

ORIGINAL ARTICLE

THE PROBLEMS OF INFORMAL CAREGIVERS ON LONG-TERM CAREGIVING OF THE ELDERLIES

Suridah Ali¹, Rahimah Abdul Aziz¹ and Mimi Hanida Abdul Mutalib¹¹Center for Research in Development, Social & Environment, Faculty of Social Sciences & Humanities, National University of Malaysia, 43600 Bangi Selangor.Corresponding author: Suridah Ali
Email: suridah22@gmail.com

ABSTRACT

Malaysia is expected to become the elder country by the year of 2035 and the elderly caregiving is the main issue in old population. Although the elderlies are expected to live for a longer period, half of them are in unhealthy condition, sick and suffering from disease. Thus, they need to be taken care for a longer period formally or informally. However, most of the family members have chosen to take care the elderlies informally. Therefore, the purpose of this article is to identify the problems that are faced by the caregivers on long-term caregiving of the elderlies. Informal caregivers need to encounter financial problem, affected health, difficulty in determining the caregiving rotation and lack of knowledge or information pertaining to elderly caregiving. Hence, the roles of caregiving in long-term period could burden and affect the informal caregivers' well-being.

Keywords: Informal Caregivers, Elderlies, Informal Caregiving, Long-term Care, Well-being

INTRODUCTION

The industrial and development processes have caused the changes in community demographics¹. The changes that happen have increased elderly total population because the life expectancy of world communities increase and the death rate decreases. The increase in the number of the elderly has resulted Malaysia to become an elder country by the year of 2035². In 2019, the population aged 60 years and above is estimated 10.3 % of the total population (32.6 million)³. In elder communities, the elderly caregiving becomes the main issue. The increase in the numbers of elderlies who are sick have also increased the demand for caregiving. The caregiving towards the sick elderlies needs to be done formally or informally for a long-term period. World Health Organization (WHO) defines long-term care as the a caregiving activity done by informal caregivers (family, friends dan neighbors) or professional caregivers (health and social service) to ensure the elderlies who are unable to take care of themselves to be taken care in a better way⁴. Formal caregiving is usually done in nursing home and day care center owns by government, non-government organization or private. In a formal caregiving, the elderlies are taken care by professional and trained caregivers. The nursing homes and care centers are equipped with the facilities according to the elderlies needs. However, the facilities that are prepared in the elderly care centers are not enough to accommodate the increasing residents⁵.

As for an informal caregiving, the caregivers choose to take care their sick family members at home. Even as the times progress, the communities in Malaysia still have the strong

values of responsibility in taking care the elderlies. Moreover, the elderlies still depend on the their family members when they are sick. In addition, the families are likely wanted to prevent in placing the sick and unabled elderlies in caregiving centers to avoid the stigma of society⁶. Usually, the close family members such as their children, spouse and relatives are the informal caregivers⁷. However, the family members are actually not capable to equip the quality caregiving to the elderlies. This is because, the long-term care of the elderlies could contribute to various problems to caregivers. Therefore, this article will dismantle the problems that are faced by informal caregivers in long-term period.

METHODS

The research on the elderlies' life expectancy was conducted in Mukim Kota Putera, Besut Terengganu. The research population was the informal caregivers who caregiving the sick elderlies for a longer period which was more than three months. This research involved 12 informal caregivers as the sample of the study. The informal caregivers consisted of elderlies' own family members which were spouse, children and daughter-in-law. The selection of smaller sample size was relevant to the in-depth case study⁸.

Data Collection and Analysis

Sampling method of *snowball* was used in the selection of research informants. The researchers have obtained information from *Penghulu Mukim* and *Ketua Kampung* to identify the informants. The selections of research informants were based on three main criteria which were; first, informants must be the primary informal

caregivers of the sick elderly, second, informants must take care of the elderly for full time for a longer period and must live together with the elderly. The researchers employed the in-depth interview method and non-participating observation to obtain the research data. Each interview session took about two hours and was conducted twice per informant. The interview session conducted in informant's house without being influenced by other individuals. After all, the informant needed to take care and monitor the sick elderly in the house at the same time. In addition, the researchers also needed to retrieve the non-participating observation data. The researchers employed thematic analysis method to analyse the research data. In the analysis process, the researchers transcribe the data first. Every collected data was rewrote, re-read and coded. After that, the potential themes emerged. The ongoing analysis was done to refine and specify each theme. Finally, each theme emerged that were suitable with the research issue.

RESULTS

Informants' socio demographic profiles

This research involved eleven (11) female informants and one male informant who taking care of sick and disabled elderlies. All informants were aged between 21 to 70 years old, Muslims and Malays. For the marital status, eight informants were married, two informants were single, one informant was a widow (husband's death) and one informant was a divorcee. The highest education status of the informants was in Diploma level while the lowest education status was in standard 6. In term of income, there were among the informants who did not have any incomes because they were not working, some received the financial aid from Department of Social Welfare Malaysia (JKM) and some were self-employed. For the informants who had working children like Kak Nah, Cik Der, Mok Cik Sah and Kak Yah, they received the grant money from their children. Moreover, there was a teacher retiree informant who received pension money every month. Besides taking care of the sick elderly, they also had the diseases such as high blood pressure, diabetes, heart disease, high cholesterol and knee pain. Informants' socio demographic profiles could be seen in Table 1.

Table 1a: Socio-demographic characteristics of the caregivers (informants)

Informant's Names (nickname)	Age (Years)	Marital Status	Number of Children (persons)	Occupation	Incomes (RM)	Type of Disease	Level of Education
Mok Su	70	Married	2	-	-	Hypertension	Standard 6
Kak Nah	59	Married	12	-	400.00	Hypertension	Standard 6
Cik Der	58	Married	6	-	300.00	Hypertension	Standard 6
Ramlah	61	Married	8	-	-	High cholesterol	Standard 6
Azi	21	Single	-	-	-	-	STPM
Azmi	24	Single	-	-	200.00 (JKM assistance)	-	Form 2
Mok Cik Sah	59	Married	9	-	100.00	Hypertension, knee pain	Form 3
Hani	31	Married	1 (Special Child)	-	*300.00 (JKM assistance) *900.00 (Husband's salary)	-	STPM

Table 1b: Socio-demographic characteristics of the caregivers (informants)

Mok Teh	57	Widow	12 *4 children who attend the school	Works in eatery	400.00	Diabetes, knee pain	Form 3
Cikgu	62	Married	7 *an OKU daughter	Teacher retiree	3000.00 (pension money)	-	Diploma
Cik Mah	46	Divorcee	-	Nanny	350.00	-	Form 3
Kak Yah	58	Married	5	-	200.00	Heart disease, Hypertension & high cholesterol	Standard 6

*STPM= *Sijil Tinggi Pelajaran Malaysia (Malaysia Higher School Certificate)*

Type of relationship, duration of caregiving and health status of caregiver

In term of caregiving, Table 2 shows the type of relationship between caregiver and elderly, duration of caregiving and elderly health status. Pertaining to type of relationship between the caregiver and elderly, it showed that the caregiver was from the close family member with the elderly. The caregivers were from the spouse, wife and children. This was parallel with

the result of the research that indicated the sick elderlies depended on their close family members to take care of them when they were sick. Table 2 highlights the caregivers who take care the sick elderlies for a long period which is between more than a year until 15 years. Besides, the types of diseases and health status are also shown in Table 2. Most of the elderlies suffered from stroke disease, high blood pressure, diabetes, chronic kidney disease and other movement problems, sick and sight problems.

Table 2: Type of relationship, caregiving duration and elderlies' health status

Name of Elderlies (nickname)	Caregiver	Relationship	Type of Disease	Caregiving Duration (year)	Health Status
Pak Hasan	Mok Su	Wife	<ul style="list-style-type: none"> • Kidney Disease • Gout • Lung 	1 >	Disabled
Pak Su	Kak Nah	Wife	<ul style="list-style-type: none"> • Stroke • Diabetes • Hypertension 	1 >	Sick
Pak Lah	Cik Der	Wife	<ul style="list-style-type: none"> • Stroke • Hypertension 	15	Movement and Speech Problem
Pak Mat	Ramlah	Wife	<ul style="list-style-type: none"> • Kidney Disease 	1	Disabled
Ismail	Azi	Child	<ul style="list-style-type: none"> • Stroke 	10	Sick, Speech Problem
Zainab	Azmi	Child	<ul style="list-style-type: none"> • Stroke 	15	Movement Problem, Paralyzed on the Left Side of the Body
Ayah Ziz	Mak Cik Sah	Wife	<ul style="list-style-type: none"> • Stroke 	1>	Disabled, Movement Problem
Mak Leha	Hani	Daughter-in-law	<ul style="list-style-type: none"> • Kidney Disease • Diabetes 	4	Disable, Amputated Left Leg
Pak Harun	Mok Teh	Child	<ul style="list-style-type: none"> • Old Age • Blurry Sight 	1	Disabled, Sight Problem
Pak Rashid	Teacher	Wife	<ul style="list-style-type: none"> • Diabetes • Heart Disease 	2	Disabled, Sight Problem
Pak Ahmad	Cik Mah	Child	<ul style="list-style-type: none"> • Stroke • Nerve 	2	Movement Problem
Pak Man	Kak Yah	Wife	<ul style="list-style-type: none"> • Heart Disease • Prostatitis 	1	Movement Problem

Caregiving problems encountered by informal caregivers

This research found out that taking care of the elderly for a longer period could bring various problems to caregivers. The problems encountered by informal caregivers were financial problem, health problem, schedule of caregiving rotation, and lack of information pertaining to elderly's caregiving and their diseases.

i) Financial Problem

Taking care of the sick elderly needed the high living expenditures. Instead of self-expenses, the caregivers also needed to spend half of their incomes to treat the elderly's health, transportation to the hospital and daily care matter. Financial problems could be the burden to the caregivers. This was because, most of the informants were from low income groups. For Mak Cik Sah, she encountered financial problem after her husband who was a sole breadwinner, diagnosed with stroke disease a year ago. She informed,

"...priorly, the income was RM2000.00 when Ayah Ziz was working...currently, there is no income, it all depends on our children who provide us RM 100 (per month)...."

The financial problem encountered by the informants has pressured them. Although they took care of the elderly as the part of responsibility in the beginning, the financial problem that arose has burdened them. Informant Azmi, who is a Human Deficient Effort (HDE), forced to quit his job to take care of his mother who was diagnosed with stroke disease. He only received the aid from Department of Social Welfare Malaysia (JKM) to support himself, the sick mother and the unemployed brother. He informed,

"...currently, I am unemployed.. no income..but I receive the financial aid..my mother has received RM300.00, I have received RM200.00.. we receive this financial aid every month..we do not have any savings, the financial aid is used for daily expenses..."

ii) Health Problem

According to the research conducted in Besut, the researcher found out that most of the informants who were the caregivers, diagnosed with hypertension, diabetes, heart disease, high cholesterol and knee pain. They informed that it was hard to execute the caregiving role very well due to their limited abilities. Therefore, they felt that the caregiving role was a burden for them. As was being told by Mak Cik Sah,

"...currently, I encounter the pain in my ass...I have swallowed the medicine...my legs feel numb...how is gout disease?...I feel the pain in here..is it gout or what..swollen at the leg joint...I was involved in the accident priorly..not capable to buy expensive medicines..."

Kak Nah also told,

"...I have hypertension...I will feel dizzy if I do not get enough sleep..He sleeps during the day, then he cannot sleep at night..."

iii) Caregiving Rotation

The sick elderly usually preferred to be taken care by their daughter than their son. The son should be responsible to take care of their sick parents but the physical caregiving usually becomes the daughter's role⁹. The research conducted by Khadijah Alavi et al (2010) found out that parents were comfortable to live with their daughter than they had strong bond than the son¹⁰. The roles of women in elderly caregiving were suitable with their caring, loving and concerned characters and personalities¹¹. As being told by informant Mok Teh,

"...Mok Teh's father does not really like to live with his son..if he goes, it is just for a while...then, he will come back here...yes...his daughter-in-law, how well does she care...my father only lives here, he goes to my younger brother for a short period... the longest is for a week...Mok Teh does not have any problems if he wants to stay here...but Mok Teh needs to go back and forth during trading..."

Informant Hani, besides taking of care other mother-in-law, she also took care of her three years old special child. She informed,

"...I am a daughter-in-law, lives only three of us..my husband works in Kuala Lipis, rarely going back...he is lorry driver...there are no other children living here, there is a child who lives nearby...the youngest lives in Sarawak, will be back during holiday...i live here, i don't have my own house...mother is sick...thus, i take care of her...i pity her because she cannot walk, only indent..."

iv) Lack of Information or Knowledge Pertaining to Elderly Caregiving and Disease

The role of caregivers needed them to always be alert and provided full attention towards the sick elderlies. The elderlies' condition needed to be monitored every time to ensure the caregivers realized about the actions that should be taken. Therefore, the caregivers need to obtain information and knowledge pertaining elderlies' cares and their health condition. Caregivers need to have exact information to ease the hospital staff in treating the elderlies better¹². Every change that happens every day must be recorded or remembered. However, most informants in this research did not have information or knowledge either in term of the caregiving role or the elderlies' diseases. Kak Nah informed the researcher that she did not have the exact information or knowledge on her husband's disease,

"...currently, he was unable to poo... he was a hard type and will be flutterly sick, once in a month...when he first encountered, it was like death... called his children to come back home...when we brought him to hospital, we got to know that actually he wanted to poo...he was admitted in hospital for two days..."

The other caregiver, Kak Yah also told,

"...the poo was smelly...the doctor asked, how long did it happen...i told the doctor, since my husband was critically sick...actually, there was bleeding in his stomach...this urinary symptom was almost a year...people said that most of the drivers always get this symptom...because they used to hold the urination... actually it was prohibited... when we went to the hospital, we knew that it was prostate (swollen)..."

DISCUSSION

The long-term care of elderlies contributed to many problems to caregivers. The caregivers who had limited financial resources were forced to endure the high living cost nowadays. Although having limited financial resources, the caregivers could not work because in the meantime, they had to take care the sick elderlies at home. The caregivers who encountered the financial problem usually having the difficulties to make the decision especially pertaining to expenditures. Thus, with the limited financial resources, they needed to plan their daily expenses very well. In addition, taking care of elderlies who have chronic health level have caused the caregivers to save up their money to be used during emergency period. This is because, the sick elderlies are frequently admitted to hospital and high cost of expenses for the treatment purpose¹³.

Moreover, some of the caregivers were old and diagnosed with disease. Nonetheless due to the bustle of caregiving role, they had to neglect their self-health. The caregivers prioritized the elderlies' health more than theirs although they needed to be healthy to perform their caregiving role. The role of caregivers requires good health condition to ease them in giving the care and attention to the sick elderlies. The caregiving roles were not an easy task to be done when the caregivers were also sick. When this situation happens, the caregivers are always in the condition of daily pain and reciprocal suffering¹⁴.

The changes that happened in the society caused the people to migrate to another places also made it difficult to determine the caregiving rotation. The caregivers who taking care of the elderlies could not rotate with other family members due to the work demands and many more. When the caregiving roles needed to be done for a long period, it could indirectly burden the caregivers. Instead of daily caregiving role, caregivers also had the other roles in their daily life. Therefore, when the caregiving role was only depended on one caregiver, it was feared that it could influence the caregiving quality and affecting the caregiver's well-being. Hence, the caregivers are also needed to be taken care to ensure their welfare is not neglected.

In addition, the lack of information related to disease and caregiving made it hard for caregivers. The researcher found out that the education level also influenced caregiving knowledge level that associated with elderly caregiving matters. The research debunked that most of the informants had low education level which only graduated from standard six. Therefore, they faced difficulties to fathom and search for the information pertaining to health and related matters with elderly caregiving.

Consequently, the role of taking care the sick elderlies was difficult and it was not an easy matter as it required patience and high committment from caregivers. The elderlies who diagnosed with chronic disease needed to depend on other people for a longer period. Besides taking care of sick elderlies, caregivers also had various roles that needed to be executed simultaneously. Plus, there were caregivers who stucked in *sandwich* family because they needed to take care two generations at the same time. As a result, the impact from caregiving role has caused most of the caregivers to get burdened, isolated and disturbed with the elderlies' caregiving role. The implication is some of the elderlies are being abused and neglected.

CONCLUSION

The role of taking care the sick and disabled elderlies has burdened the caregivers. Most of the infomal caregivers were actually not capable to

accommodate the good quality of caregiving service because of lack of financial resources, health problem, limited knowledge and skill related to the sick elderly caregiving. Although most of the people assumed that long-term caregiving of the elderly was personal matter, the caregivers also needed the support from many parties including families, government and non-government organization. The ability of the caregivers to provide the good quality of caregiving service was restricted because there were a lot of arising problems during the caregiving. However, the long-term caregiving of elderly did not only touch on the quality aspect, the aspect of caregivers' life happiness also needed to be emphasized. Despite of the caregivers' roles to take care the sick elderly, the caregivers also need to be taken care of to ensure their well-being is not affected and can provide the good quality of caregiving service towards the elderly.

ACKNOWLEDGEMENTS

We acknowledge the support and help Department of Social Welfare Malaysia (JKM). We also indebted to the informal caregivers who had kindly participated in this study.

COMPETING INTEREST

The authors declare that have no competing interests.

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