Malay Women's Perspectives as Primary Caregiver to Older Adults with Mental Health Problems: A Qualitative Study

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Abstract

Most family caregivers are usually women. They play an essential and significant role concerning family caregiving despite remaining unrecognised in the community. As the primary caregiver of older adults with mental illness, women encountered multiple roles. The challenge is severe among women with full-time employment and those who were self-employed when they had to balance and fulfil competing expectations of the older person, other family members, and the demands of their employment. A qualitative research design was utilized to gather data from 12 participants in Kelantan, Malaysia using in-depth semi-structured interviews, audiotaped, and thematic analysis to analyse caregivers' caregiving experiences to an older adult with mental illness. The findings revealed that despite the challenging situations and consequences, women caregivers were still determined to continue their caregiving role. This input informs the need for policymakers/government and service systems in health to work closely to support women caregivers in providing care for older adults with mental health problems.

Keywords: Female caregiver, caregiving, mental illness, Malay women, ageing

Introduction

Older people form an increasing proportion of the world population resulting in fundamental challenges in developing appropriate service and policy responses (WHO,2022). Informal caregiving has been recognised as central to the service system and policy responses (Schulz et al., 2020). There is a significant concern,

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however, surrounding who will be available to provide informal care and at what cost to families, and what cost will be involved in meeting caregiving needs as well as its massive impact on the lives of their families (Bom et al., 2019; Fekih-Romdhane et al., 2020) and the state (Dong, 2022; Ekman et al., 2021). In addition, mental health problems among older people have not attracted much attention in the policy response and practice (Reynolds 3rd et al., 2022). However, older people have been identified as a particularly vulnerable group suffering from various mental health problems such as schizophrenia, depression, anxiety, and psychotic disorders (WHO, 2021).

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 of (i) improving understanding of community perceptions and behaviour regarding the illness; (ii) to improve implementation in health service delivery; and (iii) to strengthen, develop and test new modalities in terms of family and community involvement strategies (National Institutes of Health, 2006). Therefore, an understanding of caregivers' experiences in this context is needed in policy terms.

It is essential to point out that the ageing population has significant implications for family and government policies regarding meeting their needs (Hamdy & Md Yusuf, 2018; Jawahir et al., 2021). An ageing population challenges families who provide the bulk of long-term care (Kong et al., 2021; Chung et al., 2020). In addition, people aging with mental illnesses present additional challenges which are not well understood—in other words, increasing longevity results in an increasing number of older people who will require long-term care. It includes the concern about their mental health status and the provision of geriatric services and facilities (Kar, 2021; Zechner et al., 2019).

Regarding gender, women are at greater risk of mental health problems (particularly depression and anxiety) because of their longevity (Kiely et al., 2019; Riecher-Rössler, 2017; Zhao et al., 2020). These facts are paralleled with the finding that older women receive significantly more formal support due to their more prolonged survival in life (Carmel, 2019) and perhaps the lack of availability of informal caregivers. Therefore, it is crucial to understand the interaction between formal and informal systems of care. Research (e.g., Cox, 2020; Udhayakumar & Ponnuswami, 2020). suggests that understanding how older people are ageing in their social environments requires special attention from policymakers, social workers, and the community at large.

At the same time as the population is ageing with its implications for family support, modernisation has implications for caregiving, especially for a developing country like Malaysia (Ali et al., 2021; Aman et al., 2020; Aziz & Ahmad, 2019). Several factors are related to modernisation, such as the changing patterns of the family from extended family to nuclear households (Carr & Utz, 2020), the deterioration of family values, and the emergence of individualism (Leung et al., 2020), women's increasing participation in the workforce (Jayasingam et al., 2021), the migration of the younger generation to urban areas because of employment and/or education and the older generation staying alone without support from the nearest extended family (Teoh et al., 2020). These changes require family members to negotiate caregiving roles. The traditional value of family care is still substantial (Yoon & Kropf, 2018; Ahmad Ramli et al., 2021), but several adaptions are needed. Modernisation also means accepting and expanding western healthcare (Yap et al., 2020), whilst at the same time considering the cultural-religious intervention (Heng & Gone, 2018) particularly within psychiatric and mental health services.

Caregiving Policy and Programmes in Relation to Family and Older Person

In the Malaysian context, the definition of older people is in line with the World Assembly on Ageing (Vienna, 1982), which defined older people as those aged 60 years and above (Md Nor & Ghazali, 2020). In preparing for the shift to an ageing population, Malaysia has promulgated relevant policies: the National Policy for Older Persons,1995 and the National Plan of Action for Older Persons,1998 (Shamsiah, 2005). Generally, both policies aspire to provide care, protection, services, and overall well-being for older people and include the roles of families and communities in providing care to this group. The role of the family as a significant provider of care was significantly recognised in implementing the 'Family First' campaign in 2003 (Malaysia, 2006). It is also in line with the concept of a caring society introduced in the Eighth Malaysia Plan (2001-2005), which reinforced the need to maintain the integrity of the family structure and to encourage family members to take care of their older relatives (Division for Social Policy and Development, 2001; Malaysia, 2001). The Malaysian government has allocated RM 842.5 million for a family and community development programme in the Ninth Malaysian Plan compared to RM 738.8 million in the Eighth Malaysian Plan (Malaysia, 2006).

Malaysia's five-year national plan also emphasises the family as the central support system for older people. Beginning with the Seventh Malaysia Plan (1996-2000) and followed by the Eighth Malaysia Plan (2001-2005), the issues associated with the ageing population and the role of the family are noted as follows: *"…caring for the elderly continues to be the responsibility of the family"* (Malaysia, 1996, p. 571) and *"…the family will continue to be encouraged to take care of older persons"* (Malaysia, 2001, p. 533). The National Social Welfare Policy is a central policy for social welfare and a major source of guidance in national development policy to strengthen the family institution towards improving social well-being. It embraces most of the target population who need welfare provision, including families and older people (Ministry of Women Family and Community Development, 2005). In general, the government has validated the importance of the family as caregivers to older people. However, no specific framework defines their roles or the support services available to carers and their elderly relatives to promote their well-being and welfare.

In general, health care in Malaysia is provided by the government and private sectors, and the increasing involvement from non-governmental organisations (NGOs) (Abd Manaf et al., 2017; Ivory, 2018). In 1997, a National Plan of Action on Community Mental Health programme was set up to train hospital personnel in 58 health clinics to upgrade knowledge and skills in mental health and issues associated with older people (Ong, 2002). This programme was organised under the Ministry of Health. However, Philip et al. (2004) argued that psycho-geriatricians in Malaysia are not readily available and general practitioners and the patient's family presently bear the brunt of providing care without having appropriate support in the community. Francis & Guan (2020) argues that programmes and services (particularly for the aged) were lacking, and geriatric care had not become a priority in health care services. The system was mainly geared towards short-term care and hospitalisation, and those geriatric services were in a very formative stage (Tan et al., 2018; Yap et al., 2020). Geriatric services are not widely established. Nursing home care is not part of Malay culture. It has to be paid for by the family, thus is only affordable for specific people and is only available to the urban population.

While many studies worldwide have examined the experiences of family members caring for people with mental health problems, very little is known about caregivers of older adults with mental illness. In Malaysia, very little is written about the family as caregivers for older people with mental health problems, particularly in rural environments. At the same time, modernisation is putting new strains on Malay families providing care to older adults with mental illness. This includes the deinstitutionalisation policy, which promotes community mental health services. However, implementing services and programmes has significant gaps (Almi & Khaiyom, 2020; Low et al., 2019). Supporting family caregivers is an increasingly important part of providing community care, with increasing numbers of families looking after older persons with mental health problems.

Methods

The findings discussed in this article are part of the more extensive study conducted to understand caregiving experiences in a mental illness context among family members of older adults with mental illness. Before data collection, the study was approved by the ethics committee at the University of Queensland and the Research Ethics Committee (Human), Psychiatric Clinic, Hospital Universiti Sains Malaysia.

Research design

This qualitative inquiry is determined by the interpretive paradigm (Alharahsheh & Pius, 2020; McGregor, 2019) that focuses on depth in meanings and understanding of participants' experiences. The semi-structured and in-depth interviews were conducted with the primary caregiver to understand their perspectives and experiences in dealing with older adults with mental illness. The interview guide was developed based on the research questions and the literature review. The researcher and advisors checked the interview guide for relevance and comprehensibility of the interview topic guide. Written informed consent was obtained from all participants before the interview started.

Sampling and recruitment

Table 1 summarises the number of women caregivers who agreed and did not agree to be included in the study.

Table 1 Participants of the Study

Family member		**Types of illness of older person**	**Agree**	**Not Agree**
Gender	**Relationship**			
	Daughter	Schizophrenia	☺	
	Daughter	Schizophrenia	☺	
	Daughter	Depression	☺	
	Daughter	Depression	☺	

	Daughter	Depression	☺	
	Daughter	Depression	☺	
	Daughter	Depression	☺	
	Daughter	Depression	☺	
	Daughter	Bipolar disorder	☺	
	Wife	Depression	☺	
	Wife	Bipolar disorder	☺	
	Wife	Bipolar disorder	☺	
	Daughter	Depression		x
	Daughter	Depression		x
	Daughter	Depression		x
	Daughter	Depression		x
	Daughter	Schizophrenia		x
	Wife	Depression		x

Of the 18 women caregivers who met the inclusion criteria (the period of caring for the older adult with mental illness was more than a year as the study aimed to examine long-term caregiving; the older adults being cared for were aged sixty or above and diagnosed with either depression, schizophrenia, anxiety or bipolar disorders; the period since diagnosis of the illness was to be over a year and their current mental health relatively stable, and the caregiver was a primary caregiver in direct contact with the person they cared for), only twelve (12) agreed to be interviewed.

Data management

All interviews were conducted in the Malay language and digitally recorded. The interviews were transcribed and translated into English. Transcripts were given pseudonyms to ensure the privacy and confidentiality of participants. The English transcriptions were used to develop codes and analyse the data using thematic analysis.

Findings

Participants

Table 2 in the next page summarises participant background information.

Caregiving experiences

In this study, caregiving emerged as a gendered phenomenon among adult children, with women taking a dominant role because the older person preferred to live with a married daughter instead of a married son to avoid conflict with a daughter-in-law. Interestingly, this study found that many older people were determined to choose which child they would be comfortable with. For instance, Melati, 32 years old, the married daughter of a mother with schizophrenia, remarked:

> "Mum refused to stay with my brother because there were many people in the house. She was afraid…you know because over there is only her daughter in law, but I am her own daughter…so it is so different …because she is only my sister-in-law, right? It will not be the same if compared to me, her own daughter, looking after her."
>
> (Melati)

Table 2 Participant Background Information

Gender and Age	12 female caregivers ranging in age from 30 to 66 years old.
Relationship to the older adults with mental illness	Spouse (Wife = 3); Daughter 9.
Marital status	10 participants were married and 2 were single mothers.
Education	Most participants were considered educated, with at least a secondary school education (*n*= 5), 4 participants had completed tertiary studies whilst 3 participants completed primary/religious school.
Occupation	Most caregivers were employed; 5 participants with full time employment, 2 participants self-employed and 5 participants were housewives.
Period as carer to an older adult with mental illness	Caregiving duration ranged from 1 to 20 years. 1-5 years (*n*=5), 6-10 years (*n*=2), 11-15 years (*n*=2) and 16-20 years (*n*=3)
Types of mental health problems of older adults	The majority cared for older adults with depression (*n*=7), three cared for older adults with bipolar

	disorder and two for older adults with schizophrenia.
Living arrangement	Eight participants lived with the older adults they cared for, and the others were either living nearby (n=3) or alternately with their children (n=1).
Location of interview	9 interviews took place at the participant's house; 2 took place at the nearby cafe/coffee house; 2 in a meeting room in the psychiatric clinic and 1 in a hospital compound rest area

For Rina, whose mother has depression, there was no evidence during the interview that her mother conflicted with her sister-in-law. Instead, it was more her mother's change of mind to move back to her daughter. Rina explained:

> "Mum was not comfortable living with the other (one)…if she went to my brothers' houses, she would bring along lots of clothes as if planning to stay for a week or two, but after two days, she would call us saying that she wants to come back … She could only stay much longer if it was with my youngest brother. Sometimes it could be a month that Mum stayed with him. But after that she wanted to come back here."
>
> (Rina)

Caregiving experiences with employer and employment

Women caregivers who juggle work and caregiving responsibilities experience different levels of support from their employers. Employers are considered part of the discussion of the formal system because women caregivers worked in the formal organisation where they needed to manage and coordinate their tasks as caregivers within the demands of their job, such as transporting the older person to a hospital.

In this study, three caregivers (Asmah, Halijah, and Aida) worked in the educational sector. Being a primary caregiver and a teacher 'caused problems because they did not have much control over the medical appointments set by the hospital, mostly during school hours. In addition, it was hard for these teachers to take leave from school for a 'personal family matter.' Five caregivers in full-time employment mentioned the role of their employer as providing support concerning their task as a caregiver. Wanie, Aida, Asmah, and Nani felt they had encouragement from their workplace, while Halijah felt unsupported by her employer.

Some caregivers talked about their relationship with the employer regarding their ability to share their caregiving issues with their employer. For example, Wanie said her boss was concerned when she said she felt tired because she had to stay up all night to look after her mother with depression, who was having a problem going to sleep.

> “He said: “I am sorry, you have to look after your kids without a husband, and now your mother is sick too”. I said: “Yes, she is sick”. He said that is okay, he understood if I want to ask for the day off.”
>
> (Wanie)

Nani’s boss gave her permission whenever she asked to take leave to bring her mother to an appointment at the hospital, provided she told the boss in advance. Nani explained during the interview:

> “Not really, for example, like right now (having the interview), I did not tell him. I just informed my workmates, but for appointments, I will inform my boss. But so far, there was no problem about this…”
>
> (Nani)

Asmah mentioned that because she has been a caregiver to a mother with depression for almost 18 years, her employer was aware of the problems that she faced throughout the years. In addition, Asmah felt that she had been supported since she had never been transferred to another school since she started her work as a teacher in the state.

> “…people from the (education) department too feel sympathy for me, so they are not transferring me far from here, because they know I have a problem. They know about Mum, because my mum is sick for very long periods. Can you imagine since 1989! So, all my friends know about it, so people from school do not put a pressure on me, because they know I am having a problem.”
>
> (Asmah)

Halijah, the only caregiver who received little support, commented on her employer's attitude to Halijah's taking leave from school to bring her mother to the hospital for a monthly appointment. Halijah felt she had inadequate time to take her mother to the hospital, given the need to wait in a hospital to see the psychiatrist and then rush back to school. Halijah said:

> "As working woman, I need some support from my employer, at least some priority from them. Because I had experience with my previous Principal, when I asked permission to bring Mum to hospital, he said: "It's your personal problem, you should take a MC (Medical Certificate)." So, I was so frustrated. I admit that it was my personal matter but he should have been more considerate."
>
> (Halijah)

Asmah also experienced some negative attitudes from her employer, although she said a particular individual influenced her experience at the school. Asmah commented:

> "Give some flexibility, special (consideration) though, that's all I need. For example, if I tell the employer that today I need to bring Mum to hospital and the employer allows me to do so. They make me feel easy but sometimes because the employer is not the same, sometimes they ask: "Could you please go after the school?" There was a case like that but it up to the person though…"
>
> (Asmah)

The employer and employment conditions are essential parts of the system for some caregivers concerning getting support. As treatment required regular trips to the hospital for medication or follow-up, and there were no community-based services, caregivers reported an impact on employment and income.

Areas of unmet needs: support to family caregivers and the care recipients

In this study, all caregivers discussed the assistance they needed to support them in their caregiving role. The main areas identified by caregivers were financial support, informational support, peer support, personal support, and practical assistance. Overall, the caregivers' views of the assistance they needed and the assistance the older person needed were quite similar. Interestingly, when caregivers talked about unmet needs, they often talked primarily of the needs of the older person they looked after. Many asked little for themselves. When participants talked about their unmet needs, it was evident that adult children's caregivers required more help and support than spouses' caregivers. This fits with the previous chapter, where the spouse caregivers discussed their role and how they dealt with the problem while caring for their husband/wife.

Financial support

Financial support was most important for self-employed caregivers, who depended on other family members to help them and/or had minimal means. Although some knew available financial support, some caregivers were reluctant to access this. Financial support needed by caregivers is related to daily expenses and needs, hospital expenses, and transportation costs. One caregiver (Siti) mentioned that she needs welfare support to make the whole family's life more satisfactory. Housing was a big problem for Siti, who repeatedly commented that her house was overcrowded. Siti felt pressure when her mother-in-law kept asking them to build their own house because they currently live together in a shophouse unit, courtesy of Siti's mother-in-law.

> “... you know, since Mum has been staying with me, I just put in some plywood as a wall (to separate the room), small room for her, she does not want anything disturbed because she needs to do a prayer too. So, the house becomes more cramped. Actually, the house is a shop house, a two-door shop house. She (mother-in-law) gives us one door to stay. I do my business there and I stay there too. I do my business at the front then I cover with walls to make a place to stay...the house is bit cramped.”
>
> (Siti)

The current cramped conditions mean her mother isolates herself from others and spends most of her time in her room. Five of the caregivers in this study were homemakers who depended on their husbands’ income and occasionally received limited assistance from other family members in contributing the money. Melati said:

> “Sometimes I feel so stressed to especially thinking about my financial status. I have my own problems though; my children too. If there is someone out there who is helping me, maybe it

> would be different…but now everything is on my shoulder, that is why sometimes I feel so stressed ….”
>
> (Melati)

Caregivers needed to bear potential increases in medical costs alongside the cost of daily living, particularly for caregivers with a large family. Regular visits to the hospital where high costs for some families as psychiatric services are located in the capital city, and transport can be expensive. In some cases of self-employed caregivers, disruption of work routines led to reduced income. The financial cost is also involved when consulting the traditional healers who received an honorarium for their treatment of the mentally ill older person.

When older people with mental health problems received financial assistance from the social welfare department, it was not because of the mental illness but the poor financial circumstances of the older person with many children. However, adult children often terminated the financial assistance when they started working and could afford to support their family members, including parents with mental health problems. Noor described her daughter’s objection to receiving financial assistance and commented that the amount received was too small:

> “My daughter did not allow us to receive it. “No need Mum…no need, such an embarrassment to us, maybe you don’t feel it but I do”. She was afraid that people would say something bad about that…people would say…their daughter is working but not able to help her father…then, later I don’t receive it anymore…it was only for a while.”
>
> (Noor)

Another two caregivers (Rina and Halijah) also mentioned that since they could afford to support the mentally ill family members, they had not contacted government agencies to seek help. In the case of Halijah, Aida, and Wanie, besides their secure full-time employment, their mothers, as widowers, also received money from their late husband’s pensions, so these caregivers did not look for assistance from any government agencies.

The situation is quite different for Khatijah. At the time of the interview, she was sending an application to the social welfare department. Khatijah said this was the first time she wanted to apply for financial support, particularly for her husband’s hospital expenses and the transportation cost to a hospital, because she did not want to burden her son anymore since he has his own family to look after:

> "I have not applied for any help so far. I was afraid and embarrassed that people might say that I should not ask for it since I have children to help. Now, since my son, who always helped me, has retired and has many children to feed as well as pay school fees, I cannot turn to him anymore right?"
>
> (Khatijah)

Peer support

Being a caregiver to an older person with mental health problems has an emotional, psychological and physical impact on most family members living in the same household. Lack of knowledge about mental illness and how to respond to the attitudes and behaviour of older people with mental health problems was the primary concern for caregivers. At the same time, addressing the problem of how to become a 'good caregiver' worried the caregivers. Although most caregivers came to the hospital monthly, they did not know or recognise other caregivers. Caregivers came to the hospital as individuals and did not take the opportunity during the waiting time to make conversation or contact with other caregivers. When asked whether she would like to be involved in any discussion groups provided by the hospital, Halijah said:

> If it is based on my current thinking right now, yes, I will join them but in those days, I wouldn't (join). I don't think they could have helped me that time, other people would not have understood my problems."
>
> (Halijah)

Caregivers need a support group for various reasons, including sharing and exchanging experiences and building a caregiving network based on different types of illness. What is incredibly fascinating in the context of peer support suggested by some of the caregivers in this study is that caregivers can become a resource to other caregivers in identifying their potential and learning new skills based on the experience of others. However, only some of the caregivers considered a support group vital to them. Four adult children's caregivers thought that this kind of assistance benefits them as caregivers. Aida and Asmah commented that the government should provide support groups for caregivers like them. Aida mentioned that the health centre should offer support and help to family caregivers since she said she had never heard that the hospital provided counselling sessions for family members like them.

Caregivers were also concerned about obtaining social support for older people with mental health problems. Concerning emotional support for older people, some caregivers think they have a problem giving such support and believe that only the doctor/psychiatrist can provide such needs to the older person. In Wanie's opinion, she said:

> "I would be very happy if the doctor could make a call to the patient, especially those with the mental health problem, asking their progress because they need more emotional support, but with other patients it is enough just take medicine. But for the older person with mental health problems, they should call because they need more inner strength.
>
> (Wanie)

Wanie added that a home visit was also appropriate for supporting the older person with mental health problems besides phone calls from the doctor. However, Wanie knows that the doctor cannot treat each mentally ill patient in such a way since most government hospitals do not have enough doctors. Peer support for caregivers and care recipients from different resources, either hospitals or support groups, may help both parties move through a difficult situation with someone who could understand the caregiving role and has similar experiences.

Personal and informational support

The majority of caregivers felt equipped personally to cope with the task of caring in terms of the knowledge of mental illness. Six caregivers from different backgrounds had also mentioned the need for counselling; four of these caregivers were caregivers of older people with depression. For instance, Amira indicated that if the government would like to provide support for the family with mental health problems, she suggested counselling to help her to deal with her mother's attitude:

> "To help the patient and also to help the caregiver knows what they should do because my mum refuses to listen to me whereas my intention is to see her recover. She sleeps all the time and that troubles me."
>
> (Amira)

There was also the view that counselling is practical when caregivers considered themselves as 'untrained caregivers' and they found communication with the older person difficult. For example, the caregiver likes Rina, and her husband suggests they need someone who can 'instruct' them on how to look after a mother with depression:

> "…to teach us how to take care of them would be great; because we don't really know about how to look after the elderly, we just do what we can ourselves. For the time being, I only know that, when Mum looks different, we know that her illness is serious. We keep taking care of her without really knowing what the real problem is. If we just don't respond to her whining, she would be okay"
>
> (Rina)

Since most caregivers have a mixed understanding of mental illness and how to deal with the impact of the illness, informational support, particularly from the hospital, was an important issue. Caregivers require information on the resources available for them as a caregiver to older people with mental health problems. Because of the different views between the caregivers and the care recipients, caregivers wished that the doctor/psychiatrist could explain mental illness to them in 'understandable language,' although they never asked for details. For instance, Melati said:

> "The doctor told me because of a sudden attack of illness, I am not quite sure what the doctor said to me, some kind of fits. I don't really know because the doctor explained that Mum's brain is divided into three parts, and one type of fit causes her loss in consciousness and makes her fall, because of the fits my mum always falls …something like …I don't know how to explain it again"
>
> (Melati)

Supporting the caregivers of people with mental illness with relevant and adequate information would assist in managing symptoms, understanding the illness and the medications and their side effects, and preparing the caregiver to communicate the treatment to other family members.

Practical support

Practical support is very much needed, particularly for women caregivers who work. For two caregivers, Halijah and Asmah, providing a day-care centre near their workplace or in the hospital would lessen their burden in balancing their roles. Halijah said:

> "Nowadays, most of the children are working, right? Sometimes I wish that they (the government) could provide something like a day-care centre, where we can place the older person. We could send them in the morning on the way to work and then pick them up in the evening after work. If there was a place like that, if they could build such place, it would be good."
>
> (Halijah)

When suggesting the need for a day-care centre, Asmah's stepson knew that no such services were available in Kelantan. As far as they knew, the Chinese community provided a day-care centre for the aged. Asmah's stepson stated:

> "If they provided one centre, a caring centre where we could send older people, especially when they are alone at home, so they could communicate with each other. I think we could manage the depression problem. If there is a centre when caregivers are unavailable, we could send them there, and at the centre they would be friends with others...they could do leisure activities and then they would not feel lonely anymore...so maybe we could overcome the problem of depression...and it will be much better than sending a nanny...that is much better."
>
> (Asmah's stepson)

The day-care centre could offer assistance to the caregiver and provide opportunities and activities where older people with mental health problems can talk and share their problems. Activities at the day-care centre could help reduce depression and loneliness among older people. However, Asmah pointed out that the older person themselves has to give consent to attend. She worried that older people with depression, like her mother, would be reluctant to go to the centre. Caregivers also mentioned in-home support as a possible option. Asmah somewhat agreed with the need for assistance from the hospital, particularly in visiting their house and asking about the progress of the older person. Asmah is also responsible for visiting and looking after her mother-in-law once in a while. She worries when she has to leave her mother with depression alone at home without supervision. Asmah desired some assistance from the social worker to accompany and provide caring support for her mother while she is away from the house:

> “I need someone to look after her, you know why, if I just go and leave her, my mind is uneasy, I keep remembering her, what is going to happen to her...whether she is eating or not, so it makes me feel uncomfortable. In my mind, makes me feel worried....so when I leave her alone at home, especially during the evening or at dusk, I feel so worried so, if possible, I want to return home quickly, as soon as I can but if there is someone available to care, if someone available to look after her...that’s my hope... I need someone that I can count on ...so I won’t face problems...if something happens to her. Oh! I know someone is there for her.”
>
> (Asmah)

In contrast to the adult children caregivers’ interest in in-home support, two spouse caregivers (Khatijah and Zainun) had differing views. Khatijah agreed that hospital staff could come and visit. Khatijah said:

> “It is okay if those from the hospital would like to come and help me. I do not have any problem with that.”
>
> (Khatijah)

However, Zainun rejected the idea:

> “For me, I am don’t really like the idea of people come to my house and chat with me because I have my own works to do right?”
>
> (Zainun)

Respite care is vital for caregivers to ‘recharge’ their energy, mind, and management of their roles. As a teacher, a wife to a husband with kidney failure, and at the same time, a person looking after a mother with depression, Asmah feels that she has much stress and would like to travel during school holidays. Asmah believed that if she could go away for a while, she would come back with a fresh mind and peaceful soul:

> “I need to go out to some place, just to take a break to release and relax my mind. For me, I need a rest, if don’t have a break the illness could affect me too...because sometimes this kind of

> illness comes from stress...because of the workload, stress because of thinking will probably cause us to be sick too. Maybe right now it won't affect me but who knows? When we are aged it will affect me...because right now I am in my 50s, I need to care about my health...so because I have to carry all this load, then the problem might come to me too."
>
> (Asmah)

Specialised staff is also essential for caregivers in terms of better communication and the quality of relations between professionals, caregivers, and older people as mentally ill patients. Good communication may indicate the effectiveness of the services/treatment received from the hospital. If the hospital has staff trained in the psychiatric care of older people, negative attitudes and bad experiences encountered by some caregivers may not happen again. Siti and Asmah discussed a similar experience with inexperienced hospital staff. Siti stated:

> "I don't remember the name but the doctor said something wrongly, the doctor asked: "Do you stress, Auntie? I don't like to hear like that, I want the doctor to know how to talk nicely...I want doctor to be more careful when they speak."
>
> (Siti)

Asmah also felt there were some unacceptable responses from some hospital staff. As a result, Asmah felt frustrated and said:

> "Two or three years back, my mum was always at emergency unit…so when Mum was there, the staff said: 'Oh! This is Auntie again, she is always here asking for medicines'…so it seems that my mum is so (problematic)….it seems that they make fun of her…I think the doctor makes fun of my mum…but then, I should just be patient because I know who am I, you know, I am not the doctor…but supposedly, as a doctor they should not say something like that, they should be more considerate…you know, every patient goes to the hospital because they are ill…if they are not they would not be there…"
>
> (Asmah)

In her experience when dealing with the hospital, some hospital staff said impolite things about the patients, with hostile looks and facial expressions. Asmah felt disappointed with staff who see a mentally ill person as a terrible patient, and in her opinion, this situation should not have happened, especially to an older person. Mental health problems among the older population can be reduced if they have some activities to do in their community and get support from the neighbourhood. This prevents them from being 'abandoned.' Asmah's stepson commented:

> "In those days, the early 70's and 80's, it was hard to find the illness in older people…I can say it is a mental illness …before this, it did not exist…because older people in those days remained at home, had a hut where they could do weaving or activities…they had neighbours around, so even if they were 70 or 80 years old, they seldom fell sick. Why? Because their life was fulfilled."
>
> (Asmah's stepson)

Siti said:

> "I am so worried because Mum does nothing at home...has no friends. I am just afraid that she becomes stiff so if Mum could join the activities, I would like Mum to be involved too."
>
> (Siti)

Overall, there was diversity in the unmet needs of caregivers and care recipients. When caregivers required support, they worried about the future and the quality of care they provided. They also worried about the extent and quality of resources for older people with mental health problems. Better resources for the older person would ease some concerns about caregiving.

Discussion

The impact of changes in work patterns is linked to the rapid modernisation of Malay society. Modernisation has meant changes in population patterns, more education, work opportunities away from rural communities, and expectations that women would work outside the home. Generally, women remain the primary caregiver for an aged, mentally ill family member. However, there are implications when more women join the workforce or migrate to other states as these changes impact their caregiving role and their availability to neighbours. These aspects were evident in the study participants' experiences. Work and caregiving expectations produced conflicts for most caregivers. This is most evident for women caregivers in full-time employment who were also responsible for household matters and caregiving. Balancing these roles was particularly difficult if other family members or employers did not support them.

Concerning conflict between work and the caregiving role (caring for an older person), the literature found that adult daughter caregivers experienced more tremendous work role strain than males and had conflict in balancing their responsibilities (Bhan et al., 2020; Kar, 2021; Sun et al., 2019). This is also revealed by employed women caregivers in this current study in that the most conflict occurred when the employer was not concerned about the caregiving responsibilities of their employee and perceived these as a personal issue of the employee. Other women caregivers who ran small businesses also experienced stress when they felt torn between serving customers and providing care.

The literature (e.g., Kropf, 2018; Labrum & Newhill, 2021; Stanley et al., 2017; Wang et al., 2022) on caregiving for mentally ill family members indicates the need to provide and establish support and resources for the caregiver. The idea of the 'caregiver/carer as a resource' model, as proposed by Guberman and Maheu (2002) as well as Rogers and Barnes (2003), suggests that government acts as a 'secondary role, intervening only to supply what caregivers are unable to provide (Guberman & Maheu, 2002, p. 32).

However, in this context, it is crucial to have a more proactive model to support caregivers, given the substantial cultural and religious obligations to assume caregiving roles within family systems and to make do with what is available. Findings from this study suggest that the caregivers of older people with mental health problems are likely to need help and support. It is expected that this group of caregivers will likely increase shortly as the population ages and mental health problems become a recognised significant health problem in most developing countries (Aris & Othman, 2022; Munawar et al., 2022; Tesfaye et al., 2021; Vaitheswaran, 2018).

The following policy and service system recommendations arise from the study:

1) Caregivers should be recognised in mental health policy and practice as a separate needs group,
2) Policymakers (government) and service systems in health and social policy need to work between family networks, community, and government so that efforts to help family caregivers provide care for older adults with mental health problems recognise local resources and culture.

Conclusion

The findings of this study clearly indicate the need to recognise family caregivers in mental health policy and practice in Malaysia. Most western countries over the past twenty years have identified caregivers as a separate policy category entitled to services in their own right; Malaysia as part of modernisation has introduced modern psychiatric treatment but has not as yet, identified the roles, contribution and needs of family caregivers particularly female caregivers' roles and responsibilities. The findings not only focus on mental health issues but also add to the understanding of caregiving in the socio-cultural and religious context and the services needed for this particular group. Although this study was conducted in Kelantan, the findings also have some relevance for Malaysia in a general. This study has made visible how significant it is to recognise and understand the local context of caregiving and resources when developing policy and services to support the caregivers of older people with a mental health problem.

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