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RESEARCH ARTICLE

A qualitative study discovering the lived experience of primary caregivers of female survivors with Major Depressive Disorder

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ABSTRACT

Major Depressive Disorder (MDD) is a rising public health concern in Malaysia, particularly among women. While many studies have focused on individuals living with MDD, limited research explores the lived experiences of their primary caregivers. This qualitative study aims to fill this gap by examining the narratives of caregivers supporting female survivors of MDD. Using a narrative inquiry approach, four primary caregivers were selected through purposive sampling. Each participant engaged in two in-depth interviews. Data were analyzed thematically using Braun and Clarke's six-phase method, resulting in five overarching themes and seventeen subordinate themes: sense of responsibility, acceptance of MDD, difficulties in the course of care, assistance obtained, and hope. Findings revealed that caregivers played a crucial role not only in managing daily responsibilities but also in offering emotional and spiritual support throughout the recovery process. Despite not explicitly identifying their experiences as "stress" or "burnout," caregivers described considerable emotional hardship, including exposure to stigma, isolation, and the burden of care. These experiences point to a complex interplay between resilience and underreported distress, shaped by cultural values, familial duty, and religious beliefs. The study highlights the importance of integrating caregivers into the recovery ecosystem through clinical interventions such as psychoeducation and support groups. It also underscores the need for policy measures that recognize and sustain caregivers' contributions, including mental health literacy campaigns, structured caregiver support, and stigma reduction efforts. These findings contribute to the growing body of research and shed light on the importance of yet overlooked experiences of caregivers in Malaysia. Based on these firsthand experiences, it is hoped that these insights will help strengthen mental health services and nurture a more supportive environment for both MDD survivors and their caregivers.

Keywords: Major depressive disorder; lived experience; primary caregiver; recovery; qualitative study

1. Introduction

Caring for family members who have been diagnosed with depression places heavy emotional and psychological burdens on caregivers. This condition, if left untreated, will negatively impact their mental

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health. A systematic review and meta-analysis done by Cham et al. (2022) found that there is a strong correlation between increased depressive symptoms and significant stress that caregivers of people with mental illness bear[1]. Another study by Perlick et al. (2016) also had found similar findings years before. According to their study, caregivers of bipolar disorder patients faced depressive symptoms due to their caregiver load. Hence, both studies have highlighted the treatments needed for the caregiver targeted at lowering their burden and enhancing their emotional well-being[2].

Major Depressive Disorder (MDD) or often known as clinical depressionm was estimated by the World Health Organization (WHO) to be the leading cause of disease by 2030[3]. Currently, an estimated 5% of adults suffer from depression, with more women affected by depression than men[4]. MDD can impact one's thoughts, feelings, and behavior and can result in a range of psychological and medical issues. In its worst case, depression can result in self-harm and suicide. More than 700,000 people die due to suicide every year, making it the fourth leading cause of death among 15-29 years old. Suicidal thoughts, which are the risk factors for suicide, are more prevalent in MDD patients-48.4% of patients report having suicidal thoughts at some point[5]. The Diagnostic and Statistical Manual 5 (DSM-V) lists the following symptoms as indicators of MDD: low mood, loss of interest in and enjoyment of nearly all previously enjoyable activities, fatigue, significant weight loss or gain, excessive guilt or feelings of worthlessness, decreased concentration, and suicidal thoughts. These symptoms must persist most of the day for at least 2 weeks in a row. To diagnose with MDD, a history of manic or hypomanic episodes must be ruled out.

According to the National Institute of Mental Health (NIMH), women had a higher frequency of major depressive episodes (10.5%) in 2020 than men (6.2%). According to estimates from the WHO, between 35% and 50% of individuals in developed nations and between 79% and 85% of individuals in developing nations who had serious mental health issues were not receiving adequate treatment from mental health providers[6]. These circumstances are caused by a lack of resources, a shortage of medical professionals with the necessary training, and the social stigma attached to mental illness[7]. Furthermore, individuals with depression are often not diagnosed accurately, and individuals who rarely experience depressive disorders have been misdiagnosed and given anti-depressants. MDD is thought to have a complex etiology involving biological, genetic, environmental, and psychosocial factors[3]. Hence, the recovery process needs to be taken holistically too, involving not only medical treatment but also the psychosocial aspects from family and community.

About 2.3 million people in Malaysia suffer from depression, but the condition is not well understood or addressed[8]. According to the National Health and Morbidity Survey (2019), approximately 2.3% of the Malaysian population, or half a million people, suffered from depression. Women made up the majority of patients (2.6%), compared to men (2.0%). The factors of these situations are believing due to the multiple responsibilities that need to be performed, which in turn increase the likelihood of having depression among them[9]. "Multiple responsibilities" refers to the typical urban situation in which working women must manage and adjust between tasks at home and at work. Research indicates that almost one-fifth (18.7%) of employed women find it difficult to reconcile their responsibilities at home and at work[10]. Previous research also has demonstrated that female-headed households (FHHs) are more likely to experience poverty due to their susceptibility to low-skilled and income-generating jobs, as well as their dual responsibilities as decision-makers, sole-income producers, and caregivers for families and children[11].

'People with lived experience' (PWLE) is the term given to someone who has personal experience of mental health problems and recovery, including primary caregivers, family members, or carers who have experience of the recovery process of someone with a mental health problem. PWLE are also considered as 'experts by experience', where their experiences have many roles in community mental health, including being

decision makers in the care of their family members [12]. The phrase "Nothing About Us Without Us" is frequently used to convey the idea that members of the impacted groups must fully participate in the creation of policies.

The causes and effects of these mental diseases have been thoroughly studied by the earlier researchers in a number of global studies[13,14]. However, it is difficult to find data on the experiences of caregivers for female survivor with MDD, particularly in Malaysia [15]. Therefore, the main aim for this study was to explore the lived experience of primary caregivers of female survivors with MDD in the journey of their recovery.

2. Literature review

2.1. Impact of caregiving on mental health and quality of life

The mental health of family caregivers who support individuals with severe mental disorders (SMD), such as schizophrenia, bipolar disorder, and major depressive disorder (MDD), has become an important area of focus for research due to the numerous challenges associated with the caregiving role. It becomes worse when the caregiver is working while caregiving, which later on can affect their mental health due to their work stress[16]. Caregiving for individuals with SMD is not only emotionally exhausting but also often physically demanding, as caregivers face unique and long-term pressures. Studies indicate that caregiving responsibilities frequently lead to high levels of stress, depression, anxiety, and a diminished quality of life (QoL) for caregivers[17,18,19]. The caregiver's role is central to the well-being of individuals with serious mental health conditions, yet it comes with profound emotional, physical, and psychological burdens.

A study by Lespine et al. (2023) conducted during the Covid-19 pandemic found that the levels of psychological stress were heightened due to the pandemic[20]. The pandemic had aggravated the already difficult responsibilities of caregivers due to the negative emotions, the stigma associated with mental illness, and a lack of positive experiences while caregiving. The negative emotions felt by the caregivers, such as a sense of helplessness, stress, and a negative self-perception of one’s health, had created the feeling of hopelessness, which later increased the health burden on the caregivers. This study found that almost half of the respondents scores were indicative of clinical depression.

In another study by Zhang et al. (2020), it was found that the caregivers of adolescents with depression (AWD) score lower on quality of life (QoL) due to a few contributing factors. This mixed-method study showed lower QoL among caregivers in both physical and mental health[21]. The contributing factors were associated with the caregiver’s educational background, family functioning, positive effect, and overall caregiving burden. The qualitative data revealed that the caregivers were feeling overwhelmed and emotionally strained. Lack of knowledge about depression had worsened their condition, which then affected their confidence and increased anxiety among them. The findings from both Lespine et al. (2023) and Zhang et al. (2020) suggest that both clinical factors, such as the severity of the care recipient’s illness, and relational factors, such as family functioning, have a significant role in determining caregivers’ physical and mental well-being[20,21]. According to Taggart et al. (2015), the hedonic and eudemonic perspectives are the two viewpoints that make up the idea of mental wellness. The hedonic perspective looks at a person's subjective perception of life satisfaction and happiness (affect) as markers of mental health[22]. On the other hand, the eudemonic viewpoint views mental health as a person's ability to achieve self-actualization, healthy interpersonal interactions, and sound psychological functioning[23]. Drawing from these two perspectives, Taggart et al. (2015) define mental wellness as a result of psychological functioning, which includes a person's capacity to create and preserve wholesome connections as well as having a satisfying and contented quality of life[22].

Oikonomou et al. (2024) looked at the prevalence of stress, anxiety, and depression in Greece as well as the effects of mental health problems on those who care for those with mental diseases. According to this study, caring for individuals with mental illnesses frequently results in a reduced quality of life for caregivers and an increased risk of mental health issues[17]. This study indicated that caregivers among younger individuals and women experienced higher levels of mental health burdens. Marital status, educational background, and employment status were examples of demographic backgrounds that significantly impact a caregiver's well-being. The findings from this study found that depression is the most significant factor associated with the QoL of the caregivers. Hence, there is an urgent need to support their social and financial care.

Another study on the impact on caregivers by Lee et al. (2023) found that caregivers also had significant mental strain due to caring for mental illness patients[24]. This study employed 120 caregivers, the majority of whom were female (59.2%), and 54.2% of them had a psychiatric diagnosis. 25.8% have been diagnosed with major depressive disorders, 17.5% with anxiety, and 15.8% with insomnia. The result of this study also found three key factors associated with caregiver depression, namely anxiolytics or hypnotics, elevated suicide risk, and lower family support scores. Lee et al. (2023) also suggests that early psychiatric assessment and tailored support for caregivers may decrease their distress while at the same time increasing their QoL.

According to Monahan et al. (2023), a similar trend was seen among 32,676 participants, representing 17.3 million of U.S. caregivers[25]. Based on this study, higher rates of depression were seen among females, American Indian/Alaskan Natives, those of race not listed, those earning under $15,000 annually, and those who did not finish high school. Interestingly, this study found that caregivers who look for their spouse or mother-in-law had a lower risk of depression, suggesting that the dynamic of the relationship and household structure may influence the stress level of the caregiver.

2.2. Social and emotional challenges faced by caregivers

Caregiver mental health is shaped by a variety of social and emotional factors, which often have a more profound impact on caregivers than logistical or physical burdens. Hu et al. (2020) examined both subjective and objective burdens among caregivers of patients with depression and discovered that these burdens were closely tied to caregivers' depressive symptoms [26]. Burden can be divided into two, which are subjective burden and objective burden. Feelings of sadness, frustration, and anger are examples of subjective burdens that had more powerful predictors than objective burdens. Those feelings of frustration and anger influenced their attitudes and responses toward the care recipient, which then increased the level of negative caregiving behaviors. This study suggests the need to address caregivers' emotional well-being to improve their interactions and attitudes toward the patients, as well as their mental health.

A cross-sectional study by Yee et al. (2018) found 30% of caregivers had depressive symptoms, and 8% among them had Major Depressive Disorder (MDD) symptoms while caring for individuals with MDD [27]. The severity of the patient's depressive symptoms, self-stigma, the patient's current depressive episode, and a lack of perceived social support from friends and family were contributing factors to caregiver depression. Hence, this study underscores the importance of addressing both patient's current depressive symptoms and caregiver's social and emotional challenges, the risks that are frequently ignored.

Furthermore, social isolation and loneliness (SI/L) were significant risk factors for poor health outcomes for caregivers, as found by the scoping review by Guan et al. [28]. Social isolation increased the risk factors for poor health outcomes among caregivers. The emotional and physical health issues that caregivers currently experience are worsened by social isolation, underscoring the need for further attention to SI/L in caregiving research and interventions. In addition, according to this study, stigma, illness-related characteristics like the severity of the patient's conditions, and sociodemographic factors such as age and marital status were among the predictors of SI/L.

2.3. Interventions and support strategies for improving caregiver mental health

Numbers of researchers have been proposing interventions in order to alleviate the burden and well-being of the caregivers. According to Lespine et al. (2023), specific psychoeducational programs should be introduced with an emphasis on lowering negative feelings, addressing stigma, and promoting good caregiving experiences[20]. This is a very important aspect to look at in order for them to understand more about their own feelings, cope with stress, and lessen their emotional strain. Furthermore, the psychoeducational interventions can also help in reducing social isolation and strengthen the caregiver's support by motivating them to turn to social networks for assistance, which may lessen the emotional strain of providing care. Oikonomou et al. stressed the societal recognition of the caring role combined with extensive support and intervention programs, especially within the unique pressures brought on by the COVID-19 epidemic[17].

Zhang et al. (2020) suggest the importance of seeking help from medical specialists among the caregivers, as they often expressed feelings of unpreparedness and being overburdened by the demands of their work, which highlighted the significance of attending to both informational and emotional needs[21]. By providing educational resources, emotional support, and advice on how to enhance family functioning by the healthcare providers, it can significantly reduce the stress of caregiving. By doing so, the quality of life of the caregivers can be enhanced and positively impact the adolescents they care for. Social support from the families may help the caregiver in managing family dynamics and lessening the caregiving burden.

The effectiveness of digital applications created to assist caregivers of individuals with MDD were examined by Minae-Moghadam et al.[29]. This study revealed that caregivers who used the app reported improvements in their quality of life compared to caregivers in the control group. This app consequently helps the caregiver to better handle their everyday pressures of caregiving by offering educational support and facilitating communication with healthcare providers. This app has helped the caregivers to communicate with medical specialists while educating themselves about the patient's condition. Even though these digital therapies have potential, the researchers emphasize the need for further research to fully understand the advantages as well as drawbacks of such tools before they are widely used.

Finally, in order to better understand the long-term impacts of social isolation and loneliness on caregivers' mental health, Guan et al. (2023) highlight the necessity of undertaking longitudinal research and creating standardized instruments[28]. According to their scoping review, standardized tools may help us better understand how SI/L affects caregivers by promoting more conceptual clarity and consistency. The review also suggests focused interventions, which include community resources, social support groups, and mental health professionals that specialize in addressing loneliness. By addressing these aspects, the caregiver's major mental health issues could be lessened, ultimately improving the general quality of life and capacity to provide care.

In a nutshell, caregivers of individuals with serious mental illnesses or long-term depression faced a variety of mental health issues in their daily lives. The psychological, physical, and emotional strain of providing care raises stress and depression rates while at the same time decreasing the quality of life, especially for those with a lack of adequate social support and who also deal with other issues, including stigma and social exclusion. Research suggests that it is essential to attend to both emotional and social needs to increase the well-being of caregivers. This action is crucial to guarantee that the caregivers can continue to fulfill their roles without compromising their own well-being.

3. Materials and methods

3.1. Research design

This qualitative study was done by using a narrative interview-based study that sought to explore the lived experience of primary caregivers of female survivors with Major Depressive Disorder. The narrative methodology was used to address the study's objectives since it allowed for in-depth examination of informants' story from their own personal experience. Four primary caregivers named Mr. K (43 years old), Mr. I (41 years old), Mrs. N (42 years old), and Mr. A (30 years old) were selected by using the purposive sampling techniques to undergo an in-depth, one-to-one interview. The search of informants was done through the data provided by the Department of Medical Social Work from Hospital Canselor Tuanku Muhriz (HCTM) and also from the Facebook page called "Depression Survivor Malaysia" group. Together with the medical social worker from HCTM, we identified MDD patients that showed reduction in depressive symptoms based on the psychiatrists' reports. 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. Thus, we used this as the baseline to identify the female survivor of MDD to contact their caregiver. The inclusive criteria for all informants included: (i) having a blood relationship with the survivor and (ii) staying with the survivor and having at least one year of experience in treatment matters such as dealing with medicines and doctor's appointments at the hospital.

3.2. Procedure

First procedure was done by giving a briefing to all informants about the study's purpose and the confidentiality of the data. They were given freedom to withdraw at any time if they no longer wanted to continue with the research. Once they were agreed, written informed consent was obtained from all of the informants before conducting the interview. The first author had used semi-structured questions as a protocol of study.

The interview was done by the first author in eight sessions (two sessions with each informant with approximately one hour each session) which took place at the informant's house and by video call. The interview process was done between November 2020 and January 2021. The total duration of interviews with Mr. K was 3 hours, Mr. I was 3 hours, Mrs. N was 2 hours, and Mr. A was 2 hours. The first author followed the interview guidelines in order to make the informants feel more comfortable during the whole interview process, such as informal conversational interviews and standardized open-ended questions. The interviews were started by a question regarding the duration that they have been taking care of the survivors, before going into more specific questions on their lived experiences such as their acceptance of the MDD, struggle, coping skills and social supports, as well as their hopes toward the survivor. When the data was sufficient and no new topics showed up, the interviews were terminated. Following the transcription of the recordings into verbatim text, the researcher noted any sensitive questions to ensure they weren't asked again in subsequent interviews. The transcribed data were analyzed by using the six steps of thematic approach described by Braun and Clarke[30] (see **Figure 1**). The six steps are as follows (done by the first author).

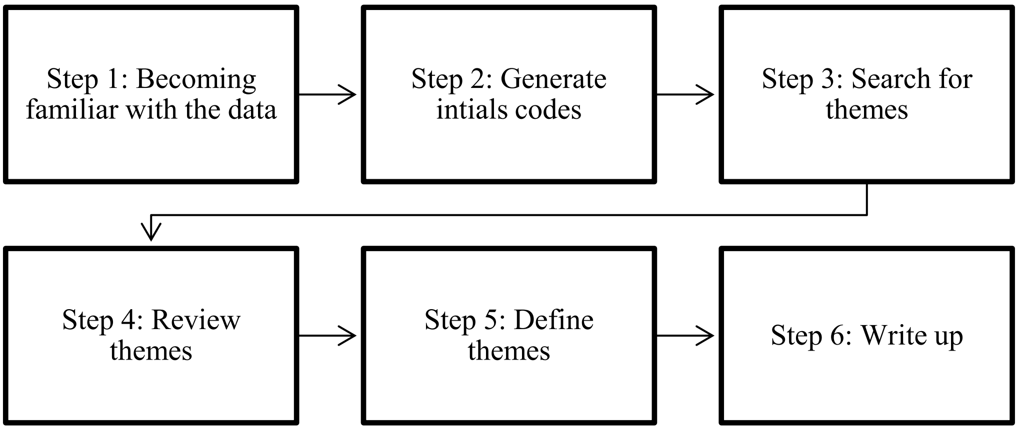

Figure 1. Data analysis process adapted from Braun and Clarke (2016)

Table 1 shows the most commonly discussed topics and sub-themes among informants. To enhance credibility and trustworthiness, all transcripts were reviewed by participants (member checking), and coding decisions were discussed and verified by the second and third authors, both experienced in qualitative research. An audit trail of the coding and theme development process was maintained to support dependability. Although the sample size was limited to four, this aligns with the principles of narrative inquiry, which emphasize rich, in-depth exploration of lived experiences. Saturation was achieved by the second interview with each participant, as no new insights emerged. Reflexivity was maintained throughout the study by the first author through journaling and reflective memos to acknowledge personal assumptions and minimize bias. Theme generation was done collaboratively, and discrepancies in coding were discussed until consensus was reached.

Table 1. Themes and subordinate themes

Themes	**Subordinate Themes**
Sense of responsibility	The patient's self-management and everyday needs. Strengths and challenges in providing care for the survivor. Managing appointments and meds.
The Acceptance of MDD	Self-assurance in recovering. Entrusting the survivor in Allah's care. Additional Initiative: Islamic Treatment.
Difficulties in the course of care	Limitations in managing daily life. Insufficient help from other family members. Addressing social stigma.
Assistance obtained	Self-Help. Support from other family members. Medications. Participating in outdoor activities.
Hope	Hope for survivors. Hope for the family. The absence of societal stigma. The extensive distribution of knowledge regarding mental disease.

4. Results

4.1. Demography of informants

This study involved four informants that had been caring for their family members who were diagnosed with MDD, named Mr. K, Mr. I, Mrs. N and Mr. A.

Mr. K, aged 34, is the husband of Mrs. R, which was diagnosed with MDD 9 years ago. He currently serves as a government servant and is also pursuing part-time studies in doctor of philosophy at a university in the southern region of the country. The couple has been married for nearly seven years and has three children, aged six, five, and two. Mr. K has extensive experience in caring for Mrs. R and was informed about her medical condition prior to their marriage. Although he initially had no knowledge of the illness, he made the decision to marry her, believing that his prior assumptions about the condition were inaccurate. Following their marriage, he gained a deeper understanding of the disease. However, his initial perception that the illness would be entirely manageable was proven incorrect. Despite this, he remained committed to caring for Mrs. R out of a strong sense of responsibility and had been caring for his wife for almost 7 years to date.

Mr. I, aged 53, is the elder brother of Miss M. He works as a store assistant and resides with his family in Klang. He has a wife, aged 48, and six children. With nearly 16 years of caregiving experience, Mr. I has been responsible for looking after Miss M, as well as their late mother, who was also suspected of having a similar illness. Mr. I first learned about Miss M's condition when she was diagnosed at the university hospital. At that time, he had lacked knowledge about the illness but gradually gained an understanding over time. Despite this, the family continued to attribute Miss M's condition to supernatural causes. They maintained their belief that she was afflicted by '*saka'* (a supernatural cause) rather than a medical disorder. However, when Miss M's condition became unmanageable and frequently worsened, Mr. I took the initiative to seek medical intervention. His first attempt at bringing her to the hospital was in 2004. Since then, he has been consistently involved in providing care and ensuring that she receives the necessary medical attention. From Mr. I's perspective, his caregiving journey has been a long and challenging one. Despite initial misconceptions about the illness, he has taken a proactive role in managing Miss M's well-being, balancing familial responsibilities with medical intervention. His dedication underscores the importance of awareness, understanding, and appropriate healthcare support in addressing mental health conditions within families.

Mrs. N, a 42-year-old homemaker residing in Kajang, has dedicated herself to caring for her family while her husband works as a security guard. Together, they have five children. Her experience in caregiving became more profound when her second child, Miss S, was diagnosed with MDD in 2018. According to Mrs. N, Miss S is naturally reserved and rarely expresses emotions or personal struggles. This made it difficult for her to recognize the early signs of depression. However, she later noticed significant behavioral changes in Miss S, especially at home. These changes became more apparent when Mrs. N faced health challenges of her own. Mrs. N believes that these circumstances contributed to her child's struggles with mental health. Over time, Miss S's condition worsened. She became increasingly withdrawn, spending long hours alone in her room and frequently experiencing fevers. Miss S also began refusing to attend school, reacting aggressively when asked to do so. In extreme cases, Miss S would scream uncontrollably, exhibiting behavior that appeared almost trance-like. Concerned for her child's well-being, Mrs. N and her husband decided to seek medical help. The emotional burden, combined with the need for constant supervision and support, significantly impacted her daily life. However, her unwavering dedication to her child's well-being highlights the crucial role that family plays in the recovery journey of individuals facing mental health challenges. This case underscores the importance of early intervention, family support, and professional medical assistance in managing mental health disorders. Mrs. N's story serves as a testament to the resilience and sacrifices of caregivers, particularly parents, who navigate the complexities of mental health within the family.

Mr. A, a 31-year-old GRAB driver, married Mrs. T in early 2020 after a year of courtship. Before their marriage, he was informed about Mrs. T's history of MDD. Unlike other informants, Mr. A has knowledge about MDD because he is also a survivor of MDD. Hence, he remained committed to their relationship. Mrs. T, aged 30 years old, is a dedicated mental health advocate in Malaysia. Her first episode of depression occurred while she was pursuing her undergraduate studies at a university. At that time, she had a strong passion for self-improvement and set high expectations for herself. The academic pressure, combined with personal struggles, eventually led to her seeking help from a counselor. From there, her mental health journey began. With the support of her university peers, Mrs. T took proactive steps to manage her condition. She sought psychiatric treatment and, for nearly five years, fought to regain control over her mental well-being. Over time, she experienced significant improvement and became more open to sharing her journey with others. Today, Mrs. T continues to advocate for mental health awareness, not just for herself but for the wider community.

The present study revealed five major themes, which are sense of responsibility, the acceptance of MDD, difficulties in the course of care, assistance obtained, and hope, with 17 subordinate themes that highlighted the lived experiences of the caregivers. These major and subordinate themes (**Table 1**) are discussed as follows. Note that the informants all gave consent regarding any of the information.

(a) Sense of responsibility

When the researchers analyzed the data from the interviews, we discovered that the recovery process of women MDD survivors is heavily reliant on the key caregivers, who are the survivor's husband, mother, and brother. This is because, despite having other important responsibilities, the majority of these primary caregivers still provide excellent care to the survivor. In fact, these survivors do not require hospitalization because they are capable of caring for themselves. The researchers were informed that if there is a capable caregiver who can care for the patient, the doctor will not keep the patient in the ward unless the condition is really critical and requires close observation by a specialist doctor. Despite having to cope with a variety of exhausting everyday responsibilities, these primary caregivers prioritize the survivor. This theme's sub-themes include the patient's self-management and everyday needs, strengths and challenges in providing care for the survivor, and managing appointments and meds.

i.Patient's self-management and everyday needs

According to Mr. K, he is responsible for managing his wife's personal management and daily needs at home, even though at the same time, he is tied to his real job at the office. According to Mr. K:

The first 3 years I could feel that life was a mess. Working, taking care of her and the children. Household and work. When the house is settled, then only I can do my work.

About responsibility and daily life, Mr. I also spoke about his sister, Ms. M. According to Mr. I:

If you want to say that it is disrupted (work), it is indeed disrupted.…but the responsibility has to be done. It means that time... (audio is not clear) when I go to work, I leave her with my wife. My wife is the one who takes care of her a lot... bathing her, feeding her, everything. Self-management.

ii.Strengths and challenges in providing care for the survivor

According to Mr. K, he is responsible for managing his wife's self-management, even though he himself is facing difficulties. He was beaten by Mrs. R when Mrs. R was going through a relapse episode.

So the first 3 years were really a struggle phase for me to take care of her. I tried to adapt to her problems and situations. So, because I had promised to take care of her, I don't want to say I'm good, a good man (laughs), but if she marries someone who is impatient or hot-tempered, the marriage won't last long. And she can't change like this either. I'm not saying I'm the good one. No! But...that's how it is.

The same thing was also raised by Mr. I. According to him:

The strength comes by itself. Because she is my sister. Who else wants to take care of her? It's us, her closest family. I can notice whenever my sister is sick. Who else do we want to hope for? Out of a sense of responsibility for our own sister, right.

iii.Managing appointments and meds

According to Mr. K, he will take his wife to the hospital if Mrs. R has an appointment with a psychiatrist.

If she wants to see a psychiatrist, I will take the day off. I will accompany her to see the doctor.

Mr. I will also do the same. All matters regarding treatment and medication will be carried out by him and his wife, Mrs. TH.

As long as we take care of her, we will monitor her medication. When the medication runs out, we follow the doctor's instructions and take her (to the clinic).

For Mrs. N, even though she is a full-time housewife, she spends a lot of her time taking care of Ms. S. She is the one who takes Ms. S to the hospital every time she has an appointment with a psychiatrist or counselor. According to her:

For the sake of the child..after the illness (molar pregnancy), to follow up, it's really tiring. You have to be strong in front of her. Every time there is an appointment at the hospital, I'm the one who takes care of everything. I will take the GRAB and go with her.

For Mr. A, he will always remind Mrs. T to always take her medicine. According to Mr. A:

We both take medicine, so we remind each other. I will make sure she will take her medicine.

(b)The acceptance of MDD

The second theme is caregivers' faith or beliefs concerning MDD. In response to the researcher's question regarding how caregivers came to terms with the survivor's illness, these caregivers acknowledged that depression existed despite their lack of knowledge of the condition. As Muslims, they believe that the survivor's illness could be cured, and Allah SWT would care for their wife/sister/child, and that every illness had a remedy.

Self-assurance in recovering

According to Mr. K, he was told about Mrs. R's MDD before they got married. However, he did not have any information about mental illness. He considered Mrs. R's depression to be just normal stress. According to him:

At that time, I didn't really explore what depression and anxiety were... I thought it was a normal problem at that time. I mean, everyone has that feeling. Feeling pressure, anxious... I think I can handle it. But apparently... mental illness really exists and needs to be treated.

However, Mr. K is confident that Mrs. R will recover completely one day. According to Mr. K:

I believe that one day she will be ok. Maybe 10 more years, 20 more years, 2 more years. It doesn't matter if it's sooner or later; the important thing is, I'm sure one day R will stop taking the medication too.

For Mrs. N, she also believes that every disease can be cured. The researcher asked Mrs. N's opinion on the potential for Ms. S to recover completely. According to Mrs. N:

Yes. I'm sure. I'm sure that one day Ms. S will definitely recover. Even now, there have been many positive changes in her. There is no more relapse like before.

Entrusting the survivor to Allah's care.

Mrs. R was once sick at home for two weeks, unable to do anything. However, Mr. K had to leave Mrs. R and their child at home to go to work. At that time, according to Mr. K:

That time was really bad. She slept, didn't wake up, didn't cook, and just lay back and looked at the wall like that, but hey, life must go on. I have to work too. I prayed a lot at that time. I left her to Allah SWT.

This matter was also stated by Mr. I. Even when Ms. M recovered and resumed her studies at university, as a Muslim, Mr. I put great faith in Allah SWT to protect his sister.

Who wouldn't worry? We've faced all sorts of things with her before. We hoped Allah would take care of her for us. We ask Allah to protect her and give her good health. That's all.

Additional Initiative: Islamic Treatment.

Mr. I went the extra mile by seeking assistance from an ustaz **(**spiritual healer or Islamic healer**)**. He shared:

Some of us brought her to meet different ustaz for help, while others opted for Islamic healing methods.

Similarly, Mrs. N took the initiative to bring Ms. S to an Islamic healer. She recounted:

I also met with an ustaz and took some blessed water. He recited surahs and guided us to do the same to help calm her down.

(c)Difficulties in the course of care

Caring for a loved one battling depression is an arduous journey, filled with trials and challenges. These caregivers dedicate themselves wholeheartedly, striving to see their children, spouses, or siblings regain their well-being. Along the way, they navigate daily struggles, cope with limited support from other family members, and endure both societal and personal stigma surrounding the illness. Yet, despite these hardships, their resilience and unwavering love shine through.

i.Limitations in managing daily life.

Mr. K has experienced being mistreated by Mrs. R during one of her severe relapse episodes. He shared:

During her worst episodes, she couldn't cook at all. But I kept the house clean—every corner of it. I took care of all the laundry. At that time, we only had one child, and I managed everything—bathing, sleeping, everything—until late at night. Back then, R had a tendency to be violent. She would hit me and our child. But I never hit back. Not once. She slapped, kicked, and punched me, but I never retaliated. Because to me, if I did the same, what difference would there be between us? It would make me just like her. Of course, it affected me in many ways, but I just went through it as part of life's experience. The first three years were chaotic—when your home isn't a happy place, even sustenance feels harder to come by. But after those three years, Alhamdulillah, things started to change. Blessings came in.

For Mr. I, caring for his sister during her severe relapse felt like looking after a baby. He shared:

She wouldn't eat, wouldn't drink, and her personal care was completely unmanageable. In the early stages of her illness, she regressed into a childlike state, almost like a baby. Even my eldest child didn't behave the way she did. The way she spoke and her mannerisms were all like a child, despite her being an adult. As for her daily care, she was completely dependent. Bathing, anything at all. She just couldn't do it on her own. (The audio was unclear beyond this point.)

ii.Insufficient help from other family members.

According to Mr. K, none of his family members or colleagues knew about Mrs. R's illness or the challenges he faced during the first three years of their marriage. It wasn't until Mrs. R started sharing her experiences on Facebook that people became aware of her condition.

During her worst episodes, she never wrote about it on Facebook. So, no one knew—my siblings didn't know, and my colleagues didn't know. But three years later, when she entered the recovery phase, she started writing a lot. And as she shared more, more people found out—siblings, in-laws, and friends. Even some of my *office colleagues started asking about her. That's when they began to understand what I had been going through with my wife.*

As for my siblings, they knew… but they didn't really ask much. Maybe once or twice, my sister asked just the basics—'How's R? Is she okay? What illness does she have?'—and that was it. My family is big, but we're the kind who don't interfere in each other's matters (laughs). Everyone's married and has their own lives. If one of us has a problem, we all know about it, but we just let them handle it on their own.

For Mr. A, he faced significant criticism from his own family. They questioned his decision to marry someone with depression, especially since he himself had been diagnosed with Major Depressive Disorder (MDD). He recalled their concerns:

How are you going to take care of her? What if she relapses, and then you relapse—what happens then?"

He responded with conviction:

That's not something we can predict. When we get married, it's about making things right in the eyes of Allah. I love her, and she loves me too." (laughs) "We're trying to do things the right way. Marriage isn't something to be taken lightly. So, I just told them-it's okay."

Despite the skepticism from his own family, Mr. A was grateful for the unwavering support from Mrs. T's family. He shared:

T's family has been wonderful—so supportive. They're easy to talk to, always open to discussions. Alhamdulillah, everything went smoothly. It's just that… my own family and society around me, they've been a bit of a challenge.

iii.Addressing social stigma.

Mrs. N and her family also faced the challenges of stigma. She shared that her daughter, Ms. S, was mocked by the neighbor's children, who called her **"CRAZY"** in a taunting manner:

They would tease her, saying, 'Your sister is CRAZY!' They would say it in front of her siblings too. She hardly went out—only spoke to her brothers and sisters. Luckily, she didn't take it to heart. Her younger sibling stood up for her, saying, 'My sister is sick! Not that kind of sick!' Then one day at school, something happened—I'm not sure exactly what her friend did to her. But she told me that she ended up pushing that friend.

Mr. I had to face stigma even within his own family. He shared:

They still see mental illnesses like MDD as just a matter of emotions. To them, if you sleep a lot, it's not because of the illness-it's just laziness. That's how they think. And sometimes, it's really frustrating when I try to make them understand. There are days when I feel okay and days when I don't. But when I try to share information about MDD, they just brush it off, saying, 'That's your part, you're fine now. What about your brother?' They turn it back on me. So, that's been my experience-dealing with the misconceptions of those around me.

(d)Assistance obtained

According to these caregivers, the recovery of MDD survivors depends on several forms of support. These include self-help, support from family members, medication, and engaging in outdoor activities.

i.Self-Help

When the researcher asked about the most crucial factor in Mrs. R's recovery from MDD, Mr. K responded:

"It starts with oneself..."

ii.Support from other family members

For Mr. K, support from family members and a spouse plays a crucial role in recovery. He shared:

Then, there's the spouse-if the person is married. If not, then siblings and parents. The people closest to them need to understand what they need. I feel that all of these aspects are important, but above all, support is the key.

Similarly, Mr. I emphasized that the support his sister received was the most critical factor in her recovery. He explained:

The most important thing is the support of those around her-especially immediate family, like siblings, relatives, and close friends. Giving her encouragement, being there for her. And another thing-don't put too much pressure on her. Avoid sharing things that might make her overthink. If there's a problem, we discuss it among ourselves first. Only when we feel she's ready, then we share it with her.

iii.Medications

When it comes to treatment and medication, Mr. K shared his perspective:

I feel that medication comes third… Not to say that it's not important, but that's just how I see it.

Meanwhile, Mr. I emphasized the importance of taking medication on time, alongside family support. He simply stated:

Medication needs to be taken properly… that's it.

iv.Participating in outdoor activities.

Mr. K strongly encouraged Mrs. R to participate in outdoor activities, as he noticed that she seemed much happier when she was active outside. He explained:

One more thing-activities. It's important for the patient to stay engaged. Exercising, socializing, and doing daily routines. whether it's jogging, cycling, or meeting people. I noticed that when she started doing those things, she became happier. She felt relieved-she looked genuinely joyful. That's just who she is. She's not the type to stay indoors all the time. She thrives in outdoor activities-meeting people, and gardening. She loves anything that connects her to nature.

(e)Hope

Each caregiver holds their own hopes for their children, spouses, and siblings. Beyond that, they also have expectations for society and healthcare providers, especially in addressing the issue of social stigma.

i.Hope for survivors.

Mr. K hopes that his wife's medication dosage can be gradually reduced, eventually leading to a life free from medication. He shared:

I hope that by 2022, she won't need medication anymore. Right now, she's taking 100mg. Hopefully, by the end of 2021, she'll be down to half—just 50mg. And then, maybe by 2022, she'll be at 25mg or even completely off medication."

Beyond recovery, Mr. K also dreams of seeing Mrs. R become independent and pursue a career like others. His greatest wish is for her to have her own studio to run a **photography class** business. He expressed:

I want her to work full-time. Right now, she's only doing it part-time, taking photos from home, but that's not what I want for her. I want her to go full-time, maybe as a content creator. I want her to have her own office—not at home, but outside. Even if it's just a small space with one desk, it's enough. The important thing is that she gets out, goes to an office, and works full-time. That's my hope for her.

For Mr. I, his greatest hope is for his sibling to recover and regain a sense of normalcy in life. More than anything, he just wants them to be able to take care of themselves. He shared:

I just hope they recover and live their life as usual. If they can take care of themselves, that's already enough. Every illness has a chance to heal—except death. We can never fully understand what they're going through. The burden they carry is far heavier than what we see. All we can do is be there, offering moral support.

Similarly, Mrs. N deeply hopes for Miss S to fully recover one day. She worries about her future, particularly her ability to form relationships and integrate into society. She expressed:

I just want her to get better, like she used to be. I don't want her to suffer like this, it could affect her future. She finds it hard to make friends now, but one day, she'll go out into the world to study and work. She'll have to interact with many people. So, my biggest hope is for her to heal completely. We pray for her recovery, hoping she won't need any more treatment in the future.

ii.Hope for the family.

Since Mrs. R's depression is closely linked to her upbringing, where she lacked attention from her parents, **Mr. K** has made it his personal mission to raise his children in a more positive and nurturing environment. He shared:

R once told me that her depression and anxiety started from a young age, even before she pursued higher education. So, I don't want my kids to feel pressured because of school. I don't want them to take on heavy courses just for the sake of it. I want them to grow based on their own talents, not just follow the mold set by their parents. Back then, going to university was everything, but for my kids, I will support whatever they *choose to do as long as they have proper guidance and direction. Whatever they do, it should have purpose and take them far in life. I don't want to treat my children the way R's parents treated her. But of course, as a parent, there are times when I get tired and frustrated after work. It's unavoidable. Still, I try my best to control my emotions and meet my children's emotional needs. That's why every evening, from 6 to 7 p.m., I dedicate time just for them. I take them out to the lake, for cycling, or to the field. That one hour is fully for them. I believe it's really important.*

iii.The absence of societal stigma.

Mr. K hopes that society can reduce the stigma surrounding mental illness. He expressed:

I really hope society can get rid of this stigma. We need to work together to support mental health patients instead of holding negative perceptions about them. Give them the chance to heal. From what I've seen, when someone has to see a psychiatrist, they often feel unsafe, like people want to distance themselves from them. It shouldn't be that way.

According to Mr. K, the stigma surrounding mental illness persists due to a lack of information being shared in the media.

That's what I've been saying. We lack awareness and knowledge about mental health. First, many Malays don't like to read. Second, we have little exposure. Third, the radio is filled with random jokes and entertainment, but there's barely any useful information about mental illness. Schools and universities don't teach what mental illness really is. From kindergarten to primary school, high school, and even university, there's no proper education on mental health. I only truly learned about it after I got married, what it is, how to deal with it, and what causes it.

Mr. I strongly emphasizes the stigma surrounding mental illness in society. He believes that media platforms should play a greater role in educating the public about mental health conditions, treatment options, and ways to support those affected.

Social media needs to provide more exposure about this illness. How to treat it, how to handle it, everything. The media, including TV, must play a role in educating people on how to help, whether it's by bringing someone to the hospital or understanding the right treatments. Our society is still far behind. When they see something like this, they easily believe in superstitions. We live in a modern age, but our mindset is still stuck in the past. Some people may appear to have modern thinking, but in reality, many are two-faced. And this makes recovery even harder for mental health patients. This issue also ties into faith (Tauhid). When we talk about Tauhid, hypocrisy comes into the picture. That's why there are so many deceitful and insincere people. We don't want that. Maybe it's due to a lack of information or simply because they've never experienced these symptoms firsthand, nor has anyone in their family. There could be many reasons…

iv.The extensive distribution of knowledge regarding mental disease.

Mr. A hopes that the government will take a more active role in disseminating information about mental health to help reduce social stigma. According to him:

When it comes to public health awareness, the government tends to focus on visible illnesses like AIDS or other physical diseases. But mental health? The attention given to it is still lacking. In my opinion, if the government takes the lead in raising awareness, people will pay more attention. When NGOs do it, some might dismiss it as just another initiative with an agenda. Ideally, both the government and NGOs should work together and be proactive in this effort. Take cancer, for example. Awareness is widespread. You walk into *any hospital, and you'll see posters everywhere. But for mental health? If you visit a hospital, how often do you come across posters or information about mental illness? Hardly ever. But you'll see plenty about diabetes and other physical conditions. The irony is that hospitals are where most people seek medical help. Yet, to find proper information on mental health, you have to go specifically to a psychiatric clinic. This shouldn't be the case. We need to normalize discussions about mental health so that the stigma surrounding it gradually fades away.*

5. Discussion

The current study identified five key themes: sense of responsibility, acceptance of MDD, problems in the course of care, support acquired, and hope, as well as 17 subordinate topics highlighting caregivers lived experiences. Informal caregiving is often seen as a heavy burden, as it can negatively affect a caregiver's social life, emotional well-being, physical health, and financial stability[31]. In more severe cases, this strain may lead to a decline in mental health, an increased risk of illnesses such as high blood pressure and depression, and a weakened immune system[32]. Eifert et al. (2015) highlight a particularly concerning issue when caregivers experience extreme burnout, it can lead to higher mortality rates among them and even cases of abuse toward the ill family members due to the intense pressure they face[31]. When it comes to motivation, some people are more prone to experiencing mental exhaustion than others[33], despite the fact that motivation is crucial for caregivers to provide the greatest results[34].

However, the findings of this study indicate that the primary caregivers interviewed did not explicitly report signs of extreme stress or burnout. This contrasts with prior studies, which often highlight caregiver depression and burden[35-39]. Nonetheless, this should be interpreted with caution. Although the caregivers did not use terms such as “stress” or “burnout,” their narratives revealed considerable emotional hardship, including experiences of physical aggression from the care recipient, social stigma, and isolation. This suggests that while caregivers demonstrated resilience, they may have underreported their distress due to cultural values, personal beliefs, or a desire to protect the family image. These findings point to a complex interplay between resilience and unacknowledged stress. The presence of hardship does not negate resilience but rather reflects a nuanced coping mechanism shaped by familial duty, religious beliefs, and societal expectations. Integrating these findings with the Transactional Theory of Stress and Coping, caregivers in this study employed adaptive strategies such as meaning-making (e.g., religious faith), problem-solving (e.g., managing medications and appointments), and emotion-focused coping (e.g., acceptance and spiritual surrender). Coping refers to the ways individuals use their thoughts and actions to manage and reduce conflict, demands, and pressure[40]. Noremy et al. (2019) suggest that coping strategies are a form of resilience that can protect individuals from experiencing psychological distress [41]. Similarly, the CHIME recovery framework, which comprises Connectedness, Hope, Identity, Meaning, and Empowerment, aligns with the themes in this study particularly “Hope” and “Support.”

From this theoretical standpoint, resilience in managing stress and perceived challenges can be developed through various approaches, such as active collaboration and focusing on the positive aspects of caregiving[42]. In this study, caregivers' strong sense of responsibility is closely tied to key aspects of resilience. When assuming the caregiving role, they not only manage the emotions of the ill family member but also provide emotional support to other family members, especially those living in the same household. This pattern was consistently observed across nearly all families interviewed. For instance, during Mrs. R's relapse, Mr. K had to shield his children from potential harm while simultaneously restraining himself from responding with violence, even as he endured physical aggression from his wife. According to Bowen's Family Systems Theory, Mr. K's situation aligns with the concept of the *Nuclear Family Emotional System*. Due to what Bowen describes as one spouse's dysfunction, Mrs. R was unable to fulfill her role as a wife, prompting Mr. K to take on additional responsibilities, caring for their children and managing Mrs. R's condition. The family functions as an emotional unit, making Mr. K's role essential. He not only had to safeguard his wife's emotions but also ensure his children's emotional well-being remained intact.

Similarly, Mr. I experienced a comparable situation. He took on a significant role by dedicating his time and energy to visiting his younger sister in the hospital. Despite his exhaustion, he remained committed to his responsibilities, not just as an older brother, but also as a husband and father to his own children. Bowen articulated this through the notion of *sibling position*. Mr. I, as an older brother aware of his obligation to his younger sister, was willing to give up time, energy, and money to support her recovery. This integration underscores the importance of social and psychological resources in caregiving, and the need to address both visible resilience and invisible emotional burdens. Interestingly, the interviews revealed that none of these caregivers explicitly reported experiencing stress while caring for their children, wives, or siblings which contradicting with prior research that found high levels of stress and depression among caregivers[43-45]. Future studies should examine these tensions more deeply, particularly in collectivist cultures where caregiving norms are rooted in duty and silence about personal suffering.

Alsubaie et al. (2019) suggest that social support for individuals experiencing depression can significantly enhance mental well-being and act as a protective factor against life stressors[46]. This aligns with the adaptation process that caregivers must undergo, as highlighted by Palacio et al.: *"to care for someone requires adaptation efforts to the illness process."*[42] Caregivers often go through a phase of trial and error as they learn to meet the needs of their children, spouses, or siblings struggling with depression[47]. During this period, strong coping strategies are crucial in managing the pressures they face. As noted by Coloni-Terrapon et al. (2020), depression within a family does not solely impact the individual diagnosed but also affects all family members[48]. Their research further indicates that depression deeply influences various aspects of a caregiver's life, often compelling them to prioritize the needs of their loved ones over their own well-being. Courses created especially for casual caregivers are therefore essential. Additionally, they must attend courses that will help them perform their jobs more effectively and prevent caregivers from quitting classes because the knowledge they get will be useful in the field[49].

Strong family bonds between caregivers and survivors enable individuals recovering from mental illness to receive essential social support from their own family[50]. Caregivers serve as key figures in providing social, physical, and emotional support[42]. However, this support will have little impact on recovery if caregivers do not attempt to understand the condition of the person they are caring for and take appropriate action. This is because individuals diagnosed with Major Depressive Disorder (MDD) often exhibit distinct interpersonal behaviors, such as a lack of desire to communicate and difficulty understanding others' thoughts and emotions[51,52]. Therefore, any assistance should also include emotional and psychological components for helping survivors to cope and bounce back from their crisis situation[53].

All the survivors interviewed experienced similar challenges. According to Villanueva et al. (2020), face-to-face interactions between caregivers and individuals with depression are more effective than virtual communication, as emotions and information can be conveyed more clearly[52]. Caregivers, driven by a strong sense of responsibility, strive to provide the best care for their children, spouses, and siblings, particularly during severe relapse episodes. Despite facing difficult and unpredictable behaviors, these caregivers remain steadfast and never give up on their loved ones.

Caregivers of family members with mental health conditions face both objective and subjective challenges[35]. Objective challenges include disruptions to daily activities, social isolation, financial constraints, and employment difficulties. On the other hand, subjective challenges revolve around the emotional burden caregivers must endure. These include feelings of fear, sadness, anger, guilt, loss, stigma, and rejection.

Aligning with the findings of Azlinda, Jamir Singh, and Jamalludin (2019), caregivers in both studies reported encountering stigma from their own family members. Some caregivers interviewed by researchers experienced stigma from relatives upon discovering that their child, spouse, or sibling had a mental illness[35]. Stigma is characterized as a combination of stereotypes, prejudice, and discrimination[54]. According to Au et al. (2019), stereotypes involve negative perceptions about a specific group, prejudice refers to emotional reactions, and discrimination is reflected in behaviors influenced by these emotions[55].

There are two main types of stigmas: social stigma and self-stigma. Self-stigma occurs when individuals adopt society's negative views about themselves[56], often resulting in feelings of shame, secrecy, discrimination, and social isolation[57]. Stigma affecting both caregivers and individuals with mental illnesses can lead to decreased self-esteem, hinder goal attainment, limit social opportunities, and lower overall quality of life[58]. Additionally, self-stigma among caregivers is associated with burnout[59]. In more severe cases, prolonged exposure to stigma without appropriate intervention can contribute to depression and suicidal ideation among caregivers[59,60].

All informants in this study indicated that awareness and understanding of mental illness have improved since the COVID-19 pandemic. This shift is largely attributed to the rising number of mental health cases, which has prompted both the government and social media to actively promote awareness campaigns on the issue. The emphasis on mental health awareness is also reflected in the guidelines issued by the Ministry of Health Malaysia (MOH). These guidelines introduce the concept of *Mental Health and Psychosocial Support* (MHPSS), referring to any local or external support system designed to safeguard or enhance psychosocial well-being, as well as to prevent or treat mental health disorders. This support encompasses interventions across healthcare, education, and community sectors. MHPSS-related concerns cover a wide range of issues, including social difficulties, emotional distress, common mental disorders like depression and post-traumatic stress disorder, severe mental disorders such as psychosis, substance and alcohol dependency, and intellectual disabilities. The MHPSS framework is widely applied to various initiatives aimed at improving individual well-being, helping individuals manage pandemic-related anxieties, and providing appropriate mental health interventions.

6. Conclusion

To our knowledge, this is the first study in the Malaysian context that examines the lived experiences of MDD survivors through caregivers' perspectives, particularly during the COVID-19 pandemic. This study provides valuable insights into their recovery journey, demonstrating that despite the various factors contributing to their condition, the survivors were still able to overcome their illness. Although there is no universally agreed-upon definition of recovery, this study provides insights into how caregivers perceive and define the recovery of their family members. In this context, recovery is seen as a journey, a continuous process that survivors undergo to regain their well-being, despite the obstacles they encounter along the way. Findings from this study highlight the idea that small progress is still progress. This means that achieving holistic recovery begins with small steps and gradual improvements. This was evident among the caregivers interviewed in this study. The findings also debunk common myths surrounding mental illness, which have long persisted due to social stigma. Stigma remains a major barrier to the recovery of individuals with mental illness. Not only does it hinder the healing process, but it also destroys the hopes of both patients and their families. This research further reinforces the fact that mental illnesses, like physical illnesses, require support, assistance, and knowledge-sharing to facilitate recovery.

In light of these findings, it is crucial that mental health professionals and service providers recognize the pivotal role that primary caregivers play in the recovery journey of MDD survivors. Clinically, caregivers should be more actively included in treatment planning and psychoeducation initiatives to enhance their coping capacity and reduce emotional burden. In addition, policy-level interventions should focus on developing structured caregiver support systems such as respite services, targeted mental health resources, and financial assistance to sustain their well-being and caregiving capacity. These recommendations not only address the caregivers' needs but also contribute to a more holistic and sustainable recovery ecosystem for individuals living with MDD. The researchers are highly appreciative of the informants' willingness to share their experiences, as their insights are invaluable. These findings hold significant value for various stakeholders, particularly the Ministry of Health Malaysia (MOH) and NGOs involved in mental health services. It is hoped that the results of this study can serve as a guideline for improving existing services. Ultimately, the researchers aspire for these positive changes to contribute to a reduction in mental illness cases in the future.

Author contributions

Conceptualization, A.I.; methodology, A.I, N.M.A; validation, A.I; N.M.A, S.N; formal analysis, A.I.; investigation, A.I.; resources, A.I.; data curation, A.I, N.M.A, S.N; writing—original draft preparation, A.I.; writing—review and editing, A.I; N.M.A, M.S.N; visualization, A.I, N.M.A, S.N; supervision, N.M.A; project administration, A.I; funding acquisition, A.I, N.M.A.All authors have read and agreed to the published version of the manuscript.

Institutional review board statement

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Conflict of interest

The authors declare no conflict of interest.

References

1. Cham CQ, Ibrahim N, Kalaman CR, Ho MC, Visvalingam U, Ahmad Shahabuddin F, Abd Rahman FN, Halim MRTA, Harbajan Singh MK, Azhar FL, Yahya AN, Roslan S, Siau CS. Factors associated with depression, anxiety, and satisfaction with life among Malaysian parental caregivers of adolescent psychiatric patients: A cross-sectional study. Glob Ment Health (Camb) 2024. doi: 10.1017/gmh. 2024.5. PMID: 38390253; PMCID: PMC10882176.
2. Perlick DA, Berk L, Kaczynski R, Gonzalez J, Link B, Dixon L, Grier S, Miklowitz DJ. Caregiver burden as a predictor of depression among family and friends who provide care for persons with bipolar disorder. Bipolar Disord. 2016. 18(2):183-91. doi: 10.1111/bdi.12379.
3. Bains N, Abdijadid S. Major Depressive Disorder. In: StatPearls. Treasure Island (FL): StatPearls Publishing; 2023. Available from: https://www.ncbi.nlm.nih.gov/books/NBK559078/
4. WHO. Depressive Disorder (Depression). Geneva: World Health Organization, 2023.
5. Basha, E.A.; Mengistu, B.T.; Engidaw, N.A.; Wubetu, A.D.; Haile, A.B. Suicidal Ideation and Its Associated Factors Among Patients with Major Depressive Disorder at Amanuel Mental Specialized Hospital, Addis Ababa, Ethiopia. Neuropsychiatr. Dis.Treat 2021. 17: 1571–1577.
6. Almanzar, S.; Shah, N.; Vithalani, S.; Shah, S.; Squires, J.; Appasani, R.; Katz, C.L. Knowledge of and Attitudes toward Clinical Depression among Health Prov iders in Gujarat, India. Ann. Glob. Health 2014. 80: 89–95.

7. Evans-Lacko, S.; Aguilar-Gaxiola, S.; Al-Hamzawi, A.; Alonso, J.; Benjet, C.; Bruffaerts, R.; Chiu, W.T.; Florescu, S.; de Girolamo,G.; Gureje, O.; et al. Socio-economic variations in the mental health treatment gap for people with anxiety, mood, and substance use disorders: Results from the WHO World Mental Health (WMH) surveys. Psychol. Med. 2018. 48: 1560–1571. http://https://doi.org/10.1017/S0033291717003336.
8. Chan, S.L.; Hutagalung, F.D.; Lau, P.L. A Review of Depression and Its Research Studies in Malaysia. Int. J. Educ. Psychol. Couns 2017. 2: 40–55.
9. VanPraag, H.M. Can stress cause depression? World J. Biol. Psychiatry 2005. 6: 5–22.
10. Nur Saadah, M.A.; Noremy, M. Empowering Informal Caregivers and Care for Family. Int. J. Acad. Res. Bus. Soc. Sci. 2021. 11: 444–452.
11. Muhamad Hilmi, A. R., Azmah, O. & Yong Zulina, Z. Women and Poverty: A Qualitative Study on Selected Female-Headed Households in Kuala Lumpur and Selangor, Malaysia. Akademika 2024. 94(3): 335-350. https://doi.org/10.17576/akad-2024-9403-19.
12. Vojtila, L., Ashfaq, I., Ampofo, A., Dawson, D. & Selby, P. Engaging a person with lived experience of mental illness in a collaborative care model feasibility study. Research Involvement and Engagement 2021. 7(1): 1–8.
13. Kader Maideen, S.F.; Mohd Sidik, S.; Rampal, L.; Mukhtar, F. Prevalence, associated factors and predictors of dep ression among adults in the community of Selangor, Malaysia. PLoS ONE2014: 9, e95395. https://doi.org/10.1371/ journal.pone.0095395.
14. Kovacs, M.; Obrosky, S.; George, C. The course of major depressive disorder from childhood to young adulthood: Recovery and recurrence in a longitudinal observational study. J. Affect. Disord. 2016: 203, 374381.
15. https://doi.org/10.1016/j.jad.2016.05.042.
16. Idris, A.; Akhir, N.M.; Mohamad, M.S.; Sarnon, N. Exploring the Lived Experience on Recovery from Major Dep ressive Disorder (MDD) among Women Survivors and Five CHIME Concepts: A Qualitative Study. Behav.Sci202 3. 13: 151. https://doi.org/10.3390/bs13020151
17. Mohd Suhaimi, M & Nasrudin, S. Relationship between Psychological Stress and Mental Health among Young Lecturers. Akademika 2023. 93(3): 213-224. https://doi.org/10.17576/akad-2023-9303-16.
18. Oikonomou, V.; Gkintoni, E.; Halkiopoulos, C.; Karademas, E.C. Quality of Life and Incidence of Clinical Signs and Symptoms among Caregivers of Persons with Mental Disorders: A Cross-Sectional Study. Healthcare; 2024: 12, 269. https:// doi.org/10.3390/healthcare12020269
19. Starr LT, Bullock K, Washington K, Aryal S, Parker Oliver D, Demiris G. Anxiety, Depression, Quality of Life, Caregiver Burden, and Perceptions of Caregiver-Centered Communication among Black and White Hospice Family Caregivers. J Palliat Med 2022. doi: 10.1089/jpm.2021.0302.
20. Cui, P., Yang, M., Hu, H. et al. The impact of caregiver burden on quality of life in family caregivers of patients with advanced cancer: a moderated mediation analysis of the role of psychological distress and family resilience. BMC Public Health 2024. https://doi.org/10.1186/s12889-024-18321-3
21. Lespine LF, Bohec AL, Dorey JM, Berbey CD, Lourioux C, D'amato T, Krebs MO, Rouch I, Rey R. Caregiving-related experiences associated with depression severity and its symptomatology among caregivers of individuals with a severe mental disorder: an online cross-sectional study. Eur Arch Psychiatry Clin Neurosci. 2023. 273(4): 887-900. doi: 10.1007/s00406-022-01451-3.
22. Zhang, Y. & Ma, Z.F. Impact of the COVID-19 pandemic on mental health and quality of life among local residents in Liaoning Province, China: A cross- sectional study. International Journal of Environmental Research and Public Health 2020. 17(7): 2381.
23. Taggart, F., Stewart-Brown, S. & Parkinson, J. Warwick-Edinburgh Mental Well-being Scale (WEMWBS) Users guide- version 2. Edinburgh: NHS Health Scotland. 2015.
24. Haikal Anuar, A., Zarinah, A., Rumaya, J., & Nurul Saidatus, S.A.S. Mental Wellbeing of Drug Addicts' Wives: Roles of Economic Strain, Marital Conflict, and Social Support. Akademika 2025. 95(1): 160-183. https://doi.org/10.17576/akad-2025-9501-10.
25. Lee Y, Lin PY, Huang YC, Chiu NM, Hung CF, Wang LJ. The Morbidity and Associated Factors of Depression in Caregivers of Patients with Depressive Disorder. Neuropsychiatr Dis Treat. 2023. 19: 1853-1864. doi: 10.2147/NDT.S415881.
26. Monahan Z, Shores D, Mack A, Bray N, Ford A, Hartwell M. 2023. Prevalence of depression among caregivers based on the condition and relationship of care recipient. J Affect Disord. 2023. 340: 442-447. doi: 10.1016/j.jad.2023.08.054.
27. Hu, Y., Cheng, C., Chee, W., Im, E.O. Issues in internet-based support for Chinese-American Breast Cancer Survivors. Informatics for Health and Social Care, 2020. 45(2): 204-216, https://doi.org/10.1080/17538157.2019.1624967
28. Yee, C.C., Mahadevan, R., Chong, G.N., Lai, F.C., Farahidah Md Dai. Caregiver Depression: The Contributing Role of Depression in Patients, Stigma, Social Support and Religiosity. International Journal of Social Psychiatry 2018. 64(6): 578-588. https://doi.org/10.1177/0020764018792585

29. Guan Z, Poon AWC, Zwi A. Social isolation and loneliness in family caregivers of people with severe mental illness: A scoping review. Am J Community Psychol. Dec 2023. 72(3-4): 443-463. doi: 10.1002/ajcp.12698.
30. Minaei-Moghadam, S., Manzari, Z., Vaghee, S. Effectiveness of a supportive care program via a smartphone application on the quality of life and care burden among family caregivers of patients with major depressive disorder: a randomized controlled trial. BMC Public Health 2024. 24: 66. https://doi.org/10.1186/s12889-023-17594-4
31. Clarke, V., & Braun, V. Thematic analysis. The Journal of Positive Psychology, 2016. 12(3): 297–298. https://doi.org/10.1080/17439760.2016.1262613
32. Eifert, E.K., Adams, R., Dudley, W. & Perko, M. Family caregiver identity: A literature review. American Journal of Health Education 2015. 46(6): 357–367.
33. Farran,J , oukissa, D., Perraud, S. & Paun, O. Alzheimer's disease caregiving information and skills. Part II: family caregiver issues and concerns. Research in Nursing & Health 2004. 27(1): 40–51.
34. Shamala, R., Cheryl, T.M.N., & Mohammed Irfan A. M. S. Workload, Achievement Motivation, and Mental Fatigue: A Mediation Study Among White-Collar Workers. Akademika 2023. 93(1): 41-50. https://doi.org/10.17576/akad-2023-9301-04.
35. Zarzycki, M., & Morrison, V. Getting back or giving back: understanding caregiver motivations and willingness to provide informal care. Health Psychology and Behavioral Medicine 2021.Vol. 9 (1): 636–661. https://doi.org/10.1080/21642850.2021.1951737.
36. Azlinda Azman, Jamir Singh, P.S. & Jamalludin Sulaiman. The mentally ill and their impact on family caregivers: A qualitative case study. International Social Work 2019. 62(1): 461–471.
37. Chai, Y.C., Mahadevan, R., Ng, C.G., Chan, L.F. & Farahidah Md Dai. Caregiver depression: The contributing role of depression in patients, stigma, social support and religiosity. International Journal of Social Psychiatry 2018. 64(6): 578–588.
38. Jeyagurunathan, A., Sagayadevan, V., Abdin, E., Zhang, Y., Chang, S., Shafie, S., Restria Fauziana Abdul Rahman, Vaingankar, J.A., Chong, S.A. & Subramaniam, M. Psychological status and quality of life among primary caregivers of individuals with mental illness: A hospital-based study. Health and Quality of Life Outcomes 2017. 15: 1–14.
39. Kim, D. Relationships between caregiving stress, depression, and self-esteem in family caregivers of adults with a disability. Occupational Therapy International: 2017. 1686143.
40. Miller, V.J., Killian, M.O. & Fields, N. Caregiver identity theory and predictors of burden and depression: Findings from the REACH II study. Aging & Mental Health 2020. 24(2): 212–220.
41. Krohne, H.W. 2001. Stress and coping theories. Dlm. Smelser, N.J. & Baltes, P.B. (pnyt.). International Encyclopedia of the Social & Behavioral Sciences. Oxford: Elsevier. 2001: 15163–15170.
42. Noremy, M. A,Mohammad Rahim, K., Aizan, S. A., Rusyada, H. M., Nur Hafizah, M. A. Exploring the coping strategies that improve resiliency among floods victims in Kelantan Malaysia. International Journal of Recent Technology 2019. 8, 2S10: 67-73.
43. Palacio, G.C., Krikorian, A., Gómez-Romero, M.J. & Limonero, J.T. Resilience in caregivers: A systematic review. American Journal of Hospice and Palliative Medicine® 2020. 37(8): 648–658.
44. Derajew, H., Tolessa, D., Feyissa, G.T., Addisu, F. & Soboka, M. Prevalence of depression and its associated factors among primary caregivers of patients with severe mental illness in southwest, Ethiopia. BMC Psychiatry 2017. 17(1): 1–8.
45. Ehsan, N., Johar, N., Saleem, T., Khan, M.A. & Ghauri, S. Negative repercussions of caregiving burden: Poor psychological well-being and depression. Pakistan Journal of Medical Sciences 2018. 34(6): 1452.
46. Siddiqui, S. & Khalid, J. Determining the caregivers' burden in caregivers of patients with mental illness. Pakistan Journal of Medical Sciences 2019. 35(5): 1329.
47. Alsubaie, M.M., Stain, H.J., Webster, L.A.D. & Wadman, R. The role of sources of social support on depression and quality of life for university students. International Journal of Adolescence and Youth 2019. 24(4): 484–496.
48. Priestley, J., McPherson, S. & Davies, F. Couples' disease: The experience of living with a partner with chronic depression. Journal of Couple & Relationship Therapy 2018. 17(2): 128–145.
49. Coloni-Terrapon, C., Favrod, J., Clément-Perritaz, A., Gothuey, I., Rexhaj., S. Optimism and the psychological recovery process among informal caregivers of inpatients suffering from depressive disorder: A descriptive exploratory study. Frontiers in Psychiatry 2020. 10: 972.
50. Siti Zulaikha, A., Khadijah, A., & Surendran, R. Exploring the Challenges among Formal Elderly Care in Home Help Services. Akademika 2025. 95(1): 74- 91. https://doi.org/10.17576/akad-2025-9501-05
51. Jennings, E.A., Ralston, M. & Schatz, E. Support in times of need: How depressive symptoms can impact receipt of social support among aging adults in rural South Africa. SSM - Population Health 2020. 12: 100666.
52. Kupferberg, A., Bicks, L. & Hasler, G. Social functioning in major depressive disorder. Neuroscience & Biobehavioral Reviews 2016. 69: 313–332.

53. Villanueva, J., Meyer, A.H., Miché, M., Wersebe, H., Mikoteit, T., Hoyer, J., Imboden, C., Bader, K., Hatzinger, M., Lieb, R. & Gloster, A.T. Social interaction in major depressive disorder, social phobia, and controls: The importance of affect. Journal of Technology in Behavioral Science 5, 2020: 139–148.
54. Noremy, M. A, Azlinda, A. & Taufik, M. Flood disaster in Malaysia: Psychosocial issues and social work intervention. Transforming Society: Strategies for Social Development from Singapore, Asia and Around the World. 2017. Routledge: New York USA.
55. Corrigan, P.W. & Watson, A.C. Understanding the impact of stigma on people with mental illness. World Psychiatry 2002. 1(1): 16–20.
56. Au, C.H., Wong, C.S.M., Law, C.W., Wong, M.C. & Chung, K.F. Self-stigma, stigma coping and functioning in remitted bipolar disorder. General Hospital Psychiatry 2019. 57: 7–12.
57. Tzouvara, V., Papadopoulos, C. & Randhawa, G. Self-stigma experiences among older adults with mental health problems residing in long-term care facilities: A qualitative study. Issues in Mental Health Nursing 2018. 39(5): 403–410.
58. Goffman, E. Stigma - Notes on The Management of Spoiled Identity. Touchstone: Pelican, Penguin Books. 1963.
59. Yıldız, M., İncedere, A., Kiras, F., Abut, F.B., Kırcalı, A. & İpçi, K. Development of Self-Stigma Inventory for Families of the patients with schizophrenia (SSI-F): Validity and reliability study. Psychiatry and Clinical Psychopharmacology 2019. 29(4): 463–471.
60. Trigueros, R., Navarro, N., Cangas, A.J., Mercader, I., Aguilar-Parra, J.M., González-Santos, J., González-Bernal, J.J. & Soto-Cámara, R. The protective role of emotional intelligence in self-stigma and emotional exhaustion of family members of people with mental disorders. Sustainability 2020. 12(12): 4862.
61. Gumus, F., Dikec, G. & Ergun, G. Relations among internalized stigmatization, depressive symptom frequency and family loading in first-degree caregivers of the patients treated in the psychiatry clinic of a state hospital. Archives of Psychiatric Nursing 2017. 31(5): 522–527.