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The effect of family appraisal on caregiver burden in family caregiver of female cancer patients

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ABSTRACT

The growing prevalent of female cancer malignancies and the cancer care transition from clinical-based into home-based care have resulted in the growing involvement of family caregiver (FCG) in cancer management. The caregiving activity may be appraised as positive or negative life aspect. Negative family appraisal may result in FCG burden. This study expected to examine the effect of FCG appraisal of cancer caregiving on their burden in community context. This cross-sectional study involved 60 FCG of female cancer patients in five communities of Surabaya. Population was all primary FCG of female cancer patients in Surabaya's communities. Family appraisal and caregiver burden were measured by questionnaires of family appraisal of caregiving questionnaire for palliative care (FACQ-PC) and caregiver burden inventory (CBI) respectively. Data analysis utilized descriptive statistic and simple linear regression tests. Most respondents were spouses with very mature age (41-50 years old), high school graduated, and working with sufficient income. The majority appraised cancer caregiving activities positively (80.67±16.31) and reported low burden (32.02±12.23). FCG appraisal has a huge impact on their burden (p=0.000). It influences 20.7% variance of burden in this population (R²=0.207).

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1. INTRODUCTION

Caring for a sick family member at home by a nonformal caregiver is a growing trend nowadays in the case of terminal illness [1]. Continuous governmental policies published to answer the demand of global citizen by purpose of engaging caregivers, families, and communities in the context of health care delivery system [2]. Family caregiver (FCG) takes the responsibility to care for the sick family member daily as the manifestation of care transition from hospital setting into community setting, so that clinical-based care has become home-based care [3]. In the case of home-based cancer care, almost all assistance needed by the patients is delivered by the FCG without a proper training background in the context of limited resources and high additional demands [4]. Conceptually, cancer family caregiving consists of three domains, namely: i) the process of stress, ii) the context, and iii) the disease course [5]. There are various caregiving activities at home, but mostly are household work, emotional assistance, and financial management [6].

Caregiving activities may be different between cases. Cancer, as a prolonged illness, has been engaged in a community-based care for some period of time because of the long-term care needed in its management. Cancer caregiving activities in community setting mostly delivered by a FCG which is usually an informal caregiver who has a limited health-related knowledge and cancer care competency. Therefore, in the caregiving process, FCG may consider the activities as difficult, complex, demanding, tiring, and

burdensome. But, the possibility of getting positive meaning in the process needs to be encourage also because the positive and negative aspects of cancer caregiving may not be separated as clear as separating white from the black. There are various factors may influence the FCG's consideration of cancer caregiving.

Cervical and breast malignancy are the most prevalent malignancies found in females living in low-to-middle-income nations [7]. Indonesia is not an exception. Nationally, in 2014 until 2017 breast cancer ranked first for incidence and mortality rates, while cervical cancer ranked 2nd, making females prone to be a cancer patients or survivors [8], [9]. It could be assumed that there are many husbands or children of female cancer patients being FCG in home-based cancer care. Husbands, as the main source of support for female cancer patients, may experience psychological changes significantly. Unfortunately, various studies proved that these changes were negative. For instance, a cohort study towards husbands of breast cancer women undergoing chemotherapy revealed that most respondents experienced social and domestic role strains resulted in psychological distress at one year after treatment [10]. Another example in qualitative research, a study towards six husbands of cervical cancer women revealed that informants felt the loneliness, experienced changes in sexual relationship, but fortunately they could share the feelings of vulnerability with their wife [11]. Husbands are the critical FCG that the health officer needs to realize to educate them because HCP is responsible for providing professional support in order to fulfill their supportive care needs.

Ideally, caregiving experience may be seen as positive and negative aspect at the same time [1]. This concept has led to the construct of family appraisal of caregiving, which is may be positive or negative. Positive caregiving appraisals include commitment, confidence, satisfaction, and intimacy development in the personal relationship between care provider and recipient; while negative caregiving appraisals include caregiver role overload and captivity, and distress (negative emotional responses: anxiety, depression, and guilt) [1]. These binary categories of family appraisals of cancer caregiving may influence the process of stress and the context of caregiving delivered by the FCG. Usually, individuals will feel happy to do something when we positively appraise the activities. Oppositely, individuals will feel forced to do something when we negatively appraise the activities. In such condition, individuals may insist to do the activities and ignoring the negative or uncomfortable feelings about it because of duty or responsibility and the absence of another option.

The diagnosis of cancer may be perceived by a family as a major event, not only being a great bad news for the patients, but also for the other family members. Various studies revealed that cancer diagnosis has a more prominent effect for the other relatives than the patients [6]. Home-based cancer caregiving could be very demanding for a working FCG because they have very limited time for providing care while juggling for work responsibilities [12]. Family members may see cancer caregiving activities as rewarding and meaningful at one hand, but burdensome and overwhelming at the other hand especially when their supportive care needs were unmet. In the case of colorectal and lung cancer, a cohort study revealed that 50% respondents reported not getting necessary training and unpaid for providing care, some reported poor or fair health, and 25% reported low confidence in providing care [4]. All of these may be the reason of expanded caregiver burden in FCG of cancer patients. Caregiver burden is one meaningful aspect to be objectively evaluated in cancer FCG continuously by the health care professional (HCP) because it may not be expressed freely. HCP needs to psychologically assess the FCG in order to notice the existence of perceived burden, and take actions to manage or prevent if from getting worse.

Caregiver burden is defined as family members' holistic problems of physic-psycho-emotion-socio-financial [1]. The caregiver burden often exceeds the critically ill patient's burden [13]. Caregiver burden is influenced by gender (female), educational background (low), personal relationship (being house-mate), caregiving hours (long duration), negative emotional response (depression), financial stress, social isolation and absence of caregiving decision [14]. Caregiver burden can be the indicator of caregiver stress and role conflict [15].

There is a possibility that a negative appraisal of cancer caregiving activities may rise the perceived caregiver burden in FCG, even caregiver strain and distress being the domains of family appraisal of caregiving [1]. Caregiver burden is a risk factor for potentially harmful informal FCG caregiving behavior at home, which may influence patient safety and care quality. Therefore, caregiving appraisal needs to be identified to make sure when it is positive whether caregiver burden is absence or presence. It is important to assure the caregiver patients safety during the home caring activities by FCG who are sometimes lacking in caregiver competency. This study expected to examine the effect of family appraisal on caregiver burden in FCG of female cancer patients in community setting.

2. RESEARCH METHOD

1 This cross-sectional study involved five communities among 63 communities existed in Surabaya, Indonesia, which were chosen by cluster random sampling (7.94% cluster). There were 60 female cancer FCG being study respondents. There was none specific sample's criteria. The permission of public health center (PHC) in the area was needed to confirm the cancer diagnosis, while the confirmation from the female

cancer patients was needed to confirm the primary FCG in the family. Promising respondents were excluded if denied informed consent.

The instrument of Family Appraisal of Caregiving Questionnaire for Palliative Care (FACQ-PC) was used to measure family appraisal of caregiving ($r=0.266-0.622$; Chronbach Alpha= 0.867). Cooper *et al.* stated that FACQ-PC was developed based on the concept of caregiving appraisal proposed by Lazarus & Folkman (1984) which tested in a study of stress process by Pearlin *et al.* (1990) and Zarit & Edwards (1996) [1]. FACQ-PC comprises four domains in 26 items, namely: i) caregiver distress, ii) caregiver strain, iii) positive caregiving appraisals, and iv) family wellbeing. For each item of FACQ-PC, respondents were approached to show their personal appraisal and feeling related to cancer caregiving as a result of caring for people with cancer quantitatively. Items were intended to be evaluated on a 5 point Likert scale going from 1 (strongly disagree) to 5 (strongly agree), with a neutral midpoint. Based on the scale ranging, the researchers then divide family appraisal of caregiving into two categories, such as: i) positive appraisal (total score: 79-130), and ii) negative appraisal (total score: 26-78).

The instrument of caregiver burden inventory (CBI) was used to measure caregiver burden in FCG ($r=0.258-0.703$; Chronbach Alpha= 0.902). The multidimensional CBI scale is a 24-item that measure five dimensions of caregiver burden, namely: i) time dependency, ii) development, iii) physical health, iv) emotional health, and v) social relationships [16]. For each item of CBI, respondents were approached to show their burden feeling related to cancer caregiving quantitatively. Items were intended to be evaluated on a 5-point Likert scale going from 0 (never) to 5 (nearly always). Based on the scale ranging, the researchers then divide caregiver burden into three categories, such as: i) low (total score: 0-32), ii) moderate (total score:33-64), and iii) high (total score: 65-96).

Data collection was carried from February to March 2020. Descriptive statistic (frequency, mean, and Standard Deviation (SD)) and simple linear regression tests were used in data analysis ($\alpha<0.05$). Ethical clearance was issued by Faculty of Medicine, Widya Mandala Surabaya Catholic University, with certificate number of 080/WM12/KEPK/DOSENT/2020.

3. RESULTS AND DISCUSSION

There were 48 spouses (husbands) and 12 other relatives being study respondents. The majority was moderately aged men with adequate instructive foundation, still effectively working with adequate pay. The demography characteristic of study respondents is described in Table 1.

Most FCG had positive family appraisals of caregiving (70%). Descriptive statistic showed that mean value was 80.67 (positive appraisals) and SD value was 16.31. Table 2 shows explains the results of caregiving family appraisals in details. Most FCG reported low caregiver burden (56.67%), despite of less or none preparation and proper training in care provision. Descriptive statistic showed that Mean value was 32.02 (low burden) and SD value was 12.23. Table 3 shows explains the level of FCG's burden in details.

In this study, the data of family appraisal and caregiver burden were proved to be distributed normally by test of one sample Kolmogorov-Smimov ($p=0.151$ and $p=0.220$ respectively). There was a huge impact of family appraisal on caregiver burden in FCG of female cancer patients in community setting ($p=0.000$). Family appraisal was accounted for 20.7% variance of caregiver burden in this population ($R^2=0.207$).

Most FCG reported positive family appraisal of caregiving. The gender of FCG may play a significant role in this study. Most respondents in this study were male. This preposition was supported by a study towards 448 FCG of cancer patients which showed that male FCG were more likely to appraise caregiving as positive aspect in their life, whereas adult sons reported mild stress related to caregiving in which this is one predictor of the FCG's quality of life [17]. Male FCG reported that by doing caregiving they could boost their self-esteem which could predict the FCG's quality of life (QOL) also [17]. Another study towards 139 FCG of cancer patients by using the Caregiver Reaction Assessment Scale showed that FCG's positive reaction to caregiving was influenced by various factors, one of them was male sex, and the other was shared caregiving responsibilities with other family members, being a religious practitioner, and perceived a higher burden of schedule disruptions [18]. Male FCG seems to positively appraise cancer caregiving activities easier than female FCG. It is widely known if male responses stressful situation better than female, making male FCG can find the positive meaning in cancer caregiving activities earlier than female FCG. We can see the positive coping strategy applied by male FCG in the context of limited resources and high additional demands like in cancer care from this study result.

Table 1. Demography characteristic

Characteristic	Frequency	Percentage
Age (years old):		
<21	2	3.33
21-30	7	11.67
31-40	15	25.00
41-50	22	36.67
51-60	10	16.67
61-70	4	6.67
Gender:		
Male	48	80.00
Female	12	20.00
Marital status:		
Single	4	6.67
Married	47	78.33
Separated	2	3.33
Divorced	1	1.67
Widowed	6	10.00
Education level:		
Elementary school	6	10.00
Junior high school	8	13.33
Senior high school	38	63.33
University graduates	8	13.33
Occupation:		
Housewife	12	20.00
Entrepreneur	2	3.33
Civil servant	6	10.00
Private employee	36	60.00
4 Jobless/retire	4	6.67
Gross domestic product (GDP) [IDR]:		
Less than minimum wage	16	26.67
Minimum wage-5 million	25	41.67
More than 5 million	15	25.00
No income	4	6.67
*House mate:		
Spouse	48	80.00
Child	48	80.00
Sibling	8	13.33
Parents	9	15

*Respondents may choose more than one answer.

Table 2. Family appraisals of caregiving in FCG

Characteristic	Frequency	Percentage
Positive	42	70.00
Negative	18	30.00

Table 3. Caregiver burden in FCG

Characteristic	Frequency	Percentage
Low	34	56.67
Moderate	24	40.00
High	2	3.33

The relationship status between the FCG and the patients may also play a significant role in this study. Most respondents in this study were the husbands of female cancer patients. This preposition was supported by a qualitative study towards 15 spousal FCG which showed that positive appraisal of caregiving has contributed to the placement of a peaceful mindset in the center of life which was not only important for maintaining their emotional health, but also for prolonging the patient's life [19]. Positive appraisal of caregiving in spousal FCG which determined by caregiving self-efficacy may be manifested as the enhanced relationship between the FCG and the patients, the rewarded feeling, personal growth sense, an perceived self satisfaction [20]. A study in another context towards advanced chronic organ failure (73 advanced chronic obstructive pulmonary disease patients, 45 chronic heart failure patients, and 41 chronic renal failure patients) and their FCGs by using exactly the same instrument (FACQ-PC) showed that most respondents reported positive appraisal of caregiving which influenced by personal relation with the care recipient, psychological condition of the care recipient, and the disease comorbidities [21]. Another study towards 47 FCG of intensive care unit (ICU) patients by using instrument of positive aspects of

caregiving (PAC: 11 items) showed that most respondents rated positive for caregiving appraisal, one of which influenced by relationship with the patients, and the other was influenced by age, occupation, religion, financial condition, social support, and psychological responses [22]. A marriage relationship usually starts by a loving and affectionate feelings between male and female, making them husband and wife in the end. Even in the marriage ceremony, the vow of getting together in health and sick condition has become a compulsory statement to be said by the married couple. Cancer, as the example of sick condition mentioned in the marriage vow, has become a condition which needs to be tolerated and accepted by the couple. Therefore, most respondents who were aware of their spouse position in life has taken the responsibilities of caregiving as an implementation of their marriage vow in the beginning.

Most respondents reported low level of caregiver burden. Contrary, most studies in the case of cancer found that FCG had a high burden, due to the high care demand at home related to symptom complexity and the total suffering. Even a study towards 96 FCG of advanced cancer patients found that most respondents had severe caregiver burden until then they had disrupted schedule and suffered from sleep problems, in which poor sleep quality was independently associated with health problems in FCG [23]. Therefore, low caregiver burden found in the majority of FCG in this study context is really an interesting and good finding. This study finding is supported by a study in another context towards 50 FCG of hemodialysis patients which found a relatively low global caregiver burden; caregiver burden was negatively correlated with FCG's age and education level [24]. In this study, most respondents aged 41-50 years old and graduated from a senior high school. If caregiver burden is low then the age and educational background potentially old and high respectively. The 41-50 years old is a very mature age for a man, but being a senior high school graduated is not considered as a high educated person. The fact is, even if their educational background is not that high, their wise thinking and positive mindset towards cancer caregiving helps them appraised cancer caregiving as a positive aspect in their life, until then they experienced a low level of caregiver burden in this study context.

The low caregiver burden found in this study was potentially occurred due to the FCG's high resilience. A study towards 210 FCGs of cancer survivors found that most respondents who reported low level of resilience also reported high level of caregiver burden and low level of QOL, therefore low resilience was correlated with great caregiver burden and poor QOL; resilience mediated the caregiver burden negatively and predicted the QOL positively [25]. Another study towards 108 pairs of breast cancer survivors and their primary FCG also showed that the patients' and the families' resilience was negatively correlated with caregiver burden in which the patients' resilience mediated the correlation between family resilience and caregiver burden [26]. Resilience is the ability to survive in an uncondusive environment. In this study, most respondents has experienced challenges in cancer caregiving at home for some period of time. In the process, they must be learned about many new things and got life lessons by caring for their loved ones. The passionate feeling for their loved ones has increased their ability to survive in a high demanding and limited resources environment.

The low caregiver burden found in this study was also potentially occurred due to the problem-focused coping implemented by FCG or due to the caregiver support provided by the HCP working in nearby PHC. An integrative review towards many articles in various databases showed that problem-focused coping was correlated with positive caregiver's outcome psychologically, such as: low burden, mild depression, and better adaptation; while emotion-focused coping oppositely was correlated with negative caregiver's outcome psychologically, such as: high distress and worst post-traumatic growth in cancer caregivers [27]. Another experimental study testing the effect of caregiver support intervention on caregiver burden in FCG of cancer patients approaching death showed that this intervention could decrease the subjective caregiving burden and increase their caregiver self-efficacy significantly [28]. Coping is the way individuals respond to stress. Cancer caregiving activities are a really stressful situation, especially when the FCG has no proper training background, even the process of stress is one of the domain of cancer family caregiving. So, coping strategy is relevantly related to cancer family caregiving. The adaptive coping strategy or the problem-focused coping has the potency to lower the stress response in FCG, which may influence the caregiver burden.

Caregiver burden is a risk factor for potentially harmful informal FCG care-giving behavior at home, which may influence patient safety and care quality. Therefore, HCP needs to be very cautious about this aspect because of the threat potency of caregiver burden. Caregiver burden is another important aspect which may influence the FCG's and the patients' QOL. Strategies or intervention development aiming at alleviating the caregiver burden may assist with breaking this endless loop to upgrade the health status of FCG. There is also a need for assessing caregiver burden periodically and managing it timely so that FCG's optimum QOL may be assured despite of their important and demanding role in cancer care management at home.

Positive appraisal of caregiving is an important aspect which influences caregiver burden significantly. Results showed that there was a huge impact of family appraisal on caregiver burden in FCG of

1 female cancer patients especially in community setting, in which family appraisal was accounted for 20.7% variance of caregiver burden in this population. Similar study about the effect of caregiving family appraisal on caregiver burden in cancer was hard to find online freely. It seems that this is a new area of research in cancer caregiving. Research on it actually has tremendous growth from 2000 to 2010, but study of caregiving family appraisal and caregiver burden in cancer caregiving at one scientific article was none to be available online to our knowledge. We tried to give scientific reasons regarding our study finding.

Caregiving family appraisal has a huge impact on caregiver burden in FCG of female cancer patients potentially because they had a positive mindset or positive caregiving appraisal towards cancer caregiving activities so that most respondents reported low caregiver burden. Caregiver burden is subjective and it is related to individual mindset and emotional responses toward the caregiving activities [29]. This reason was supported by a study in different context of Alzheimer disease towards 57 FCG of elderly with Alzheimer which showed that the way to decrease the negative outcomes in FCG was by gaining positive aspects of caregiving, such as: i) dementia experience and condition acknowledgment, ii) a feeling of direction and obligation to the care provider role, iii) sensations of satisfaction when the patients was better, iv) dominating abilities to deal with the patients, v) expanded persistence and resistance, vi) developing good implications and humor in the midst of troublesome conditions, vii) relinquishing things, for example, when the patient's characteristics had been lost or individual plan had become ridiculous, viii) fostering a closer relationship with the patients, ix) tracking down help, and x) feeling valuable aiding different caregivers [30]. The positive mindset and positive emotional responses have helped the FCG to appraise cancer caregiving activities as a positive life aspect until then influenced their low level of caregiver burden.

Another reason why caregiving family appraisal has a huge impact on caregiver burden in cancer family caregiving is because FCG has a self-compassion feeling towards the care recipient so that they appraise cancer caregiving positively and feels that this is not burdensome, in fact they are families after all. This reason was supported by a study in different context of dementia symptom towards 73 informal caregivers of elderly with dementia which showed that self-compassion was adversely associated to caregiver burden and dysfunctional coping strategies, and emphatically associated to emotion-focused coping strategies [31]. This reason was also supported by a study towards 208 FCG of cancer patients in China which found that self-compassion was correlated with a decreased negative influence of burden on depression [32]. Self-compassion may arise due to the personal relationship between the care provider and the care recipient. Most respondents were the husband of the cancer patients, and they live in the same house, making them a close person for each other. Self-compassion is relevantly related to functional coping strategy and problem-focused coping which may influence their caregiving-related stress response.

Family appraisal and caregiver burden are two variables important to be measured overtime because of various influencing factors, such as internal and external factors, in which social environment may play an important role in mediating the relation of both variables. Research in the area of caregiving family appraisal is relatively new, so that there is a wide chance for global researchers to explore more about it. This study has set a basis for the upcoming similar study in this area, and may catalyze a development of caregiver support intervention from the HCP working in the PHC. Professionally, the HCP needs to measure both variables periodically in order to make sure that FCG's caregiving experience at home remains a positive aspect in their life. Cancer may be a long-term threat for those who are affected directly, the patients, and indirectly, the FCG, but it should not disrupted the family wellbeing if both parties committed to remain positive. The attributes to positive family appraisals need to be considered if HCP would like to give some interventions. The limitation found in the field (community setting) sometimes making this aspect missed from HCP's attention, and FCG frequently considered this aspect as not a problem due to low knowledge and awareness.

4. CONCLUSION

In community setting, most FCG appraise cancer caregiving of female patients positively, so that the majority reported low level of burden. FCG appraisal of cancer caregiving has a huge impact on their perceived burden. Family appraisal influences 20.7% variance of burden in FCG of female cancer patients. In the future, it is recommended for community nurses working in the PHC to assess family appraisal and caregiver burden overtime because both variables were correlated and may influence FCG's well-being and quality of life. Caregiver support intervention may be developed by using this study findings as one of its basis.

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