

BURDEN AMONG FAMILY CAREGIVERS OF ADVANCED-CANCER PATIENTS IN INDONESIA

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Abstract

Background: There have been various studies into the family caregivers' experiences in taking care of advanced-cancer patients. But, a study exploring the burden among family caregivers has not yet been conducted in Indonesia, a country which has strong family bonds among family members.

Objective: This present study aimed to identify the burden among family caregivers of advanced cancer patients.

Methods: This study was a cross-sectional study conducted from December 2016 to February 2017 on 178 consenting family caregivers and advanced cancer patients, selected using a purposive sampling technique. The Caregiver Reaction Assessment (CRA) was used to measure their burden. Data were analyzed using descriptive analyzes and bivariate analyzes.

Results: The burden among family caregivers was 2.38 ± 0.38 (mean range 1-5). The highest burden was in the disrupted schedule domain.

Conclusion: Our findings identified that the burden among family caregivers was at the medium level. The length of care per day and family support are potential targets for preventative intervention strategies to reduce the burden among the family caregivers.

Keywords: burden, cancer, family caregivers, Indonesia, palliative care

INTRODUCTION

The World Health Organization (WHO) predicts that by 2020, more than 15 million people worldwide will suffer from cancer, and the mortality rate will increase by approximately 70% in the low- and middle-income countries (WHO, 2016). Cancer is one of the chronic diseases that has become a major health problem in Indonesia, one of the developing countries. The highest prevalence of cancer in Indonesia is found in Yogyakarta, and is recorded at 4.1% per 1,000 population for all ages (Riskesdas, 2013).

Cancer is a group of diseases characterized by uncontrolled cell growth and abnormal cell spreading (ACS, 2016). It can metastasize to other organs and can be incurable, i.e. advanced-cancer (ACS, 2016; National Cancer Institute, 2016). Advanced-cancer patients can experience multiple suffering from the disease itself, and also from the side effects of treatment, i.e. physical, psychosocial, and spiritual problems (Effendy et al., 2015).

The patient's immediate family members, commonly known as family caregivers, are the people who are most responsible for the care of cancer patients (Rha, Park, Song, Lee, & Lee, 2015). Family caregivers experience a change in their lives, since they are responsible for taking care of cancer patients. Subsequently, the family caregiver, for the most part, assumes that such change is a pressure resulting in a burden for them (B. A. Given, Given, & Kozachik, 2001). The burden felt by family caregivers may have various underlying factors. It may come from the family caregiver, their environment, and/or the cancer patient undergoing treatment (Chou, 2000; Goldstein, Concato, Fried, & Kasl, 2004; Papastavrou, Charalambous, & Tsangari, 2009, 2012; Rafiyah, 2011). There have been various studies into the family caregivers' experiences in taking care of advanced-cancer patients conducted in Asia and America (Effendy et al., 2015; Goldstein et al., 2004; Rha et al., 2015). Indonesia, like other Asian countries, has strong family bonds among family members (Effendy et al., 2015). But, a study exploring the burden among family caregivers has not yet been conducted in Indonesia. This can provide new findings from Indonesia. The aim of the present study is to identify the burden among family caregivers of advanced-cancer patients.

METHODS

Setting and population

A cross-sectional design was used in this study. Data were collected from general hospitals in Yogyakarta and Purwokerto, Indonesia from December 2016 to February 2017. The eligibility criteria for the family caregivers were as follows: (a) Adults (older than 17 years); (b) taking care of advanced-cancer patient (stage III or IV) regardless of the type of cancer, or whether the cancer was newly diagnosed or recurrent, or treated with chemotherapy or radiotherapy; (c) being confirmed as the main caregiver by the patient (d) having accompanied the patient during hospitalization for at least 3 days, (e) taking care of the patient's daily needs, (f) being able

to communicate; and (g) willing to consent to participate in the study. The eligibility criteria for the patients were as follows: (a) Adults (older than 17 years); (b) advanced-cancer patient (stage III or IV) regardless of the type of cancer, or whether the cancer was newly diagnosed or recurrent, or treated with chemotherapy or radiotherapy; and (c) willing to consent to participate in the study. A total of 191 family caregivers with their patients met the inclusion criteria, but only 178 consenting family caregivers with their patients formed our final sample (9 family caregivers did not stay in the room with the patient, and 4 patients did not agree to participate).

Measure

Demographic variables

The first section of the survey instrument were the characteristics of the family caregivers, including their demographic characteristics' questions such as age, gender, ethnic type, marital status, relationship with the patient, education level, income, and health status; the characteristics of the family caregivers included caring characteristics' questions such as the length of care provided per day, previous caring experience, health education experience, time spent travelling from their home to the hospital; and patients' characteristics such as their age, gender, and performance status.

Family caregivers' burden

The Caregiver Reaction Assessment (CRA), developed by Given et al. (C. W. Given et al., 1992) was used in the present study. It has 24 items that contain five dimensions for the family caregivers' situation: Self-esteem (7 items), lack of family support (5 items), impact on finances (3 items), impact on daily schedule (5 items), and impact on health (4 items). The perceived impact is rated on a 5-point Likert scale, with the format: 1 (strongly disagree), 2 (disagree), 3 (neither agree nor disagree), 4 (agree), 5 (strongly agree). Each domain was added to a sum score, which was divided by the number of items, reflecting the unweighted mean-item score, with a mean range from 1 to 5. This kind of scoring was modified by Grov et al. (Grov, Fosså,

[Tønnessen, & Dahl, 2006](#)). In order to calculate the sum score, the self-esteem dimension was recoded. The CRA's total score, as the sum score of the 24 items overall, reflects the caregiver's situation. The higher scores reflect a higher burden. The CRA was translated into Indonesian, and then back-translated, following the appropriate processes. Cronbach's alpha for the CRA was 0.761 at the baseline. Two items about the caregivers' esteem (numbers 1 and 12) were not valid (Pearson correlation (r) < 0.199) but it was decided to still use them in this study.

Family support

The family's Adaptability, Partnership, Growth, Affection, and Resolve (APGAR), developed by Smilkstein, Asworth, & Montano ([Smilkstein, 1978](#)), was used in the present study. It has five items to assess a family caregivers' perception of the functioning of the family by examining their satisfaction with the family's support. The response options were designed to describe the frequency of feeling satisfied with each parameter on a Likert scale ranging from 0 (hardly ever) to 2 (almost always). The scale was scored by summing the values for the five items for a total score, ranging from 0 to 10. A higher score indicated a greater degree of satisfaction with the family's functioning. The family APGAR was also translated into Indonesian and then back-translated following the appropriate processes. Cronbach's alpha for the family APGAR was 0.896 at the baseline. All items were valid because it has a Pearson correlation (r) > 0.182.

Patients' performance status

The Palliative Performance Scale (PPS) is a tool to measure the performance status of palliative care, developed by Anderson, Downing, & Hill ([Anderson, Downing, Hill, Casorso, & Lerch, 1996](#)). The PPS is divided into 11 categories that are measured at 10% decreasing stages (100% to 0%). The lower the PPS level, the higher is the need for help from professionals or family caregivers. There are five observable parameters included in the functional assessment, such as the degree of ambulation, the ability to carry out activities,

the ability to do self-care, the intake, and level of consciousness. The PPS was translated into Indonesian and back-translated following appropriate processes. Cronbach's alpha for the PPS was 0.982 at the baseline; Cohen's Kappa was 0.814; and the average measure of the Interclass Correlation Coefficient (ICC) was 0.982.

Statistical analyzes

The Statistical Package for the Social Sciences (SPSS) (version 16, SPSS, Inc., Chicago, IL, USA) software package was used for entry data and analyzes. The descriptive normality test was used to describe the normality of the numerical data. Mean values and Standard Deviation (SD) were used when symmetrical. Median values and Inter-quartile Ranges (IQR) were used when skewed. The independent t -test was used in order to compare the difference in the mean of the burden, according to the family caregivers' and patients' characteristics. The Pearson correlation and the Spearman Rho coefficient were used in order to correlate the burden with the family caregivers' and patients' characteristics. A p -value of < 0,05 was considered statistically significant.

Ethical Consideration

The Institutional Review Board of the Faculty of Medicine at Universitas Gadjah Mada, Yogyakarta, Indonesia, approved all the materials and protocols used in this study (Number: KE/FK/1318/EC/2016). All the family caregivers and patients gave their written informed consent to participate in this study.

RESULTS

General characteristics of family caregivers and patients

The characteristics of the respondents are summarized in Table 1. One-hundred and seventy eight consenting family caregivers and patients were included in the final analysis. The mean age of the family caregivers and patients was 44.03 ± 12.69 years old and 51.64 ± 10.84 years old, respectively. Most of the

family caregivers were married (83.1%), almost half of them (47.2%) were spouses, and 60.7% of them had a low income (< 1,338,000 IDR). Most of the family caregivers have no

previous experience of caring, or health education about cancer (59%; 67.4%, respectively).

Table 1 General characteristics of family caregivers and patients (n = 178)

Characteristic	Family caregivers (n/%)	Patients (n/%)
Age (years) (Mean±SD)	44.03±12.69	51.64±10.84
Gender		
Male	73 (41.0)	63 (35.4)
Female	105 (59.0)	115 (64.6)
Ethnic		
Javanese	168 (94.3)	
Non-Javanese (Sunda, Batak, Minang, Sasak)	10 (5.7)	
Marital status		
Married	148 (83.1)	
Non-married (single, widow, widower)	30 (16.9)	
Relationship with patient		
Spouse	84 (47.2)	
Non-spouse (parent, child, relatives)	94 (52.8)	
Education level		
Illiterate to senior high school	146 (82.1)	
College	32 (17.9)	
Family income ^a		
< Minimum income level	108 (60.7)	
≥ Minimum income level	70 (39.3)	
Time spent from home to the hospital (hours) (Median;IQR)	1.5(1.00-2.00)	
Length of care per day (hours) (Median; IQR)	24.00(17.5-24.00)	
Previous caring experience		
Yes	73 (41.0)	
No	105 (59.0)	
Health education experience about cancer		
Yes	58 (32.6)	
No	120 (67.4)	
Health status		
Good	145 (81.5)	
Have symptom of disease	33 (18.5)	
Family support (Median; IQR)	10.00(5.00-10.00)	
Performance status (Mean±SD)		68.76±16.04

^aThe minimum income level in Yogyakarta and Purwokerto, Indonesia: 1,338,000 IDR; SD. Standard Deviation; IQR. Inter-quartile Range

Family caregiver burden

As seen in Table 2, the mean overall burden score was 2.38 ± 0.38. The highest burden was the impact on the daily schedule's dimension

and the lowest burden was on the caregiver's self-esteem dimension (mean 3.26 ± 0.80; 1.65 ± 0.33 respectively).

Table 2 Family caregiver burden (n = 178)

Domains (items)	Mean range	Mean±SD
Caregiver self-esteem (7 items)	1.00-5.00	1.65±0.33
Lack of family support (5 items)	1.00-5.00	2.62±0.78
Financial problem (3 items)	1.00-5.00	2.47±0.71
Disrupted schedule (5 items)	1.00-5.00	3.26±0.80
Health problem (4 items)	1.00-5.00	2.20±0.61
CRA total score (24 items)	1.00-5.00	2.38±0.38

CRA. Caregiver Reaction Assessment; SD. Standard Deviation

Bivariate analyzes

As seen in Table 3, we found that the family caregivers' age ($p = 0.008$), marital status ($p = 0.009$), relationship with the patient ($p < 0.001$), education level ($p = 0.001$), family income ($p < 0.001$), length of care per day ($p <$

0.001), health status ($p = 0.042$), family support ($p < 0.001$), and the patients' gender ($p = 0.001$) were statistically significant with the burden (CRA) of family caregivers.

Table 3 Correlation/comparison between family caregiver and patient characteristics with burden (n=178)

Independent variables	Mean±SD ^a	Correlation coefficients (r) ^b	p-value
Family caregivers age (years)	-	0.200	0.008**
Family caregivers gender		-	0.457
Male	2.36±0.38		
Female	2.40±0.39		
Family caregivers ethnic		-	0.671
Javanese	2.39±0.39		
Non-Javanese	2.33±0.24		
Family caregivers marital status		-	0.009**
Married	2.42±0.37		
Non-married	2.22±0.43		
Relationship with patient		-	<0.001**
Spouse	2.50±0.34		
Non-spouse	2.28±0.39		
Education level		-	0.001**
Illiterate to senior high school	2.43±0.38		
College	2.19±0.32		
Family income		-	<0.001**
< Minimum income level	2.50±0.36		
≥ Minimum income level	2.21±0.35		
Length of care per day		0.372	<0.001**
Previous caring experience		-	0.290
Yes	2.35±0.41		
No	2.41±0.37		
Health education experience about cancer		-	0.323
Yes	2.34±0.39		
No	2.40±0.38		
Family caregivers health status		-	0.042*
Good	2.36±0.37		
Have symptom of disease	2.51±0.44		
Family support		-0.287	<0.001**
Time spent from home to the hospital (hours)		0.026	0.728
Patients age (years)		-0.027	0.722
Patients gender		-	0.001**
Male	2.51±0.37		
Female	2.32±0.38		
Patient performance status		-0.077	0.309

^aIndependent *t*-test; ^bPearson correlation or Spearman Rho; ** $p < 0.01$ indicate significance; * $p < 0.05$ indicate significance; SD. Standard Deviation

DISCUSSION

Main findings

In the present study, the mean of the family caregiver's burden was 2.38, with a mean range of 1-5 (Table 2). This finding corroborates a previous study (Rha et al., 2015), although using different instruments to measure the burden. Korean family caregivers

experience a moderate burden when taking care of cancer patients (Korean version-Zarit Burden Interview (K-ZBI) = 36.45 range 10-74). A study in Taiwan (Lee, Yiin, & Chao, 2016) also showed that the mean of the family caregiver's burden in taking care of cancer patients in the terminal stage was 62.2-64.3, range 24-120 using a CRA instrument (the score was not divided by the total number of

items). This similarity is because these two countries are located in the same area of Asia. Asian cultures hold strong bonds among family members (Effendy et al., 2015; Rha et al., 2015; Yoon, Kim, Jung, Kim, & Kim, 2014). They also have the belief that taking care of family members is an obligation (Effendy et al., 2015; Yoon et al., 2014). The difficulties experienced by family caregivers, in terms of the lack of family support and disruptions to their daily schedule were secondary to their desire to care for their loved ones (Yoon et al., 2014).

In contrast with this present study, a study on family caregivers taking care of advanced-cancer patients conducted in the South of England showed different results (Higginson & Gao, 2008). That study found that the family caregivers' burden was low (ZBI score 18.55 range 10-74) (Higginson & Gao, 2008). In taking care of advanced-cancer patients, England applies a home-based palliative care service, the implementation of which is carried out in a participative manner by actively involving the patient and the family caregiver. Beside that, England is one of a number of European countries which value independence (Effendy et al., 2015; Vernooij-Dassen, Osse, Schadé, & Grol, 2005). Therefore, the family caregivers' burden was low.

Family caregivers who take care of male patients experience a greater burden compared to family caregivers who look after female patients. This is in line with a study conducted in Greece (Govina et al., 2015). That study specified that female patients will be more independent in addressing their own daily needs (Govina et al., 2015). In terms of social status, the male is the head of the family. If he is sick or unable to provide for his family, surely this will be a burden for his family caregiver.

Based on this present study, the older the family caregiver is, the greater is the burden on the family caregiver. This is in line with a study conducted in Iran which stated that the age of a family caregiver is related to the burden they face, although the average age of

the family caregivers in Indonesia and Iran is different (Vahidi et al., 2016). The greater burden experienced by the more elderly caregivers is mainly due to the social status, physical, and psychological factors of the caregiver (Harding et al., 2015). The social status changes in middle and late adulthood, commonly this is caused by unemployment; while, in terms of the physical issues, the aging process plays a significant role. Whereas in terms of their psychology, family caregivers face the fear of losing someone they love due to aging (Harding et al., 2015). That result was in contrast with an American study which found that younger family caregivers felt more of a burden than older ones (Goldstein et al., 2004). The younger family caregivers felt a greater burden because they had to take care of their own family, as well as their patients, so that they had multiple roles to fill (Goldstein et al., 2004).

In this study, the greater the family's support is, the lesser the burden is on the family caregiver. This result is supported by the greater average rate of family caregivers' burdens, in terms of the lack of family support. It is in line with the previous study conducted in Korea and two studies in America (Burton et al., 2012; Francis, Worthington, Kypriotakis, & Rose, 2010; Yoon et al., 2014). These three studies concluded that a lack of family support and visits will make the uncomfortable situation of taking care of a patient, in an advanced stage of cancer, much worse (Burton et al., 2012; Francis et al., 2010; Yoon et al., 2014).

Family caregivers with low incomes carry a very heavy burden, compared to a family caregiver with a large income. Economic issues, evidently, are one of the main findings in developing countries (Ratnawati & Loebis, 2014; Vahidi et al., 2016). The two biggest concerns for family caregivers are insurance and treatment costs (Vahidi et al., 2016). Family caregivers are under pressure, not only due to their income, but they also have to pay for their patients' required treatments, as well as their own and their family's needs (Ratnawati & Loebis, 2014).

In this present study, the longer the family caregiver spends taking care of an advanced-cancer patient, the greater will be the family caregiver's burden. This is in line with the studies conducted in Korea and Greece which signified that the length of care per day serves as the significant factor in terms of the greater burden borne by the family caregiver, particularly because of its impact on their schedule (Govina et al., 2015; Yoon et al., 2014). The longer they spend each day caring for their patient, the less time they have for their hobbies, social life, and meeting their own basic needs (Yoon et al., 2014). The longer the family caregiver spends with the patient will result in the greater dependency of the attended family member on the caregiver to meet the attended family member's needs (Govina et al., 2015). Surprisingly, this factor had the strongest effect on the family caregivers' burden. Length of care per day was not the strongest factor in two previous studies (Govina et al., 2015; Yoon et al., 2014). This could be due to the difference in the duration of care per day between Korea, Greece, and Indonesia. Family members in Indonesia accompany the patient almost 24 hours a day (Effendy et al., 2015). This may have positively impacted on the family caregivers' burden.

In this present study, family caregivers with a lower education level have a greater burden compared to a family caregiver with a higher education level. A person having a higher education level will employ issue-focused coping when facing difficulties, instead of emotional coping (Papastavrou et al., 2009). The level of education is closely related to a person's socioeconomic status (Govina et al., 2015). A person with lower education levels will struggle to find a high-paying job, and they will end up in a low-paying job (Govina et al., 2015; Ratnawati & Loebis, 2014). This subsequently will trigger the burden.

The results of this study showed that the married family caregivers have a greater burden compared to the single ones. Family caregivers having a spousal relationship

(husband/wife) with the advanced-cancer patient bear a greater burden compared to the family caregiver with a non-spousal relationship. The results of this study are supported by research conducted in Greece (Govina et al., 2015). Although the family caregiver is not always the spouse of the patient, when the family caregiver's marital status is married, he/she must also take care of his/her own family members, in addition to attending to the needs of the cancer patient (Govina et al., 2015). This will increase the burden of the family caregiver. A study conducted in Canada affirmed that the spouse holds the greatest burden when attending an advanced-cancer patient (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007). A spouse is the person at the highest risk of experiencing the burden when taking care of an advanced-cancer patient (Braun et al., 2007).

In this study, a family caregiver suffering from symptoms of the illness bears a greater burden compared to a healthy one. This is in line with research conducted in Iran (Vahidi et al., 2016). Family caregivers who are in good health are physically stronger and more capable of providing for their family member with advanced- cancer, and therefore feel less of the burden (Vahidi et al., 2016).

This study was the first study about the family caregivers' burden for advanced-cancer patients in Indonesia, a developing country with a huge population, with a diversity of cultures and many people who still have a low socioeconomic status. Because this study has not been explored previously, it provides a better understanding of the family caregivers' burden and helps identify family caregivers who are at higher risk of being overburdened.

This study has several limitations that must be improved by the next research. Firstly, it is difficult to generalize our result, because there were only two hospitals included in this study, in only two provinces in Indonesia. Secondly, there were two items on the CRA instrument (number 1 and 12) that were not valid, but were still used. It was due to the importance of these items that we measured the caregivers'

esteem on the family caregivers' burden. The exploration of the CRA instrument must be done on the other populations.

Using our results, preventative interventions could be possible in the early days of admission, to reduce the family caregiver's burden. Since the nurses are in close contact with the family caregivers, we recommend that they pay more attention to the family caregivers' needs. They can also make an assessment of the family caregiver with the highest risk of burden. The long duration of care can create possible moments for the nurses to conduct a health education or basic skills training program for family caregivers so they are not bored.

CONCLUSION

The burden was higher for family caregivers who spend a greater amount of time per day caring for their patient, suffer from a lack of family support, and have symptoms of the disease. These three characteristics were identified as modifiable factors that could be potential targets for preventative intervention strategies to reduce the burden. Developing and applying interventions, such as giving an education program about cancer care, or involving family caregivers in advanced care planning, may be important to reduce the burden among family caregivers in caring for a family member suffering from advanced cancer.

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Conflict of Interest

The authors declare that there is no conflict of interest.

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