

Informal Caregiving of Senior Parents in Malaysia: Issues & Counselling Needs

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Caregiving can be challenging as it impacts the quality of the caregiver's life. This study focuses on two research questions: 1) Issues faced by adult children in caregiving for their senior parents, and 2) Counselling support needed by the caregivers. Qualitative data was collected from in-depth interviews with thirteen (age = 30-59, gender = 9 females and 4 males) middle to high-income adult children residing in various places in Malaysia. Data was managed and analysed using Atlas.ti8 to find emerging themes. Two themes emerged for issues of caregiving including management of the senior parents' health, emotions, and finances; and personal management of the caregivers and their relationships. Three themes emerged for counselling: the need for counselling services; the content of the counselling session and; the type of counselling. The results of this study support a need for more research and education on the elderly developmental process and caregiving as well as the development of related counselling services.

Keywords: *Caregivers, Adult Children, Senior Parents, Issues, Counselling.*

Introduction

Trends in global population aging are growing faster than all other age groups. Based on World Population Prospects 2019: Highlights, it is estimated one in six people in the world will be over age 65 (16%) by 2050, up from one in eleven people in 2019 (9%) (DESA, 2019). This global phenomenon is a significant issue and is increasingly a concern in developed and developing countries, especially where the process of the number of senior citizens is increasing (Wee & Sanmargaraja, 2014). It occurs worldwide at different rates with developing countries set to reach an aged nation faster than developed countries (MOH Family Health Development Division, 2008). At present in Malaysia there are 3.23 million senior citizens, which is 10% of the total 32.3 million population. (Department of Statistics Malaysia, 2018). By 2035, Malaysia is expected to become an aged nation when 15% of the total population is

60 years old and above, according to the United Nations (UN) projections. Therefore, this situation has indirectly led to increased demands and needs on the care of older people.

Literature Review

Generally, caregiving is a genuine act of kindness to the individual whose life influences us and to whom we feel responsible (Toseland, Haigler & Monahan, 2011). There are two types of formal caregiving (government and private agencies) and one type of informal caregiving (by family members or significant others). In Malaysia, formal caregiving has been provided by the government and private institutions for elderlies since the 1990s. Most of the elderly who populated government institutions were poverty-stricken, abandoned by their families or choose not to burden their families (Nayan, 2006). Previous studies on senior's informal institutions showed there was an experience of emotional challenges such as loneliness and boredom (Mulok, Kashim, Abidin, Hadi, Mahmud & Karim, 2016). The Malaysian government has now stopped building new institutions and now supports NGO's (through grants) to care for poverty-stricken senior citizens in addition to encouraging adult children to be responsible for the care of their senior parents. Even though formal private senior centre services are on the rise, most families still provide informal care for their elderly.

Specifically, informal caregiving is an act of providing free assistance and support with physical, psychological and developmental needs without any financial benefits to family members, friends or acquaintances. Informal caregivers or family caregivers are not health professionals and do not get paid for their caregiving services (Houts et al., 1996). Anyone can become a caregiver and a care recipient and it is considered as caregiving if the activities performed on behalf of others are outside of expectations or norms, such as taking care of adolescents who have cancer; a parent with Alzheimer's disease; a spouse who has suffered from heart attack. (Gouin, da Estrela, Desmarais & Barker, 2016). The task of caregiving is usually very demanding and requires a high level of commitment (Gray-Davidson, 2002). It is a relationship that is very personal and involves intimacy.

There are many previous studies around the world on adult children taking care of their elderly or senior parents (Aneshendel et al., 1995; Merrill, 1997). According to Gray-Davidson (2002), two-thirds of the American population becomes a caregiver to their family members, friends or older acquaintances and some are looking after neighbours. More than one-third of parents expect and depend on adult children to help with at least one type of daily life activity such as bathing, wearing clothes, getting ready, getting out of bed and movement in the home (Aldous, 1994). Yamamoto & Wallhagen (1997) conducted a study to find out the reasons for family caregivers in Japan continuing to look after their elderly with dementia despite facing various issues. Three reasons can be identified. The value of caregiving itself is the norm of society and is a form of togetherness in family relations. Indirectly it becomes the primary motivation to continue looking after older adults with dementia despite having to deal with various

hardships. The same cultural background is shared by Malaysia, thus making caregiving a non-significant issue traditionally.

The social impact of caregiving has been exposed by Malaysian research only recently (Alavi, 2007; Abdullah, 2009; Alavi & Sail, 2010). Previous studies discussed the issues faced by informal caregivers, which are largely shouldered by women, especially in Malaysia. Alavi's (2007) first study showed women from low SES were burdened by financial issues when caregiving for their elderly. Abdullah (2009) and Alavi & Sail (2010) highlighted that the role and duty of care becomes challenging when women had to play many roles at one time as daughters, wives, mothers, sisters, and even more as workers if they have permanent jobs outside their homes.

Furthermore, the prevalence of the burden of informal caregivers has increased due to the aging population and the lack of formal support for caregivers (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). Caregivers may become depressed and eventually too tired to carry out their tasks as usual (Gray-Davidson, 2002). Informal caregivers or family caregivers who are known as primary caregivers often faced the highest-burden for in-home care or caring for their senior parents in their own homes, compared to formal caregivers at daily care centers and other institutions such as senior citizens nursing homes (Jeong, 2007). Besides, informal caregivers who are caring for an individual with mental illness only or combination with a somatic disease tend to feel more burdened than caregivers who look after individuals with somatic diseases only (Hastrup, Van Den Berg & Gyrd-Hansen, 2011). Long-term caregiving for a chronic illness patient is also challenging, and the caregivers face a high level of pressure (Akosile, Okoye & Odunowo, 2009).

High levels of caregiver stress was predicted in addition to financial hardship and physical strain among young adult caregivers. Reducing caregiver stress is believed to be very important by undergoing effective initiatives and also avoiding care recipients from nursing home entry (Spillman & Long, 2009). Some caregivers seek professional counselling support as their coping strategies in the challenging caregiving journey (Levine et al., 2005). Counselling services, psychoeducation, or information exchange and guidance for caregivers mostly show a positive influence on caregivers' psychosocial wellbeing (Sabat, 2016; Cheng, Chair, & Chau, 2014; Toner & Shadden, 2002). There are many different forms of counselling for caregivers. Participating in family counselling is a great way for some to share feelings of inadequacy, frustration, and stress. Meanwhile, most caregivers prefer individual therapy sessions, where they feel more comfortable to vent out their issues or feeling. It is essential to understand the caregiver's experience. To carry out their responsibilities better, assistance and guidance are needed (Othman, Mahmud, & Karim, 2019).

Methods

For this phenomenology study, qualitative data was collected from in-depth interviews with thirteen (age = 30-59, gender= 9 females and 4 males) middle to high-income adult children residing in various places in Malaysia using a semi-structured interview protocol which has been checked and validated by three experts in related fields after it was prepared by the researcher. It includes background information, caregivers' issues and types of counselling questions. In a most qualitative study, data was collected by interview techniques, and interview protocol was used as the main instrument (Merriam & Tisdell, 2016; Mahamod, 2004).

Attempts to find suitable respondents was by sending invitations through social media, followed by a snowballing technique. Many people gave a positive response and supported by referring their friends, relatives and colleague to participate. A total of thirteen caregivers were selected by using a purposive sampling technique, where a few criteria need to be fulfilled. Adult children caregivers must be aged eighteen and above and employed with middle to high monthly household income (RM 3,860.00 and above). They also need to be the primary caregiver living together with their senior parent in the same house or nearby, and at least have one-year caregiving experience. Meanwhile, criteria for their senior parents are aged sixty and above, frail, having physical or mental illness where they need assistance in at least one activity of daily living or two instrumental activities of daily living. Initially, caregivers were contacted to explain the research briefly and to confirm their acceptance for participation in this study.

Then a suitable date and place of the interview were set up. The interview took place in comfortable surroundings preferred by respondents such as homes, cafeterias, libraries and workplaces. All interview sessions were audio-recorded with permission from respondents. Most of the interview sessions lasted one to two hours, some three hours.

Besides interviews, observations are also a primary source of data and common in qualitative research. However, the researcher must seek informed consent from those in the situation of interest before starting the observation process (Merriam & Tisdell, 2016). In this study, respondents agreed to be observed while they took their senior parents for treatments at hospitals and health centers. Respondents' behaviour and interactions with their senior parent and other family members or relatives who followed to assist were observed using an observation protocol as guidance. According to Othman (2017), congruencies of participants' information through interviews can be seen and checked by following their nonverbal behaviours.

Another data collection strategy in qualitative research is document analysis, which is a ready-made source of data (Merriam & Tisdell, 2016). Documents can be relevant materials to the study ranging from photos, videos, films, letters, memos and written diaries as an additional

source of data to the primary data interviews or observations. In this study, health documents and letters of the respondents' senior parent and related photos were analysed accordingly to strengthen primary data.

Data collected was transcribed, shown and validated by the respondents, where it is known as the member checking process. This technique may help the researcher to avoid bias issues (Bloomberg & Volpe, 2008). Validated transcriptions and all data were managed and analysed using Atlas.ti8 to find emerging themes. Results showed two main themes for issues, which are management of the senior parent's health, emotions, and finance; and management of self and relationships. While three themes emerged for counselling: the need for counselling services; the content of counselling sessions; and the type of counselling.

Results and Discussion

Demographics Data of Respondents

This study was participated in by thirteen respondents, (9 females and 4 males) working adult children who are taking care of their senior parents at home. Most of them are full-time employees and others are self-employed with middle to high monthly household income range from RM 6,000.00 to RM 27,000.00. Their age range is between 30 to 59 years old. Table 1 shows the biographical data of all respondents.

Table 1. Respondents Biographical

No.	Age	Gender	Household Income	Marital Status	Years of Caregiving
R1	36	F	RM 6,000.00	Single	3
R2	32	F	RM 10,000.00	Married	10
R3	34	F	RM 25,000.00	Married	6
R4	40	F	RM 16,000.00	Married	11
R5	31	F	RM 7,000.00	Single	9
R6	46	F	RM 7,000.00	Single	2
R7	43	F	RM 15,000.00	Married	2
R8	54	F	RM 6,000.00	Widow	5
R9	53	M	RM 14,000.00	Married	4
R10	37	M	RM 6,000.00	Single	7
R11	36	M	RM 9,000.00	Married	7
R12	44	F	RM 15,000.00	Married	6
R13	44	M	RM 27,000.00	Married	11

The care recipients in this study are respondents' senior parents who are old, frail, and have an illness. Caregivers have to attend to their parents' basic physical, psychological, social, and spiritual needs. The recipients depend on the caregivers for their activities of daily living either in eating, bathing, getting ready, using the toilet, taking medicine, moving in the house, getting

in or out of bed, preparing food or instrumental activities of daily living such as shopping groceries, doing house chores, going for treatment at hospitals, driving, using public transport, managing their finances, walking outside from the house area, using a mobile phone, gardening and doing laundry (Calmus 2013; Lai 2012).

Akil, Abdullah & Sipon (2014) mentioned that in managing formal elderly care places, relevant aspects include financial, infrastructure, professionalism, collaboration and support, living arrangements, different socio-cultural backgrounds and emotional and psychological needs of the elderly people. Informal caregivers in our study highlighted two main concerns, namely (i) management of the senior parents' health, emotions, and finances (ii) management of caregivers' self and relationships.

(i) Management of the Senior Parents' Health, Emotions, and Finances

87 percent of senior citizens in Malaysia are having health problems in the noncommunicable disease categories based on a report by WHO (2014). The illnesses of the senior parents in this study include diabetes, high blood pressure, dementia, stroke, arthritis, cardiovascular problems, cancer, visual problems, kidney disease and acute gastrointestinal bleeding. The conditions of these senior parents include being bedridden (3), having to use wheelchairs or a support cane for moving (6), blurry vision (2), constant pain (3), emotionally unstable and a special diet. All of them need medication and supplements to help them keep up with daily activities. Most of them have regular hospital appointments, while two have nurses visit them at the house as their mobility is limited.

Caregivers in this study need to ensure a daily intake of medication is followed. Most agree that complying with proper medication is very important to make sure their senior parents' health is maintained at an optimum level. They are vulnerable to various dangerous health conditions because of their health deterioration. This impacts the caregivers as they worry about the uncertainties of their parents' health condition. Most caregivers worry their parents may fall and fracture something. Thus, they have to be prepared to manage emergencies or receive any news regarding their parents' health condition as portrayed in respondent numbers 3, 4, and 5 in the citation below.

“After dialysis, she'll feel tired. She can't even shower by herself because all of her body will feel in pain. Sometimes she will get hypo shaking due to not enough glucose in body her body. She will need to rest and sleep. So, at that time, I have to limits all my activities and can't do so many other things.” (R3/L857)

“We always have to plan and standby if my father gets sick. My husband and I are very used to emergencies with my father. Last time we even had an emergency when my father

suddenly got a stroke attack in the clinic while waiting for a turn to meet the doctor" (R4/L1116).

"It's the fear of facing the uncertainties. It's like new illnesses just popping out just like that, like one after another. And sometimes, I wonder if I'm capable enough to deal with it in terms of emotional, financial, and also like effort and timewise. It's at the back of my mind all the time. Oh my God, what's next? Frozen shoulder is a new thing to me, and last week both of them (my parents) had a fever. So, I brought the two of them to our clinic." (R5/L358)

Previous studies showed that senior citizens in formal care institutions experience emotional challenges such as loneliness and boredom (Mulok, Kashim, Abidin, Hadi, Mahmud & Karim, 2016). In this study, even when staying with their family members, senior parents do experience social and lifestyle changes, which in turn impact their psychological wellbeing. These cause them to be highly emotional, sensitive, sometimes uncontrollable. Adult children reported their parents showing various signs of emotional discomfort such as not feeling at ease with many people, not accepting their children's' views or advice, and are easily hurt and offended by petty issues. R3 has both her mother (kidney patient who has to go dialysis) and mother in law (senile and dementia) in the same house. Her mother feels that the daughter sides more with the mother in law on many issues. These moms even used to argue about TV channels.

Caregivers also ensure their parent's emotional state is taken care of by fulfilling the parents' wishes. Respondents in this study have old parents who have limitations in mobility, but still want to go out and meet people. In this case, their adult children will help their parents to the car and drive them to attend functions, meet relatives and friends. Meanwhile, for parents with the bedridden condition, their adult children invite and encourage family members, relatives, friends, and neighbours to come over and visit.

In contrast with Alavi's (2007) findings on low SES caregivers, most of these children who are of middle to high income do not face financial issues in providing basic needs and wants for their parents. However, for certain special medications and treatments, the costs are quite high. They say it would be nice to have some kind of financial help. R6 said that the medicine for her mother's dementia costs RM500 per box, which was prescribed by a specialist doctor from a private hospital. While R3's mom has treatment aid from SOCSO and R13's dad, who is a former government pensioner, both receive some aid from the government for their dialysis, but other medications are quite pricy.

ii) Management of Self and Relationships

Caregivers in this study are all working people. Thus, other than doing the care work for their parents and caring for their own family, they also have outside job commitments. Playing multiple roles can be overwhelming, as discussed by Abdullah (2009) and Alavi & Sail (2010). Moreover, a study from LPPKN showed 46.5 percent of women in Malaysia aged between 15 to 59 years old, have been married and are working. 18.7 percent of them have a problem in balancing roles between career and family (National Population and Family Development Board, 2016). Informal caregiving of older adults can also have negative impacts on mental and physical health, especially for female, married women (Bom, Bakx, Schut & Doorslaer, 2019). The respondents in this study report that they experience physical stress, emotional stress and exhaustion.

“My mother (76 years old with blurry vision) sometimes keeps repeating certain questions, which irritates me, especially when I just come home from work and exhausted.” (R2/L823)

Time management and personal lifestyle are also affected when someone plays a caregiver role. R1 and R4, who are also part-time students, agree that caregiver's time for socialising is very limited.

R4 says, "I am a daughter, mother, wife, worker, and student. Sometimes I feel frozen on how to manage time. I can't think properly to make sure everything and everyone is managed.”

Reports by National Alliance for Caregivers & AARP (2009) showed 31 percent of caregivers are emotionally affected and felt stress because they had to sacrifice their time to be with their own family and friends due to caregiving responsibilities. Many of the respondents in this study described how their interpersonal life is impacted (R2, R3, R4, R7, R9, R10). R2 said her husband sometimes gave hints and wished that they could have private time at home and also when they go on vacation. While R4 shared she can't go out with her husband buying groceries together as they used to before her dad was diagnosed with cancer, and could no longer go window shopping for hours with her husband. Even to attend weddings, they have to take turns. R9, who took care of her mother and mother-in-law complained that he missed the time when he and his wife could go out just the two of them “dating”.

Positive aspects of caregiving are also referred to as rewards, meaning, satisfaction and gains, which are associated with better caregiver well-being (Quinn & Toms, 2019). Adult children caregivers reported some gains for this experience despite the challenging situation. Some of the benefits include a feeling of a more blessed life, increased humanity, such as love, kindness, and compassion. Most significant is the increase in patience and spirituality. Overall, adult

children mentioned an increase of knowledge in elderly human development and also in doing medical nursing at home. Higher mastery and higher preparedness in caregiving resulted in higher self-gain. These included success in negotiating care and healthy behaviours with the care recipient, caregiving as a means of preparing caregivers for the future and also caregiving as a means to enhancing relationships (Bargerter, Griffin & Dunlay, 2019)

R6, R7, R12, and R13 felt closer with their parent since taking the role of a caregiver. The researcher observes how R6 treated her mom at the hospital. When transferring her mother from the bed to the wheelchair, she lovingly hugged and kissed her mother before putting her down.

The caregiver's relationships with siblings are also very interesting to analyse, as they have positive and negative narratives. Negative issues include i) caregivers feeling they were sometimes questioned about the quality of care provided for their parents, and ii) some siblings not wanting to contribute to caregiving. Caregivers want their siblings to at least ask how the parents were doing and visit them as much as possible.

“My elder sister, when she comes to visit, will complain about the cleanliness of the house. She also questions why I lock the door (when I am not around), making it hard for her to enter. I am hurt with this. If she (my sister) feels the house is not clean, she should help to clean it. It is her mother too that lives here...” (R1/L142)

“Sometimes, when other siblings have not contacted my mother for a long time, my husband will make an inquiry. I even don't get it why my siblings never invite my mother to go vacation with them and their family. I see them share in WhatsApp Family Group wherever they go” (R2/L546)

Positivity is also gained from the siblings' relationship. The researchers observed some caregivers when taking their parents for hospital appointments. The observations on R4 (with niece accompanying) and R8 (with three brothers accompanying) showed that family members become closer when they help the caregiver. R4's niece not only pushes the wheelchair but also makes sure the grandfather was comfortable by massaging his legs and shoulders, and adjusting his sweater to keep warm. The granddaughter also talks with the older man all the time to distract him from feeling pain and bored with waiting so long. R8's brothers took turns to wait for their mother, in going to different counters for medications, and getting the next appointment. They chatted happily and joked with their mother at the hospital cafeteria during having lunch together. Then the third brother was responsible for transporting them home.



Counselling Support

Othman, Mahmud, & Karim (2019) recently reported caregivers needed assistance and guidance to carry out their responsibilities better. While in this study, when asked if counselling support is required, caregivers gave mixed reactions. They do agree that caregivers must receive emotional support. However, none went for the counselling session. Most respondents revealed that they talk to friends and family members, mostly about their emotional state and daily struggles. When asked if they were to come for counselling sessions, what the content of conversation would be, the responses were “how to manage time” (R1 and R4), “how to manage parental emotion” (R2, R3, R8), “how to make myself happy” (R1, R3), “how to keep fit and healthy” (R1), “how to deal issues with my family members besides taking care of my senior parent” (R8, R12). Some would like to get more information on the illness their parents have and also knowledge of elderly caregiving (R1, R5, R6, R8, R13).

When asked if they would like individual or family counselling, more respondents prefer only individual counselling as they would like to share their feelings or issues privately. On the other hand, the ones who choose to go for family counselling said they would like to have their siblings’ commitments in the caregiving.

Conclusion

This study explored the issues faced by working adult children who are taking care of their elderly at home. Results showed two major themes relevant for this population: management of the senior parents and; management of self and relationships. Regarding support, caregivers in this study wished to get more support from family members as they felt it was very crucial. They are not aware of counselling services, which can help them cope with caregiving experiences. However, if there are opportunities, they would like to have a counselling service.

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