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Qualitative Study On Perception Of Adults With Mental Disorder On Stigma Towards Them In Malaysia

Aina Affrina Mohd Nor, Aisyah Waheeda Rosaini, Alissa Lai Azman Lai Chong Huan, Maria Zalina Abdul Rahim*

Faculty of Medicine, University of Cyberjaya (UOC), Persiaran Bestari, Cyber 11, 63000, Cyberjaya, Selangor, Malaysia.
Corresponding Author: maria@cyberjaya.edu.my

ABSTRACT

This study is done to determine the perception of adults with mental disorders on stigma towards them in Malaysia. Stigma is defined as a mark of disgrace that disqualifies its bearer from full social acceptance, often leading to several forms of discrimination. Nine adults with mental disorders were interviewed in an in-depth, online, semi-structured interview. Triangulation and thematic analysis was used to analyze data. The results indicated that stigma is perceived as a form of judgement, negative perception and stereotype where it was experienced in the form of public and self stigma. Family and friends were mentioned to have the most impact on adults with mental disorders resulting in a behavioral or emotional response. Results are discussed with respect to potential strategies to overcome stigma. The implications of the study and recommendation for future research are presented.

Keywords: Qualitative study, Mental disorders, Stigma, Adults, Malaysia.

1.0 INTRODUCTION

Stigma, commonly defined as a mark of disgrace indicating physical-moral-social taint. Stigma can arise from and give rise to feelings of shame and embarrassment on the part of the stigmatized person [1]. Stigma is widespread and commonly experienced by people who are thought to be "different" than the norm. This is commonly experienced by people with mental disabilities [2]. The lives of people with mental illness has been plagued with prejudice, stereotypes and discrimination that it affects their way of living leading to poverty [3], low employment rates [4] and more importantly discrimination in receiving health services that will affect their quality of treatment [5].

The problems are made worse by the stigma and discrimination they experience from society, families, friends and employer. A study states that stigma from significant others was pervasive. Stigma from such closely bonded individuals was much more hurtful than that arising in the public domain, where mental illness was easier to conceal [6].

The stigma experienced by patients with mental illnesses can be categorized into public stigma and personal stigma. Public stigma is the prejudice endorsed by the general population and manifests as discrimination toward people with mental illness [7]. Self-stigma is an individual's sense of shame, embarrassment, and worry about others' responses to their mental health problems, resulting in negative feelings about one's self, lowered sense of personal mastery, and a narrowed future outlook [8].

Thus, this study was designed to determine the perception of adults with mental disorders on stigma towards them in Malaysia. Therefore, findings can be used to change the perception and to justify the importance of interventions in overcoming the perception.

2.0 METHOD

University of Cyberjaya students conducted this research as a part of the Research and Evidence Based Medicine subject. First approval was obtained from the University of Cyberjaya Research Ethics Review Committee (CREC). Primary data collection for this study was conducted between April and May 2020.

2.1 Background

The study on Perception of Adults with Mental Disorder on Stigma Towards Them was conducted among the adults with mental disorders who were living in Malaysia. It was conducted via virtual setting as it was a convenient platform for the researcher to interview the subject during the Movement Restriction Order. In order for the researcher to obtain clearer view and insight about the perception of adults with mental disorders on stigma towards them, qualitative research had been conducted. Ethnography, to observe and study the patterns of behavior and attitude of the subject was the study design. The sampling method used was purposive sampling in order for the researcher to maximize the variation of the obtained data. The inclusion and exclusion criteria was taken into consideration during the sampling. Three methods were used during the primary data collection, which were online interview, participant observation and Participatory Rural/Rapid Appraisal (PRA) tools. The parameter of interest for this research was the perception of adults 19 years old and above with mental disorder on stigma towards them.

2.2 Participants

Adult Malaysians aged 19 years and above are diagnosed with mental disorders (with proof from their prescription, letters, medication or treatment card). They are also stable and not in relapse or impending relapse which are able to interact and answer questions relevantly. The study started with 7 adults with mental disorders but this number may increase or decrease as per saturation point.

2.3 Procedure

Potential adult Malaysians aged 19 years and above with mental disorders had been contacted personally (using purposive sampling method) and an appointment was set where the time and date was convenient to each participant to carry out the interview. Information sheet and consent form had been provided before the commencement of each interview and patients had read the sheet and then signed the consent form. The online interviews were carried out according to the SSI guideline and participant observation.The Participatory Rural/ Rapid Appraisal (PRA) tools was used along with the interview: Venn diagram, Scoring and ranking table.Sample size was 7, but it increased to a total of 9 adults with mental disorders. The subject's privacy was protected, as there were no identifying marks on any of the diagrams used as well as any mention of names in the recording.

2.4 Data Analysis

The data from the interviews was transcribed and field notes were recorded. Thematic statements that described stigmatic experiences were isolated from transcriptions of the interviews and field notes. Using the complete set of phrases, sentence clusters and field notes, data were then analyzed through grounded theory and finally reduced into essential themes.

3.0 RESULTS

3.1 The perception of adults with mental disorders on stigma towards them

Table below shows how adults with mental disorders perceive stigma.

Participant	Perception on stigma
Participant 1	A form of judgement, element of comparison and labeling
Participant 2	Public perception
Participant 3	Perception and stereotype
Participant 4	Bad prejudice
Participant 5	Judgement
Participant 6	What society looks at you
Participant 7	A form of judgment to people with mental illness
Participant 8	What people think, negative perception
Participant 9	Bad perception

Table 1.0 Participant's perception of stigma

3.2 The various forms of stigma upon adults with mental disorders

Based on this study, two main forms of stigma are identified, which is public stigma and self-stigma. Both may be understood in terms of three sub-themes, stereotypes, prejudice, and discrimination. The sub-themes are broken down further into several different categories

Theme	Sub-theme	Number of participants
Public stigma	*Stereotype* *Prejudice* *Discrimination*	9
Self stigma	*Stereotype* *Prejudice* *Discrimination*	7

Table 2.0 Two main forms of stigma and its corresponding sub-themes

Category	Number of participants
Abandonment	4
Abuse (Verbal/physical)	5
Avoidance	6
Bad mouthing	3
Belittling	5
Betrayal	1
Courtesy stigma	1
Disrespect	3
Distancing	2
Distrust	2
Double standard	4
Exploitation	3
Fear	1
Humiliation	1
Ignored	1
Indifferent	6
Insensitive	6
Insulting	1
Intimidation	1
Judging	4
Labeling	7
Less interaction	1
Mockery	2
Negative emotional reaction	4
Negligence	2
Oppression	3
Over generalization	1
Ridiculed	1
Rejection	4
Shame	4
Social exclusion	1
Social media mockery	3
Take advantage	3
Threatening	1

Table 2.1 Categories on forms of stigma

3.3 The perceived committers of stigma on adults with mental disorders

From the study, there are eight main themes of stigma committers found.

Themes	Number of participants
Family	7
Friends	7
Healthcare alliances	2
Workplace	5
Media	7
School	0
Community	0
Others	0

Table 3.0 Committers of stigma

3.4 The reaction of adults with mental disorders on stigma towards them

Theme	Sub-theme	Number of participants
Behavioral response	*Aggression*	5
	Isolation	5
	Acceptance	5
	Avoidance	4
	Self-harm	3
	Ignore	3
	Indifference	2
	Blame others	1
	Educate	1
	Felt challenged	1
	Keep quiet	1
	Prove oneself	1
	Suicidal thought	1
	Trauma	1
	Turns to substance	1
Emotional response	*Anger*	7
	Sadness	5
	Frustration	4
	Worry	4
	Disappointment	1
	Embarrassment	1
	Offended	1

Table 4.0 Two main reactions towards stigma and the corresponding sub-themes

Findings from this study showed two main reactions of stigma, which are behavioural and emotional response.

4.0 DISCUSSION

4.1 The perception of adults with mental disorders on stigma towards them

The majority of our participants recognize stigma as a form of judgement, negative perception and stereotype. Definition of stigma was given as mark of disgrace indicating physical-moral-social taint [1] and also defined by E. Goffman in 1936 as a visible or invisible attribute of an individual that is deeply discrediting, that disqualified its bearer from full social acceptance, often leading to several forms of discrimination [9].

4.2 The various forms of stigma upon adults with mental disorders

All of the nine participants claimed they experienced public stigma while only seven experienced self stigma. This showed that different individuals would have different experiences of stigma. In terms of self stigma, there are several factors that probably influenced the level of self-stigmatisation in people with mental disorders. According to Kalisova L. (2018), self-stigmatisation correlates with the presence of employment or social inclusion, duration of illness in patients with psychosis and treatment adherence [10].

4.3 The perceived committers of stigma on adults with mental disorders

The two main comitters of stigma having the most impact on adults with mental disorders were found to be family and friends, as mentioned by seven of the participants during the interview. In one focus group study by Gonzalez et al (2007) family members were said to express stigma in the form of exaggerated worry, paternalism, and belittlement, all of which undermined the individuals' sense of maturity and mastery [11]. Research on stigma directed by peers has largely focused on social stigma, namely the negative perceptions of youth toward peers with mental health disorders (Connolly et al., 1992). [12]. Meanwhile, the stigma with the least impact on adults with mental disorders were found to be committed by healthcare alliances, media and the community. Henderson et al (2014) stated that mental illness-related stigma, including that which exists in the healthcare system and among healthcare providers, has been identified as a major barrier to access treatment and recovery, as well as poorer quality physical care for persons with mental illnesses [13]. Wahl (1995) described that media contributes stigma through illustrations that people with mental illness are homicidal maniacs who need to be feared, they have childlike perceptions of the world that should be marveled, or they are responsible for their illness because they have weak character [14] .

4.4 The reaction of adults with mental disorders on stigma towards them

There are two types of reaction which are behavioural and emotional responses as a reaction to stigma. Majority of the behavioural response which were described by five participants includes aggression, isolation and acceptance. Morrison, Renton, French, and Bentall (2008) documented aggression as "safety behaviours" in psychosis [15]. In terms of isolation, a participant stated, "I'm always more closed off and talk less" (Participant 4). According to Howe et al (2014), it has been identified that participants would avoid perception from others by maintaining to be secretive, relational closeness and tend to isolate about the diagnoses [16]. Acceptance is a positive reaction from the participants. Instead of

changing people's perception toward them, they try to control their feelings and remain positive as they are unable to force others to understand their conditions. The most common emotional response mentioned was anger. They react angry toward people who label, discriminate and disrespect them. Schulze and Angermeyer (2003) stated that more emotional distress has been experienced by highly stigmatised users [17].

4.5 Strategies to overcome stigma

Several strategies have been identified in order to overcome stigma which are education, contact, person centered, peer support and reflexive consciousness.The starting point for all target groups is education. Corrigan and O'Shaughnessy (2007) claimed that education could be done through campaigns and awareness programs as they are very popular and readily available to the public. They also described about contact strategy, which heavily involves the concept of disclosure. The power of contact can be increased by encouraging people with mental disabilities to disclose their experience [18]. Lassonde and Pietrus (2011) explained that the person centered strategy focuses on the health professionals. It is achieved by paying attention to the whole person, beyond the diagnosis and symptoms [19]. Mental health peer support is another strategy to combat self stigma. Research done by Whitley and Campbell (2014) have found that peer support helped reduce internal stigma [20]. Corbiere et al, 2012 defined reflective consciousness as a process by which a person reflects and attempts to restructure one's experience or knowledge to deal with attitudes and behaviours as objects of observation [21].

4.6 Limitations and discussion

This study was done during the Movement Control Order (MCO) that was issued by the government amidst the Covid-19 pandemic. Availability and access to the internet played a major role participant selection and commencement of online interviews. Therefore, participants of older age groups were not able to be recruited due to their lack of access to the internet and the absence of assistance to help them set up an online interview through virtual platforms. Hence, this study did not explore the perceptions of geriatrics with neurocognitive disorders. Therefore, it is recommended that future studies should explore more on the perception of geriatrics with mental disorders on stigma towards them. The study should also have more variation in terms of samples and study the perception of people who are committing those stigma instead.

5.0 CONCLUSION

In conclusion to the results of this study, the stigma of mental illness is a profound phenomenon in Malaysia. The participants perceived stigma as a form of judgement, negative perception and stereotype. They had described that stigma was experienced in the form of public and self stigma. Family and friends were mentioned to have the most impact on adults with mental disorders. Ultimately, this resulted in them reacting with a behavioral or emotional response. Different individuals portrayed different perspectives of stigma in accordance to their age group, social circle and experiences. The implications of stigma caused people with mental disorders to bear stigma as a second illness, having a less defined quality of life, low employment rates and plagued with prejudice, stereotype and discrimination. Thus, the issue of stigma needs to be addressed as it highly affects their welfare. Awareness on mental illness and stigma needs to be raised amongst the public through strategies such as education. Most importantly, the role of education needs to be played by mental health professionals. Further research involving the public and health system is required in order to develop effective interventions to overcome the stigma towards adults with mental disorders in Malaysia.

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