



The impacts of COVID-19 pandemic and lockdown on caregivers of family members with mental health issues: The untold story

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Abstract

COVID-19 was officially declared as a global pandemic in March 2020, confirming the disease's threat to human health and well-being. Since then, the world is dealing not only with the infections, but also with the negative effects on mental health. Countries have closed their borders in the war against the pandemic, travel between and within the country has been restricted, and life has come to a halt in many parts of the world. The government-imposed limitations in all pandemic-affected nations, including Malaysia, have had an indirect and harmful impact towards the caregivers of family members with depression. This has been the subject of several studies by the researchers. However, there was paucity of information regarding this issue in the Malaysian context. Hence, this article aims to explore the challenges faced by the caregivers before the pandemic, psychological impacts of COVID-19 towards the community and caregivers of family members with mental health issues, as well as the needs to help the latter during the pandemic. To the researcher's knowledge, no such study has been performed in the Malaysian context. Thus, more research on this topic is required in the future. This kind of research gives light to the untold story from the caregiver's point of view. Recommendations for future research and implications for social work practice are discussed.

Keywords: caregiver, COVID-19, family members, issues, mental health, pandemic.

Introduction

The first COVID-19 cases were detected in Wuhan, Hubei Province, China, in December 2019. Since then, it has spread swiftly over the world. Within a short time, it has become a global emergency for public health. There were 264 million confirmed cases as of December 1, 2021, with more than 5 million deaths recorded globally. In order to stop the transmission of COVID-19, health officials around the world, including the World Health Organization (WHO) and the Center for Disease Control (CDC), have urged self-quarantine, isolation, and physical separation

for everyone. The Malaysian government has taken the same initiative too. Following a surge in COVID-19 instances, Malaysians were told to stay at home, practice social distancing, and limit interaction with non-household members starting on March 18, 2020, when the statewide lockdown, known as the Movement Control Order (MCO) was implemented. The MCO has included six orders: i) complete prohibition of mass movements and gatherings, including religious, sports, social, and cultural activities; ii) complete restrictions on all Malaysians travelling abroad; iii) complete restrictions on the entry of all foreign tourists and visitors into the country; iv) complete closure of all public and private childcare, kindergarten, primary and secondary schools, and pre-university institutions; v) The closure of all public and private higher education institutions and skills training institutes across the country; and vi) The closure of all government and private buildings except those involved in essential services.

Quarantines are undoubtedly essential, but it has been indirectly affecting the mental health of people, especially those who suffer from depression or other types of psychiatric problems. Systematic review done by Vindegaard et al. (2020) found that, patients with pre-existing psychiatric problems claimed that their symptoms had gotten worse during the pandemic. According to Yee et al. (2021), people quarantined during the previous epidemic of influenza, severe acute respiratory syndrome (SARS), middle east respiratory syndrome (MERS), and Ebola epidemics was found suffered with depression, anxiety, and post-traumatic stress disorder. With the newly detected variant named Omicron, the world seems to have to live with the virus for years ahead. According to Brooks et al. (2020), affected people may suffer negative emotions such as boredom and loneliness due to the brief lockdown and self-quarantine. This occurrence demonstrates that the global population has to contend with both the infections and emotional consequences.

Mental illness patients sometimes unable to take control of their lives and in need of major assistance to perform their daily activities. Hence, they are depending on the caregivers. Caregivers are the backbone for the mental illness patients. However, they have been unnoticed. Just like the mentally ill patients, they too need strong social support to be able to maintain their well-being and good mental health. Mental health is not just about mental illness. It also encompasses the life satisfaction, contentment, ability to confront challenges as well as having a positive attitude (Mohd Suhaimi & Rozita, 2018). Because of the lockdown, the caregivers might not get help from others in taking care of their family members with mental health issues. Consequently, it can affect the treatment that they are giving (Afifah et al., 2021). Burdens among caregivers are not a new issue. These topics have long been discussed. Referring to Zarit et al. (1980), the burden of caregiving is the amount to which caregivers view their mental or physical health, social life, and financial position to be negatively impacted as a result of caring for their relatives. Therefore, this issue needs focus because those who have more social support are less likely to experience depressive episodes (Cabral et al., 2014), preventing them from sinking into depression (Rohany et al., 2015). Thus, this article will focus on the impacts and the needs to help the caregivers of family members with mental health issues during the COVID-19 pandemic.

Methodology

In order to fulfill the purpose of the study, which was to explore the impacts of COVID-19 pandemic and lockdown on the caregivers of family members with mental health issues, the methodology of this concept paper was based on library research. The selection of appropriate

secondary materials was highly emphasized to obtain articles and online reference materials that met the needs of the study. Through this method, every material such as journal articles, books, proceedings and official reports related to the study were collected to increase knowledge and improve understanding of the issues studied. Resources obtained via this method were critical to support the already available data. Once these secondary data were obtained, the study continued by classifying the themes by using content analysis technique. As a result of the content analysis conducted, there were two main themes discussed, namely the impact of COVID-19 pandemic and lockdown towards the worldwide community, from which two sub-themes emerged, namely the suicide cases related to the pandemic and the psychological issues related to the pandemic in Malaysian context. Another main theme was the impact of caring on the caregiver's mental health. This theme had two sub-themes: the psychological impacts towards caregivers during COVID-19 pandemic, and the needs to help caregivers of family members with mental health issues during COVID-19 pandemic.

Results and discussions

The Impact of Covid-19 Pandemic and Lockdown Towards the Community Worldwide

In this part, the focus of discussion will be on the issues of suicide cases associated with COVID-19 pandemic among the community worldwide and the psychological issues related to the pandemic in the Malaysian context.

Suicide Cases Associated with COVID-19 Pandemic

Suicide is the world's leading cause of death. Suicide has been a serious public health concern even before the appearance of the new coronavirus pandemic (Corpuz, 2021). Since the emergence of COVID-19 pandemic, the suicidal cases have arisen globally. Suicide attempts are a severe and potentially preventable health issue (Carlin et al., 2021). On the one hand, attempting suicide could be a cry for help; a deliberate or unconscious attempt to get others to notice how horrible the person is feeling. Contemplating suicide, on the other hand, may be the result of a strong desire to die (Carlin et al., 2021). Ali and Khan (2021) reported that the first COVID-19-related suicide incidents were reported in India and Bangladesh in March and April 2020, when two men who were afraid for their life committed suicide. According to this study, the social isolation and quarantine measures put in place to stop the disease from spreading have resulted in a rise in loneliness, worry, stress, and depression among the public. A study examining the rates of positive suicide-risk screens in a Pediatric Emergency Department, Houston found that in comparison to the 2019 statistics, the rates of suicide ideation and suicide attempts were higher among the youths during the COVID-19 pandemic (Hill et al., 2020). The importance of social interactions and social support in avoiding suicide cannot be overstated. When suicide attempts or completed suicides are investigated, it was often discovered that the people's social relationships had deteriorated recently (Hocaoglu, 2021). The current COVID-19 pandemic is anticipated to significantly impact mental health. According to Kahil et al. (2021), an increase in anxiety and depression symptoms is expected not only during the pandemic, but also in the months and years ahead. Thus, sufficient understanding by the caregivers on how to help them can assist them with recovery (Mohd Suhaimi et al., 2016). Hence, the caregiver's mental health needs to be monitored to prevent any future

social problems that involve them.

Mental health awareness is very important in times of uncertainty (Kumar & Raj, 2021). During the pre-pandemic days, seeking help from mental health professionals has been proven to be extremely beneficial (Kumar & Raj, 2021). However, because of the pandemic, it is difficult for them to seek for professional help when needed. Not only the caregivers are prone to indulge in suicidal thoughts due to the stresses during lockdown and lack of social support, but also their emotional well-being also deteriorates when their family members with mental health issues attempt suicide. How do they live in the coming days? How do they continue with their life despite the psychological impacts due to the suicidal attempts by their loved ones?

Psychological issues related to pandemic in Malaysian context

In more than a year since the COVID-19 case was first discovered in Malaysia, the rise of social cases related to depression and other types of mental illness could be observed. Many people lost their job. On June 22nd 2021, a team of firefighters had to save a woman and her two children who were locked up by her husband. He was believed to be suffering from emotional stress and depression because he had no job during the lockdown. As a result, he confined his family in his house, and unfortunately lost the key. Fortunately, the firefighter came in the nick of time to rescue them. Other cases included a senior citizen who had been depressed since he was tested positive for COVID-19 twice and was found dead on suspicion of suicide at his home. According to his wife, the man had paid high costs for COVID-19 treatment in private hospitals, and often complained that it was better for him to die rather than to bear the pain. The 66-year-old victim was found covered in blood with bruises on his neck. These two cases were among the many numbers of social cases happened within the community because of the pandemic and lockdown. Referring to the annual statistics, cases involving suicide attempts or victims who have died recorded an increase of 20% in 2020 compared to 2019. According to Malaysian Fire and Rescue Operations Division Director, there were 188 recorded cases attended by the firefighters in 2019 while in the year of 2020, there were 226 cases recorded as of 30th November.

People have been trying to cope with the lockdown for more than a year now. According to the clinical psychologist, Shazeema Mashood Shah in *themalaysianreserve.com*, some people might know that they could well get out of the lockdown because they had gone through it before, but for others, the first lockdown was probably the worst moment of their lives, and they might not want to go through it again. Everyone may suffer from emotional consequences, be they normal people, mental illness patients, and the caregiver of family members with mental health issues. Many studies have been done on the effects of the pandemic toward mental illness patient. However, there is a lack of information on the emotional effects among caregivers. They too suffer the emotional consequences of the lack of social support from other family members. According to Yee Chin et al. (2018), because mental health treatments are primarily focused on the patient's disease progression, caregivers are frequently disregarded as they cope with a range of changes in their home environment, job, recreation, income, and relationship with the patient. Many doctors and health care personnel, particularly psychiatric nurses, tend to focus their attention on the patient while neglecting the patient's family and primary caregivers (Akbari et al., 2018). Mental illness does not happen in one night. With the never-ending issue of stigma, it was discovered that stigma might lower caregiver's morale and cause them to retreat from prospective supports (Wintersteen et al., 1995). Thus, it is vital to pay attention to the mental health of caregivers as they are also at risks of acquiring depression (Afifah & Noremy, 2021). Caregivers can be deemed

as hidden patients if they are left without enough social support (Hudson et al., 2013).
The Impact of caring on caregiver's mental health

This part will discuss on the psychological impact towards caregivers and the need to help the caregivers of family members with mental health issues during COVID-19 pandemic.

Challenges for caregivers before the emergence of COVID-19 Pandemic

Caring for mentally ill family members poses significant challenges to caregivers, even before the pandemic happened. According to Choo et al. (2003), the caregiver's role is frequently associated to psychological and physical morbidity, such as higher-than-usual psychotropic drug usage, alcohol, cigarettes, and mood-altering medicines, poor self-rated health, a weakened immune system, and an increased risk of cardiovascular disease and depression. Compared to non-caregivers, caregivers themselves report experiencing higher stress, psychological issues, physical health issues, social isolation, and family conflicts. Not only that, caregivers were also reported feeling stigmatized as a result of their involvement with the mentally ill family members (Iseselo et al., 2016). Burden among caregivers were found to be different among ethnics. Research conducted in 2003 by Choo et al. found that, Chinese and Indian caregivers were found to be more highly burdened than the Malays. This is because, despite being overburdened, Malay caregivers do not grumble about their condition and are generally able to accept the negative symptoms of their schizophrenic family members (Salleh, 1994). On the other hand, a study by Stueve et al. (1997) found that, Black caregivers of family members with mental illness felt less burdened in their caregiving role compared to White caregivers. To date, no study can provide an explanation on how ethnicity can exert its impact on burden among caregivers. However, the challenges among them were profound.

The Malaysian government has been aiming to move the responsibilities of caring for individuals with mental illnesses from hospitals to the community since the 1960s (Abdullah et al., 2013). Since then, as stipulated in the Mental Health Act 2001, Malaysian government policy has encouraged families to care for their mentally ill family members at home after they have been discharged from hospital. According to Azlinda et al. (2019), burden in caring for mentally ill family members can be either objective or subjective. Objective burden is a disturbance of the caregiver's everyday routines, social isolation, financial and employment issues. Subjective loads, on the other hand, include emotional pressure on family caregivers including dread, grief, anger, guilt, loss, stigma, and rejection (Swaroop et al., 2013). According to Zahiruddin & Salleh (2005), Malaysian caregivers face a wide range of burdens, with 40% of caregivers feeling severe subjective burden and 35.6% facing objective burden. Four major challenges found in a research done in Kedah, Malaysia were in terms of financial impact, social impact, psychological impact and physical health impact (Azlinda et al., 2019). Lack of knowledge and willingness in taking care of their mentally ill family members were also part of the challenges for the caregivers (Abdullah et al., 2013). Hence, it gives impact towards the caregiving role.

In order to cope with the challenges, caregivers need to have a good coping skill. Study by Azlinda et al. (2016) found five coping strategies that mostly used by the caregivers. The five strategies were religious coping, emotional coping, acceptance, engaging in leisure activities and traditional healing. Based on the study, caregivers had been getting help from others for their emotional support. Some of the informants formed support groups to share their issues and feelings with other caregivers. Not only that, some of the caregivers indicated that engaging in leisure

activities such as exercising, taking a vacation, and watching television helped them not to focus about their difficulties as much and allowed them to relax (Azlinda et al., 2016). 87% of the participants in this study gotten emotional support from their immediate family members, friends, neighbours, and other caregivers as their ways of coping with the current situation. But not all caregivers have a good coping strategy. Hence, as a result of a lack of coping skills and awareness, some Malaysian families prefer their mentally ill family members to be hospitalised (Deva, 2004). This situation shows that, caring for mentally ill patients can be very difficult, and the caregivers typically employ a variety of tools and coping mechanisms to keep the entire family running smoothly.

Psychological impacts toward caregivers during COVID-19 pandemic

According to a longitudinal study by Kuan-Yu Pan et al. (2021), during the COVID-19 pandemic, there was a larger increase of symptoms in those without depressive, anxiety, or obsessive-compulsive disorders compared to those with existing mental health issues. The lockdown might cause the caregivers to be caring their family members who have mental illness without the help from the other family members. In other words, they do not have enough social support. In a study by Bergmann and Wagner (2021), the longer the caregiving time provided to their sick family members, the higher their risks are to endure the mental health pressures such as feeling sad, depressed, and anxious or nervous. The study also demonstrated the magnitude of the cost borne by the caregivers as a result of unintended consequences of COVID-19 related epidemiological control measures (Bergmann & Wagner, 2021).

The lockdown had indirectly and negatively impacted individuals and communities due to isolation, stigma, employment uncertainty, or a lack of medical supplies (Simon et al., 2021). According to Simon et al. (2021), these consequences cause a wide range of emotional reactions, and they are especially common among those who contract the disease or are at an elevated risk due to their age or pre-existing medical condition. The caregivers might experience the same situation. Caregivers come from different backgrounds: they may be the senior citizens who have to care for their sick children, or single parent, sister, brother, or anyone else who may need extra help from others, especially if they have their own medical circumstances. It becomes worse if the caregivers and their sick family members need to self-quarantine. In a rapid review study done by Brook et al. (2020), those who just ended their self-quarantine due to the exposure to the SARS outbreak in 2003 showed signs of acute stress disorder soon after the quarantine period of 9 days ended (YaMei Bai et al., 2004). The rapid review also found that the longer the quarantine period, the more it affected the mental health, post-traumatic stress symptoms, avoidance behavior and anger (Brook et al., 2020).

Some of the caregivers might also have to face the financial burden, as well as work and social functioning impairments. These situations are closely linked to increased sadness and anxiety symptoms, as well as lower psychological well-being. These are the significant predictors of poor mental health (Dawel et al., 2020). Referring to Dawel et al. (2020), essential public health measures around the pandemic have substantial consequences for community mental health since they face disruptions in social and workplace functioning. According to Coloni-Terrapon (2020), caregivers are socially isolated and lacking social support from other family members as well as healthcare providers. During the pre-pandemic days, taking care of family members suffering from depression or other types of mental illness can cause psychological distress (Coloni-Terrapon et al., 2020; Yee Chin et al., 2018; Jeyagurunathan et al., 2017; Derajew et al., 2017; Cabral et al.,

2014). The situation got worse when the COVID-19 pandemic began. The caregiver's depression is linked to the longer hours they are required to spend caring for their sick family members (Afifah & Noremy, 2021). This is because, mental illness patients infected with COVID-19 show a lower level of happiness and a slower psychological recovery (Caqueo-Urizar et al., 2021). Thus, it increases the caregiver's burden.

Derajew et al. (2017) discovered a high frequency of depression among caregivers, specifically when caring for patients for more than six hours per day and for those who have attempted suicide. Other factors that contributed to the caregivers' sadness included the patient's current depressive episodes, severity of the patient's symptoms, caregiver's perceptions of social support, and caregiver's self-stigma (Yee Chin et al., 2018). Referring to the 2019 National Health and Morbidity Survey (NHMS), about 500 thousand Malaysians suffered from depression symptoms. The rate of depression is expected to rise as a result of the ongoing pandemic. This is where the issue begins. Caregivers require social assistance in order to care for their loved ones. Caregiving-related strain is intensified by a perceived lack of social support, impacting the caregiver's resilience (Mulud & McCarthy, 2017). Caregivers are at risks of getting depression as the restrictions are likely to be extended and as anxiety and depression have been shown to be strongly linked to caregiving (Park 2021; Adelman et al., 2014).

The need to help caregivers of family members with mental health issues during pandemic COVID-19

In their daily lives, the primary caregivers of people with depression confront a variety of challenges. Prior to the COVID-19 pandemic, a study indicated that caregivers might endure difficulties and stressors because of insufficient support or coping methods, which could damage their life quality and biopsychosocial credibility. Hence, it influenced the therapy they provided (Sharif et al., 2020). Caregivers are also part of the vulnerable group that needs attention from the public health sectors. With the current situation, many countries have specific teams that provide mental health support and psychiatric liaison services to health-care workers (Moreno et al., 2020). It is no doubt that this group is also prone to suffer psychological distress due to their workload during the pandemic. However, we must acknowledge the needs of caregivers to gain mental health support as well. This is because, the recovery and well-being of people with mental illness are inextricably linked to the well-being of the caregivers (Azlinda et al., 2019). Referring to the UNICEF's *Caring for Caregivers during the Covid-19 Crisis*, ways to help the caregivers are to:

- Pay attention to the emotional needs of caregiver;
- Support the caregiver's ability to manage with emotion and stress;
- Enlist aid from partners and family to resolve conflicts/disagreements; and
- Resolve barriers to accessing resources and services in the community

According to Moreno et al. (2020), patients who experience acute stress, and who are distrustful of and avoiding the mainstream health services critically require help to diverse and flexible access to mental health care. With the frequent discussion on social media regarding the status of the pandemic, people find themselves unable to cope and emotionally tired (Roy et al., 2020). Study by Schafer et al. (2020) found that women were more prone to be stressed compared to men. The possible factors that contributed to this finding might be due to the feeling of anxiety

during the lockdown because they were overburdened with childcare responsibilities. According to Noremy, Azlinda & Adi Fahrudin (2021), previous studies have found that men and women have different types of coping mechanism when dealing with crisis whereby man are more likely to use a problem-focused coping mechanism that leads to solving the problem by changing the source of stress. Women, on the other hand, are more likely to use an emotionally focused coping mechanism that tends to manage emotional stress instead of dealing with problems. Thus, what about women caregivers whose caring their mentally ill family members? As caregivers have to spend more than six hours per day to take care of their sick family members (Derajew et al., 2017), their sleep quality might reduce too. Worst, some of the caregivers might have other types of somatic symptoms that increase their mood disorder (Park, 2021) or the stress level (Shah et al., 2020).

More attention has been given to the mental health of the impacted patients due to the COVID-19 pandemic. During the pandemic, new stressors are created while old ones are amplified: abrupt and extreme changes in lifestyle, worry and anxiety for loved ones or oneself, and limitations on social activities and physical movement due to quarantine (Son et al., 2020). Sharif et al. (2020) found five themes when conducting a study on the experience of family caregivers of people with mental disorders in Saudi Arabia. The five main themes were messages to others, caregiver perception of public awareness, coping and support mechanism, challenges encountered, and type of care provided. According to this study, the caregivers were psychologically distress, and mental diseases such as depression were common among them. The same result was found by Bergmann and Wagner (2021). Their study found that 30% of caregivers said they felt depressed and nearly 40% said they were anxious during the pandemic. Family caregivers emphasized on their recognition to be involved in policy, and on the necessity for better navigation and communication (Parmar et al., 2021). Parmar et al. (2021) also found few problems related to caregiving: the need to allocate more resources to the continuous care system, develop a timelier pandemic plan, and minimize silos in healthcare. Therefore, caregivers should be designated as a vulnerable group since they are forced to provide continuous treatments, affecting their physical and emotional well-being and adding to their stress load (Gallagher & Wetherell, 2020).

Conclusion

In view of the mounting concerns about the COVID-19's influence on the mental health of vulnerable groups, there is an urgent need for research to address the mental health burden on the caregivers of family members with mental health issues during the pandemic. Caregivers, as well as their care recipients have been hit hard by the pandemic. Caregivers are the backbone for the mental illness patients and yet, they have been overlooked. Health-care systems should prepare for a rise in unrealized mental health support among these susceptible populations and encourage adjustments that close gaps in care. With the aim to lessen the psychological discomfort among caregivers, it is critical to plan for psychosocial interventions that cover lifestyle intervention. These actions will not only assist their sick family members to recover faster, but also help caregivers to retain their well-being. Achieving this involves the role of social workers. In special cases, social workers should visit their clients who have a history of mental illness to ensure their well-being. By doing the home visits, social workers may identify the current emotional states that the caregivers and patients are going through, as well as helping them with the necessities. Social work will focus on giving psychosocial support, and empowerment and resilience practices among

caregivers and family by promoting the use of internal and external resources in the community. They also aim to help people cope with the latter's own potentially upsetting individual experiences. Based on the social work perspective, psychosocial support activities should be planned for the caregiver and family of mental health survivors to overcome stress reactions and adopt positive coping mechanism through support group activities. To date, the majority of the current research was done in western countries that related to specific subpopulations, such as students, frontline workers, or communities. Interventions that effectively minimize the burden and symptoms of mental illness among caregivers are desperately required. To the researcher's knowledge, no such study has been executed in the Malaysian context. Thus, more research into this topic is vital in the future to prepare for the rise of social problems related to mental illness due to the COVID-19 pandemic. By doing the research, the untold story from the caregiver's point of view can be heard.

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