ELDERLY WOMEN AND MENTAL HEALTH PROBLEMS: A QUALITATIVE STUDY IN KELANTAN, MALAYSIA

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Abstract

In the developing world, the disease burden of mental health problems of the aged is associated with demographic and economic change, education, urbanization, widowhood, war and displacement. In fact, data on non-organic disorders specifically among the aged in countries of the developing world are limited and varying in terms of type of mental illness. This situation is influenced by different cultural interpretations of psychiatric disorders. People ageing with mental illnesses present additional challenges which are not well understood. This includes the concern about their mental health status and the provision of geriatric services and facilities. These mental health problems among older adults suggest a need to understand the issues for individual and families in greater depth and to develop services and resources to support them. The paper will be discussed on how the caregivers conceptualised mental health problems and their perspectives on the trigger factors linked to mental illness among their older family members. Caregivers reported many different causes of mental illness. How they recognised the early signs of mental illness in older people and how they learned about the illness will be discussed further. Participants were recruited through a psychiatric hospital to ensure that a care recipient has a diagnosis of mental illness. Fourteen Malay caregivers of older people diagnosed with schizophrenia, depression and bipolar disorder were interviewed using semi-structured interviews. All interviews were fully transcribed into the Malay language before being translated into English. All transcriptions were analysed using a thematic analysis supported by the qualitative software (NVivo8). Identifiable themes and patterns of history, symptoms and diagnoses of illness among Malay older people with a mental health problem were reviewed to develop an overall story. Quotations from all participants are presented accordingly in the analysis to maintain rigor and trustworthiness

Keywords: mental health problems, older people, qualitative study, Malaysia

Background

In the developing world, the disease burden of mental health problems of the aged is associated with demographic and economic change, education, urbanization, widowhood, war and displacement (Levkoff, MacArthur, & Bucknall, 1995). In fact, data on non-organic disorders specifically among the aged in countries of the developing world are limited and varying in terms of type of mental illness. This situation is influenced by different cultural interpretations of psychiatric disorders (Levkoff, et al., 1995). Mental health problems among older people have not attracted much attention in the policy literature (Lloyd, 2000; Stalker, 2003), although older people have been identified as a particularly vulnerable group that suffers from a range of different types of mental health problems such as schizophrenia, depression, anxiety and psychotic disorders (WHO, 2002).

Recently, emerging issues around mental health problems, roles of family and older people have become a concern of the Malaysian government. The government, through the ninth Malaysian Plan period (2006-2010), has emphasised the need for health research, particularly mental health as a priority research area with the purpose to improve understanding in community perceptions and behaviour regarding the illness. In addition, health beliefs, perceptions and practices in rural families are shaped by the socio-cultural and traditional values systems (Ariff & Beng, 2006; Wan Ibrahim Wan Ahmad & Zainab Ismail, 2003). In terms of gender, women are at greater risk of mental health problems (particularly depression and anxiety) because of their longevity (Wykle & Musil, 1993). Based on the data from the National Mental Health Registry from January to May 2003 compiled by the Ministry of Health Malaysia, of the 907 registered cases of mental health problems (the data is limited to people with schizophrenia), Malays made up the majority of cases (53 per cent) with older people aged 61 and over comprising 6.5 per cent (Salina, NorHayati, & Sarfraz Manzoor, 2003). A study by Mohd Sidik, Mohd Zulkefli and Shah (2003) using the Geriatric Depression Scale (GDS) questionnaire found that 18 percent of the elderly patients aged sixty years and above attending a primary health care clinic in Malaysia had depression. This is supported by the recent studies by Rashid, Ab-Manan and Siti Rohana (2011) which show that depression is a common psychiatric problem among the elderly Malays living in rural Malaysia. The study was conducted among the older adults in 24 villages and involved 428 villagers who were 60 years and above in north Malaysia. The studies found that the prevalence of depression was 30.1 per cent and higher among the female who live alone. Findings similar in other studies (e.g. Mohd Aznan & Samsul, 2007; Mohd Sidik, Rampal, & Afifi, 2004) conducted in clinical settings suggests that the prevalence of depression in older adults in Malaysia varies but trends show an increase. The most common mental health problems diagnosed for older people are depressive disorders (depression) which is estimated at 15 percent of the elderly in the community (Krishnaswamy, 2008). Another study reported the existence of depression among older people (Zailina Mohamed, 1996 cited in Roziah, 2000) found that 22% of the elderly in Malaysia were depressed for different reasons.

The prevalence of cases of mental illness is a significant problem for adults 65 years old and older (Swett & Bishop, 2003). Collinson and Copolov (2004) have highlighted that schizophrenia is a major mental health issue occurring within the elderly population. McInnis-Dittrick (2002) argues that depression is one of the most under diagnosed and under treated mental health problems of elders. Jorm (2000) suggested emphasis is needed on the “ability to recognise 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 (Fuller, Edwards, Procter, & Moss, 2000; Swami, Loo, & Furnham, 2010).

The paper will be discussed on how the caregivers conceptualised mental health problems and their perspectives on the trigger factors linked to mental illness among their older family members. Caregivers reported many different causes of mental illness. How they recognised the early signs of mental illness in older people and how they learned about the illness will be discussed further.

Methods: qualitative interviews

This study utilizes semi-structured interviews guided with the interview guidelines covers the following topics:

- demographic background of caregiver and the older person with mental health problem
- experiences related with the task as caregivers
- participation with health providers

A purposive sample of fourteen Malay caregivers of older people diagnosed with schizophrenia, depression and bipolar disorder were recruited from the outpatient psychiatric clinic. All interviews were fully transcribed into the Malay language before being translated into English. All transcriptions were analysed using a thematic analysis supported by the qualitative software (NVivo8). Identifiable themes and patterns of history, symptoms and diagnoses of illness among Malay older people with a mental health problem were reviewed to develop an overall story. Quotations from all participants are presented accordingly in the analysis to maintain rigor and trustworthiness

Findings

Brief description of caregivers and care recipients

Twelve female and two male caregivers ranging in age from 30 to 69 years old were interviewed. Caregiving duration ranged from 1 to 20 years. The majority cared for older people with depression (*n*=8), four cared for older people with bipolar disorder and two for older people with schizophrenia. All caregivers are closely related and have a close personal relationship with the older person they cared for. Adult children (*n*=10) who look after their aged parents can be categorised into two groups: adult children caring on their own (*n*=7) and adult children caring with siblings (*n*=3). Primarily caregivers were adult daughters looking after their mothers with depression. Spouse caregivers (*n*=3) were a wife looking after partners with a mental illness. Older people ranged in age from 62 to 85. In terms of the characteristics of the older person, mostly they were mothers whose husbands had passed away and who suffered from depression.

Perceived causes of the life events linked to mental illness

The onset of mental health problems among these older people varies from person to person. In addition to the diagnosis made by doctors in a psychiatric clinic, it is important to look at how the caregiver, the person who is intimately involved and has direct contact with the care recipient on a daily basis, understood the mental illness of the older person. The history of the illness from the point of view of this family member impacts on how caregivers deal with it in their everyday lives. Participants linked the history of the illness to what had happened during the older person's life. In addition to the effects of ageing, a variety of other factors contributed to the illness. Caregivers' observations and reflections on the issues faced by the person they cared for are discussed in the next section.

Experience of loss and loneliness

Losing their spouse because of death and living as a widow has been identified as a trigger factor that contributed to depression among the female older people in this study. When their spouse was available, they were doing daily activities and spent most of their time together, supporting and complimenting one another's roles as husband and wife. For instance, Rina, 44 years old, daughter of a mother with depression said:

> *"She got used to staying with (my) Dad. Before this both of them worked in the same business. Usually in the morning they went out together, they were always together so when Dad passed away Mum felt so lonely. She felt de-motivated. Since then Mum has been like that; she was always preoccupied in her thoughts."*

The loss of a life companion for most (*n*=6) older people with depression in this study left them without someone to share their feelings with and a shoulder to cry on. This is how a daughter and son-in-law described the situation concerning their 85 year old mother with depression:

> *Asmah*
> *"…but even before that she was already sick and Father's death made her worse, it worsened after my father died."*
>
> *Asmah's husband*
> *"…they can share their feelings with their husband; although they are quarrelling, they can still communicate, right? She has someone to release her feelings to."*
>
> *Asmah*
> *"But then when her husband died, she is not in this situation anymore. She can't release her feelings anymore, and the children make Mum more stressed…"*

Halijah, the daughter of a mother with schizophrenia, echoed Asmah's beliefs, stating in reference to her mother's grief at the loss of her husband:

> *"After the week when Dad passed away her blood pressure was up to 200…when I brought her to hospital and the doctor checked on her, they wanted to admit Mum again…but then I asked the doctor not to because I told them maybe Mum feels stress because of Dad's death …"*

In this context, older people are reported as feeling 'empty' because children could not fill up the 'space' left by their late husband because of their own work commitments and their responsibility to their own family. The scenario was worse in relation to the death of a loved one when the adult children who had married and were working had left home. Having their own family and life 'distant' from the relationship with their widowed parent meant they seldom paid a visit and gave less attention to the older person. Asmah, the daughter of a mother with depression also stated in reference to this:

> *"…like I said earlier Mum needs all her children and grandchild to come and visit her. Her children must come visit her, even once in a while, because she doesn't really need the money, she has*

money. She only needs her children and grandchild to come and have a chat..."

Asmah also felt that the older person with depression also needs special attention and a touch from her children and grand children to counter the loneliness. Asmah described her mother's condition:

> *"…sometimes Mum feels afraid, during dusk or late evening. At times she feels so scared. Because she's sick, she feels anxious. Then also with her asthma, because she needs help, if possible, with massage. She needs her children to touch her, that kind of thing."*

However, Siti, the daughter of a mother with bipolar disorder felt that sometimes because of the unexpected behaviour of the older person, their children who do not understand of the illness are hesitant to help their parent to overcome the loneliness. Siti said:

> *"Actually Mum misses her children but when her children are here she keeps behaving negatively so that makes my siblings feel reluctant to visit her"*

Some caregivers thought other family members did not understand why the older people behaved in response to loss or loneliness in such ways. It was hard for the caregiver to make them understand because they too did not know how to explain the older person's response to a matter. For instance, Asmah expected that her siblings would become more considerate and supportive in helping her to ease their mother's isolation, however it created another dilemma. Asmah said:

> *"My siblings, they did come to look after (Mum) but not completely. Frankly speaking, they do care, but half heartedly, so when my siblings do not care enough for Mum, I cannot rely on them…"*

Loneliness for the older person was not just limited to the loss of their spouse but they also have little social contact with friends of the same age. When the older person's circle of friends becomes smaller because of varying factors, then life becomes empty. Asmah, the daughter of a mother with depression mentioned that:

> *"Most of Mum's friends passed away and that's the one reason Mum feels lonely, because when they were still around they always came to the house to have a chat together. Now no one is available for her to talk. She keeps thinking about these things and finally it became a problem for her."*

In another situation, Nani, the daughter of a mother with depression believed that her mother was unhappy because:

> *"…most of them have passed away, there's not many left in the village. Plus, my mum lived in another village before, so she doesn't really have many friends around here…"*

Furthermore, Asmah added that her mother is a person who loves to talk and if her mother could have a chat with others, indirectly her illness seems to 'disappear'. This situation is very similar to that of Amira's mother. Amira said:

> *"…if there's many people in the house, she seems so happy, she will come out whenever all her children are here. She seems more active!"*

It seems that with the presence of other people near them, in particular children, and contemporaries, the older person with mental health problems seems more cheerful, even if only for a short time. Wanie, the daughter of a mother with depression, also agreed that once the children left home to study or work in another state, the older person started to behave in a different way. Wanie said:

> *"During their short break, in the company of my two youngest sisters, Mum's condition seemed to improve. But when the two went back to their study, her condition again deteriorated. So I asked my younger sister in KL to come back again. After she stayed and went back to KL, my aunt who's living nearby, frequently came to sleep over. I noticed that sometimes Mum was very ill, sometimes she was not…"*

Wanie also felt that somehow when her children (Wanie's siblings) were with her, her mother was calmer and more relaxed. She stated that:

> *"…and now my sisters are with Mum because they spend their holiday with her. So it's okay if all Mum's children are with her. If she feels unwell Mum would become better because her children are with her."*

Caregivers believed that when the older people were having problems they preferred to talk through their problems with other female friends or someone close to them (but not with their children). When these social interactions are restricted it makes the situation worse and this contributed to the older person's mental health problems. Experience of loss was not limited to the loss of the spouse but also to the loss of friends, and this can be compounded when children leave home because of employment. A combination of what was happening in the family, as well as the nature of the illness, produced issues for caregivers and impacted on the experience of caregiving.

Children's problems and family issues

Two caregivers believed that the problems of their children are a factor in the older person becoming depressed. A number of caregivers believed that a mother always has a special connection to her daughter no matter whether her daughter is married and independent. As a mother, she still wants to play her part and show concern about the problems of her children, particularly her daughters. When a mother keeps thinking about her children's problems she is indirectly involved in any difficult situation and become depressed about it. Nani, 46 years old, a divorcee and daughter of a mother with depression explained:

> *"Sometimes I think Mum is sad because of my condition. Yet she never told me so. Perhaps she wants me to remarry. She used to scold me by saying "What are you waiting for?" But I never told her about my worries or the reasons why I'm not getting married again. I never asked her about this, but I got the feeling that sometimes she is worried about me not getting remarried. I have this thought sometimes."*

Another aspect of family issues was disputes in dividing property among siblings. Constant wrangles between siblings over property, especially in dividing the *rumah pusaka* (inherited house) resulted in conflict between family members. As a result the older person who acts as a 'trust-holder' (responsible for distribution of property) feels tense, stressed

and eventually goes into state of depression. One caregiver believed that being a widow, combined with an upsetting situation, brought on the illness. Asmah, a 53 year old daughter of a mother with depression, explained her mother's situation:

> *"I think her problems arise most probably because of my siblings; her own children made her feel like that. The stress comes from her children too. They are not satisfied with the allocation of property, that's the main reason I think. You know what? My siblings they always put pressure on Mum. For example, this house, let me tell you the truth, this house, they are interested in this house. They want more properties but Mum is still alive; they are greedy even when my mum is still living here..."*

Asmah raised the issues of conflict over property several times during the interview. She gave more details about the crises arising in her family. She mentioned:

> *"One of the factors is because of the properties, but they (the other siblings) are irrational. I'm the one who has cared for Mum for ages. Actually this is the old house but I've renovated it, so what do they want actually? I can say that, because of their greediness, one of the reasons is that they're unsatisfied. They came after my mum, put the pressure on her, kept asking her to give them more, so then Mum becomes worried and her problems double and it's hard for her to forget (all the issue which arise. This makes her sicker, that's why I've told you. It is because of her own children and I'm telling you the truth based on my observation (of Mum)..."*

Because of property disputes in her family, her relationship with her siblings contains conflict, when they half heartedly care about their mother's illness and refuse to compromise in terms of sharing responsibility for the caregiving. Asmah summed up this issue by quoting what her mother said to her in reference to what happened in their family and her constant worry:

> *"My children are always in conflict and always in a bad mood. That makes me more worried"*

The impact of physical health problems

Loss of valued roles and limitations in activities because of problems relating to physical health problems among older persons in this study represented a significant cause of depression. Physical weakness limited some older people's mobility and daily activities. This was linked to depression. For example, Nani, the daughter of the mother with depression, shared that the story of her mother's depression becoming worse when her mother had a stroke. Her mother keeps thinking about her inability to do any housework.

Both Zainun and Nani reported that because of the incapacity of their care recipients, the older people had short tempers, and the person who lived with them, most of the time, had to bear the consequences of complaining, nagging and whining about their problems. Both caregivers although aware of the situation, did not speak about it, or ignored it, to avoid it becoming worse. They sometimes felt impatient, bored and tense, but over time they learnt to cope with their mother's condition. Nani said: "*Of course I feel bored. Even if I feel bored I just keep quiet but then later I understood about her condition, so I just ignored it."* Concerned that physical health problems and depression

are linked, caregivers tried to adjust their lives practically including the job that they had so that the care recipient could cope with the problem and minimize the depression. Nani said:

> *"I did tell my colleagues I have to look after my mum. I can't leave her alone for a long time, in case they required me to do overtime (at the factory). I can't do it…poor Mum, sometimes she scolds me if she's not well, she asks me to come home early."*

Again Nani highlighted her decisions about changing her work situation after her mother became depressed because of the stroke:

> *"…I was working somewhere else (before this). I quit my job because I felt pity my mother as I returned home late at night. She asked me to quit the job too, so that I could look after her. So, I stopped working because she wanted me to look after her all day long. Only after she got better did I start this recent job. The factory (which I worked at) has also been moved nearby, so I applied to work there again as it is nearer to my house."*

Both caregivers commented that they were often required to make significant adjustment in their life to cope with the condition of depression arising from the physical health problems of the older person.

Marriage problems

Two caregivers suggested distressing past experiences, particularly divorce, as a contributing factor to an older person having mental health problems later in life. Siti's mother has been married and divorced four times and her husbands have all passed away. Siti, the 30 year old daughter of a mother with bipolar disorder, explained that these unpleasant experiences faced by her mother influenced the development of her illness. Siti said:

> *"…I know that Mum feels stress because of her life history…"*

Halijah, the daughter of a mother with schizophrenia commented on the impact of her mother's marriage breakdown on her mental health. Halijah considered her mother to be someone who liked to conceal her own feelings and never complained about her husband's actions towards her.

> *"But one thing that I am sure about her, she hid her feelings, so that whatever Dad did to her, she never complained. It's the opposite with me. If I feel angry with my husband, I will let him know my anger. I'm not the type of person who conceals my feelings. At one level if I cannot control my feelings, I will let him know: "I'm so angry! I'm so angry!" But Mum is not like that. As far as I can remember, since I was a kid until I grew up, she never opposed Dad; whatever Dad did to her, she just accepted. I think that's the one reason why Mum becomes like this, looks depressed".*

Halijah's late father married another woman and left her mother, who at that time was unwell, alone. During the interview Halijah said:

> *"…Dad too at the time had two wives. His second wife stayed at Kedah (in the northern state of*

Malaysia), so he sometimes stayed with the new wife, (and stayed) on and off with Mum; a month in Kelantan, a month in Kedah…"

Regarding what her father did to her mother, Halijah further stated:

"I was also frustrated when Dad married another woman. I was so frustrated. Dad left Mum because she was sick, and flirted with another (woman)…"

Uncertainty about the causes

Besides the dominant factors discussed above, there were two caregivers who said that they were uncertain why the person they cared for had a mental health problem. However, their knowledge about the cause of the mental illness was connected to their specific understanding of psychiatric matters. In his interview, Ali, the husband of the wife with depression stated:

"What could she possibly think of? She has no problem with the children, no problem with finances, nor with the domestic situation. She didn't have any reason (to think about the existing problem) because there is none. I don't think it's because of bad spirits from others (caused by anger or envy) either, because my wife didn't really say bad things or disturb other people's lives."

Wanie, the daughter of the mother with depression felt this as well:

"I feel weird too because although Mum said she's not thinking very much, she still has problems sleeping. I just had a thought that Mum is not telling me the truth, because sometimes I also don't share my problems with my children so it might be the same situation as Mum."

Ali and Wanie both discussed not knowing why their family member became ill. However, towards the end of the interview, Wanie said that her mother started to feel something was not right with her after she got back from visiting a relative in hospital who suffered from cancer and had an operation on the head. Wanie explained that:

"…Mum told me that she visited an ill person when she was having a headache. She blurted out: "Hmm that day, when I was starting to get a headache, I went to visit someone with a headache problem at the hospital…"

Wanie summed up this condition:

"the point is, as she said, she visited someone with a headache, or someone who's put next to a person with a headache problem. It turned out that that person's head had to be operated on because of cancer, and Mum's throbbing head was similar to that person. When she came home, she kept thinking of the possibility of having cancer as well. After that, her headache became more painful than before…"

According to Wanie, the doctor said:

"Oh, never mind, perhaps your Mum's illness is because she thinks too much". Perhaps, she's a bit ill, but it gets worse as she thinks too much of it – the 'somatic pain'"

Wanie and Ali both have a tertiary education but had different majors (pharmacy and education respectively), however, their understanding of mental illness does not differ greatly. Their 'ignorance' about the factors that contributed to depression was only alleviated with reassurance from the psychiatrist. Although the primary caregiver has problems understanding the mental illness, they also felt obliged to help other family members understand it.

Discussion

There was a wide variation in the histories and causes of mental illness of older people in this study and the understanding of the mental illness from the point of view of the caregivers. Based on the above discussion, it can be summarised that the history of the illness is understood to be related to family or marriage crisis, widowhood, pressure in life, chronic pain and stress because of the loss of someone close to them. Not one factor but many aspects of their lives make the older person more 'fragile' and therefore susceptible to mental health problems. When the older people found it difficult to accept to the situation and the challenges that they faced in their lives, their capacity to cope with the illness also declined. Depression occurred because of some events in their life, while with other conditions the illness was already there and people aged with the illness. Most of the life events surrounding the mental illness were linked with problems with children, family issues and marriage problems that caused stress and impacted on the well being of the older person. In conclusion, there were a range of views between caregiver and the care recipients about understanding the nature of illness, but among the caregivers there was also an effort to understand the illness. In some cases the older person in a way tried to influence their caregivers to believe and accept the symptoms they had, and in some circumstances the caregiver had to follow the older person's intention to avoid more problems.

These findings report family members' observations and reflections on the person they cared for. Older people were not interviewed and there was no access to their medical records at the hospital. Family reflections on the illness were based on their understanding of mental illness, and the caregiver tried to relate it to the trigger factors before they took the older person to hospital, for diagnosis and treatment. The causes and symptoms that have been discussed in the section were related to the living situations and the physical health of the older people.

Most caregivers, although having minimal knowledge about the illness, adopted and balanced their roles to improve their awareness of the mental illness. Caregivers struggle to understand the illness, experience dilemmas and do not know what to expect. Another dilemma was also related to making other siblings understand and help the primary caregiver to help older people to overcome the loneliness or grief with frequent visits and efforts to share the emotional burden. In relation to this, the caregivers felt that sometimes they failed to 'fill in' the emptiness, as some of them were in full time employment and had to balance their role as adult children and career women as well as wife or mother to their own family.

Children's problems and family issues were seen as impacting on the older people's mental health problems. As caregivers, they learned to acknowledge the older person's thoughts and feelings while at the same time they were

often in a conflict situation with siblings. When caregivers tried to understand mental illness, it would also contribute to their understanding of the behaviour and problems occurring from it.

Conclusion

The above discussions demonstrated the caregivers' understanding in the context of what triggered and caused the mental illness in the older person and the impact on their role. Most caregivers did not discuss the cause of the illness in relation to medical or genetic aspects. These mental health problems among older adults suggest a need to understand the issues for individual and families in greater depth and to develop services and resources to support them.

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