



TECHNIUM
SOCIAL SCIENCES JOURNAL

Vol. 20, 2021

**A new decade
for social changes**

www.techniumscience.com

ISSN 2668-7798



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Female Caregivers Stress in Caring for Hospitalized Elderly with Chronic Disease at Universitas Sumatera Utara Hospital: A Phenomenology Study

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Abstract. The elderly is prone to suffer from physical illness and experience hospitalization due to physiological decline. Researches showed that the majority of the family caregivers are females, who are responsible for the caregiving delivery. This study aims to explore the female caregiver stress caring for hospitalized elderly with chronic illness at USU Hospital, Medan. This research is a qualitative study with a phenomenological approach. The sampling technique was the purposive sampling method with several criteria; female with mild to high stress level, the prominent caregivers in the family, and had been caring the elderly for more than 1 year. The female caregivers would be assessed for stress levels with the Zarit Burden Inventory instrument, which is commonly used to assess the stress burden of caregivers caring for the elderly. The data collection is conducted through in-depth interview. The data are transcribed and analysis for sub-theme and theme. The research result found nine participants with an age range of 32-67 years. All participants are the elderly daughter's and spouses. The stress score is 15-25 which means that the participants are experiencing mild-moderate to severe stress ranges. The thematic analysis revealed four main themes namely; (1) Financing elderly, (2) Caregiver fatigue, (3) Experiencing negative relationship, and (4) Indonesian culture associated with female gender. According to the research result, it should be a basis data for further research related to the elderly caregivers. Therefore, the need for the specific interventions is provided for the elderly and the caregivers who are vulnerable to stressful conditions.

Keywords. Female caregiver stress, Hospitalized elderly, Qualitative Study

Introduction

According to (Conley & St Pierre, 2016) the elderly are a group of individuals over the age of 65 years and undergoing an aging process, such as a gradual decline in bodily physiological function, starting from the cardiovascular system, respiration, genitourinary, endocrine, immune system and the mental status alteration (Saxon et al., 2010)

In terms of the elderly mental health status decline, the majority of the elderly experience issues in memory, intellectual and cognitive function (Chen et al., 2009). This is often the cause of the elderly suffering from Alzheimer's and Dementia (Dewey, 2016). Both

of these diseases were found to be one of the triggers for depression and anxiety among the elderly (Fiske et al., 2009).

Professionals are asserted that providing quality care to the elderly is a challenge for the family health services (Birkeland & GK, 2009). This is inseparable from the role of family and people closest to the elderly in providing care for the elderly (Gholizadeh et al., 2016), such as couples, children or the daughter-in-law of the elderly who are mostly women (Annisa, 2016; Sørensen, 2011).

According to (Wasilewski, 2016), family caregiver or informal caregiver is a family member who provides comprehensive services to family members who are sick and unable to care for themselves. The women who become the primary caregivers of the elderly generally help the elderly in fulfilling their basic daily needs, and taking responsibility for domestic household duties. These female caregivers also the primary financial resources, and provide care for the whole family members (Desbiens et al., 2018). Multiple roles as mothers, workers and caregivers lead to fatigue which worsens the physical and mental health condition of the caregiver (Ho et al., 2009; Ward-griffin et al., 2019).

Researches showed that providing care for the family members are often considered as a burden for female caregivers (Annisa, 2016). This can lead those who are at risk of increasing the incidence of depression and anxiety (Bevans & Sternberg, 2012b; Noble, 2005). (Schoenmakers et al., 2010) stated that one in three female caregivers who provide care to the elderly with special conditions suffer from depression.

Some triggers that are indicated to be the stressors for female caregivers are related to the decreased of the elderly physiological abilities, elderly emotional disturbances, changes in behavior and decreased in cognitive function (Pinquart & So, 2018). Shifting the financial burden to caregivers while the elderly is cared for is a challenge for female caregivers in handling emotional and physical fatigue due to the overlap household chores (Kao et al., 2004).

According to (Kementerian Kesehatan Republik Indonesia, 2017), the main focus of the state health services is oriented towards the sick person, but there is no health service targeting the family caregivers, especially women. Therefore, female caregivers who care for the elderly at home often become neglected and continue to experience a decrease in physical and mental abilities.

(Empeno et al., 2011) states that one of the efforts to minimize the impact of depression among the elderly is with the caregivers who are free from depression as well. A stress free caregiver with minimal physical burden tends to provide a better care so that it does not become a stressor for the person being treated (Roth et al., 2015). Therefore, baseline data related to the stress burden of these female caregivers is needed to design appropriate interventions for caregivers, especially women and their beloved one.

Methods

This research is a qualitative study with a phenomenological approach. The population in this study were female caregivers who took care of the elderly at Universitas Sumatera Utara Hospital/USU Hospital. To get a sample that will be used as a research participant, several criteria are determined for the initial screening of the participant determination. (Anson et al., 2013). The sampling technique used was purposive sampling with the following inclusion criteria (Kim & Schulz, 2008):

- a. Nine female caregivers who experience mild to moderate stress level
- b. Female caregiver over 18 years old (children, wife, daughter-in-law, or granddaughter) who taking care of the elderly at USU Hospital

c. Female caregiver is the main caregiver who has been caring for the elderly for more than one year for the specific illness

d. The female caregiver is a person who is responsible for fulfilling the basic needs of the elderly, such as eating, drinking, bathing, and dressing and responsible for the financial burden of the elderly.

e. The elderly who are treated are the elderly with chronic diseases, such as cancer, diabetes, dementia and frail elderly conditions.

f. Able to speak Indonesian and well cooperative

In data collection, initial screening was carried out using Zarit Burden Inventory / ZBI (Bédard et al., 2018), which is an instrument commonly used in assessing stress among the caregivers while caring for the elderly. Caregiver stress load calculation using ZBI with a range of ratings:

- 0-10 : No stress
- 10-20 : Mild to moderate stress
- >20 : Heavy stress

If a female caregiver does not experience the stress level, then it is not examined further for in-depth interviews related to stress experience. In depth interviews is only conducted with female caregivers with the certain stress score after identifying caregiver stress with ZBI (≥ 10). The interview guide consists of several questions related to stress caregiver while caring for the elderly. Thematic analysis is done in determining research themes and sub-themes.

Results

The research revealed two main points that are the demographic characteristics and the research themes and sub-themes.

1.1. Demographic Characteristics

All participants are the female caregivers who took care of the elderly for more than one year; most of the caregivers are the elderly daughters who provide financial support and fulfill the elderly activities daily living. Eight of the elderly are cared for total treatment and only one of them is capable to do the activity daily living. The elderly is hospitalized for some medical issues such as stroke, cardiovascular diseases and cancer. The demographic characteristics are shown below.

Table 1. Participants Characteristic

No	Participant ID	Age (years old)	Family Relationship	Occupation	Marital Status	Duration of Care	Stress Score	The Elderly Care Status	Elderly Medical Diagnosis
1	Mrs. RN	38	Daughter	Laundry women	Married	5 years	16	Independent	Hypertension
2	Mrs. SL	41	Daughter	Housemaid	Married	10 years	15	Total Care	CHF + CKD
3	Mrs. PF	34	Daughter	Vegetable vendor	Married	5 years	19	Total Care	CKD Stage V
4	Ms. NB	40	Daughter	Retired Nurse	Single	A year	17	Partial Care	CHF
5	Mrs. TH	67	Wife	Tailor	Married	3 years	15	Total Care	Stroke
6	Mrs. B	60	Wife	Housewife	Married	5 years	11	Total Care	Stroke

7	Mrs. S	59	Wife	Housewife	Married	A year	25	Total Care	DM, HT, CKD, Stroke
8	Mrs. LH	36	Daughter	Housewife	Married	7 years	21	Total Care	Stroke + Breast Cancer
9	Mrs. RS	32	Daughter	Housewife	Married	2 years	19	Total Care	Stroke + Hypertension

1.2. Research Themes

According to the research, it showed four main themes namely; (1) Financing the elderly, (2) Caregiver fatigue, (3) Experiencing negative relationship, and (4) Indonesian culture associated with female gender.

1. Financing the elderly

Research showed that all participants are responsible for the elderly financial support. There are two sub themes found that are; supporting the elderly daily living expenses and less income during hospitalization.

1.1. Supporting the elderly daily living expenses

One participant complained about the financial support burden during hospitalization.

"But sometimes I feel tired because once a week I have to take my mother to the doctor. Every time I bring my mother for the doctor treatment, it costs me more than 700 thousand rupiahs. Sometimes I don't have any more money to get the treatment and it really hard for me to finance all my mother's expenditure (P3, L304).

This statement is supported by one participant who act as the elderly's wife and complain about the high cost of her husband treatment.

"...And then the nurse told me that the treatment costs two and a half million rupiahs. I don't have that much money. I'm so confused to think how to finance my husband treatment during his illness" (P1, L39)

1.2. Less income during hospitalization

During the elderly hospitalization, the caregiver spends more money during the hospital visit as the caregiver have no chance to go to work. It supported by the participants' statement:

"We drive from our house with public transportation and it costs 100 thousand rupiahs each day. Sometimes we have to come here quickly, so we don't have time to eat at home, and should buy our meal from the food stall again. It costs more than 100 thousand rupiahs. It made my income less than usual every day" (P2 L 170).

2. Caregiver fatigue

The female caregiver complained of physical and mentally fatigue related to the elderly care. There are three main sub themes found that are; taking care of the elderly daily living activities, the elderly misbehavior and mentally exhausted

2.1. Taking Care of the Elderly Daily Living Activities

All participants comment about the need to fulfill the elderly daily living activities. The caregiver need to serve the elderly in every aspect of the elderly life. This situation is supported by some comments below.

"Yeah, it's like he can't do anything. I have to take care of all his needs" (P6, L237)

2.2. *The Elderly Misbehavior*

The research also showed that the elderly behavior who can't control their way to adhere the medication, or show a desperate feelings impact the family members especially the caregiver. This is can be seen from some comments below.

"It gave an impact for us if our mother shows no motivation at all. We are so upset to see her health status are getting worse for her behavior are so negative (P2 L325)

"I feel so emotion when I found out that my mother's head is full of bruise. Even though she is very sick, but she loves to work. So, she is very often hit the wall, or fell down during her chores. It made us so mad since we don't want her to get hurt (P9 L87)

2.3. *Mentally Exhausted*

Some participants' complaints about the lack of time to rest and it lead to the mentally exhausted condition. Some participants showed some comments below:

"I feel that I'm so tired. For instance, I used to wash all my husband urine's cloth. When he wet the bed, I found it all wet, all his clothes, his linen, pillow, all wet. I told him not to do that because I'm so tired, but he still does. That's what I feel like a burden" (P6, L221)

"I used to have less sleep time. I can't sleep if my mom wakes me up to fulfill her need. I'm so tired physically, but deep inside I'm sick of it (P2, L41)

3. Experiencing Negative Relationship

There are two sub themes found related to the negative relationship that are; had a negative relationship with the siblings and negative relationship with the family in law. The comments are below.

3.1. *Negative Relationship with the Siblings*

Some participants acknowledge that their relationship with their sibling sometimes bring the conflict out.

"For instance, before my mother's hospitalization, I took her to the hospital with my little boy last night. My sisters came to the hospital in the evening. And, I think they are not fast enough to visit my mother. That's sometimes become a dispute among us" (P2, L283)

"I push my brother to take care of our father every night, since I have my own job to do. Sometimes we fight for our father schedule in the hospital. He also has a job to do (P3, L324)

3.2. *Negative Relationship with the Family in Law*

"Yeah, I can say that my sister in law's family are too meddling with my brother's household affairs. It is normal that my brother should take care of his own father, but my sister in law's family do not like it and I feel upset about that" (P3, L372).

4. Indonesian Culture Associated with the Female Gender

There are two main themes found related to the Indonesian culture associated with the female gender, that are females' obligation in the family and female multiple role in the family.

4.1. *Females' Obligation in the Family*

"What should I say? I'm the only female in my family. It is my obligation as a daughter of my parents" (P5, L 173)

"I have to take care of my mother. I quit from job since it's my responsibility to take care of my mother" (P8, L26)

A wife comment about her responsibility to take care of her husband. This is like a destiny that she should receive and cannot be refused even though

“I said to my sister that this is what I should be, as a wife and as a caregiver for my husband” (P6, L222)

“I quit from my job since I need to take care of my mom. I cannot complain about it” (P8, L82)

4.2. Female Multiple Roles in the Family

Most respondents showed multiple roles in the family as a daughter, a wife, a mother, a financial provider and a caregiver. This lead to a complicated situation for the female caregiver. Some respondents support this with some statements.

“Yeah, I need to arrange all my responsibilities. Before 3 o’clock in the evening, I cook cookies to sell. Then, I work as a housemaid in one of the college students’ house. I prepare my son’s needs for his school then I also need to take care my mother after I did all my jobs” (P5, L78)

“Definitely I feel exhausted since I need to do my chores, taking care of my husband, taking care of my grandsons, do laundry and clean the house” (P7, L82)

Discussion

According to (Wasilewski, 2016) caregivers are non-professionals who are paid to care for the children, the sick person and the disabled person including the elderly. Informal caregivers are individuals who provide daily care assistance without payment, such as family members, friends or a close neighbor. These caregivers usually spend more than 50% of their time for care delivery. This research results showed that seven out of nine elderlies are provided with total care, and asked the female caregivers then quit their jobs. The caregivers consist of six daughters and three elderly wives with an average age of 45 years. (Collins et al., 2011) stated that 75% of the average age of caregivers is 69.4 years, which is dominated by elderly wives. And, (Desbiens et al., 2018) mentioned that 75% of informal caregivers are women who provide care to all family members who needs care, especially the elderly. Thus, these female caregivers also have very poor health status, suffer from depression, anxiety, and loneliness (Bevans & Sternberg, 2012a). The results showed that all caregivers were exposed to stress with a stress score of 15-25 which means that the participants were experiencing mild-moderate to severe stress ranges. Normally, stress is occurred as a response to stressor stimulus towards human conditions, but stress in female caregivers shows a decrease in productivity in elderly care services and a decrease in the quality of caregiver life (Ho et al., 2009; Schoenmakers et al., 2010).

According to the study result, the female caregiver’s fatigue is mostly caused by the taking care of the elderly daily living activities, the elderly misbehavior and mentally exhausted. This is related to the elderly cognition and mental status alteration (Saxon et al., 2010), especially in the age range above 65 years (Conley & St Pierre, 2016). As a result of the elderly health status decline, most of those experience behavioral changes that tend to be considered maladaptive by the caregivers. This situation leads to the caregiver’s experience in physical and mental fatigue. It impacts the caregiver with a poor mental health conditions while dealing with the elderly physiological and psychological conditions (Desbiens et al., 2018). According to a research conducted by (Sharma et al., 2016), women are the majority of groups that provide health services to the sick family members without a qualified knowledge of care. But, the family and community have a high expectation that these women are able to provide maximum

services to the elderly with minimal knowledge (Wasilewski, 2016). As a result, these caregivers tend to feel helpless and not confidence enough in meeting the elderly needs. Moreover, the society's view of caregiving process tends to ignore the condition of the caregiver's physical health (Collins et al., 2011; Sharma et al., 2016). Obviously this is the leading to a chronic disease development (Schulz & Beach, 1999). The results of this study indicate that the female caregivers who were the participants of this study were the daughters and the wives of the elderly. These people are demanded by Indonesian culture to provide care services for the family members especially the parents (Annisa, 2016). Therefore, these female caregivers feel exhausted related to the Indonesian culture associated with female gender. In this case, the female caregiver felt that being a caregiver was an obligation that women should not leave aside from being mothers, wives, daughters, and the financial supporter. Therefore, the multiple roles of these women are contribute to the depression in most female caregivers (Mausbach et al., 2013). And, in a severe case, the female caregivers who do not get physical and mental health care showed a high risk for suicide (Park et al., 2013).

According to (Lai, 2012), one of the factors that aggravate the health condition of these female caregivers is the financial condition of the elderly, which is mostly borne by the caregiver. This is due to the condition of elderly people who have retired and is totally dependent on the caregivers. The results of this study indicate that most participants are also a financial supporter and endure the lives of the elderly. These female caregivers in some cases experience a lack of income if the elderly have to get a hospitalization. The hospitalization is a condition where the female caregivers have to cope with excessive financial burdens as those are also experience severe fatigue, suffer from sleep disturbance, physical problems and emotional imbalances (Ho et al., 2009)). Most participants suffer from emotional imbalance and trigger the conflicts with other family members in terms of sharing the burden of care and financial burden. The results of this study indicate that these female caregivers experienced negative relationships with siblings and negative relationships with family-in-law. Disputes between relatives often occur during elderly care due to several things such as the dominance of one other family member over elderly care and financial mastery of the elderly (Lashewicz & Keating, 2009). This then triggers conflict and causes poor communication between the family members.

Conclusion

Based on the analysis of the research theme, four main themes were found in this study, namely 1) Financing the elderly, (2) Caregiver fatigue, (3) Experiencing negative relationships, and (4) Indonesian culture associated with female gender. Themes that emerged from the results of this study indicate that the majority of these factors cause stress on female caregivers while caring for the elderly at home and hospital. This stress condition then triggers changes in the physical and psychological conditions of female caregivers who are at risk of decreasing quality of life and risk of suicide.

Acknowledgements:

This research was supported by the University Sumatera Utara for the 2018 TALENTA research funding program. The researcher would like to thank the University for supporting research funding. And gratitude to the nurses and policyholders at USU Hospital who facilitated the researchers during the data collection process and supported the researchers throughout the research process. Most thanks to female caregivers who have been willing to make time to be interviewed thus providing very valuable data in this study.

Conflict of interest. There is no conflict of interest to declare

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