregivers are accepted by their clients if they demonstrated clinical knowledge and skill to meet the clients' needs [8].

As violence in people with severe mental illness are due to delusions and auditory hallucinations, well trained caregivers are necessary to handle these patients. Previous studies have demonstrated that more than 50% caregivers are afraid of sudden burst of violence by mental ill patients affected their motivation and quality to provide proper health care service [11].

Trained caregivers are necessary in assisting patients in acquiring social skills through group activities. Through the participation in these group activities, patients are provided with the opportunities to learn conflict resolution, respect and problem solving skills. They will feel a sense of acceptance and belongingness thus improving their self awareness and self efficacy. Several studies have demonstrated that self efficacy is a strong predictor of mental health [12], [13].

Besides, self efficacy also has significant effects on personality and situation specific behaviors thus further reducing physical and psychological problem [14]. This need to enhance self efficacy through occupational activities is also well expressed by a participant who lamented *"Maybe we can be provided with the opportunity to learn tailoring, baking and sewing. It is a good for us to learn some practical skills."*

IV. DISCUSSION

The findings of this study demonstrated the need for the provision of better health care services for people with mental illness. The lack of understanding, kind and caring caregivers, the inexperienced, untrained staff and the insufficient rehabilitation interventions resulted in a sense of frustration and dissatisfaction of the patients in the community based rehabilitation centre. All the participants reported that they were unhappy residing in the centre as they were often treated as less competent and rejected by the caregivers.

Although recovery from mental illness required individual process, an integrated approach involving community, family and government agencies are essential in facilitating improved health care. The increased need to de-institutionalized mental health services for people with mental illness has resulted in many mentally ill patients being taken care by their family members or placed in community based rehabilitation centre operated by non government agencies or private home care. The lack of knowledge, lower mental health literacy and devotion to traditional multicultural belief systems among Malaysian might posed challenges to family caregivers, mental health service users and service providers [1].

Studies have shown several benefits of home care such as fewer psychotic symptoms, better social functional outcome and more cost effective [8]. Comfortable and trustful home environment assist in the recovery process of mentally ill patient. Schwartzman in their studies found that positive

family support increased active coping by providing a context for obtaining constructive feedbacks [15]. Patients who interacted with their family members in an affirming and nurturing manner are more likely to use problem solving behaviors instead of emotion focused coping behaviors. Thus it is essential for health professionals to provide home based caregiver support system such preparing and training these family care providers with knowledge and skills in managing their relatives who are mentally ill. Mental Health professionals such as nurses, psychiatrics and social workers should work in collaboration with home caregivers to ensure an effective management of caseload. Regular meetings with home caregivers provide the opportunities to share problems encountered by family members in their management of their mentally ill relatives. Through the sharing of information family caregivers learnt how to cope with the burden, distress, anxiety, depression and economic constraints while playing a major role in caring for their mentally ill family members. Besides, the provision of Mental Health First Aid training course for home caregivers and community based rehabilitation care givers will further enhance their knowledge on how to provide mental and emotional support to family members who are in mental health crisis [16]. Caregivers are more confidences in providing help and are able to get professional assistance through web based intervention as they will be provided with websites carrying information about treatment options, what caregivers can do and links to other resources thus improving their self efficacy in handling mental health issues.

To further improve the health care services for mentally ill people government policies may focus on creating public awareness on mental health issues, provision of sufficient economic support, provision of long term care facilities creating more community rehabilitation centre, sheltered home, providing training for more social workers in assisting mental health professionals. Government should conduct more anti-stigma campaigns to educate the public against discriminating people with mental illness. Children, medical practitioners and community are important target audiences for these educational campaigns. Strategies may include nationwide television advertising campaign and special documentary. Monitoring media negative reporting can also encourage non –discriminating reporting of mental health stories. National Health Insurance may have provision for the treatment of mental illness to provide patients with financial accessibility to proper health care services such as good clinical care, rehabilitation program and support from mental health professionals. Studies have shown that many people receiving psychiatric treatment experienced various forms of stigma in their daily interpersonal relations [17]. According to Sartorius, "stigma and discrimination are the most significant obstacles to the development of mental health care and to ensuring a life of quality to people suffering from mental illness" [18].

The provision of more government aided community based rehabilitation centre might be beneficial in the recovery process of mentally ill patients. As these centers will be managed by trained social workers and counsellors who are assisted by collaborative mental health team workers

occasionally, hence the patients are assured of proper treatment and care. Although studies have shown that family support is important in the recovery process of people with mental illness, many Asian and Malaysian families still prefer their mentally ill relatives to be in institution. One major reason is a misunderstanding or lack of knowledge about mental health and their devotion to the traditional cultural belief systems. They interpreted mental illness as possession by evil spirits, a moral weakness or punishment from higher being or God [19]-[20]. In these community based rehabilitation centers patients may be provided with occupational therapy interventions conducted by trained social workers and therapists. As the therapy interventions in mental health care are activity group based which focus on experimental learning and problem solving, patients have the opportunities to understand themselves. Through these projective and psycho-educational interventions and human occupation groups the patients will feel a sense of acceptance and hope of gaining success in dealing with group conflicts. As the group activities are conducted in a secure environment the ability to contribute to group members' progress through interaction and exchange of experiences will further enhance a sense of value as a human being among the patients. Studies have shown that group activities had stimulated spontaneity, humor and energy thus influenced self efficacy and well being [21]. Besides, through the group interaction patients learnt to create interpersonal contact that will support them rather than stress them.

Treatment models such as the provision of mobile clinic might be beneficial to patients as it allow them to receive medical treatment in a convenient and familiar environment. As treatment are provided near to the patients' homes it increase patient appointment attendance rate. It also decreases patient travelling and waiting times. Besides it facilitates closer follow-up as patients and caregivers are able to communicate thus avoiding cultural misunderstanding.

Mental health providers in their interaction with the caregivers might provide them with information on better preventative care, nutrition, education on healthy living and the importance of medical treatment. Mobile clinic will also reduce the economic and financial burden of family caregivers.

While this present study only focus on the problems encountered by mentally ill patients in a community based rehabilitation centre, future research should include the voice and views of family caregivers, employers and family members on their roles in assisting these people in their recovery process.

Another limitation of this study is the sampling and design of the study. The small sample size which consists of only 8 female participants residing in a community based rehabilitation centre might be bias. Like most qualitative research, the construction of semi structured interview questions which were thoughtfully worded might be susceptible to biasness. Besides, the self reported data of the participants might reflect the subjective perspective of the volunteered interviewed participants. Hence the result of the present study does not allow for generalization.

V. CONCLUSION

As de-institutionalization and the provision of home care mental health services are a common international concern it is essential to develop a locally and cultural appropriate model of community mental health services for people with mental illness. Policy makers may consider the voice of different stake holders of mental health services such as the patient themselves, mental health professionals and service providers, family caregivers, educators and local community. A collaborative effort among the different stake holders is necessary in further assisting the people with mental illness in their recovery process and improving their quality of life.

REFERENCES

- [1] S. T. Chong, M. S. Mohammed, and A. C. Er, "The mental health development in Malaysia: history, current issues and future development," *Asian Social Science*, vol. 9, no. 6, 2013.
- [2] Malaysian Psychiatric Association. (2005). *Survey: Stigma Keeps Million with Anxiety Disorders from Treatment*. [Online]. Available: http://www.psychiatry-malaysia.org/html/consensus_intro.shtml
- [3] C. Brown and K. Lloyd, "Qualitative methods in psychiatric research," *Advances in Psychiatric Treatment*, vol. 7, pp. 350-376, 2001.
- [4] M. B. Miles and A. M. Huberman, *Qualitative Data Analysis*, SAGE Publication, 1994.
- [5] S. E. Chase, "Narrative inquiry: multiple lenses, approaches voices," in *The Safe Handbook of Qualitative Research*, Ed., N. K. Denzin, Thousand Oaks, CA, Sage Publication, 2003.
- [6] E. A. Kaufman, M. G. McDonell, M. S. W. Cristofalo, and R. K. Ries, "Exploring barriers to primary care for patients with severe mental illness: Frontline patient and provider accounts," *Issues in Mental Health Nursing*, vol. 33, pp. 172-180, 2012.
- [7] U. K. Schon, "Recovery from severe mental illness, gender perspective," *Scandinavian Journal of Caring Science*, vol. 55, pp. 557-564, 2009.
- [8] J. F. Chen, X. Y. Huang, M. J. Lin, T. C. Yang, and Y. S. Hsu, "Intervening condition of hospital-based home care for people with severe mental illness," *Public Health Nursing* vol. 29, no. 4, pp. 320-329, 2012.
- [9] M. I. Merican, Y. Rahaizat, and S. Haniza, "Developing the Malaysian health system to meet the challenges of the future," *Medical Journal of Malaysia*, vol. 59, no. 1, 2004.
- [10] X. Y. Huang, M. J. Lin, T. C. Yang, and Y. S. Hsu, "The functions of hospital based home care for people with severe mental illness in Taiwan," *Journal of Clinical Nursing*, vol.19, pp. 368-379,2010.
- [11] P. C. Ma, "The essentiality of psychiatric home nursing specialist system strengthen the home health care for the psychiatric patients," Unpublished Master Thesis, Taiwan: National Yang Ming University, 1998.
- [12] D. W. Chan, "Stress, self efficacy, social support and psychological distress among perspective Chinese teachers in Hong Kong," *Educational Psychology*, vol. 22, no. 5, pp. 557-569, 2002.
- [13] A. M. S. Wu, C. S. K. Tang, and T. C. Y. Kwok, "Self efficacy, health locus of control and psychological distress in elderly Chinese women with chronic illness," *Ageing and Mental Health*, vol. 8, no. 1, pp. 21-28, 2004.
- [14] M. Jerusalem and J. K. Hassling, "Mental health promotion in schools by strengthening self-efficacy," *Health Education*, vol. 109, no. 4, pp. 329-341, 2009.
- [15] D. Schwartzman, K. Thopson, D. D'luso, K. S. Dobson, U. Kramer, and M. Drapeau, "Assessing the link between coping patterns and interpersonal behaviours in depressed women," *Archives of Psychiatry and Psychotherapy*, vol. 2, pp. 23-33, 2012.
- [16] A. F. Jorm and B. A. Kitchener, "Noting a landmark achievement: Mental health first aid training reaches 1% of Australian adults," *Australian and New Zealand Journal of Psychiatry*, vol. 45, pp. 808-813, 2011.
- [17] P. Switaj, W. Ciorta, P. Gryiel, M. Anczewska, E. Schaeffer, K. Tyczynski, and A. Wisiniewski, "Experiences of stigma and discrimination among users of mental health services in Poland," *Transcultural Psychiatry*, vol. 49, no. 1, pp. 51-68, 2012.
- [18] N. Sartorius, "Stigma: What can psychiatrists do about it?" *Lancet*, vol. 352, pp. 1058-1059, 1998.

- [19] A. Hague, "Mental health concepts and program development in Malaysia," *Journal of Mental Health*, vol. 14, no. 2, pp. 183-195, 2005.
- [20] P. M. Deva, "Malaysia mental health country profile," *International Review of Psychiatry*, vol. 16, pp. 167-176, 2004.
- [21] B. Sunsteigen, K. Eklund, and S. D. Ivanoff, "Patients' experience of groups in outpatients mental health services and its significance for daily occupations," *Scandinavian Journal of Occupational Therapy*, vol. 16, pp. 172-180, 2009.



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