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Quality of Life of People with Mental Illness Who Lives in the Community in Sarawak

Saloma P, Zabidah P, Rekaya VB, Jane B

Faculty of Medicine and Health Sciences, Universiti Malaysia Sarawak, Malaysia

Abstract

This study explores the quality of life, social integration and the effects of perceived stigma of people with mental illness living in the community. Adopting a complimentary mixed method, this study was represented by 165 people with mental illness in Kuching, Sibu and Miri. Findings indicated that the quality of life scale was poor, 49.67% and 78.43% often experienced stigma. Anticipated stigma 43.79%; 16.99% all the time and 4.58% never experienced stigma. Findings also noted that people with mental illness living in the community are still largely depending on and needed continuous support from their family members/carers for financial aid and their living arrangement for a “better” quality of life. Where treatment is concerned, follow up care at home by health care providers continue to play a significant role. In order to “erase” the perceived or stigma experienced, establishing therapeutic relationship, communication and creating awareness on “stigma discrimination paradigm” poses a phenomenal challenge in the current misrepresentations of mental health messages.

Keywords: Quality of Life, People with Mental Illness, Community

Introduction

Mental illness forms a major part of the global burden of disease due to the mere fact that people with mental illness experienced significant disability which affects not only their families but the community at large. Having to live on their own in an individualistic community pose a great challenge as integration into community life is a complex process especially when stigma affects the course of illness. This is further aggravated when societies that customarily offered support to their less fortunate members through family and social bonds find it harder to do so. In extreme instances, the mentally ill people in the community are subjected to cruel human rights violations such as abuse, imprisonment and institutionalized. In view of this, it seems that their vulnerability is not inevitable but rather brought about by their social environment.

Quality of life of people with mental illness is further questioned when people with mental illness are more likely to be unemployed, have less income, experienced
a diminished sense of self and have fewer social supports. In Malaysia, unemployment among people with mental illness was excessively high between 70 to 90 percent, compared to people with other physical disabilities or illnesses.

**Background**

Studies have shown that mental illnesses have been subjected to misunderstanding not only in Malaysia but also in the global arena. Public perception of those with mental illness is severely tainted with negative connotations, ridicule and are commonly linked with crime and deviance. Social stigma remains a persistent barrier because of misconceptions about the causes and nature of mental illness which lead to being habitually scorned, ostracized and discriminated as they are thought to bring shame to their families.

Quality of life is very important for optimum social functioning and social integration. Various studies have reported that the quality of life of people with mental illness is less satisfactory. They are affected by the effects of stigma posed on them in relation to social functioning and social integration which does not only put a great burden on the family members/carers but towards the community at large. This is an interesting phenomenon to explore whereby the magnitude of the problem as loss of years in terms of human production as well as social functioning is highlighted as a global burden.

The elements addressed in this study are important because the multi and diverse cultural ethnicity and social background of Malaysians might have different influences on the quality of life of people with mental illness.

**Aim**

This study aimed to explore the quality of life, social integration and the effects of perceived stigma of people with mental illness who lives in the community in Sarawak.

**Methods**

This study adopted complementary mixed method whereby a cross sectional study using purposive sampling was the basis for the selection of participants. Mixed method was employed as it is able to best understand the complexities of quality of life and social integration of people with mental illness.

Quantitative approach is adopted to study the objective indicators pertaining to social functioning, material comforts and conveniences. Since quality of life is highly subjective, domains reflecting on satisfaction and feelings of well-being will need qualitative approach.

**Instruments**

Quality of Life was measured using sixteen items from Burakhardt 1989. Participants need to indicate their responses pertaining to their living arrangement on a scale from 1 (terrible) to 7 (delighted) with higher scores indicating greater satisfaction.

Anticipated Stigma was measured using eight items from Link, 1987 Devaluation-Discrimination Beliefs Scale. Participants need to indicate the extent that they will be rejected by the community with responses coded on a scale from 1 (strongly disagree) to 4 (strongly agree) with higher scores indicating a greater expected rejection.

Stigma Experiences was measured by asking participants their experiences of whether they have been discriminated against or
stigmatized because of their mental illness using Link, Devaluation-Discrimination Beliefs Scale, 1987.\(^5\) Items asked include employment or work difficulties, social exclusion, verbal derogation, denial of rights and adverse treatment by service providers. Responses were coded on a scale from 1 (no) to 6 (all the time) with higher scores indicating greater stigma experiences.

**Setting and Selection of Participants**

This study was conducted in three major towns of Sarawak namely Kuching, Sibu and Miri towns where there are referral centers. The inclusion criteria includes those who are mentally stable; drug compliance and able to function in the community. The key informants for this study were family members/carers and health care providers. Data collection was done at home of the mentally ill while the health care providers were interviewed in their office.

**Ethical Considerations**

Ethical approval was obtained from the National Institutes of Health, the Medical Research and Ethics committee of Universiti Malaysia Sarawak.

**Data Collection**

Fieldwork was conducted from December 2011 to March 2012. Participants answered the questionnaires. For those who were unable to read, the researcher interviewed them. In depth interviews were conducted on the key informants ie family members/carers and health care providers.

**Data Analysis**

SPSS Version 19 for Windows was used to analyze data. Field notes and transcripts were thematically analyzed. Excerpts that exemplified the quality of life of people with mental illness were extracted from the transcripts to enhance the description of the phenomenon understudied and rigor of the study.\(^2\)

**Results**

**Demographic data of participants and key informants**

A total of 165 participants were involved in this study. The key informants comprised of 165 family members/carers and 12 health care providers.

**Quality of life Scale**

49.67% of the participants indicated that their quality of life was poor.

**Anticipated Stigma**

43.79% of the participants noted anticipated stigma was present.

**Experiences of Stigma**

78.43% participants often experienced stigma; 16.99% all the time and 4.58% never experienced stigma.

The above findings showed that people with mental illness continued to be stigmatized. Both experienced and anticipated stigma lead to negative impact not only on their psychological but also psychosocial functioning. This is because stigma poses a significant problem for people with mental illness through the distress, discrimination and rejection.

The above findings are further supported by the ten emergent themes reflecting the quality of life, social integration and stigma experiences as reflected in the excerpts. Names are pseudonyms.
**Meaning of Quality of Life**

The people with mental illness described the meaning of quality of life as basic needs being fulfilled.

*To me, having food, cloth and place to stay is already good.....it means that I live like other people* (Amira).
*I have enough food and other basic needs such as home to stay and be with my family members* (Lipan).

**Health Status**

People with mental illness informed that their health status was better as they were taking their medication. However, some described their experiences of some side effects such as headache and body ache. They were also others who continued to hallucinate.

*I feel better after taking medication.....but sometimes I experienced some kind of side effects such as headache, body aches* (Lee).
*I always have headache each time I take the medication.....I also hear voices asking me not to take medication* (Bunga).

The health care providers indicated that most of the people with mental illness were showing improvement in the aspects of well-being and way of living. They claimed that this was due to their regular follow ups and patients’ compliance to medication. However, most patients still needed close guidance from family members/carers to help them with activities of daily living.

*My experience involved with the community mental health teams showed that most of the patients’ health and ways of living had improved* (Health care provider - Kuching).
*I can see that the mentally ill patients are healthier after taking medication and follow-up care by community mental health teams* (Health care provider - Miri).

**Living Arrangement**

Most of the people with mental illness noted that their living arrangement as good although some found it uncomfortable.

*Good..... I do not have any problem* (Guntor).
*I feel hot and uncomfortable* (Kumbang).

While the patient reported that they were happy with the living arrangement, the family members/carers claimed otherwise.

*I see my son is slowly improving but it is at a very slow pace* (Muna).
*I don’t know.....mmm....each time we say something, she always get irritated and sometimes she turns verbally abusive and aggressive. She said that we are talking about her* (Ching).

*We cannot leave the patient to handle the kitchen and do the cooking alone* (Wee).
*When they are in the good mood, they can help in cleaning the house* (Long).
The health care provider indicated that the living arrangement as acceptable.

Some of the patients’ houses are not in a mess…..but there are patients who still need their family to monitor and support in keeping their house clean and tidy (Health care provider - Kuching). They are some patient’s houses that are not well kept (Health care provider - Sibu).

Financial Situation
Majority of the people with mental illness were jobless. They depended on their family and some needed social welfare support.

I am not working…I have no money.....I ask money from on my mum, sometimes from my sister and brother (Rimong). I received RM 60 from the social welfare people every month....still not enough....(Selaseh).

Employment
Some people with mental illness were employed as labourer, working at café, lorry driver, security guard and farm helper. They claimed that they were happy and able to cope with their work. However, some shared their disappointment due to low salary and the work was temporary. They reported that they were often being scolded by their employers and workmates.

I am a logging lorry driver....I can cope with my work... well, occasionally I do feel stress if not called up for work as this job is not permanent......no work means no money (Lau). There are times I dread going to work ..... my boss scolded me, my workmate always ask me to do this and that ..... so many works ....(Salus).

Relationship with Family
Most people with mental illness mentioned that their family understood and were concerned about them. However, some of them claimed that their family members always scolded them which led to arguments.

I have good relationship...my sister always bring me outing..... buying vegetables and eat mee kolok....ya, everything is ok....(Dayung). Sometimes we [brothers and sisters] quarrel....they scold me.....just because I ask them for some money.....they said I used a lot of money.....(Bujang).

50% of the family members/carers viewed that their relationship with the mentally ill people were good. However, most of the mentally ill preferred to be alone and did not want to mix around.

Well, it’s good......but they seldom mix around with people, neighbours.....they prefer to stay alone in the room (Kumo). You know lah.....as usual this people ......with this illness......difficult to mix around with people....some of the villagers are frightened of them....(Kiah).

The health care providers described the people with mental illness relationship with family members/carers depended very much on individuals’ condition. If the patients were compliant with medication, they had better relationship with their family members and community.
Well, it depends ...sometimes ok....sometimes there is no support from family or relative.....a few of them are staying at the hut nearby the house compound (Health care provider - Sibu).

Each time I visit the family, I notice that those who are compliant to medication are able to cope and have better relationship with their family members....(Health care provider Miri).

**Relationship with friends**
Most of the people with mental illness had no friends. While some who had friends, noted that some friends were good and others always wanted to quarrel.

*I have no friends....I don’t want to mix around with others....*(Karim).

Some people are good....some are very bad....they always want to quarrel. with me...that’s why I don’t like to mix with them......(Belalang).

The family member/carers noted that the people with mental illness preferred to be left alone hence not mixing around.

*My daughter likes to be in her room......not mixing around therefore no friends* (Tini).

*My son seems to stay in his room most of the time...not interested to mix around with others......*(Juling).

**Relationship with neighbours**
Majority of the people with mental illness preferred to be left alone but there were some who were seen to have minimal contact with their neighbors.

*I talk with my neighbor sometimes only.....*(Tung).

I don’t like to mix around with my neighbors......some of them make fun of me.....better I am on my own......(Simbah).

The family members/carers noted that the people with mental illness were not friendly with their neighbors especially when their mood was “down”.

*My daughter does not seem to like to mix with our neighbors* (Kiki).

*Sometimes my son is friendly with neighbors....mostly depends on his mood.......*(Lau).

**Adaptation to Community**
The people with mental illness adapted slowly in the community setting. They needed encouragement, support and tolerance especially from their family members.

*Hmm..... I slowly got adapted living with my family and community .... my mum has been encouraging me to mix with people ... she usually brings me to meet her friends and we have drinks in the shop* (Minah).

*Yes, I can cope with the surrounding slowly.... my family is helping me and tolerate my condition ....I know they try to understand me* (Cindy).

The family members/carers as well as the health care providers viewed the people with mental illness’ adaptation to community was rather slow.

*I can see that most of them are slow to adapt to the surrounding but they are able to cope ... it can be improved with the support from family members and the community* (Health care provider - Kuching).
My daughter is adapting, hmmm but slow ... I bring her along to shopping and even visiting friends ... so that she gets familiar with the surrounding ... and hope others will be able to accept her as she is .... (Wong).

**How Society “Received” Them.**

Some people with mental illness felt that the community “accepted” them while some felt that people were avoiding them. Some of them were aware that the people were still “scared” of them. These ‘thoughts’ induced them to stay away from the community.

Ooo..... some accepted me.... some cannot ... they just look at me ... not talking ... people are avoiding me ...(Wat).

I don’t know ... people are “scared” of me [sigh] ... the other day, I sent to the shop wanting to buy biscuits but the shopkeeper chased me away ... she said I’m scaring people ...(Derek).

The family members/carers viewed that people with mental illness was generally accepted by the community. However, there were those who still could not accept them.

I brought my daughter to the shop the other ... and some kids laughed at her ... I also heard them talking about her ... I know they looked down upon due to the illness (Rony).

Involvement in Community

Majority of the people with mental illness preferred not to socialize. They described that even when they were involved in the community it would be very minimal.

I only socialize with people outside there sometimes. Most of the times I prefer to stay at home...I only mix with people during Hari Raya (Hanum).

I like to stay at home. Not much involved outside....unless people call me then I join them for a while. Help a bit, then I go back home (Endang).

The family members/carers similarly indicated that their relatives refused to be involved in the community while some would help when being asked.

My daughter refused to be involved in any activities outside the home. Her mother always asked her to be involved with many activities in the kampong, but she refused. She is just not doing anything. She spends her time sleeping, eating and smoking (Hassan).

My son can help ‘gotong royong’ at the church when I asked him to do so. But if I did not bring him to the church he would not go himself (Morris).

Problems faced

The family members/carers seemed to face various problems while looking after their relatives with mental illness. Problems such as financial constraint and unemployment were common. Others relayed on problems like non-compliance with medication, chain smoking and wandering around the villages especially at night.
My difficulty looking after my son is he always refused to take his medication. Each morning I have to serve him and make sure he takes his medication. If I don’t do that he will not take his medication (Ho).

My mum smokes a lot. She will smoke whole day, one after another. Also she likes to wander around the villages especially at night...I am so worried lah... (Barbara).

Discussion

The findings of this study generally depicted a “fair” quality of life despite presence of anticipated and experienced stigma.

Quality of Life

Quality of life represents how well human needs are met or to the extent to which individuals or groups perceive satisfaction or dissatisfaction in various life domains. This study found that the people with mental illness living in the community perceived good quality of life by having fulfilled basic needs and that their life is better than during their admission at the psychiatric unit. It seems that unmet needs are a strong predictor of less favorable health perceptions and a lower quality of life.

This study is consistent with a study on quality of life of severely mentally ill individuals in Quebec, Canada. The study on 59 participants suggests that the mentally ill are satisfied with the availability of basic needs. On the contrary, a study on the quality of life on 201 people with schizophrenia living in the community in Hong Kong suggests that there are other factors that offer and enhance quality of life. These could be rehabilitation strategies that could improve social competence. This is further supported by a study conducted by Williams and Mfofo-M’Carthy, 2006 who identified in their study on 21 schizophrenic participants that relate to the importance of care. It seems necessary to use various measures and not relying only on one measurement to look into the quality of life especially for the mentally ill living in the community.

People with mental illness suffer societal scorn and discrimination because of the stigma that evolves out of misrepresentations. The mentally ill participants also experience similar situation. This kind of societal stereotyping frequently leads to diminished self-esteem, fear of pursuing one's goals and loss of social opportunities. This is consistent with a study conducted by Blay and Peluso, 2010 on 500 representative samples in Sao Paulo, Brazil showed that society continue to express stigma towards people who are mentally ill. Hence, they suggested that this group of people need supportive family and community. Supportive relationships are consequential for quality of life especially when they are with significant others because they shape self-esteem. Moreover, when individuals are under stress, the need for support may be higher and self-image more vulnerable.

Social Integration

The stigma of mental illness expresses itself in the situation that it represents a major obstacle denying access to social integration. According to Wong and Solomon 2002, social integration is the degree to which an individual is able to interact with others.

This study showed that much of the problem on social interaction was related to stigma. Not only the individual but also the families of individuals with mental illness face a range of practical and emotional stresses
resulting from this stigma. In addition, the illness imposes barriers on access to employment as they were denied the opportunity to return to one’s job after a period of psychiatric treatment.

Consequences included social isolation of the families, difficulties experienced by the mentally ill patients when trying to obtain competitive employment and financial difficulties. Subjective burden resulting from social stigma included frustration, anxiety, low self-esteem and helplessness. This study is therefore congruent with Saxena et al, 2007, who highlighted that the resources for mentally ill people living in the community are not only scarce but also inefficient.22 This is also supported by several other studies23-25 who reported that the burdens could come from the stigmatizing attitudes towards individuals with mental illness and inadequate public resources.

Stigma Experiences

Consistent with other studies, this study also found out that stigma is a problem for most people with mental illness and perceptions of stigma have a significant negative relationship with patient’s quality of life. Stigmatization is a dimension of suffering added to the illness experience leading to social isolation, limited life chances and delayed help-seeking behavior.26-29

The results of this study also indicated that discriminatory persist and the experiences has an adverse effect on life satisfaction. This is consistent with a study by Link, 1987 who suggests that stigma affects life satisfaction in the areas of employment, income and housing. This is because the social consequences of stigma are very severe whereby the people with mental illness are discriminated in many different ways and is typically rejected by his fellows. Furthermore, with life chances very often much reduced, they are considered as less desired companion, workmate, employee or tenant.5,30

The study by Teachman et al, 2006 concerning stigma among undergraduate university students and health workers also showed that there is strong evidence of explicit and implicit stigma in relation to people who are mentally ill.31 A two-year quantitative study on social stigmatizing attitudes of 29,248 participants by Mojtabai, 2009 has shown consistently that there was a close association between social stigmatizing attitudes specifically in that social beliefs about dangerousness and unpredictability of mentally ill, their blame worthiness for their illness and pessimism about the likelihood of recovery were each strongly and specifically associated with respective individual beliefs after controlling for individual characteristics.32

Limitation

The small sample size does not enable its findings to be generalized to the bigger population of Malaysia, neither globally. However, the quantitative data results and the rich narratives obtained from the interviews reflected the quality of life and social integration of the people with mental illness living in the community. In addition, the interviews with the health care providers in this study can yield better outcome strategies in the management of people with mental illness in the community. Therefore, further research studies covering all the towns in Sarawak as well as the other states in Malaysia need to be conducted for more comprehensive findings.
Conclusion

In this study, people with mental illness are satisfied with their life though it means just having shelter and basic needs met. However, people with mental illness face multifarious problems which are beyond their control due to social stigma. They are adapting into the community slowly. This study suggests that while the psychosocial care for the people with mental illness in the community requires continuous support from their family members/carers, the health care provider’s role in the follow up care treatment is significant. It is essential to plan appropriate strategies to disseminate positive mental health messages to challenge current misrepresentations in order to promote social inclusion and reduce stigma.

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References


**Corresponding Author**
Saloma Pawi
Nursing Department
Faculty of Medicine and Health Sciences
Universiti Malaysia Sarawak
Lot 77, Section 22, KTLD
Jalan Tun Ahmad Zaidi Adruce
93150 Kuching
Tel: 082 292 288 (direct)
Fax: 082 422 564

Email: psaloma@fmhs.unimas.my