Review Article

"TODAY, I HAVE A REASON TO LIVE": EXPLORING THE LIVED EXPERIENCE OF WOMEN MDD SURVIVORS

Afifah Idris, Noremy Md Akhir, Mohd Suhaimi Mohamad, Norulhuda Sarnon*

Department of Psychology, National University of Malaysia, Selangor, Malaysia

Abstract

Depression is estimated to be the leading cause of disease by 2030 and is already the leading cause in women worldwide. In Malaysia, nearly 2.3 million people have experienced depression at least once, yet this problem has not been thoroughly investigated and addressed. Hence, a study exploring the lived experience of the survivors needs to be investigated. This study focused on the women Major Depressive Disorder (MDD) survivors to understand their journey of recovery. Survivors or also called 'People with Lived Experienced' have a range of first-hand experiences with treatment and recovery, making them an expert by experience. Four women with MDD were selected by using purposive sampling, and in-depth interviews were conducted before analyzing using thematic analysis. This qualitative study has found four major themes with fifteen subordinate themes: survivor's efforts, challenges, social support and hopes. Then, the findings of this study were integrated with CHIME framework known as the guiding philosophy of recovery for mental illness patients. These findings contributed to a better understanding of the recovery process and supports needed for MDD patients to recover. In addition, this study also proved that patients with MDD could recover. Therefore, it breaks the social stigma that is still prevalent in the community. Based on these first-hand experiences shared by the survivors, it is hoped that the present interventions conducted by related organizations and caregivers can yield improvements so that the current patients who are still struggling with MDD can recover faster holistically. *ASEAN Journal of Psychiatry, Vol. 24 (7) July, 2023; 1-11*

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Introduction

Major Depressive Disorder (MDD) or better known as clinical depression is a chronic illness that contributes significantly to disease burden [1]. At its worst, depression can lead to suicide. Every year, over 700,000 people die due to suicide, and it is the fourth leading cause of death for people aged 15 to 29 years old. Referring to the National Institute of Mental Health (NIMH), the prevalence of major depressive episodes in 2020 was higher among adult females (10.5%) compared to males (6.2%). In addition, 10% to 25% of women and 5% to 10% of men are at risk of having MDD once in their lifetime [2]. Depression is estimated to be the leading cause of disease in 2030 and is already the leading cause in women worldwide. World Health Organization (WHO) estimated that 35% to 50% people from developed countries and 79% to 85% people with severe mental health problems from developing countries were not receiving any proper treatments from the mental health providers. Reasons behind these situations are due to the lack of resources, lack of trained health care providers and social stigma associated with mental illness [3]. In addition, individuals with depression are often not diagnosed accurately, and individuals who rarely experience depressive disorder have been misdiagnosed and given anti-depressants.

In Malaysia, depression has affected nearly 2.3 million people, but this issue has not been fully explored and treated. Referring to the national health and morbidity survey in 2019, about 2.3% or half a million people suffer from depression, with most patients being women (2.6%) compared to men (2.0%). High stress among women occurs due to various responsibilities that need to be performed. This situation is common in urban areas where working women must carry out and adjust tasks at home and office. It was shown that nearly one-fifth (18.7%) of working women struggled to strike a balance between their roles at home and work [4]. Additionally, some women also play a significant role as informal carers because they have to look after the younger members of the family as well as the elderly and disabled family members. Some are even single mothers who are forced to bear

greater responsibility after being left by the husband [5]. This condition has indirectly caused a heavy mental burden among them in the long run. Other factors include stress before and after childbirth (prenatal and postnatal), physical and sexual abuse as well as violence committed by couples. Due to its high prevalence and morbidity factors, depression has become a popular research topic in Malaysia.

Depression can cause the affected person to function poorly at work or in the family setting, feel worthless and guilty, lose interests or pleasure in most or all normal activities and many other symptoms for a duration of at least two weeks (DSM-V). The journey for recovery for each patient is different. It is a complex and time-consuming process. There are some people who recover quickly, and there are others who need more time. Not only the patients with MDD must take their medicines to heal, but also the type of assistance they receive is crucial. When mental illness was first treated, the focus of professional care was on the psychosocial aspects of treatment [6]. Today, the recovery does not solely concern with the symptoms or signs reduction. The idea of recovery today encompasses social and personal procedures in which one's internal issues are resolved together with their reintegration into the society.

Researchers have extensively addressed the causes and effects of these mental diseases in several studies that have been carried all over the world. Most of this research are based on clinical reports as well as worries about the stigma that people with mental illnesses experience. However, it is difficult to find data on the experiences of women MDD survivors particularly in Malaysia. When discussing the problems of depression and the actions that need to be taken to hasten the recovery process, the survivors or also called the People with Lived Experience (PWLE) should be engaged. They are the experts by experience who have various personal experiences with respect to mental illness, services and rehabilitation, and participated in the design delivery of mental health services [7]. Therefore, the main aim for this study was to explore the women survivors' experience. It is very crucial for everyone to understand their life experiences to help current patients who are still struggling with MDD. With the increasing numbers of depression due to the current COVID-19 pandemic that leads to more emotional pressure, it is hoped that the findings will help to reduce the statistics of MDD in future, as well as the social issues related to depression.

Literature Review

Research Design

This was a narrative, qualitative interview-based study that sought to explore the lived experience of women MDD survivors. Narrative research is the procedure used to comprehend a person's experience over time in a specific location or locations, and in social contact with the environment [8]. The survivor's recovery from depression was measured based on the reduction in depressive symptoms that occurred over a relatively long period of time or that showed only mild symptoms. According to DSM-V, a minimum of two months of having no relapse and no significant symptoms can be considered as full remission of depression. As studies showed that MDD and stigma associated involved more women aged 55 years old and below, the survivors were all from that age range. Four women survivors named as Mrs. R, Miss M, Miss S and Mrs. T were selected by using the purposive sampling techniques and were in-depth, one-to-one interviewed. The inclusive criteria for all informants included: (i) having experiences being diagnosed with MDD by psychiatrist; (ii) relying on low-dose medications or having been freed from any medications; (iii) not experiencing relapse for at least two months before the interview; (iv) being aged 55 years and below and (v) able to speak and understand Malay or English language [9].

Procedure

Ethical approval for the study was given by the research ethics committee of the national university of Malaysia (JEP-2020-565). Before conducting the interview by using semi-structure questions as a protocol of study, each informant received a briefing about the study's purpose and the confidentiality of the data. They also had the rights to withdraw at any time if they no longer wanted to continue with the research. The written informed consent was obtained from all informants before conducting the interview. The interview was done in eight sessions (approximately one hour each session) which took place at the informant's house and by video call.

Data collected were then transcribed and analyzed by using the thematic approach described by Braun and Clarke for analysis

process [10]. According to this approach, there were six steps to be followed:

- Become familiar with the data
- Generate initial codes
- Search for themes
- Review themes
- Define themes
- Write-up

Demography of Informants

This study involved four women survivors who had been diagnosed with MDD between three and 17 years named as Mrs. R, Mrs. T, Miss M and Miss S. The factors of the MDD occurrences were different from each other. For Mrs. R, the factors were lack of attention from her parents since childhood, often being differentiated with her siblings, abusive relationships and genetics. For Miss M, the difficulty to accept the death of her parents, genetics and educational stress were the cause of her suffering from MDD. Miss S, who was the youngest survivor in this study, suffered from MDD due to bullying and often being embarrassed by the teachers at school. As for Mrs. T, she was not sure of the main cause for her MDD because she had no genetic factors or history of trauma [11].

Results

The present study revealed four major themes with 15 subordinate themes that highlighted the lived experiences of the women MDD survivors. These major and subordinate themes are discussed as follows (Table 1).

Table 1. Themes and subordinate themes.

Subordinate themes	Themes
Good coping skills	Survivor efforts
Getting help from health services	
Completing one task at a time	
Taking care of the food intakes, sleep and emotions	
Acceptance by family members	Challenges
Social stigma	
Struggle against self-stigma	
The challenges of starting a new life	
Good care by the caregiver	Social Support
Support from other family members	
Indirect assistance from others	
Expectation for self	Hope
Expectation for family	
Expectation for community	
Expectation for health care workers and service providers	

Survivor Efforts

Recovery from MDD depended on the survivor's own efforts. Among the efforts by the survivors were to have a good coping skill, get help from health services, complete task one by one, and take care of the food intakes, sleep and emotions [12].

Good coping skills: For Mrs. R, she had some coping skills that helped her through her recovery process. Coping skills that helped her most was by writing about her illness on the social media site, especially on Facebook. As she started sharing, her family members started to find out about her illness and stories on Facebook. According to Mrs. R:

Writing had helped me deleting bad memories in my brain. When I did the writings, it seemed to help remove the unwanted things that I did not want to remember, and those things made my brain feel free.

Despite getting criticism, Mrs. R still continued her sharing [14].

take the medicine. According to her, her recovery factors also depended on her nutritional, emotional and sleep patterns.
No problem (if forget to take medicine). You got to take care of your emotions and food intake (nutrition) and have enough sleep. That's all.

Challenges

The survivors have also experienced various challenges during the recovery process. Among the challenges that they faced were the acceptance of family members after being diagnosed with MDD, social stigma, struggle against self-stigma and the challenges of starting a new life.

Acceptance of family members: For Mrs. R, the first challenge she had to go through was the acceptance of her own family members when they found out about her illness. After her first sharing went viral on the social site Facebook, her mother did not want to communicate with her. Mrs. R also was deeply saddened by the words of her father's family members, who accused her father of having been reckless in carrying out his responsibilities as a father. According to Mrs. R:

My mother said, when I got an invitation to go live on television and talk about my depression, my father's side started to talk about me on their WhatsApp group. My mother told me that she had never seen my father look very sad. Not long after that, he got a call from his sibling. They said, "what are you doing with your daughter? You don't know how to take care of your children." When I found out about his, I was very sad. Because for me, this is only one factor (among other factors that caused depression).

Her sharing on television and Facebook also made the relationship with her mother better although it took some time. According to Mrs. R, her mother has begun to understand her daughter's illness.

So, one day my mom came to my house. We both hugged and apologized. And I think the main core that made me depressed is gone. And my health is getting better after that. (crying)

Social stigma: For Miss M, the stigma from her own family was her biggest challenge during her recovery process from MDD. Her family members were more convinced that her illness was the result of saka (a mystical related illness believed for generations by most people). According to Miss M:

For example, my siblings may understand, but not my uncles and aunties. They don't understand until now. They still believe in the saka thing. So, this thing cannot be solved if they still believe in the mystics.

The stigma against depression was also still growing. According to Miss M, the common stigma she received was:

There is no cure for this disease (laugh). (Miss M) The problem of stigma also happened to Miss S. According to her:

People say depression happens because we don't pray. Many people feel that this thing (depression) does not exist.

Mrs. T also informed about the stigma among health care workers that she had gone through before. According to her:

Like me, I've been before this many times... like previous relapse, I went to XXX clinic. There, the staff asked me "Are you not praying? If not, why are you feel like committing suicide, right?" So, I feel like the staff themselves need to be educated.

Struggle against self-stigma: For Mrs. R, not only she had to face social stigma from the family and society, but also she could not escape from the self-stigma she felt. According to Mrs. R:

It's just hardest when…for me, when I started to feel better and saw the rhythm of wanting to be healthy, but then, I felt I was a loser. I spend much time on Facebook (doing sharing), but sometimes I will indirectly judge and differentiate myself from others. As a result, it affects my mental health.

According to Mrs. R, sometimes she wanted to stop writing on Facebook. But she did not want all her previous sharing to disappear if she closed her Facebook account. She was also aware of her responsibility to educate the community about mental illness. According to Mrs. R:

I feel like I want to close (Facebook). But at the same time, I have a responsibility to society. My way of helping and educating is by sharing. If I deactivate my Facebook, all my writing will be lost.

According to Miss M, she also had self-stigma due to the social stigma she heard.

The stigma that said we're crazy. We can't recover. No one else is sick like me. It's only me.

For Miss S, she also had self-stigma against the illness she suffered before she was diagnosed with MDD. According to her:

I feel like…crazy…I remember I was very sensitive… Apparently what I felt… was a disease…

Challenges of starting a new life: In addition to facing criticism from family members and community, Mrs. R biggest challenges was to start a new life. According to her, when her mental health showed improvements, she had to face difficulties to continue her life because she was heavily depending on her husband in daily life when she was sick. According to Mrs. R:

Frankly speaking, I wanted to go out to work, but I did not know what to do. For example, when I got an invitation to something, it's actually my husband who took care most of the things. He will tell me what I should do. He will say "R, you need to ask for invitation letter as a speaker", "R, you need to ask for quotation", "R, you have to do this, that..." My husband is the one who encourages me a lot, especially in terms of technical support.

She added, she was afraid to shoulder a responsibility. According to Mrs. R:

Because I used to be in a phase where I did not want to do anything in life (when relapse), now I'm learning to take responsibility. But, I do not dare to do many things at once. (Mrs. R)

She then added:

It was my husband who taught me to look for solutions, not problems. But, it took me three years to finally taught my brain to always think about solutions whenever problems occurred. Before this, if I was angry with my child, I would make a fuss. But, I see that my children will still make the same mistake. I just realized that they didn't understand. For example, when they spilled water, I would be very angry. I would say many bad things to them. Then, I realized, if they spilled water, I just asked them to take cloth and wipe it. Settle. That's the best solution.

Social Support

According to the survivors, their recovery process depended on the several aspects, namely good care by the caregiver, support from other family members, indirect assistance from others and efforts in seeking alternative treatments.

Good care by the caregiver: For Mrs. R, she was very fortunate to get an excellent care from her husband. According to Mrs. R, despite being beaten before, Mr. K, her husband, still took a good care of his wife. In fact, Mr. K never once abused Mrs. R throughout their marriage, especially when Mrs. R's mental health deteriorated. According to her:

After I gave birth to my first child, I had post-partum depression. I could feel that I did not like my baby. I felt like it's hard to take care of the baby. I used to rage, I hit my husband, I kicked him. That's not normal right? Usually, I raged when my parents were asleep. So, my husband was the one who saw my true colors.

According to Mrs. R, she was once asked by a psychiatrist to be warded while going through a severe relapse episode. But, on her husband's assurance, the doctor allowed Mrs. R to go home and be cared for by Mr. K. According to her:

I should have been warded. But, because the bed was full, and I had a baby to breastfeed, on my husband's assurance, I took a very high dose of medicine, and I was like a living corpse for two weeks at home. I just slept all the time. During that time, my husband was a very tired person. Before he went to work, he would prepare the breakfast. At 10 o'clock in the morning, he would come back to bathe the kids and went back to work. At 12 o'clock, he would buy lunch and sent to us. At 5 o'clock, he would buy food for dinner, bathe and take care of the kids. I just lied down. Slept.

As for Miss M, she also received a good care from her brother, Mr. I, and his family from the beginning knew about Miss M's poor health. Miss M also shared how she was taken care of despite being warded in the psychiatric ward. Her brother would commute to the hospital almost every day to feed and ensure that the care by the hospital to Miss M was done well. According to Miss M:

Although I have been warded, my brother would come every day. He would come to bring the food, and I would eat with him with his wife and his children. In another aspects, it's harder for him because he worked as a security guard at a school. After work, he would come to the hospital. That was his routine every day. Only then, he could sleep after seeing me. He also gave some conditions to the ward if they wanted to detain me. He told the doctor and nurses to bathe and feed me, every day, just like how he would take care of me at home.

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Corresponding author: Afifah Idris, Department of Psychology, National University of Malaysia, Selangor, Malaysia
Email: afifah.idris90@gmail.com

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