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Malay Caregivers' Responses to Depression among Older Adults

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ABSTRACT

World Health Organization (WHO) have been identified older people as a vulnerable group that suffers from a range of different types of mental health problems particularly depression. Thus, providing caregiving for older people with depression has an impact on caregivers' family life. This study sought to understand the Malay caregivers' experiences of caregiving in the context of caring for older people with depression in Kelantan, Malaysia, as well as caregivers' responses to them. In- depth interviews were conducted with eight Malay caregivers of older people with depression recruited from the outpatient psychiatric clinic. Data were digitally recorded and fully transcribed before being analyzed using thematic analysis. Participants reported that depression was particularly challenging, requiring a lot of attention and supervision because of the continuous distressed behaviour.

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INTRODUCTION

Caring for an elderly person with mental health problems is a complex process. The older person, and hence those providing care, are faced with the combination of the implications of an ageing body and the personal and social impacts of chronic mental illness. Older people who suffer from mental health problems have faced significant difficulties through their lives, for example around disrupted employment (Schofield, Simon, Rupendra, Callander, Percival, & Passey, 2011), relating to others or coping personally with the impact of the symptoms of their mental illness. Caregivers predominantly linked the mental health problems with 'environmental factors' such as a supernatural cause, or personal, social or cultural factors, with little reference to medical explanations. This reflects findings from a study of 42 African American older adults suffering from depression who linked their interpretation of depression to myths and cultural folklore (Conner, Lee, Mayers, Robinson, Reynolds, Albert et al., 2010). They believed that depression is part of the ageing process and could not be cured by treatment from hospital other than a culturally sanctioned strategy of prayer and the enhancement of a relationship with God. Other studies have revealed the influence of religious and cultural understanding on the interpretation of mental health problems (Eltaiba, 2007; Mohamed A.Sayed, 2003; Shankar, Saravanan, & Jacob, 2006).

Mental health problems provide particular challenges to caregiving. Rose and colleagues (2002) suggested that families caring for a family member with mental illness are most likely "living with ambiguity", particularly when there are problems "understanding the behaviour they were seeing and helping others to see the behaviour as illness based" (p. 531). The experience become more complex where family members have to deal with the mental illness for a long duration and over different phases: before a diagnosis; getting a diagnosis; recognizing the permanence; and acceptance of the mental illness (Karp & Tanarugsachock, 2000). In one study in Maryland, United States, participants (N=308) who were recruited from two local mental health authorities reported that they and their family members were concerned about the progress of treatment; assertive community treatment; future planning for care of their ill relative and advocating for services for their ill relative.

Jorm (2000) suggested emphasis is needed on the "ability to recognize specific disorders or different types of psychological distress; knowledge and beliefs about risk factors and causes; self-help interventions; knowledge about professional help available; attitudes which facilitate recognition and appropriate help seeking and knowledge of how to seek mental health information" (p. 396). These issues are particularly relevant when mental health literacy in relation to depression and schizophrenia is viewed differently in urban and rural areas

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(Fuller, Edwards, Procter, & Moss, 2000; Swami, Loo, & Furnham, 2010). The medical diagnoses of mental illness have recently recognized cultural elements in understanding the causes of mental illness. The new inclusion in DSM-IV diagnoses of a culture bound syndrome in the category of mental illness describes different explanations of mental illness (Parzen, 2003) reflects this. It can be suggested that "descriptions of mental illness developed in one set of cultures are equally applicable to other cultures, but if this assumption is incorrect and the nature of emotions, thoughts, and behaviours can be expected to vary by culture, uncritical application of standard diagnostic (such as the DSM) cross-culturally might yield misleading or erroneous results where such criteria are locally inappropriate" (Bass, Bolton & Murray, 2007).

MATERIALS AND METHOD

This study utilizes semi-structured interviews guided with the interview guidelines covered the topic of experiences related with the task as caregivers. A purposive sample of eight Malay caregivers of older people diagnosed with depression was recruited from the outpatient psychiatric clinic. Participants were eligible for this study if they met the following inclusion criteria: (i) the period of caring for the older person with depression was greater than a year as the study aimed to examine long term caregiving, (ii) the older person being cared for was aged sixty or above and diagnosed with depression, (iii) the period since diagnosis of the illness was to be over a year and their current mental health relatively stable, and (iv) the caregiver was a primary family caregiver in direct contact with the person they cared for. All interviews were fully transcribed into the Malay language before being translated into English. All transcriptions were analyzed using a thematic analysis supported by the qualitative software (NVivo8). There are five key stages: (i) familiarization with the data, (ii) generating initial codes, (iii) searching for themes and reviewing the themes, (iv) defining and naming the themes and (v) producing the report. Similarities and differences were drawn to develop an overall story of their experiences and quotations from all participants are presented accordingly in the analysis to maintain rigor and trustworthiness.

RESULTS AND DISCUSSIONS

Depression is one of the most common forms of mental health problem in this study (eight out of fourteen older people). Depression manifests itself in various forms and to varying degrees. For older people in this study, depression has a range of symptoms. The following discussion focuses on these symptoms of depression among Malay older people and how the caregivers reported responding to the symptoms on a daily basis and throughout the period of being a caregiver.

Dealing with depression:

This section explores the understanding, impact and responses of the eight caregivers who were dealing with an older person where depression was the primary diagnosis. Despite a range of family backgrounds and levels of education among the caregivers, six of these eight caregivers were confused about the nature of this illness. Failure to understand the nature of the illness restricted the caregiver's ability to respond confidently to behaviours shown by the older person to the extent that one caregiver felt that the older person was just trying to get attention. These caregivers noted a range of symptoms but could not always link these to the mental illness.

Physical health complaints:

It is interesting to note that all the caregivers talked about their attempts to be considerate when the older person described the symptoms of an illness, particularly when it involved physical symptoms. Caregivers often thought the older person tried to convince them the symptoms were 'real' although medical practitioners had demonstrated there were no other health problems. One example of this situation relates to symptoms of headache and stomach ache. Two older people with depression in this study reported experiencing constant pain in the head combined with an unpleasant feeling in their abdomen. For example, Aida, 41 years old the daughter of the mother with depression said:

"… if she couldn't sleep then her gastric problem would suddenly occur, but when we took her to a specialist at a private clinic, they (the doctor) said she didn't have it, but she (my mum) thought it was gastric. She said she felt like that, she said so but when we went for a (medical) check up, it was not gastric but she said it was. So I don't know (what to say)."

On the other hand, Wanie, caregiver of 62 years old mother diagnosed with depression believed there was a connection between light, heating and depression for her mother. Wanie said:

"Mum's headache seemed to be very painful, yet at other times was all right. Since the headache, she got other illnesses too, like when we went to Kota Bharu, She couldn't stand the heat. During the night, when the light was on, we had to switch off the (ceiling) fan because the movement of the fan's blade and their shadows made her dizzy. So, we had to use the standard fan. When she came here, we had to use the standard fan

because she couldn't bear the movement of the shadows. I don't really remember when she first had the illness."

Unexplained physical complaints made it difficult for caregivers to react appropriately. Some caregivers tried not to argue but tried to convince the older person they were fine. Caregivers learned about the symptoms when they were aware of the noticeable changes in the older person's health problems which sometimes make the older person more prone to anxiety and worry about things they previously would not have been concerned about. As a result of the physical health related problems faced by the person they cared for, caregivers said that in some circumstances they became impatient with the constant complaints. Zainun, 62 years old, a wife who looks after her husband aged 76 who has depression said that: "*I'm just a human being. I'm not an angel. So, sometimes I do become impatient (with his attitude). I'll easily get impatient if I am also tired at the same time"*. Nani, 46 years old experienced the same situation when she almost lost control towards her mother aged 73 years old who suffered with depression, since her mother was unable to do house chores as a result of the stroke that made her mother depressed and limited her mobility, Nani said:

"This one day, I was almost pissed off with Mum because I had just come home from work, I was very tired yet she asked me to water the plants, sweep the floor and everything…I was quite angry with her (giggle). Well, my mum can't stand it if there is an undone task even though it is a small one".

Physical symptoms did not generally distress caregivers. Disturbed behaviours, however, presented particular problems for caregivers.

Disturbed behaviour:

In addition to the physical symptoms outlined above, half of the caregivers reported disturbed behaviour among the care recipients. Behaviour changes in terms of sleeping and eating disorders among the older people with depression also caused some difficulty for caregivers in looking after their older family members. As caregivers, they needed to provide emotional support to the older person even when the older person was irrational. A common issue for all older people who were depressed in this study was disturbed sleep patterns. Some caregivers noted that when the older person was unable to sleep one day, they were able to sleep the next day or two day after that. Sleep disturbance was linked to other issues such as loss of appetite and other physical symptoms. For instance, Wanie stated that:

"It started with the headache and I brought her to the specialist in HUSM…the headache made her unable to sleep. It wasn't serious at first, but after that, she lost her appetite, got the gastric, constantly burped until she couldn't sleep…"

Wanie further explained that at that time her mother could only eat a small amount of rice daily because she kept complaining about an uneasy feeling in her stomach. Whereas, Nani, the daughter of the mother with depression similarly noted that:

"She stopped taking the medicine and coming to the hospital for several years, and these made her lose her appetite. She refused to communicate, only kept to herself, was unable to sleep at night, and used to suddenly awake in the middle of the night."

There was evidence that, when the older person seemed to have sleeping problems, the prompt responses from the caregivers were to ensure that they were able to be at the side of the older person. They tried to just be there to listen to the older person's problems. Aida said:

"If let's say Mum couldn't sleep, I slept (with her) in the living room. When she got worse, she cried and cried. When she cried I asked her what's the problem. If she wouldn't answer than I stayed with her, waited until she spelled it out, or calmed herself down… I needed to calm her down, like find out the causes of it. For example, I made her stomach warm using the 'stove stand', to take her mind off the problems or sometimes I massage her..."

The impact of disturbed sleep became a particular problem for the caregivers in paid work, particularly when the problem occurred continually and the caregiver was unable to solve it on their own. Aida said: "*but after a while, we took turns in taking care of her. I'll asked my husband (to help too) because I needed to go to work the next day."* The same response applied to other caregivers. When caregivers were unable to control their feeling in the situation, they became aware that they needed to overcome such problems by being 'away' from their role in order to prevent an argument between them. Wanie said:

"*Sometimes I felt angry and stressed too. I told Mum to fight the illness. If she doesn't want to fight, that's the time I feel like getting angry with her, so I said, I wouldn't take care of her that night because I was worried that I would say the things that I should not say, I needed to watch my mouth after that. Actually I said that with the intention of asking Mum to fight her illness."*

Besides the 'external/physical solutions', in Wanie's case, in responding to and coping with her mother's sleep disturbance, religious practices were used to calm down the mother. They decided to share and resolve the problem within their family. Wanie revealed what she and her siblings did:

"*It was stressful during her illness. My chest throbbed painfully when she was ill. Not to mention all those tears, I did the 'solat Hajat' (a special prayer) when she couldn't sleep. All of us would stay up and perform the*

prayer and then recite the specific verses from Qur'an and keep blowing the air to her. When I felt tired and wanted some sleep, I would wake up my younger sister: "Wake up! Wake up! Wake up!" She woke up. If she didn't want to pray, she would just recite the Qur'an and keep blowing to Mum. We didn't leave Mother when she was sick, we kept reciting the Qur'an verses, … When we saw she seemed sleepy, we took some rest, but when we were about to rest, she was sick again, that's how she was then. Of course we're stressed by it, with my job and all, but I had to fight the stress because if we're sick, how can I look after Mum, right?"

However, the most common response to sleep disturbance was the use of medication. Caregivers mentioned that when the older person had a problem sleeping, they would depend more on medication. A number of older people believed that only the pills could solve their sleeping difficulty. For instance, Asmah, 53 years old and her husband, caregivers to her mother aged 85 years old with depression said:

Asmah

Her symptom is she is unable to sleep, but when she takes the medicine, then she can sleep.

Asmah's husband

Even if we said the sleeping pills are not good… risky …she still insists…as long as she can sleep…she only wants to sleep…if she's awake, maybe it will be 'dangerous' to her…she likes to think, so if she keeps thinking then it would be a problem…thinking this and that.

As a result of being unable to sleep, the older person would wander back and forth from one side to another side of their room, thinking and pondering. There was also a situation where the older person would disturb the caregiver while they were sound asleep. Rina, 44 years old, the daughter of a mother with depression said:

"The doctor asked Mum to take the medicine to be able to sleep. It's okay if she can sleep, if she can't, then she is restless. When she can't sleep, she knocks on our bedroom door telling us to wake up, in the middle of night."

When the care recipients were not relaxed and were disturbed, the caregiver had to cope with the impact of this situation. Caregivers, particularly working caregivers, reported that they did not have enough rest. Aida said:

"The only thing that made me stressed was when I couldn't sleep too and had to go to work the next morning. I have to monitor her, which creates tension. Another thing, when she had gastric during the daytime, then I had to take care of her. (There are) so many things to take care of, which create tension for me… (To think of) myself, my mother, house duty, my children, I have to take care of all of it alone. When she couldn't sleep then I couldn't sleep either."

In relation to not having enough rest, some caregivers made an effort to have time-out but their actions created conflict within family members when the siblings did not want to 'contribute' to the responsibility. Asmah said:

"I only left Mum (with them) for a week, not for a long period. They questioned me: "What are you going to do? I'm busy"! You know why (they act like that), because they are afraid Mum will cause them trouble. If they came to look after Mum, they do not care enough, meaning that they do not do the caring task completely..."

Because of caregivers' attempts to help the care recipient, some of them did not notice that they ignored their own health, until someone else commented on their wellbeing. Wanie said:

"One day when I was at the hospital, Dr. S____ once commented on me when he saw my face. He said: "You need to slow down a bit, because I can see that you are more stressed than your mother". That time he asked: "Have you taken your breakfast"? And I said: "Not yet doctor". "You better take your breakfast now because I can see that you are more stressed than your mother, or else you going to die earlier than your mother."(Laugh)

Knowing that her husband easily gets depressed and at one time was intending to jump out the window, Zainun just followed whatever her husband asked because she did not want her husband to have the same intention again, which made her scared not knowing what would happen. Zainun said:

His behaviour even sometimes got on my nerves, but I love him (laugh). Even I felt so tired without any energy left to cook. But I still cooked because I don't have the heart to refuse. He always said: "Never stop me from eating, or you'll regret it one day"… (He said) something like that.

Dealing with the person with depression meant that the caregiver needed to deal with the anxiety as well and respond accordingly in order to stop the depression from developing further. Performing tasks such as cooking and preparing meals was a way for the caregiver to provide care to the person with depression so they did not feel neglected.

Anxiety:

Other disturbed behaviours occurring among the older people in this study were linked also to a high level of anxiety. Aida and Nani both discussed this in reference to their mothers. Aida said:

"....because she's the kind of person who likes to think, if she takes something seriously she can't relax. If she wants something she wants it right away. She wants everything to finish as quickly as possible, wants everything on time....everything like that. So we have to be patient with her. Even though she can sleep, there are still other things that will bother her....sometimes they trouble her mind a lot."

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Nani echoed Aida's beliefs, stating that:

"…When I was giving Mum her nightly dose of medicine, I told her: "The reason for the sleepless night is because you didn't take the medicine". I asked her: "What actually goes through your mind when you can't sleep?" She said: "Thinking of my inability to do any work". It seems that this matter is always on her mind; sometimes it is a money matter. She must always have money, it's not like she really wants it, it's just that there must always be money in her purse. Mum always thinks about unnecessary problems."

Aida believed that her mother's attitude of not sharing problems with her children is a source of her depression. Aida stated:

"She refused to talk. If she had high blood pressure...she still could relax. If (she has) depression she won't sit still.....and she keeps on crying. Sometimes she cried for three to six hours."

In relation to the anxiety among the care recipient, the caregiver's response was to provide emotional support in avoiding the negative thinking. Wanie said:

"…if Mum said she felt a little bit sick, I told her: "Just ignore the feeling. It's normal just like normal people's headache". I tried to get rid of it as quickly as possible to avoid Mum from thinking about it too much.

In contrast, Asmah, in response to her mother's anxiety about staying alone and her hope that someone would be always available with her at home, Asmah asked either her brother or sister who live nearby to lend a hand to look after their mother. As a consequence, she felt stressed and 'trapped' when the siblings said: "*You tried to stay away from your responsibility right?"* As a result of this, Asmah faced the problem of balancing her role as a daughter with that of a wife to a husband who had been diagnosed with kidney disease. Asmah said she needs to accompany her husband to the hemodialysis centre and sometimes her husband wanted her to tag along when visiting her step children in another state. An unsympathetic response from her siblings meant she was unable to leave her mother.

It is interesting to note caregivers' perceptions about how depression can be prevented. Asmah's step-son said that mental health problems, particularly in reference to depression among older people, could be avoided if the relationship with the family is good. Older people who have good support from all the family members would age successfully and live without any illness:

"Actually we can see how the family's relationship is…With most families who have a good relationship with their parents, when their parents are getting older, we seldom hear that they have any serious illness…nothing like that, but if in the beginning the relationship between parents and children is not right…then the parents will have a problem when they reach the age of 55…they will start to have illness …you know why? (Because of) their feelings… the older people, even though their children are grown up, still feel responsibility for their children although the children are already 50 years old…it seems that for them their children are still kids…that's the nature of older people, right?"

Similarly, Asmah's husband added to what had been said by her son, saying that:

"But actually if they regularly could recite Al-Qur'an…her mind will be calm…she could perform a prayer…when they're alone recite the Al-Qur'an, repeating God's name…if they know about religion. If they don't then the bad things easily influence (them)…When they know about religion, they will always remember God…They recite the good things on the Prophet and repeat God's name."

Many caregivers believed that religious practices could prevent depression from getting worse and help caregivers and the older person to deal with the situation. On the whole, it is interesting that some caregivers, despite their difficulties dealing with the symptoms, often see depression as an understandable problem that is caused by life events, for example grief over the loss of a spouse or having adult children who cause the older person to worry. These issues are superimposed on any issues associated with getting older. In this study, caregivers described the symptoms of disturbances in thoughts and emotions as well as the sadness and social withdrawal which occurred for both types of illness: depression and psychosis. The following section will discuss these symptoms and how the caregivers responded to them.

Dealing with symptoms of moods, emotions and thoughts:

Mental health problems linked to depression and psychotic illness also manifest with frequent changing moods and inappropriate emotions. The older people tended to become emotional easily and caregivers had to consider this. For example, Zainun, the wife of a husband with depression revealed:

"….I can't talk harshly to him. He's sensitive about it. He doesn't like it if people raise their voice to him. He's afraid that he'll become worse."

Researcher:

"What if you suddenly do that? What would be his reaction be?"

He'll surely get angry, he'll be furious, but then he'll be quiet. He won't speak. He'll scold me: "Don't speak to me like that again, I don't like it", he'll say.

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Amira, the daughter of a mother with depression also discussed a similar experience with her mother, stating:

"When she has mood swings she goes into a tantrum...talks to herself, screams, jumps around…that happens if she is not satisfied with her children or grandchildren...."

Caregivers responded also to 'protect' the older person, to 'control' the situation and stop it from becoming worse. For instance, Rina's husband said:

"Just go along with her temperament, just let her 'win'. In this situation she's always right, we don't have to argue with her. If we argue back, she'll cry. What to do then? She'll become worse and more depressed then. It's better for us to not to raise our voice at her."

Since Rina's husband spends most of his time at home after work with her mother-in-law who has depression, this is his response in dealing with the situation:

"When Mum gets nagging, I feel angry sometimes so I just keep my distance. I go out, let the pressure out, that's it. When I want to release my stress I'll play football because I can't stand her nagging (laugh), and my wife keeps silent and doesn't argue back, only listens, listens and keep quiet."

Ali, whose wife has depression, talked about his wife's tendency to talk to herself:

"When she's speaking alone, I wondered "Hmm, exactly what is she thinking of right now?" I just wondered about it but I didn't ask her why. Even if I asked, she would ask me back: "I heard somebody talking to me, can't you hear it?"

It was difficult for him to know how to respond. Ali believed that his wife's mind was not really like that of a normal person's and that made her feel unstable. As a result of this situation, it was more difficult for Ali to maintain the usual family and marriage relationships with his wife. At the same time, Ali had to make an adjustment in his life since his wife was unable to play her role. In his interview, Ali stated:

"…that's why I've employed a maid service too…to lighten my burden…if not, my daughter has to come here (to help take care of my wife). It's hard if there's nobody to look after her, because I can't run my business …I don't trust leaving her alone…"

Ali said his wife who has depression tells him about the strange voices she hears. At one point, Ali's wife also questioned whether Ali too could hear the voices. Ali said:

But very recently, she still could hear as if somebody was talking to her. "I heard somebody talking to me, can't you hear it?" She would ask me back.

Researcher:

Oh, she thought she heard people's voices, did she?

Yes, as if a person was talking (to her). One night in the last week she went out through the back door. There was a banana tree at the back yard. She fell down there. The maid told me this. I thought, maybe she heard that 'someone' had asked her to (go out).

For this spouse caregiver, the response was to become more dependent on the assistance of a 'paid caregiver'. In the case of Ali, after his wife had been diagnosed with depression, he had employed two maids. When his first maid's work contract ended, he without delay employed another one. Ali would bring the maid to hospital every time his wife had an appointment with the psychiatrist. Therefore, Ali hoped that the maid would understand and, while doing her job, would care for his wife, and Ali would just have to monitor the care. Ali said: *"Before this, I took care her by myself, but I passed on (the role) to the maid. I taught the maid how and when to give the medicines and all other things, so now, the maid is the one who gives the medicine to my wife. I taught everything to the maid"*. This situation was rather different for female spouse caregivers, where they would 'remain' and play their roles as caregiver without 'delegating' the task to other people although some were in a position financially to allow them to employ a maid as well. For instance, Zainun, whose husband has depression said:

"My eldest son once told me that he would employ a maid to take care of us. He always asks me if I need any domestic helper so it would be easier for me, so I don't need to do all those things. I said I could manage it for the time being. I'm still 'strong'. God willing!"

Zainun's response demonstrates the way in which traditional Muslim women act in relation to their husbands. Women were keen to follow traditional ways rather than use paid caregivers. Although there was only one man caregiver who employed a housemaid, his situation suggests how differently men and women manage and deal with their caregiving roles. Symptoms of sadness and social withdrawal happened regardless of the diagnosis. Some older people experiencing mental health problems disconnect themselves from people around them. Depression for example leaves an older person isolated and unwilling to mix with people and maintain good relationships with those around them, particularly with family, friends, relatives and neighbours. In some cases, continuously feeling sad made an older person seem trapped in their own world, preventing them from doing meaningful activities. For example, Nani, whose mother has depression said:

"She seemed like she couldn't withstand large crowds of people…she'd be confused especially when she

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seems depressed…before this I didn't bother much because I was still young…if we made any noise, usually she would scold us…so she preferred to stay quiet in her room. She wouldn't be interested if anybody wanted to have a chat with her…she preferred to be alone."

Nani added more about her mother's behaviour, saying that:

"She didn't really like to chat…sometimes when I came back home at night, she'd be watching TV; there's a TV in her room. I have no idea why she doesn't seem to enjoy doing anything much…after night prayer, she just goes to sleep. Once I wanted to take her to Terengganu. She refused to go at first, but I insisted on taking her, just to give her some fresh air".

Amira, the daughter of a mother with depression also felt her mother behaves the same way. Amira stated:

"…she's just quiet and does not talk much. When she first fell sick she didn't want to meet with other people. She did not talk, she only talked to people she knew well, like the neighbours, and when she met with strangers or people she didn't know she would hide in the room and not come out. Even if you called her or knocked on her door it was no use."

In this situation, caregivers felt that they needed to cope with others' responses to the mother's behaviour because they did not know the real situation. The caregivers felt that the socially withdrawn behaviour shown by the older people does not only concern family members but it also concerns others. For example, Amira aged 60 years old had to inform other people about the illness. Amira said:

"I had to tell them everything when Mum first had this illness and asked them not to ask her (Mum) anything. Here, all my neighbours are our relatives so they understood."

It is clear that in Nani and Amira's context, the status of their mothers as widows plays a part in their caregiving as well as the presence of mental illness. All older people have shown that their symptoms are most likely very similar despite different diagnoses. Social withdrawal and isolation were common symptoms. Caregivers believed that the older person didn't want other people involved in 'their world'. This in some ways made the situation visible to others when they allowed the matter to become public as well as personal. Social withdrawal became a public issue outside the family sphere when non-family members showed their concern and sometimes their puzzlement noticing the changes of the behaviour of the older person. When caregivers shared their problems with others, colleagues, friends, neighbours or relatives, things became later for them in terms of stress and emotional burdens. However, it became a personal issue when some of the caregivers thought that they should manage the situation. Their way of coping was an attempt to minimize 'involvement' from non-family members which could create more tensions for the caregiver. Rina said:

"… Other people don't feel what we've been through, because Mum stays with us and not with them, that's why I don't bother if they want to say anything. If they want to accuse us of not treating her nicely it's up to them. Let them be. I'm tired of it."

The main issue among caregivers in this context related more to their concern and ability to ensure family members and acquaintances understood the changing behaviour shown by the older person. From the point of view of the caregiver, the main effect of the symptoms of the illness was that they came to miss the value of the relationship with the older person in the family system. In Malay culture, older people are always seen as someone who should be treated with respect, as a reference point for younger generations to seek advice and opinions particularly in regard to actions and decisions. For instance Amira said: "*Usually I would ask her, what is wrong with her, why does she behave like that in front of the grandchildren. Don't you feel ashamed, behaving like this? So she stays quiet and she'd be okay. That always happened."* Younger generations value the older person and expect them to provide moral guidance and support to define the identity and to protect the self-esteem of the family. However, some of the caregivers in this study lost the 'close-attachment' with the older person when that person was diagnosed with mental health problems. For instance, Amira, the daughter of the mother with depression reported that when her mother was diagnosed, she felt that her mother could no longer be a source of reference for her to ask for any opinions and suggestions when problems occurred in the family. Amira felt that she could not do activities that usually both mother and daughter do together, and that her mother could not play her role in comforting Amira in crucial situations. Amira said:

"I really hope that she can recover from her illness...to be normal again, if possible. I hope she's going to be fine. Hopefully she will fully recover so that I can chat with her and discuss (things) with her (like before)…because nowadays I cannot accept her opinion. I cannot ask her anything if I have problems and I cannot also share my feelings with her…"

When dealing with the social withdrawal, the major concern among the caregivers was to cope with other people's responses to the illness. Although the three caregivers experienced social withdrawal of their mothers the impact differed. Once caregivers began to worry about this matter, they felt more stressed. Nani and Amira felt it was difficult to include their mother in terms of social relationships. When the impact affected both their families and other people, caregivers encountered unusual distress. Caregivers attributed mental health symptoms to problems in the older people's life such as problems in a marriage or with their children, loneliness, physical health problems, or grief and loss as triggering factors. As a result of a range of understandings of mental illness, both the older people and their family members tended not to seek help from

health professionals. In this study it was clear that different generations had a different understanding of mental illness and its treatment and this affected treatment experiences for caregivers, older people and family members. Although the symptoms occurring for mentally ill people elsewhere are similar, the explanations given about the illness may be different in some countries. Clearly an understanding of mental illness needs to be developed that reflects traditional views of this condition, because some societies' understandings of mental illness are different from western perspectives. Perhaps this issue also means that there might be different ways of treating mental illness since it is conceptualized differently by different people/societies. Caregivers' experiences differed according to the nature of the mental illness. Participants reported that depression was particularly challenging, requiring a lot of attention and supervision because of the continuous distressed behavior. Caregiving experiences for an aged mentally ill family member did enable the caregivers to feel good about their contribution to the family member and this in turn strengthened family relationship. The positive impact of caregiving in terms of an enhanced sense of worth and deepening their faith is also clearly evidenced for most caregivers in this study.

Conclusion:

Caregivers tried to make sense of what they were experiencing and responded to the problems accordingly within their own family structure. A major issue for the caregivers in this context is their efforts to comprehend and interpret the mental illness despite their limitation to understand the illness from medical/scientific perspectives. In term of the challenges faced by the caregivers, depression seemed to be 'harder' for them to control if compared to psychotic illness. The major issue in dealing with the impact of depression on the older person was to deal with the person's inconsistent behaviour. For some caregivers it was more complicated to deal with the older person who was deeply sad compared to consistently by caregivers of an older person who showed destructive behaviour, since the destructive behaviour only occurred once in a while. The condition of sadness and crying happened continuously. The sadness not only impacted the older person but also had an impact on the health of the caregiver too. Depression seemed very 'infectious'; living with people who were depressed all the time, affected people around them. The impact occurred not only in terms of their social life but also with regard to the psychically, emotional and psychological dimensions as well, such as the health of caregivers. Caregivers identified negative and positive aspects of the illness and they made sense of this according to what they had experienced.

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