

Extended Family, Neighbourhood and Friends' Network in Supporting Caregivers of Older People with Mental Health Problems¹

(Sistem Sokongan dalam kalangan Penjaga Warga Tua Bermasalah Kesihatan Mental oleh Keluarga Luas, Jiran Tetangga dan Rakan Taulan)

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Abstract

Caregivers of older people with mental health problems encountered with minimal support and assistance in their caregiving responsibility. Despite all the positive and negative experiences faced by the caregivers, the family network, network of friends and some local informal networks supported their roles although there were contested beliefs between traditional, religious and modern perspectives. The article will be addressed the different help and support provided by the extended family, neighbourhood support, neighbours and friends' network. Caregivers address the need for appropriate support and resources to help them in managing and providing 'good quality care' to their mentally ill family member.

Keywords: *older people, caregiving, mental health*

Abstrak

Penjaga kepada pesakit warga tua yang mempunyai masalah kesihatan mental berdepan dengan masalah sokongan dan bantuan yang minima dalam melaksanakan tanggungjawab penjagaan mereka. Ketika penjaga ini berdepan pengalaman positif dan negatif, sistem jaringan keluarga, rakan-rakan dan jaringan tidak formal di peringkat komuniti sedikit sebanyak membantu peranan penjaga ini dalam penjagaan tersebut, walaupun adakalanya berdepan dengan pertelingkahan kepercayaan tradisional, keagamaan dan perspektif pemodenan dalam masyarakat. Artikel ini membincangkan kepelbagaian bantuan dan sokongan yang wujud dalam keluarga luas, sokongan kejiranan serta sistem jaringan dalam kalangan rakan-rakan dan jiran tetangga. Responden kajian menyatakan tentang keperluan untuk

mendapatkan sokongan yang mencukupi di samping sumber-sumber lain dalam menguruskan dan menyediakan 'kualiti penjagaan yang baik' kepada ahli keluarga mereka yang mempunyai masalah kesihatan mental.

Kata Kunci: *warga tua, penjagaan, kesihatan mental*

Background

Numerous studies in the social sciences literature between 1970 and 2000 have demonstrated that family caregivers of people with mental health problems encounter overwhelming experiences (Saunders, 2003). There is recognition, too, that such caregivers perform a range of roles (Bland, Renouf, & Tullgren, 2009) including the need “to learn a range of advocacy skills to ensure that they receive services their family members needs” (Bland, et al., 2009, p. 193). Biegel and Schulz (1999) disclose significant differences in caregiving responsibilities and tasks for caregivers of elderly persons as compared to caregivers of persons with mental illness. Guberman and Maheu (2002) note that the caregivers “continue to hold ambiguous status in their relationship to formal services and a marginal place in social policy” (p. 28). Williams and Mfoafo-M’Carthy (2006) in Toronto believe that there is tension and contested social practice between individuals and society, between family members and the individual and between community and policies in the provision of care for people diagnosed with mental illness. Recently, emerging issues around mental health problems, roles of family 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 strengthen, develop and test new modalities in terms of family and community involvement strategies (National Institutes of Health, 2006).

In the context of care for older people, caregivers are spouses, daughters, sons, daughters-in law, siblings (Hatfield & Lefley, 2005; Matthews & Rosner, 1988; Piercy, 1998), or neighbours and sometimes friends (Himes & Reidy, 2000). Family members have long been recognised as the principal source of care and support, particularly for older people and users of mental health services (Bland, et al., 2009; Levkoff, McArthur & Bucknall, 1995). 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. Therefore, it is contended that in the future a large proportion of the ageing population will be recognised as having mental health issues and will need long term care from informal support networks, particularly from the family network.

The family system remains the main support structure for most Malaysian elderly with the majority living with their children (Chan & Davanzo, 1996; Helen Wu & Rudkin, 2000). Indeed, as in other developing countries, the family is considered the most appropriate provider of care for older people (Phillips & Chan, 2002; Zimmer & Martin, 2007), although recent trends show that for some families caring is 'transferrable' to housemaids who are often foreign helpers (Roziyah, 2000). Given that families continue to play a major role in supporting older people, policies clearly need to focus on enabling families to provide appropriate support for this group in contemporary Malaysia (Chan, 2005).

As Levkoff and colleagues (1995) argue, the family network is the most important system of care and remains the primary caregiving unit for an older person. More recent caregiving literature, however, introduces the notion of caregiving networks. It is broadly suggested that extending caregiving networks beyond their family members is beneficial to care outcomes (Chen & Greenberg, 2004; Saunders, 2003). In Canada, some research has shown that relationships between care networks of family members have a positive impact on the quality of long term care received by older people (Fast, Keating, Otfinowski, & Derksen, 2004). Keating and colleagues also suggest that although diversity still exists, further understanding is needed to enable the capacity of caregiving networks to link caregivers to services (Keating, Otfinowski, Wenger, Fast, & Derksen, 2003). The article focuses and addresses the different help and support provided by the extended family, neighbourhood support, neighbours and friends' network to caregivers in helping them with their caregiving roles.

Research Method

Sample

Participants in this study included fourteen family caregivers of older people with mental health problems recruited through the psychiatric outpatient clinic in Hospital Universiti Sains Malaysia (HUSM) at Kubang Kerian, Kelantan. In this study, the person who appeared to spend most of the time in caregiving roles generally identified themselves as primary caregiver. The demographics of these family caregivers were twelve female and two male caregivers ranging in age from 30 to 69 years old. Most of these family caregivers cared for older people with depression ($n=8$), four cared for older people with bipolar disorder and two for older people with schizophrenia. Among all the caregivers, ten participants lived with the older people they cared for and three caregivers were either living nearby or alternately with their children ($n=1$). While the education level of the family caregivers, most participants were

considered educated, with at least a secondary school education, some had completed tertiary studies whilst some had not completed primary school. The characteristics of participants and the person they cared for is summarised in the tables below.

Table 1

Summary of characteristics of primary caregivers

CHARACTERISTICS OF PRIMARY CAREGIVER	N = 14
Gender	
Male	2
Female	12
Age	
30 – 39 years old	3
40 – 49 years old	5
50 – 59 years old	1
60 – 69 years old	5
Relationship to the older person with mental health problem	
Spouse (Wife = 3; Husband=1)	4
Daughter	9
Son	1
Marital status	
Married	12
Single mother	2
Education	
Primary education (Not Completed)	2
Secondary education (Completed)	6
College/University education (Completed)	5
Others: Religious school (Not Completed)	1
Occupation	
Full time employment	5
Self-employed	4
Home duties/housewife	5
Period as caregiver to an older person with a mental health problem	
1 - 5 years	6
6 - 10 years	2
11 - 15 years	1
16 - 20 years	5

Table 2

Summary of characteristics of older person with mental health problems

CHARACTERISTIC	N = 14
Gender	
Male	4
Female	10
Age	
60 - 65 years old	6
66 - 70 years old	3
71 - 75 years old	2
76 - 80 years old	2
81 - 85 years old	1
Types of mental health problems	
Schizophrenia	2
Bipolar disorder	4
Depression	8
Marital status	
Married	6
Widowed	8
Period diagnosed	
1 - 5 years	5
6 - 10 year	2
11 - 15 year	2
16 - 20 year	5
Living arrangement	
Living with caregiver	11
Living nearby	1
Other (alternate with children)	2

Measure

The primary technique in collecting information from the family caregivers was the use of in-depth semi-structured interview. Interviews were guided by themes and sub-themes with room to respond to the participant's responses. Nigel and Raymond (1998, p. 212) note that a process of this kind is 'semi structured by a thematic guide with probes and invitations to expand on issues raised' or continually 'seeks depth rather than breadth' (Ambert, Adler, & Detzner, 1995, p. 880). The interview guide included open-and closed-ended

questions to gather data and information from informal caregivers regarding their views and experiences. The former focuses on participant demographic backgrounds exploring age, gender, periods of being a caregiver, relationships with people under their care and types of mental health problems in question. Open-ended questions focus on issues such as meanings given to and perspectives employed in caring for older people with mental health problems, participation with health providers, as well as networking within the contexts of both formal and informal support.

Procedure

Each caregiver was given written information about the study and asked to sign an informed consent and a permission to digitally recorded the interview for the study. All interviews were fully transcribed by the researcher into the Malay language and then translated fully into English by the researcher. The English transcriptions were used to develop codes and analyse the data. The analysis, based on an interpretivist perspective, acknowledged common understandings and different views from each participant in the context of the researcher's practical understanding as a member of particular culture.

BRIEF BIOGRAPHIES OF MALAY CAREGIVERS AND THE PERSON THEY CARED FOR

Malek

Malek is a male caregiver aged 39 years old. He is married with a very supportive wife and blessed with two girls' aged twelve and thirteen years old and a boy aged eight years old. So there are five people in the household living as a nuclear family. Malek completed his secondary school and works fulltime in his own business as a building contractor. He comes from a big family of seven siblings. Malek has been a caregiver for almost five and half years to his father aged 74 years who has bipolar disorder. His father was diagnosed with bipolar disorder almost six years ago, since 2003. His father lives separately from Malek in a nearby village with his wife aged 73 years. Besides the mental health problem, the father also has high blood pressure. His father has never been hospitalised but has only been an outpatient at the psychiatric clinic and still continues with drug treatment. His appointments with the doctor at the psychiatric clinic are on a monthly basis.

Siti

Siti is 30 years old, a female caregiver, married with three children aged between four to twelve years. She runs a small business as her fulltime job.

Siti's husband is self-employed too, doing welding work to support the family. Siti completed secondary school. Siti has three sisters and three brothers. She is the third of the siblings, but they are from a different father because her mother married and divorced four times and the husbands passed away. Siti is currently the primary caregiver for almost a year to a widowed mother aged 63 years with bipolar-disorder. Her mother was diagnosed with bipolar disorder in April 2008. Besides the mental health problem, her mother also has diabetes and high blood pressure. Her mother is an outpatient in a psychiatric clinic and went to see the psychiatrist on monthly basis. Currently, they are living together in a shop-house unit, courtesy of Siti's mother-in-law, and are planning to have their own house if they have enough money soon. There are six people in the house and three generations involved which is considered an extended family.

Halijah

Halijah aged 43, is a degree holder in Mathematics from the local university and is teaching in secondary school. She is married and has five children, and the eldest in form two and the youngest in standard four. Halijah is the eldest of six siblings, and most of her siblings are sisters. Both Halijah and mother co-reside in the same household and there are eight people in the house living together as an extended family of three generations. She provides daily care and supports for her mother a widow aged 64 who has schizophrenia. Her mother was diagnosed with schizophrenia in 1991 but Halijah's role as a caregiver started earlier than that (in 1988) when her late father married another woman and left her mother alone. Basically she has been a caregiver to her mother for almost 21 years. Besides the mental health problem, her mother also has high blood pressure. Her mother was once hospitalised in a psychiatric ward for a month after many years just relying on traditional treatment with a *bomoh* (shaman). Currently, her mother continues taking medicines as an outpatient and having monthly consultations with the psychiatrist.

Zainun

Zainun is 62 years old, a wife who looks after her husband aged 76 who has depression. They have been married for almost forty-four years and have four children aged twenty two to forty years old. Three of the children are married and live separately from them and the youngest son is at university. Therefore there are only two of them, an adult couple (one generation) in their house.

Zainun received her primary education from a religious school, however she did not finish her schooling. Zainun has lived together with her husband since they married in 1964 and since then has been a fulltime housewife to her husband. The husband is a retired academic from one of the universities in

Malaysia. When her husband was diagnosed with depression in 2002, Zainun's responsibilities changed indirectly. Her husband is an outpatient in psychiatric clinic and continues to receive treatment every month. Besides depression husband also has problem with the nerves of his feet.

Wanie

Wanie graduated as a pharmacist and works in one of the health centres in Kelantan. She is 41 years old, a single mother with two sons' aged fourteen and thirteen. In her family, Wanie is a third daughter from eight siblings of three brothers and six sisters. She looks after mother with depression and since three years ago shared the role with her eldest sister. Her mother is 62 years old, diagnosed with depression in early 2008. Besides depression, her mother also has gastric problems and high blood pressure. Her mother was widowed when her husband passed away in 2005. Mother lived in her own house in the nearby village and sometimes alternated living between Wanie and her eldest sister, but most of the time Mother is with Wanie. There are only Wanie and her mother (two generations) in the house most of the time because both sons are in boarding school. It may be said that her mother is living with a single parent family. Her mother is an outpatient in a psychiatric clinic but there was no information on the frequency of the mother going to hospital.

Noor

Noor is 62 years old, a housewife who looking after her husband aged 64 years who has been diagnosed with a bipolar disorder. They have been married for almost forty seven years and have thirteen children, mostly of whom are married. Noor was only able to attend school until standard four and did not complete her schooling. Noor mentioned that she is only capable of reading simple and easy words. Noor's husband was diagnosed with a bipolar disorder in 1991 and has a history of being admitted twice to a psychiatric ward. However, her husband is free from other health problems. Noor's husband attends a psychiatric clinic every month to continue drug treatment. Besides being a caregiver to a husband with bipolar disorder, Noor also looks after four of her grandchildren (who live nearby) with help from her third daughter who recently stayed with her after she quit her job. They are living together as a nuclear family and only three people make up two generations at the house.

Melati

Melati is 32 years old. She completed her secondary schooling until form five and is a housewife. Melati's husband works as a lorry driver and they are staying together with five children in the same household including, Melati's parents and Melati's youngest brother. Melati's family is an example of an extended family with ten people in the same household which comprises three

generations. She comes from a family of four siblings. Melati has been looking after her mother with schizophrenia, aged 62 for almost two years. Her mother was diagnosed with schizophrenia four years ago. Her mother has a history of being hospitalised in the psychiatric ward several times because she had 'run amok' and caused a bad injury to a villager. However, currently, her mother continues with the medicines and consultations from the psychiatric clinic every month. Her mother also has a skin problem.

Aida

Aida is 41 years old and works as a teacher in one of the secondary schools in Kelantan after completing her tertiary education in business management. She is the eldest of four siblings. Aida is married and has three children aged nine to thirteen years. Aida has been a caregiver to a mother with depression for almost three years. Her mother is sixty seven years old and was diagnosed with minor depression in the early 1990's. Her mother was widowed when her husband passed away in 2006, when she became more depressed and following that came to live with Aida, where she remains. There are three generations in the house consisting of six people and classified as an extended family. Besides the depression her mother is free from other health problems, however, she claims that she also has a gastric problem. Her mother is treated as an outpatient at the psychiatric clinic and her visits to hospital for follow up treatment are on a monthly basis.

Asmah

Asmah is 53 years old and the youngest of four siblings. She is working as a teacher in a primary school in Kelantan after graduating from teachers' college. Asmah married her husband at the age of forty four and has no children of her own. She has six step children. Most of whom are married and working. Asmah is a caregiver to a mother with depression who is 85 years old. Asmah became a caregiver to her mother because she has been living with her mother from the beginning. There are currently only three people in the house, from two generations. For almost twenty years she has been a caregiver to her mother. Her mother was diagnosed with depression in 2003. Her mother was widowed when her husband died in 1989. Besides depression, her mother also has asthma and a history of tuberculosis. Her mother continues to receive consultations and medicines from the psychiatric clinic every two months and was once admitted to hospital.

Rina

Rina is 44 years old with her own business as a goldsmith trader. She is married with her husband working as an administrative assistant in a government office.

Rina completed secondary school. They have two children, a son aged twenty two and a daughter aged six years. Rina is the only daughter from four siblings. Rina became a caregiver to a mother with depression thirteen years ago after her father passed away in 1995. Her mother aged 79 was diagnosed with depression since 1996, a year after her husband died. Since then, her mother has lived together with Rina as an extended family. There are five people in the house consisting of three generations. Besides depression, her mother also has diabetes, high blood pressure and gastric problem. Her mother is an outpatient in a psychiatric clinic and has a scheduled appointment with the doctor every two to three months.

Amira

Amira is a pensioner, aged 60, a retired assistant nurse from one of government hospitals in Kelantan. She has completed a secondary school education. Currently, she is a housewife and looks after her mother who has depression. At the same time, Amira looks after her two grandchildren. Amira is married and has eight children. Amira is the second daughter from ten siblings, three of whom have died. Besides Amira, her husband and mother, other family members live with her: her daughter, son-in-law, two grandchildren and other three children who are still single. They are living together as an extended family consisting of four generations. Amira's mother is 78 years old, a widow and was diagnosed with depression in 1998. Besides depression her mother also has fibroid problems. Amira has been a caregiver to her mother for almost eleven years. In the past couple of years her mother has been living alternately with other children. However, most of the time her mother is with Amira or her brother who is staying in Kelantan too. Her mother is an outpatient and sees her doctor every two to three months at the psychiatric clinic.

Ali

Ali is 64 years old, a spouse caregiver, married with a 62 year old wife who was diagnosed with depression in the early 1990s. Both of them have been living together since married. They have three children, two daughters and a son. The children are aged between 29 and 38, and all married and working, an all live separately. Ali is involved as a caregiver to his wife because of this married relationship. Ali completed his education at teachers' college and since 1999 has been living in a retired teachers' pension. Currently he has a small business at the night market. Ali's wife has been diagnosed with depression for almost 18 years. Besides than depression, his wife also has high blood pressure and diabetes. His wife is only an outpatient at a psychiatric clinic, however, throughout the interview there was no information on the frequency of contact with the psychiatric clinic. Ali hired a maid from Indonesia to assist him in the caregiving of his wife. She lives with them so there are three people in the house: the couple and their maid.

Khatijah

Khatijah is 66 years old, a spouse caregiver to her husband who has bipolar disorder aged 70 years. Khatijah is a housewife, however she teaches children at their village to recite the verses from the Quran and she gets some money from the job. In their marriage they have seven children. All their children are married and live in another state except a son who lives nearby her in the same village. Khatijah only has schooling until standard two and did not complete her primary education. Khatijah's husband has no other health problems but was diagnosed with bipolar disorder when he was admitted to a psychiatric ward in 2004. Since then Khatijah has been a caregiver to her husband. That is the first and last time her husband has been hospitalised, and after that has only been as an outpatient at a psychiatric clinic. There was no information on the frequency of visits to the psychiatric clinic. There are only two of them living together as an adult couple in the house.

Nani

Nani is 46 years old and a single mother without children. She works full time in a ketchup factory nearby her village. She completed secondary education until form five and after that did not continue to another level. Nani the third of four siblings, she has two brothers and a sister. Nani has been a caregiver to a mother with depression aged 73 years old for almost twenty years. Her mother was widowed when her husband died in 1965. Her mother was diagnosed with depression in early 1990s. Nani's mother has never been hospitalised and has only been treated as an outpatient. Every two to three months, her mother would have an appointment at the psychiatric clinic. Her mother also had a stroke and suffers from high blood pressure. Nani has lived with her mother since her divorce, while other siblings have their own families and live in nearby villages in Kelantan. There are therefore, only two generations in Nani's house: the care recipient and a single parent.

Findings

In this study, informal support systems are centered on the relationships of caregivers with people in their locality. Most caregivers mentioned the assistance from their extended families, neighbourhood, village headmen and friends' network in relation to their roles as caregivers. Extended families are important in the Malay family system and play a big role in contributing their assistance and support to the primary caregiver as well as becoming 'resources' to the family. Extended families in this study refer to spouse, parents, children, siblings and in-laws and divided into two groups: extended family who live locally (in a nearby village or district) and extended family who live at a distance (outside Kelantan).

The range of help and support from the extended family differed from one family to another. Six caregivers reported that they received considerable assistance, in contrast to eight caregivers who reported that they did not get much help from their extended families. The following discussions address the different help and support provided by the extended family: shared-caregiving; access to resources; choices of resources as well as emotional and general support. In addition, neighbourhood support came in many forms such as helping to look after the older people at home; suggesting a relevant traditional treatment; helping send the older person to hospital; coming for a visit and asking about the progress of the mental illness; giving advice and sharing problems as well as being a companion for the older person when the caregiver is working. Neighbours and friends' network gave information about assistance from the related government agency and providing information and exchanging ideas about the mental illness. Similarly, the role of village headmen was to connect with the systems in relation to accessing financial resources.

Access to resources

Access to resources included the financial contribution and advice or information. In financial terms, there were two conditions reported by the caregivers: family members who gave financial support and the other groups who did not provide financial because they were unable to do so. For the spousal caregivers, two out of four reported that their adult children were responsible in terms of financial assistance except for Khatijah. However, Khatijah's son helped her in providing the 'Guarantee Letter (GL)' from his employer (since he is public servant) when the father was admitted to hospital. Noor's father-in-law was involved in helping her financially when her husband was admitted to a psychiatric ward, but nowadays since all her children are working; they were responsible for financial support. Noor said:

“During that time his father was still available. When he (my husband) was admitted at the hospital...they (family in-laws) helped me a lot...at least, they were able to help me...they did give me (money)...because all my children were kids during that time...I have many children too...all of them still at school and I'm not working either...but then once in a while my siblings help me.”

Malek, Nani, Melati, Siti and Amira reported that their siblings contributed by giving money although this was not frequent. For instance, Malek said:

“...there are some of them who considered my sacrifice, so they gave money to me. I didn't ask for it

but I accepted it when they gave it, that's their mature position, maybe they think that they can't help in other ways."

Aida, Halijah and Wanie reported that other siblings also helped them with financial support when they deposited the money directly into the mother's account, although their mothers have their pension as widows when their husbands worked as public servant. They as a caregiver could afford to meet the expenses of the hospital and daily expenses. Halijah said:

"My late father was a public servant although Mum is a fulltime housewife (so she has the pension from father). Then most of Mum's children graduated (from university) and have their own job...so every month they will deposit some money into Mum's account."

The financial assistance involved both locally and distant extended families and usually it was depending on the readiness or financial status of the family members in supporting the primary caregiver.

Some siblings helped the primary caregiver in relation to giving information about the mental illness. Aida stressed that her family members were important resources in caregiving for her mother. Aida said: *"No, I never seek help from other people. I mean only among us, our family members.* For instance, her brother who is a doctor became a reference in relation to the side effect of the medicine that caused more headaches for the mother. Aida said:

"I just called my brother, called my brother and told him (about Mum's condition). My brother would call his friends to get information."

The above discussions demonstrate the importance of extended families as part of the informal support systems although not all members in the extended families were helpful. Some reported that their caregiving was also supported from the circle of neighbourhood and network of friends. Aida, the daughter of a mother with depression described her neighbours' assistance in the following way:

"... when everybody went to work, some of the neighbours would watch over Mum so that she wouldn't become worse. They kept her busy by talking to her and not letting her sit alone. They offered that kind of help to Mum."

However, three caregivers (Amira, Melati and Halijah) also mentioned that there was no assistance from the villagers because they did not get involved or socialize with the neighbourhood. Neighbours did not really know what was happening in their family. Melati did not expect any help from her neighbours, knowing that they also had their own problems. Halijah said:

“In term of the villagers, I do not even bother because I don’t mix with them. Back from work, I just close the door and don’t bother to have a chat with the neighbours. My house is on my own land, only my house, if we stay at terrace housing we need at least to say ‘Hi’ with our neighbours, right? But since I live at my own property, I just mind my own business, not become involve with others, and even if they said something bad about my family, I don’t even hear that.”

Amira and her family were new in the neighbourhood. Sometimes caregivers did not expect much help from the neighbours because they were “ashamed” in relation to the mental illness. Unlike Halijah and Amira, Siti finds it was comfortable to get some advice and information from her neighbour:

“..and by chance, there is HA (Hospital Assistant) at my village working at the psychiatric ward in Kota Bharu. I asked her because I’m afraid something is wrong with Mum. I always ask around (about Mum’s mental illness).”

Shared caregiving tasks

The involvement of extended families in providing support to caregivers is the focus of this section. Ten primary caregivers reported that they were receiving assistance from other family members in getting the older people to hospital appointments. Spousal caregivers (Zainun, Khatijah and Noor) except Ali were fully dependant on their adult children to drive and accompany them to the hospital. Khatijah, whose husband suffered from a bipolar disorder said:

“Sometimes my son who works as the driver would bring us along if he was going to Kota Bharu. He would take us to the hospital but we had to get back on our own. He wouldn’t bother after that because he needed to go to work then, besides his work needs him to follow some schedules. You know the nature of work as driver, right?”

Before having a housemaid, Ali's daughter who lives at the teacher's quarters in the nearby district helped him to accompany her mother but then Ali said: "*I don't want to burden her anymore because she had to take leave because she is teaching.*" For some adult children caregivers like Amira and Asmah, their brother would assist and transport the mothers to the hospital due to both of them being unable to do the task on a regular basis. If her brothers were unable to help, Amira's husband and children would help her with the task. Amira said:

"Lately since I had to take care of my granddaughter, it's such a problem for me. When she was a baby, it was okay. I could carry her when we went to the hospital, but now it's quite difficult. I easily get tired chasing her around the doctor's room, so every time Mum needs to see a doctor for her medical appointment, I will call my brothers in Pasir Tumboh¹ or in Kubang Kerian². I will ask them to take Mum to the hospital. I told them that it was not that I don't want to take Mum to the hospital, but I had to care for my grand children too, so it was difficult to handle two people at one time. So when Mum needs to go for her follow up with the doctor, my brother would come and fetch her and sometimes I send her to my brother's house, then they would bring Mum to the hospital and usually my sister-in-law (brother's wife) would accompany Mum to the doctor's room."

The situation was also different when it involved a working caregiver; involvement and understanding from other siblings or their partner was much appreciated. Asmah's brother who lives in the same village helped her:

"My brother would bring Mum for the appointment, because he is retired, and I cannot leave my work at school since the time for the appointment is always in the morning, so if I leave school for that, it would affect my work at the school."

In the case of Rina, her husband took over the task to bring her mother to the hospital on a tri-monthly basis. Rina's husband commented:

"Because I'm working in the office while my wife is doing her business, there might be customers coming (to the shop). When Mum was more comfortable with

1 A place in the district of Kota Bharu

2 A place in the district of Kota Bharu

the doctor, I didn't come in because the doctor could talk to her alone, so when the doctor called up (her name), I just guided her to the doctor's room (in the clinic), that's all."

Some extended families who lived nearby each other would look after the older person when the primary caregiver went out to work. Usually they just prepared the meals. Primary caregivers were sometimes aware that they could not rely on other family members because they have their own responsibilities and their own family to look after. Noor, whose husband has a bipolar disorder, lives in the village surrounded with all the relatives. Her family fully supports her and she never thought of receiving any help from other people. For Noor, family problems should be shared within their own family. Wanie also had a good support network from her extended families including those who live locally or outside Kelantan:

"So far, my siblings play their parts very well. They don't leave it for me alone to take care of our mother. We take turns. Sometimes it's my sister, sometimes my youngest sister and at one time my auntie too because I was not always available at Mum's house. Sometimes when I was at work, my sister would call me and tell me that Mum is sick...things like that. I feel grateful that all my siblings and in-laws help me to take care of her."

Assistance with medication was also provided by other family members to the caregiver. Melati and Halijah's children helped her to assist and to make sure that the care recipient takes the medicine on time.

The support provided by the extended families that live far away from the primary caregiver was classified as shared-care. The primary caregiver acted in coordinating, assisting and arranging the 'caregiving schedules' among the family members. Halijah, the eldest of six siblings, in relation to caregiving of their mother who suffered with schizophrenia said:

"I'm the one who would decide (on the arrangement) but somehow it was an open decision. I sent an SMS (Short Messaging System) to all (of them), sent it to my siblings and said: "Next month, (our) sister in Kedah will have Mum first". I will let them know then they will reply: "It's okay then if our sister in Kedah would like to have Mum first. After that send Mum to KL." It would be like that. They will have their turn.

If then suddenly I feel that Mum is away too long with them, I will ask them to bring Mum back home to Kelantan again.”

Halijah would make sure that all her siblings were well informed about the medication and remind them to bring their mother back to Kelantan when it was near to the next appointment with the psychiatrist. However, the situation was quite different for Rina. As the only daughter of four siblings who look after a mother with depression, she sadly said during the interview that when she told her brothers who live in another state about their mother’s condition and asked them to come back, she had an unpleasant response from one of the brothers. Rina’s husband described the situation:

“If they come back to visit they would scold us, can you imagine that? “Oh Mum is not too serious but you’ve been calling us only for this”. But the thing is, Mum is the one who asked us to call her children to come back (to see her). She felt uneasy, she felt like dying... so when everybody was here, they would moan to us. That was the hard thing.”

Some of the caregivers also reported that their other family members assisted them in terms of monitoring and informing the primary caregiver about the current progress and condition of the older person. For two working caregivers (Wanie and Asmah) the sister and the husband helped these caregivers while they were away at work. Asmah said:

“My husband is always available at home, meaning that if something happens, he can contact me...but not before this. No one was in the house to contact me...Mum knew nothing about my contact number... since my husband is always here...”

Making decisions about service use

The extended family has a say in relation to particular decisions about the older person’s welfare and interests particularly in relation to the mental illness. The decisions were related to getting psychiatric treatment or treatment from a traditional or religious healer. Sometimes the decision made was based on mutual agreement and sometimes it was left to the eldest in the family, particularly the son although they were not the primary caregiver. For instance Asmah said:

“All the decisions is made by my brother...if we want to bring Mum to the hospital, I need to ask him first...”

but if Mum's condition is really bad, I just bring her then later I will inform him and our other siblings, especially if Mum is admitted to the ward. I will call my sibling...telling them that Mum is in the hospital... no problem with that."

In the case of the spousal caregiver, Zainun said that her husband made his own decision to cure his depression, while Noor was dependant on her children. Although, the eldest sibling, especially the brother, would have influence in some circumstances the final decision was made by the primary caregiver after the problems had been discussed and the whole family had been informed about it. Amira said:

"Normally, my brother from Kubang Kerian would come over and discuss the situation with me but sometimes all my siblings would stay at my house to discuss any matters and all final decisions are made here."

Other family members just agreed with the decision made by the primary caregiver as long as the older person is cured. Siti said:

"I just told them (my siblings) what the doctor already told me...so I told them that the doctor wants to refer Mum to P.S.Y. (psychiatric clinic). That's fine then, they're supportive and had no objection to that... because before this they also don't know what to do... so we just thought that we cannot let Mum just be like that...harming other people."

In contrast, in the case of Rina, not all her siblings would be involved when making the decision in relation to the mental illness of their mother:

Rina's husband
"...if I asked the other siblings, calling for discussion, there'll be no decision. Finally it'll be back to us... just adding more headaches."

However, the input of family members was generally important in decision making which was sometimes joint and sometimes dominated by the primary caregiver. When the extended families supported the role played by the primary caregivers, fewer problems occurred in the family. However when there was not much help and no cooperation, seven caregivers worried about the future caregiving of their mentally ill family member. For instance Malek said:

“... sometimes I tried to tell my wife, if I destined to die earlier, who is going to take care of them? What’s going to happen if I die before him? I don’t know, really don’t know, ‘Wallahualam’ (Allah knows better).”

In some cases, the extended family living at as distance from the caregiver and the care recipient suggested getting treatment from a traditional or religious healer and trying to search for a cure and alternative treatment of the mental illness. Amira, Halijah and Wanie mentioned that their extended families helped to find the best treatment for the mentally ill person. Sometimes when Wanie did not have time because of her work commitment, her siblings or brother in-law also helped her to bring their mother to see the *ustaz*.

“My brother-in-law really tries to find the healing water. Sometimes when Mum wants to see the religious teacher, he would take leave and bring Mum there. He was not much fussed about it. He’s really a responsible person even though Mum is only his mother-in-law and not his own mother.”

Amira’s siblings especially her brother also helped her at the beginning. Amira’s siblings were responsible in supporting her role although most of them live in another state.

“I wanted to bring Mum to the hospital but she cried and refused to go. She got immediately frantic about going to the hospital. Then all her children (my siblings) came home and tried to console her. We advised her “Mum you have been sick too long; you need to go to the hospital”. It took us some time before she agreed.”

Emotional support

In terms of encouragement, there were different responses from the caregivers when asking them about the involvement and assistance from their spouse. Siti mentioned that her husband was not really supportive to her as a caregiver to a mother with bipolar disorder. Siti said:

“When Mum was unwell and got furious some days, he did nothing, because (he said) his family is not like that. My husband once told me that he will never forget what Mum did then. He seemed not to accept

that but he says too that although he could not accept it he is trying because Mum is destined to be like this."

In contrast, six caregivers (Rina, Halijah, Asmah Aida, Amira and Malek) reported that they feel supported by their spouse. Aida, Amira and Malek mentioned that their husband and wife respectively did not feel burdened and could understand the condition. Amira said:

"My husband has no problem with that, he can understand my mother's condition, that is why he doesn't complain when my mother stays (with us) for quite some time. He doesn't say a word...not even a complaint like "I got fed up with this old lady"not even a word. Alhamdulillah (All Praises to Allah) my husband is very understanding."

Rina, Halijah and Asmah indicated that their spouses were a 'great support' in relation to their role as a caregiver to mothers with mental health problems. The husbands of these three caregivers became the person who shared caregiving problems when siblings 'refused' to hear their story (Rina); became an 'initiator' in suggesting seeking another option for treatment (Halijah) and accepting the condition of the older person with mental illness without doubt. Halijah said: *"My husband gives full support (to me). He never looked down on Mum.* Asmah believed her husband's presence gave her strength to continue with her role as caregiver to a mother with depression. She said:

"Alhamdulillah (All praises to Allah). Even my husband cannot do much work (because of the kidney problem). At least I have someone with me, someone to inspire me, inspire Mum too. Whatever happened, of course I will tell my husband, I feel so relieved... so enthusiastic because of my husband. My spirit is getting stronger."

Most of the women caregivers have their own children, some of the children also made some efforts to help the caregiver with the caring tasks. For instance, Aida said that her children know that their grandmother is unwell but did not know details about the illness. Aida said:

"They knew, but they did not really take it in (take it seriously). They're just children so they don't care much about it. When their grandmother is okay, they come closer (and chat with her)...children right? If we asked for a little help it's okay then, but not if we

ask them to take care of her...they're just kids..."

Amira's children only support her by giving motivation when dealing with her mother's depression.

"My children know and only say something like: "What can I do? It seems destined for you to care of grandmother." This is the kind of reactions my children gave me. "Just let it be mother, be patient." I said: "Yes, I've been patient all this while. If not surely your grandmother would have left (this house)."

Malek feels frustrated that some of his siblings, especially his eldest brother, did not show their concern about their father who suffered from bipolar disorder. However, he felt grateful because his mother, wife and sister (married and living in another state) were always supportive of him particularly when Malek needed to share his emotional burden of the caregiving and his disappointment because of his other sibling's attitude.

"There's one of my sibling, who never cares at all, doesn't bother, but there are some of them who considered my sacrifice, so they gave money to me. I didn't ask for it but I accepted it when they gave it. That's their cleverness. Maybe they think that they can't help in other ways. But there was one time when I felt like I wanted to rebel, as I'm just a human being right? If I'm the only one who cares for my father and others don't, sometimes deep inside my heart I feel that I want to protest."

For the spousal caregiver, although most of their adult children were married and living separately, there was evidence of their support in terms of advising and motivating the primary caregiver. For instance, Zainun said:

"My children always said that I have to take care of their father well, avoid making him feel sensitive... because they're afraid that he'll get worse. (They advised) something like that."

Networks of friends were important for some caregivers to assist them to balance their life with their role as caregiver. These networks are mentioned more commonly by caregivers who are in fulltime employment. Four caregivers reported their experiences of using the friend's network as part of

their informal support. For example, Halijah said that her friend ‘lends her ears’ to her problems. Sharing problems and being introduced to a specific treatment by colleagues helped ease the burden of care. Wanie stated:

“Sometimes when I chatted with my friends about our work, I told them: “My mum’s sick again, her head throbs.” I asked them whether they had heard about which ustaz to go to for ache in the head. One of my friends said: “Oh, it’s quite hard if she’s having that kind of pain” and she continued “But you’ve tried your best, right”. She also urged me to continue praying. Some friends had helped by bringing some healing water as well.”

Some caregivers also did not think that neighbours were concerned with what was happening and were unhelpful about offering assistance to both the caregiver and the older people with mental health problems. Asmah commented on the current situation of neighbourhood spirit:

“..but neighbours these days, they are not same as in those days. During the old days, if they heard someone was sick, they would come for a visit but nowadays, it seems this ‘event’ became faded, it’s so different now.”

In summary, extended family who lived nearby the primary caregiver supported the role in many ways although in few cases conflict occurred when caregivers often had to manage multiple roles, as a caregiver, paid worker or as a parent/children. In some circumstances, some of the caregivers were part of a complicated family which impacted on their caregiving role. When the primary caregivers felt that the nearby family members were unable to help, they continued to share or delegate the responsibilities with other family members who lived at a distance. On the whole, the caregivers relied on family members for support and getting access to different resources.

Caregivers have to balance up their needs and the needs of other family members including the older people with mental health problems. Undoubtedly, most of the caregivers experienced lots of support from their family. In some circumstances they had managed to achieve the balance but sometimes the balance was somewhat costly to the caregivers. There were areas of unmet needs that need to be taken into consideration.

Discussion

The importance of family and the impact of caregiving on the family system

Caregivers in this study were largely members of extended families of several generations. These participants valued the support of other family members. Even though in most of the cases, other family members did not live in the same household, family ties and obligations are strong for most family members, despite the domestic conflicts that existed for some families. In some cases, shared caregiving was practised by adult children caregivers for a parent with mental health problems. This gave an opportunity for the extended families to become involved in providing support for parents by assisting the primary caregiver. The willingness of other family members to assist the primary caregiver or share the caregiving role also depended on their capacity and their physical location.

While the caregivers' experiences had these similarities, differences related to how family members managed the problems that occurred in their family and how caregiving was negotiated within the family. The system involved in caregiving is a big system, generally larger than a nuclear family system. At the same time, there were many different external care systems with which caregivers had to work, integrating traditional, religious and modern systems. The majority of care was provided by family. The additional tasks of caregivers centre on managing all of these three systems. The study affirms that when the family system was unsupportive or relationships were strained, the caregiver was stressed. It was hard practically to manage because there were many gaps caused by a lack of resources in the formal system. Most caregivers relied on family members to help meet these gaps and struggled if such support was not available. For many of the participants in this study, there were a range of family choices, so care provision could be negotiated, flexible and shared; generally it was not only one person 'trapped' in the caregiving role. It was also apparent from the study that none of the participants intended institutional care for their family member. They wanted to continue with their family role despite all the challenges. The caregiving role was viewed as a privilege, even though there were stresses in the role. This perhaps differs from caregiving for mentally ill family members in other countries, particularly seen in western studies where most of these studies assumed that the caregiving role brings negative impacts to caregivers' lives (e.g. Baronet, 1999; Ohaeri, 2003).

It was clear that some gender differences are suggested in the caregiving role. A study by Pinqart and Sorensen (2006) which summarised 229 studies using meta-analysis approaches reported that there were significant differences among the male and female caregivers of older adults aged 60 years and above in terms of caregiving tasks and use of social resources. In the current

study, there was evidence that for the two male caregivers, caregiving for a family member with mental illness was not a 'hands-on' role but was involved more with managing, organising and making sure plans were carried out and problems were resolved. The male caregivers in this study seemed to manage the roles and tasks by delegating to others including 'sharing' the roles with a paid caregiver when this could be afforded. These findings also support Jegermalm's (2006) study which found large differences between males and females in caring tasks where usually women provide personal care and men were involved in more practical help. The male caregivers in this current study (one husband and one son) supported the contentions that there were gender differences in managing caregiving, though the small number of the present study's sample limits any generalisation.

Spouse and adult children caregivers differed in how they coped with their caregiving experience, supporting the findings of other studies (e.g. Pinquart, 2011; Stoller & Miklowski, 2008). In Pinquart's study, which used a meta-analysis of 168 empirical studies, spouses who were involved with caregiving for their older partner provided care with little additional help compared to adult children. Children were more likely to experience psychological distress because of conflicting responsibilities (Pinquart, 2011). In this study, spouse caregivers did not expect to share caregiving with their children, but amongst the adult children looking after parents shared caregiving was practised. Findings from the study demonstrate financial status also influenced the degree to which care was shared. The situation of the husband in this study was different from that of wives in relation to financial status. The husband had a helper to assist him. The role of the helper in providing help '(did) not act as a substitute for the primary caregiver to ease their burden but served to supplement their support because the needs of the care recipient are so great' (Lima, Allen, Goldscheider, & Intrator, 2008, p. 236). However, again it is difficult to generalise from this one situation.

For some of the children, the length of time the older person had had the mental illness and its severity had a great impact on their childhood. Some caregivers reported that their family members had been attacked by the older person with mental illness. For others, having a parent with a mental illness (e.g. schizophrenia) impacted later in adult children's lives, when the caregiver married late in her life and they needed to negotiate with their future husband in relation to the marriage and their caring responsibilities. Impacts on their marriage also included the conflict in their relationship with their partner as well as in-law family members linked to their parents' illness. Talwar and Matheiken's (2010) study of Indian caregivers in Malaysia and India on the impact of schizophrenia on family and marital relationships supports these findings. The study reported that in terms of family relationships, 36 percent of caregivers in India felt that their patients' illness inhibited them from having

a 'satisfying relationship' with the rest of the family members compared to 24 percent in Malaysia.

Nevertheless, for the spouse caregiver, the impact was less severe, generally because the mental illness developed late in their marriage and care was integrated into the marital role. The change was in family dynamics when the wife took care of the husband and vice versa and they had few other responsibilities, unlike child caregivers who had young families to look after. In terms of financial support, spouse caregivers did not expect their children to help them, while child carers did expect assistance from their siblings. In one case the wife made an effort to apply for financial assistance from the social welfare department rather than ask the children. On the whole children cared in the context of relationships with siblings, while spouses cared with much less support. Malay caregivers experiences of providing care for older people with mental health problems influenced strongly by the cultural and belief system and the family system played a major role in this context.

Conclusion

In this study, while most caregivers had reasonable family support, the village network support was very limited and poorly coordinated. Most of the caregivers in this study are really on their own with minimal help and support outside their families. There were several reasons that kept family caregivers isolated and not picking up services or in some cases not demanding services that they required, although they could identify the support and assistance which they needed. One of the reasons was lack of information about the related services and lack of knowledge about to whom they should refer to get the support. One of the participants was concerned that because of modernisation, the neighbourly spirit among the village community had declined and they were no longer concerned about other people's problems.

In terms of implications for social work practice and education in Malaysia, it is important to engage social workers in understanding and meeting the needs of caregivers of mentally ill older people. Although some caregivers were in need of help and support, social workers will need to understand that many will not identify as caregivers and will not initiate contact in relation to their own needs. This requires a proactive approach from social workers in clinics and hospitals that makes contact with caregivers and initiates discussion around caregivers' needs and issues.

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