

The Caregivers' Perceptions Toward Self- Stigma and Quality of Life Among Individuals with Mental Illness in Sarawak

Rekaya Vincent Balang^{1*}, Saloma Pawi¹, Shalin Lee¹, Merikan Aren¹, Ong Mei Fong¹, Razjesh Robert Drahman²

¹Universiti Malaysia Sarawak (UNIMAS), 94300 Kota Samarahan, Sarawak, Malaysia

²Ministry of Health Malaysia, 62590 Putrajaya, Malaysia

*Corresponding Author's Email: vbrekaya@unimas.my

ABSTRACT

Introduction: Stigma is a condition whereby a person adopts stigmatizing views widely held by the public, resulting in low self-esteem and a lack of hope. People with mental illness experienced a loss of control over life and diminished function, which caused them to be discriminated against and rejected, which led them to experience a poor quality of life. **Objective:** To explore self-stigma and its role in affecting the quality of life among individuals with mental illness in the community in Sarawak. **Methods:** The study utilized a generic qualitative descriptive approach that aimed to explore the perceptions among family members and caregivers towards stigma and quality of life among individuals with mental illness in the community. Purposive sampling was utilized. Twenty semi-structured interviews were conducted in the major divisions of Sarawak. Thematic analysis was used to identify categories and themes in respondents' accounts of their perceptions related to their self-stigma and quality of life as individuals with mental illness in Sarawak. **Results:** Five main themes were constructed, namely: meager quality of life, poor sense of self-reliance, feelings of discrimination by the community, and inability to contribute and participate socially. These findings demonstrate that self-stigma does have a role and affects the quality of life of these individuals and their caregivers pessimistically. **Conclusion:** Hence, there is a dire need to incorporate non-governmental organizational active reduce participation and policy to establish positive mental health initiatives and social support to self-stigma and improve the quality of life of individuals with mental illness within Sarawak and in the global context.

Keywords: *Mental Illness; Quality of Life; Self Stigma*

INTRODUCTION

Self-stigma is a condition whereby a person adopts stigmatizing views widely held by the public, resulting in low self-esteem and a lack of hope (Vrbova *et al.*, 2016). People with mental illness experienced a loss of control over life and diminished function, which caused them to be discriminated against and rejected, which led them to experience a poor quality of life (Corrigan *et al.*, 2014). Self-stigma has a negative effect on one's thoughts and thus one's ability to do things (Shimage *et al.*, 2022).

Mental health screening is an important as it may pose danger to the patient if risk assessment is not done adequately that can lead to mortality and morbidity (Singh, 2023). The perception of mental illness and the inability of people with mental illness to communicate generally indicate a poor quality of life. Mental illness presents as a disability, thus creating problems for the individual, family, and community, whereby disability causes chaos and ambiguity in the social world (Henderson *et al.*, 2013). This is because people with mental illness experience loss of control over life and diminished function, which further causes them to be discriminated against and rejected, which leads them to experience poor quality of life (Monnapula-Mazabane *et al.*, 2023). Several studies have indicated that care givers perceive that individual with mental illness experience stigma, including self-stigma and affiliated stigma (Krawjeski *et al.*, 2013; Ebrahim *et al.*, 2015; Gater *et al.*, 2014; Link & Phelan, 2014; Ociskova *et al.*, 2015).

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Self-stigma has a great impact on the lived experience of those diagnosed with mental illness. The impact of deteriorating functions and performing ADLs is that those most affected by self-stigma experience a loss of self-esteem and self-efficacy (Thomas *et al.*, 2020). Individuals' negative perceptions of themselves resulted in stress, an inability to cope, and social and physical isolation, thus creating a barrier to seeking help (Link & Phelan, 2014). Previous literature suggests that societal stigma has led men to be less open about seeking help for their mental health issues compared to women who are often more willing to share their emotional concerns (Dimbulana *et al.*, 2023). Stigmatizing attitudes, such as viewing individuals as incompetent, dangerous, and unpredictable, led to the rejection and discrimination of those who were tagged and labeled, ultimately contributing to the marginalization of the mentally ill. (Thornicroft, 2016).

Affiliate stigma is defined as an internalized stigma among family members of the stigmatized individual (Shimage *et al.*, 2022). Zhang *et al.* (2018) reported that a high proportion of caregivers of individuals with mental illness experience affiliate stigma, which affects the quality of life of individuals with mental illness. Furthermore, they perceived that their significant others with mental health illnesses were unable to demonstrate acts of self-reliance and self-health seeking behavior (Corrigan *et al.*, 2014). They understood these setbacks could be due to the inevitable manifestations of the mental health illnesses that their significant others were suffering from. As a result, individuals with mental illness are hindered from participating in and/or being involved in society and community activities. However, the residual symptoms of being socially isolated can contribute to this situation (Baxter *et al.*, 2022). The negative symptoms of mental health illnesses could influence the current behaviors and responses of the affected individuals, which can be wrongly perceived by others as a deliberate act.

Family members and caregivers of individuals with mental health illnesses are prone to having notions about their coping strategies and dealing with and managing their significant others. Coping by family members and caregivers of individuals with mental health illnesses is understood as a process for them to manage and mitigate external or internal demands that are considered vigorous, exhilarating, or exceeding their capacities and capabilities (Grover *et al.*, 2015). Continuous support from family members and caregivers is essential to ensure individuals with mental illness are able to be consistent and strengthen the pathway to their holistic recovery (Yin *et al.*, 2014). The need for support from various agencies, such as psychiatric services and family support groups, shall be established for them.

There is a paucity of research exploring the perceptions of caregivers toward self-stigma and quality of life among individuals with mental health illnesses, particularly in Sarawak. Thus, this study aimed to generate new knowledge and/or information in relation to caregivers' perceptions towards self-stigma and quality of life among individuals with mental illness within Sarawak's prominent and global context.

The research objectives of this study are:

1. To explore the perceived quality of life among caregivers towards individuals with mental illness with regards to self-stigma in Sarawak.
2. To identify factors influencing the quality of life of individuals with mental illness in the community in Sarawak as perceived by their caregivers.
3. To identify coping strategies to sustain the quality of life of individuals with mental illness in the community in Sarawak from their caregivers' perspectives.

METHODOLOGY

The study utilized a generic qualitative descriptive approach that aimed to explore the perceptions among family members and caregivers towards stigma and quality of life among individuals with mental illness in the community. Purposive sampling was conducted according to the eligibility criteria. Participants consisted of family members and caregivers who directly gave care to individuals with mental health illnesses in their home settings in Sarawak. semi-structured interviews with regards to how self-stigma affects QOL. Family members or caregivers of the cases identified in the community who can communicate in English and *Bahasa Melayu* and who have been taking care of their significant others for more than a year were included in the study.

The study has obtained ethical approval from the Faculty of Medicine and Health Sciences, UNIMAS Ethical Committee, National Medical Research Registry, Medical Research and Ethics Committee, Ministry of Health, Malaysia. Interviews were conducted at the participant's home. This process was facilitated by members of the Community Mental Health Team at all the participating mental health settings. The researcher introduced the

study and obtained participants' consent for voluntary participation in it. Respondents were informed that the interview would be guided by interview questions and recorded if permission was given. Participants were also informed of their rights, and issues of confidentiality were addressed. An interview guideline consisting of 10 open-ended questions adapted from several studies (Gater *et al.*, 2014; Nxumalo & Mchunu, 2017; Papadopoulos *et al.*, 2013; Shamsaei *et al.*, 2015; Yin *et al.*, 2014) was used for the semi-structured individual interviews with the family members and caregivers of the individuals with mental health illnesses. The semi-structured interviews were recorded via digital voice recorders and conducted by the researchers of this study at their respective homes.

Interviews were transcribed verbatim, and the translations occurred in the chosen excerpt for the presentation of the findings. Referring to the translations, all the researchers in this study are bilingual (Bahasa *Melayu* and English). Qualitative data from the interview was thematically analyzed to obtain an in-depth understanding of the caregiver and family members to construe the presence of stigma and how it affects or influences the QoL of individuals with mental illness. Coding and thematic analysis were used to identify categories and themes in respondents' accounts of their perceptions related to their self-stigma and quality of life as individuals with mental illness in Sarawak. This process involved preparing and organizing textual data for analysis, reading through textual data, coding to generate themes, representation of themes, and interpretation (Braun & Clarke, 2006). The analyzed findings were presented as themes. Pseudo-names of the participants were given for the presentation of the findings of this study.

Ethical Consideration

This study obtained approval from the Medical Research & Ethics Committee, Ministry of Health Malaysia on 18th November, 2020, with reference number NMRR-19-2579-50521 (IIR).

RESULTS AND DISCUSSION

A total of 17 respondents were interviewed in various cities in Sarawak. These respondents are the direct caregivers of individuals with mental health illnesses at their respective homes. These individuals with mental health illnesses are fully managed by community psychiatric services, which are available at the nearby tertiary hospitals across Sarawak.

Five main themes were constructed, namely: *meager quality of life, poor sense of self-reliance, feelings of discrimination by the community, inability to contribute and participate socially, and coping with life among individuals with mental health illnesses*. These findings demonstrate that self-stigma does have a role and affects the quality of life of these individuals and their caregivers. These individuals with mental health illnesses are fully managed by community psychiatric services, which are available at the nearby tertiary hospitals across Sarawak.

Meager Quality of life

All of the respondents shared their thoughts that individuals with mental health illnesses have substantial impacts on their quality of life. They further explained that individuals with mental health illnesses experience a poor quality of life as a result of the complications and treatment for their illnesses. One respondent, Janting, mentioned,

"There is no meaning to live because he doesn't do or know anything; he just eats and sleeps, smokes, and is unemployed. He doesn't know how to work..."

(Janting)

The respondents elaborated on indicative occurrences of poor quality of life among individuals with mental health illnesses. Poor quality of life among respondents could be influenced by poor insights that evidently appear in mental health illnesses, specifically schizophrenia. Their self-perceived cognitive deficits could interfere with their relationship with internalized stigma and their quality of life (Krawjeski *et al.*, 2013). The relationship between quality of life and self-stigma shows that self-stigmatization leads to a lower quality of life in patients with schizophrenia and depression. They further reported that patients with schizophrenia have lower quality of life in the domains of physical health, feelings, leisure, and general well-being (Ociskova *et al.*, 2015). Guo *et al.* (2018) dignified the impacts of insight on psychosocial outcomes, which imply that identifying and correcting self-stigma in people with schizophrenia could be beneficial.

Poor sense of self-reliance

Ten respondents view individuals with mental health illnesses as not living a good, rewarding life independently. They construe that these individuals are more likely to be dependent on their family in various aspects, such as ADLs. One respondent in this study shared her thoughts:

"He doesn't know how to self-care; he doesn't do anything... sitting all the time, waiting for others to serve food to him. He only knows how to eat... After eaten, he goes to bed for nap..."

(Minah)

Interestingly, one respondent shared her thoughts that taking care of her sister is manageable, and she perceived this experience as manageable. She stated, "... not really good and rewarding, but manageable. She can take care of her own needs (ADL) and help in the house."

(Chong)

Caregivers who care for patients with psychotic symptoms face a greater burden than those who care for patients with bipolar disorders, with a higher burden reported by laborers and housewives (Cham *et al.*, 2022). Interestingly, symptoms of psychosis, such as disorganized thoughts, hallucinations, and delusions, may require constant supervision to ensure the patient's personal hygiene and grooming and prevent the patient from engaging in negative behaviors such as skipping medication (Mak & Cheung, 2012; Grover *et al.*, 2015; Rahmani *et al.*, 2022). The massive burden felt by caregivers of schizophrenia patients may also be due to the need for caregiving even during remission and the social exclusion experienced by the caregivers or the individuals with mental illness.

The caregivers' burden of schizophrenia patients was higher among older and unemployed individuals, mothers, those reporting lower educational levels, and caretakers of younger patients (Shamsaei *et al.*, 2015). The caregiver burden may be due to higher psychological morbidity and maladaptive coping in caregivers or schizophrenia patients (Rahmani *et al.*, 2022). They are also worried about the future and finances of the patient (DiLorenzo *et al.*, 2021). Caregivers of schizophrenia patients also reported providing more motivation and encouragement to schizophrenia patients in the latter's care (Chronister *et al.*, 2021). Greater worry and the provision of nursing care may have contributed to a greater burden among caregivers for patients with psychosis or schizophrenia spectrum disorders. Moreover, the higher stigma against individuals with schizophrenia, depression, or other mental illnesses, particularly in terms of perceptions of dangerousness and negative stereotyping for schizophrenia patients, may further isolate the caregivers from sources of social support (Ebrahim *et al.*, 2020). To improve the quality of nursing care and perform mental health care proper training and education programs is needed to reduce mental illness stigma (Rubio, 2023).

Feelings of Discrimination by the Community

In addition, most of the respondents in this study implored the notion that there is a feeling of discrimination towards individuals with mental health illnesses in the community. One respondent shared her disappointment in how people around her discriminate against her mother.

(Crying) "I notice people in the village are not comfortable with my brother. In front of me, they tend to act nicely and show no hatred towards my brother. Once, when my brother went missing, no one in the village told me. My brother always walks in the village; they do not even greet him. People and my relatives began not to be keen to come to my house anymore since they knew about my brother. They always use the reason that it is not appropriate for me to entertain because I have to focus on taking care of my brother. Some elderly people in the village keep on telling me to send my brother to the hospital or halfway home. I feel sad when I think of it."

(Juriah)

Families of individuals living with a mental illness are vulnerable to stigma by association (Nxumalo & Mchunu, 2017) and are vulnerable to negative emotions similar to those experienced by those with mental illness, such as low self-esteem, shame, and anger. In Africa, mental illness is associated with certain cultural beliefs and traditions and has been found to impede access to health care services as well as militating against the integration of people with mental illness within society (Dako-Gyeke & Asumang, 2013; Egbe, Brooke-Sumner, & Kathree,

2014).

Quality of life, self-stigma, and coping strategies in patients with neurotic spectrum disorders conclude that the higher the stigma of persons with schizophrenia in the community, the lower the subjective quality of life is (Holubova *et al.*, 2019). This suggests that the reduction of self-stigma should be considered in the improvement of the quality of life of people with schizophrenia in the community.

Inability to Contribute and Participate Socially.

The majority of the participants in this study recognize that individuals with mental health illnesses are unable to contribute to society in many aspects. They also reported that individuals with mental health illnesses do not go out to meet their friends or join any social and/or recreational activities. Moreover, they reported that individuals with mental health illnesses were experiencing poor relationships with their friends. Interestingly, only three respondents mentioned that their siblings have a good relationship with a few friends and others. Lim reported,

"a good relationship with friends. Go out with friends for drinking and smoking."

Contrarily, the findings of this study noted that the majority of the respondents reported that individuals with mental health illnesses have a good relationship with their parents and siblings. For instance, Juslina stated,

"So far, he has listened to his parents when being asked to help with housework, but he is only like sweeping and throwing rubbish."

A study by Guo *et al.* (2018) examined the relationship between self-stigma and subjective quality of life for individuals with chronic schizophrenia in the community and found poor psychosocial outcomes for individuals diagnosed with schizophrenia in non-Western societies, in which self-stigma plays a pivotal role. This finding elucidates the direct and indirect effects of insight on psychosocial outcomes and implies that identifying and correcting self-stigma in people with schizophrenia could be beneficial (Millner *et al.*, 2019). However, self-stigma is an inevitable reaction among individuals with mental health illnesses, which could lower their self-esteem and make them depressed (Husk *et al.*, 2016).

Coping with Life among inDividuals with Mental HealthIllnesses

The majority of the respondents in this study established the notion that individuals with mental health illnesses were unable to cope with their illnesses whenever they were at home, as one respondent shared her observation.

"He doesn't do anything; no one has ever asked him to soak the noodles with water, but he also doesn't know how. Likes sitting all the time."

(Patricia)

However, five respondents mentioned that their siblings managed to cope with the living arrangements at home by helping out with house chores such as sweeping, washing dishes, and throwing rubbish. One respondent shared an interesting discovery:

"Sitting and making his own handicraft, like a necklace. Most of the time was smoking."

(Agan)

Interestingly, one respondent shared her thoughts that taking care of her sister is manageable, and she perceived this experience as manageable. She stated,

"... not really good and rewarding, but manageable. She can take care of her own needs (ADL) and help in the house."

(Lina)

Another respondent shared an intriguing experience when his sibling was helping out with the house chores.

"He did try to help out at home, putting the kettle on, but later he forgot to switch it off, so I told him to put the kettle on and boil it using the cooker."

(Juriah)

The caregiver burden may be due to higher psychological morbidity and maladaptive coping in caregivers or schizophrenia patients (Grover *et al.*, 2015). Greater worry and the provision of nursing care may have contributed to a greater burden among caregivers for patients with psychosis or schizophrenia spectrum disorders (Sharma *et al.*, 2017). Self-stigma, quality of life, and disorder severity can affect the coping strategies of individuals with mental health illnesses (Gupta *et al.*, 2014). From the same point of view, stigma from the caregivers could lead to negative perceptions of their significant others who were living with mental health illnesses (Krawjeski *et al.*, 2013).

Quality of life is significantly correlated with all coping strategies (Karnielli-Miller *et al.*, 2013). It is seen that community mental health professionals need to provide more tailored interventions to people with mental illness to enhance their participation performance even during the pandemic era (Li, Zhuo, & Liu, 2023). On potential coping interventions, both caregivers and service users indicated that support groups might be helpful. The support groups strengthen the relationship between caregivers and their significant others, reduce caregiver burden, and strengthen coping capabilities (Yang *et al.*, 2013). The use of multi-component approaches, such as face-to-face training, telephone training, and digital platforms, is necessary to improve the efficacy of supporting family members, caregivers, and individuals with mental health illnesses (Shamsaei *et al.*, 2018). These multi-component approaches could be formulated and implemented with consideration of the surrounding culture, norms, and policies (Millner *et al.*, 2019; Thomas *et al.*, 2020). Further, multi-component approaches would ensure that financially vulnerable families are accommodated in choosing a convenient support method.

CONCLUSION

The study of self-stigma and quality of life of people with mental health illnesses in a community in Sarawak was adapted, and it was found that most of the study findings are balanced and consistent with studies conducted in other countries. What needs to be paid attention to is how to assist patients in managing their daily lives as well as their personal health care, in addition to empowering the knowledge and skills of the patient's caregivers. In addition, there is also a need for more effective monitoring, especially for those who are outside the city or who are far from health centers such as clinics and hospitals. Awareness of mental health and issues related to social stigma need to be given attention to help patients and their families live more prosperously.

Conflict of Interest

The authors declare that they have no competing interests.

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