

# Family caregivers' involvement in caring for a hospitalized patient with cancer and their quality of life in a country with strong family bonds

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## Abstract

**Background:** Being involved in caring for family members during illness is part of the Indonesian culture, even during hospitalization. It is unknown which factors influence the quality of life (QoL) of family members taking care of their loved ones. The present study aims to identify factors influencing the QoL of family caregivers of hospitalized patients with cancer in Indonesia.

**Methods:** A cross-sectional survey was performed. Data were collected in a general hospital in Yogyakarta from September to December 2011. Family caregivers of patients with cancer were invited to participate. Regression analysis was used to determine which aspects of caring and which demographic characteristics influenced their QoL. The Caregiver QoL Index—Cancer questionnaire was used to measure the QoL.

**Results:** One hundred of 120 invited caregivers (83%) completed the questionnaire. Being involved in psychological issues in caring ( $\beta = 0.374$ ;  $p = 0.000$ ), younger age ( $\beta = -0.282$ ;  $p = 0.003$ ), no previous caring experience ( $\beta = -0.301$ ;  $p = 0.001$ ), and not being the spouse ( $\beta = -0.228$ ;  $p = 0.015$ ) negatively influenced the QoL and explained 31% of the variation (adjusted  $R^2 = 0.312$ ;  $F = 12.24$ ;  $p = 0.000$ ). Gender, education level, and time spent on caring did not influence the QoL of family caregivers.

**Conclusions:** Our findings identified modifiable factors such as dealing with psychological issues and lack of experience in caring that negatively influenced the QoL of family caregivers. These factors are potential targets for intervention strategies. Education and intervention programs focusing on dealing with psychological problems in cancer care might improve the QoL of both patients and their families.  
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## Background

Cancer is one of the major health issues in Indonesia. No national cancer registration system exists, but the Department of Health estimated that cancer incidence is about 240,000 persons per year [1]. The prevalence of cancer is about 4.3 per 1000 inhabitants [2]. It has been estimated that two out of three patients are in an advanced stage when they visit the hospital for treatment [3]. During hospitalization, family caregivers play an important role [4].

Family caregivers in cancer care are individuals who provide uncompensated care and health-related assistance to a family member who has cancer [5]. Mostly, they are the spouse, child or parent of the patient and most of them are not trained in caring [6]. They assist the patient in addressing his/her physical, emotional, and medical problems; social issues; communicating with professional caregivers, and coordinating the care [7]. However, care for patients with cancer exceeds usual family activities,

such as household chores. Consequently, this implies that they have to rearrange the tasks and obligations that they usually perform, such as their own household activities, professional job, or care for others who depend on them, for example, their children.

Particularly when the cancer is incurable and in an advanced stage, the role of the family caregivers increases, in a physical and an emotional way [5,8]. In advanced stages of patients with cancer, the complex care required challenges the family caregivers' knowledge and skills, as well as their actions in caring for their loved ones [8]. Caring for a family member who is chronically ill challenges the family caregivers' own quality of life (QoL) [7], because of the fear of losing their loved one, the substantial impact of caring on the financial well-being and the restrictions placed on their social life [9]. Therefore, not only the patient with advanced cancer but also the caregivers need attention. This is also reflected in the WHO definition of palliative care, in which caring for

the family caregiver is mentioned as an essential part of palliative care [10].

A study in Europe found that family caregivers for patients with cancer experienced significant impairments in comparison with nonfamily caregivers [11]. Many family caregivers become overburdened [12]. Steel *et al.* found that 38% of family caregivers reported symptoms of depression while caring for their loved one [13]. Family caregivers' coping mechanisms are challenged by an ongoing involvement in complex personal and nursing care and confrontation with the suffering of and threat of losing their beloved one [14]. Even though several studies have documented some positive effects of providing care to a family member such as enjoyment, meeting obligations, gaining a sense of meaning or fulfillment [15], QoL issues for patients and their families should be viewed as a priority for professional attention.

Norms, practices, expectations, and also culture influence caring for a family member with cancer [16]. In contrast to Western countries, in Indonesia, a country with strong family bonds, being involved in caring for a family member during illness is part of the Indonesian culture [4,17]. Such a strong family bond implies that family members protect each other and demand and provide loyalty throughout life [17,18]. Even during hospitalization, the role of the family is obvious [4]. Although family caregivers' experience in caring has been studied for terminally ill patients with cancer [5,6,11,13], there is little information on the type of care activities, and on its influence on the QoL of family caregivers, and none of these studies has been performed in Indonesia.

Therefore, this study aims to identify factors influencing the QoL of family caregivers of hospitalized patients with cancer in Indonesia, a country with a strong culture of family care, particularly of modifiable factors as a potential target for intervention strategies.

## Methods

### Setting and population

From September to December 2011, data were collected by a research assistant in the adult inpatient ward in a general hospital in Yogyakarta, Indonesia, by means of a cross-sectional survey. Inclusion criteria for the caregivers were as follows: (a) taking care of a patient with advanced cancer (stadium 3 or 4) regardless of the type of cancer or whether the cancer was newly diagnosed or recurrent, (b) being 18 years of age or older, (c) having accompanied the patient during hospitalization for at least a week, (d) taking care of the patient's daily needs, (e) being able to fill in a questionnaire, and (f) having consented to take part in the study.

### Ethical permission

The study was approved by the Medical Ethics committee of *Universitas Gadjah Mada*, Yogyakarta, Indonesia

(Number: KE/FK/582/EC). All family caregivers gave their written informed consent to participate in the study.

## Measures

### Demographic variables

Information on the caregivers' gender, age, education level (none, elementary, junior high school, senior high school, or university/college), marital status (married, single, or widowed), the relationship with the patient (spouse, child, parent, or relative), time spent in caring (not every day; every day but <6 h, 6–12 h, or >12 h), and having previous caring experience (yes/no) was collected.

### Caregivers' involvement in caring for patients with cancer

We used the domains and problems of the validated Problems and Needs in Palliative Care—short version questionnaire [19] to develop the Family Caregivers Involvement in Caring—Cancer (FCIC-C) questionnaire to identify family caregivers' involvement in caring for patients with cancer. The seven domains of this questionnaire are activities in daily living (ADLs), physical, social, psychological, autonomy, spiritual, and financial issues [19]. To illustrate the type of caring per domain, we used the problems of the Problems and Needs of Palliative Care questionnaire [19] to generate examples of caring to relieve these problems. For example, in the ADL domain, it is possible that a patient has problems with bathing, toileting, and eating. To identify family caregivers' involvement in caring, we asked the family caregiver 'Do you assist the patient with bathing, toileting and eating?' The questionnaire consisted of 29 questions with a four-point Likert scale ranging from 0 (never) to 3 (always) being involved, so the total score can range from 0 to 87. A higher score indicates a higher level of involvement in caring for a hospitalized patient with cancer. To examine the validity of the FCIC-C, Kaiser–Meyer–Olkin (KMO) and Bartlett tests were performed, and internal consistency was calculated. The KMO subscale appeared to be good (>0.75) and the Bartlett tests' value <0.001. Cronbach's alpha was good (>0.72) with ( $r=0.3–0.8$ ; Table 2).

### Family satisfaction in cancer care during hospitalization

The FAMCARE questionnaire, measuring aspects of satisfaction [20] and having a high internal consistency, test–retest reliability, and mean inter-item correlation [20,21], was used to identify family satisfaction in cancer care during hospitalization. This questionnaire consists of 20 items about information giving (five items), availability of care (four items), physical care (seven items), and psychosocial care (four items). It consists of a five-point Likert scale from 1 (very satisfied) to 5 (very dissatisfied). The total score can range from 20 to 100. A higher score indicates a lower satisfaction of the family caregiver [20].

### Quality of life of family caregivers

The QoL of the family caregiver as a dependent variable was measured using the Caregiver QoL Index—Cancer (CQOLC) questionnaire. This questionnaire is multidimensional and a reliable tool that has been designed specifically for caregivers of patients with cancer [22] and has been validated in many countries [23,24]. Test–retest reliability was 0.95 and internal consistency 0.91 [22]. It consists of 35 items divided over four domains (burden, positive adaptation, disruptiveness, and financial concern) with a five-point Likert scale, ranging from 0 (not at all) to 4 (very much); the total score can range between 0 and 140. A high score indicates a low QoL.

### Data analyses

We used descriptive analysis (frequencies, percentages, means, standard deviations, and median) to describe sociodemographic characteristics of the respondents. The independent variables in this study were demographics, family satisfaction, and family involvement in caring. The dependent variable was the QoL of the family caregiver. To more precisely identify those aspects of family caregiver involvement in caring for a hospitalized patient with cancer that influence the QoL of the family caregiver, we applied a two-step analysis. For the first step, we performed a bivariate analysis using Pearson correlations to measure the correlations between each separate independent variable (demographics, family satisfaction, and family involvement in caring) with the QoL of the family caregiver. In the second step, a multivariate analysis using stepwise linear regression analysis was performed with those independent variables that had a significant correlation in step one. A value of  $p < 0.05$  was considered to be statistically significant. All the statistical analyses were performed using the software program SPSS—version 20 (IBM SPSS Statistics, Armonk, NY, USA).

## Results

### Characteristics of family caregivers

One hundred twenty family caregivers were invited to take part in the study, of whom 100 (83.3%) filled in and returned the questionnaire directly to the research assistant.

About the same percentages of men (52%) and women (48%) took part in the study. The mean age of the family caregivers was 41 years (range: 14–71), and for the patients that they cared for, it was 49 years (range: 20–80). Most of the family caregivers were married (79%); almost half of them were the spouse (42%); 34% were the children, and 11% were the parents taking care of their child. Of the total population, 8% of the patients were between 20 and 30 years of age. Thirty-nine percent of

the respondents had completed senior high school. About three-quarters of the family caregivers (78%) had no previous caring experience for a patient with cancer. More than half of the family caregivers (53%) took care of the patient more than 12 h a day (Table 1).

### Family caregivers' involvement in caring of a hospitalized patient with cancer

The mean overall score was  $38 \pm 16.8$ . Caring by the family caregivers most often consisted of helping the patient with psychological symptoms (mean  $5.5 \pm 2.6$ ). Next, family caregivers were involved in addressing social issues (mean  $6.3 \pm 3.6$ ), autonomy (mean  $5.9 \pm 3.1$ ), physical (mean  $5.0 \pm 2.9$ ) and daily activities (mean  $7.3 \pm 6.9$ ), and spiritual (mean  $4.6 \pm 2.9$ ) and financial issues (mean  $3.6 \pm 2.4$ ) of the patients (Table 2).

### Family caregivers' quality of life

The mean overall family caregivers' QoL score was 67.34 ( $\pm 19.30$ ). The subscale scores for positive adaptation was 19.53 ( $\pm 4.50$ ), for burden was 16.42 ( $\pm 10.08$ ), for disruptiveness was 9.33 ( $\pm 5.07$ ), for financial concerns

**Table 1.** Respondent demographic

Characteristic of family with N = 100	n; % <sup>a</sup>	
Sex	Male	52
	Female	48
Age (years)	<30	18
	30–50	57
	51–65	18
	>65	6
	Mean $\pm$ SD	41.1 $\pm$ 13.1
	Median (range)	40.5 (14–71)
Age of patient cared for (years)	<30	8
	30–50	46
	51–65	36
	>65	10
	Mean $\pm$ SD	49.2 $\pm$ 13.1
	Median (range)	49.0 (20–80)
Marital status	Single	18
	Married	79
	Widowed	3
Relationship with patient	Spouse	42
	Child	34
	Parent	11
	Relative	13
Time of care per day	<6 h	28
	6–12 h	13
	>12 h	53
	Not everyday	6
Education	None	3
	Elementary school	30
	Junior high school	16
	Senior high school	39
	University/College	12
Previous caring experience	Yes	22
	No	78

<sup>a</sup>As n = 100, it is equal to the percentage (%).

**Table 2.** Family caregivers' involvement in caring for patients with cancer: mean, standard deviation, maximal score, ceiling effect, floor effect and Cronbach's alpha of subscales FCIC-C<sup>a</sup> (*n* = 100)

Subscale	Max score	Mean ( $\pm$ SD)	$\alpha^b$	Floor effect (%)	Ceiling effect (%)
ADL (six items)	18	7.28 ( $\pm$ 6.95)	0.82	35	6
Physical (five items)	15	5.02 ( $\pm$ 2.96)	0.77	11	1
Autonomy (four items)	12	5.89 ( $\pm$ 3.14)	0.80	8	1
Social (four items)	12	6.35 ( $\pm$ 3.63)	0.80	13	11
Psychological (three items)	9	5.49 ( $\pm$ 2.58)	0.82	9	11
Spiritual (three items)	9	4.60 ( $\pm$ 2.88)	0.83	18	10
Financial (four items)	12	3.59 ( $\pm$ 2.38)	0.72	6	1
Total score of FCIC-C (29 items)	87	38.20 ( $\pm$ 16.78)	0.74	1	1

FCIC-C, Family Caregivers Involvement in Caring—Cancer; Floor effect, the worst possible score; Ceiling effect, the best possible score.

<sup>a</sup>A higher score of FCIC-C indicates a higher level of involvement in caring for a patient with cancer.

<sup>b</sup>Cronbach's alpha.

was 7.48 ( $\pm$ 3.09), and for other subscale scores was 27.22 ( $\pm$ 4.72) (Table 3).

### Bivariate analysis

We found that a higher age ( $p=0.03$ ), higher level of education ( $p=0.006$ ), being the spouse ( $p=0.04$ ), and having previous caring experience ( $p=0.001$ ) were significantly correlated with the QoL (CQOLC) of family caregivers. Besides, almost all subscales of the FCIC-C except for the social and autonomy domains were positively correlated with CQOLC. Family caregiver satisfaction, as measured with the FAMCARE (total score), appeared not to be significantly correlated with their QoL ( $r = -0.047$ ,  $p = 0.643$ ).

### Multivariate analysis

A stepwise linear regression was performed to measure the factors that influenced the QoL of family caregivers (Table 4). The independent variables entered in the analysis were the ADL, physical, psychological, spiritual, and financial domains of the FCIC-C as well as age, education, being the spouse, and having caring experience with the total score on the CQOLC as dependent variable. Being involved in psychological issues of the patient ( $\beta=0.374$ ;  $p=0.000$ ), a younger age ( $\beta=-0.282$ ;  $p=0.003$ ), not being

**Table 3.** Quality of life of the family caregivers: mean, standard deviation, maximal score, and Cronbach's alpha of subscales CQOLC (*n* = 100)<sup>a</sup>

Subscale	Max score	Mean ( $\pm$ SD)	$\alpha^b$
Positive adaptation (seven items)	28	19.53 ( $\pm$ 4.50)	0.69
Burden (10 items)	40	16.42 ( $\pm$ 10.08)	0.77
Disruptiveness (seven items)	28	9.33 ( $\pm$ 5.07)	0.71
Financial concern (three items)	12	7.48 ( $\pm$ 3.09)	0.80
Other <sup>c</sup> (eight items)	32	27.22 ( $\pm$ 4.72)	0.70
Total score of QoL (35 items)	140	67.34 ( $\pm$ 19.30)	0.73

CQOLC, Caregivers Quality Of Life Index—Cancer.

<sup>a</sup>A higher score of CQOLC indicates a higher level of QoL.

<sup>b</sup>Cronbach's alpha.

<sup>c</sup>Item without categories.

**Table 4.** Factors influence Quality of life of family caregivers

Independent variable	$\beta$	t	p-value
Demographic			
Age	-0.282	-3.061	0.003*
Caring experience	-0.301	-3.578	0.001*
Education level	0.133	1.472	0.144
Spouse	-0.228	-2.466	0.015**
FCIC-C			
ADL	0.150	1.573	0.119
Physical			
Psychological	0.374	4.457	0.000*
Spiritual	0.181	1.846	0.068
Financial	0.092	1.048	0.297

Stepwise multiple regression analysis of family caregiver's quality of life (dependent variable) and demographics and subscales of the FCIC-C (independent variables; *n* = 100).

Dependent variable = total score of quality of life (CQOLC).

Adjusted R squared = 0.312; SE estimate = 16.01.

FCIC-C, Family Caregivers Involvement in Caring—Cancer; CQOLC, Caregivers Quality Of Life Index—Cancer.

\* $p < 0.01$ .

\*\* $p < 0.05$ .

the spouse ( $\beta = -0.228$ ;  $p = 0.015$ ), and having no previous experience in caring for a patient with cancer ( $\beta = -0.301$ ;  $p = 0.001$ ) negatively influenced the QoL of the family caregiver and explained 31% of the variation (adjusted  $R^2 = 0.312$ ;  $p = 0.000$ ). Gender, level of education, and time of care did not independently influence the QoL.

## Discussion

### Main findings

In an Indonesian study with 100 family caregivers of hospitalized patients with cancer, we found that being involved in addressing psychological issues, being younger, not being the spouse, and having no previous experience of caring for a hospitalized patient with cancer negatively influenced the QoL of family caregivers.

During hospitalization, patients with cancer experience many symptoms and issues [25]. Even though another

study showed that psychological issues were not the most prevalent problem faced by patients, they appeared to be more burdensome for the family caregiver than other issues and symptoms. This finding is consistent with the negative correlation between family caregivers' QoL and patients' depression and emotional well-being found in a Canadian study with 191 family caregivers of outpatients with advanced cancer [26], and also in a study on family caregivers of patients with HIV in Thailand [27].

Our findings are also supported by several studies that showed that psychological issues experienced by a patient also burden the family caregivers because of their strong relationship [28,29]. Caregiving is demanding and overwhelming and can be a very stressful experience that affects all aspects of the caregivers' QoL [9,26,30].

We also found that younger family caregivers had a lower QoL than the older ones. This finding is in accordance with an American study on family caregivers of cancer survivors [[31], and an Italian study on caring for a family member with a stoma [32]. Younger family caregivers are more likely to experience more distress than older ones when performing their (new) role as a caregiver of a patient with cancer [33,34]. The distress of those who are younger might be related to the fact that younger family caregivers more often combine this caregiver role with a job and being a parent of young children [35,36]. Particularly daughters experienced more stress than sons [37]. As the percentage of young family caregivers that take care of young patients in our study were very small (less than 5%), the lower QoL in younger family caregivers will not or will hardly be influenced by a higher burden when a young person dies.

In our study, 58% of the family caregivers were non-spousal caregivers, often being the adult child of the patient. Being the nonspousal caregiver appeared negatively correlated to their QoL. Also, Wadhwa *et al.* found that a better QoL of caregivers was associated with not providing care for other dependents [26].

In Indonesia, the family is a key element in caring for the ill family member. It is a tradition and considered an obligation to take care of a family member who is ill, at home as well as during hospitalization [4]. Most respondents (78%) did not have much experience in caring and were untrained. Also, Palma showed that most family caregivers of patients with cancer are neither prepared nor trained to support the burden of caregiving [32]. Providing care for a family member with cancer can be very stressful. A major stress factor for caregivers is the uncertainty about their own knowledge and skills [32]. Therefore, it is not a surprise that having no previous caring experience increases the family caregiver burden and affects their QoL.

We were surprised that we found no differences in QoL between men and women, as in other studies, women were more stressed and experienced a lower QoL than men

[38]. Family values in the Asian culture might be related to this finding [16]. Indeed, our finding was consistent with a study of family caregivers for patients with HIV in Thailand [27].

### Strengths and limitations

This is the first study in which predictors for the QoL of family caregivers of hospitalized patients with cancer in Indonesia were studied.

The study also has several limitations. Firstly, this is the first time that the FCIC-C questionnaire has been used. Although the psychometric properties appeared to be good in the studied population, further exploration of the instrument in other populations is necessary. Secondly, the family caregivers were caring for patients with a variety of types of cancer, levels of health status, and symptoms. Although this might have influenced the type of caregiving, all patients were in an advanced stage of their disease. Several studies have shown that in patients with advanced cancer, five symptoms occur very frequently [40]. For that reason, we expect that the type of cancer of the hospitalized patient that was cared for is less important than the advanced stages of the conditions of the patients. We also did not control for type of interventions during hospitalization, like surgery, chemotherapy, or radiotherapy. Thirdly, this study was conducted in just one area of Indonesia, so cultural variations in different areas might have an influence on caring for a patient with cancer and thus on the QoL of the family caregiver. Also, for that reason, generalization is not allowed. Nevertheless, this figure can be used to give more information about the QoL of family caregivers in Indonesia and can also be used as some basic data to improve the quality of care for hospitalized patients with cancer.

### Implication in practice

Studying family involvement in caring for a patient with cancer at home would be useful to obtain a complete view on this topic. Family caregivers who have to deal with patients having psychological problems and having no previous caring experience need specific attention from a professional caregiver to decrease their burden and enhance their QoL. Timely screening the family caregivers on psychological problems will have a positive effect on their QoL and capability to care for their beloved one [39]. Courses for patients and family caregivers in how to care for their loved ones and how to handle emotional and other symptoms might contribute to a better QoL for family caregivers [40]. It is also very important to help the family caregivers with psychosocial interventions during their obligation in caring for their loved one with cancer during hospitalization. Courses for professionals in health care, on how to coach the family in taking

care for a patient and on how to recognize that a family member is overburdened, might be useful [6].

## Conclusions

Our findings identified modifiable factors such as dealing with the psychological issues and lack of experiences of caring that negatively influenced the QoL of family caregivers. These factors are potential targets of intervention strategies. Education and intervention programs focusing

on dealing with the psychological problems in cancer care might improve the QoL of both patients and their families.

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## Conflicts of interest

The authors have declared no conflicts of interest.

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