The impacts of breast and cervical cancer in a community setting are predictors of the quality of life of family caregivers

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Background: There is a growing trend for those with a terminal illnesses to be cared for by their families at home. Globally, there is a growing governmental policy to engage caregivers, families, and communities in the healthcare delivery system. Family caregivers (FCG) have taken responsibility for the day-to-day care of their ill loved ones at home. A cancer diagnosis is a major event for the person diagnosed and also for his or her family and caregivers. The caregiving activity has a significant impact on FCG's quality of life (QOL). This study aimed to analyze the best predictor of FCG's QOL of female cancer patients in a community setting.

Methods: This cross-sectional study involved five Public Health Centers (PHCs) among 63 PHCs in Surabaya (7.94%), Indonesia, which were selected by one-stage cluster random sampling. There were 60 FCGs of female cancer patients who participated in this study (n = 60). The Caregiver Quality of Life – Cancer (CQOLC) was a valid and reliable instrument that was used to collect the data. Linear regression and one-way ANOVA tests were used in data analysis ($\alpha < .05$). Ethical clearance was issued.

Results: Most respondents were middle-aged married men with sufficient educational background and still actively working with sufficient income. Their QOL was mostly at a moderate level (Mean ± SD = 62.57 ± 16.23). Burden ($p < 0.000$), disruptiveness ($p = 0.001$), and financial concern ($p < 0.000$) were significantly different between the low, moderate, and high FCG's QOL. The best predictor of FCG's QOL of female cancer patients in a community setting was disruptiveness ($R2 = 0.622$; $p < 0.000$) compared to burden ($R2 = 0.531$; $p < 0.000$) and financial concern ($R2 = 0.184$; $p = 0.001$), especially when other family members have not shown interest in caregiving ($R2 = 0.539$; $p < 0.000$).

Conclusions: FCG's QOL of female cancer patients in a community setting is at a moderate level. Disruptiveness, burden, and financial concern could predict FCG's QOL significantly. The other family members' disinterest in caregiving which belongs to the disruptiveness domain is the best predictor of FCG's QOL of female cancer patients in a community setting, which accounted for 53.9% variance of QOL in this population.

INTRODUCTION

ABSTRACT

There is a growing trend for those with a terminal illness to be cared for by their families at home. The quality of life (QOL) of the entire family unit is affected by a terminal illness and families are likely to face additional stresses and difficulties associated with caring for someone who is dying [1]. Globally, there is a growing governmental policy to engage caregivers, families, and communities in the healthcare delivery system [2]. As the provision of care has transitioned from the hospital to an outpatient setting, family caregiver caregivers (FCG) have taken responsibility for the day-to-day care of their ill loved ones at home [3]. FCG is prone to impaired QOL due to caregiving activities.

Cancer diagnosis is a major event for the person diagnosed and also for his or her family and caregivers, even in some studies report that a cancer diagnosis has a greater impact on family members than on patients [4]. Cancer patients will potentially have some degree of physical, cognitive, and/or psychological impairment, periods of unemployment, financial concerns, social isolation, and existential questions, any or all of which can impact the family and friends who surround them [5]. Given outpatient care, longer survival, and patient's wishes to be cared for at home, most cancer care is community-based [4].

Girgis et al. [4] stated that caregiving activities are varied and numerous, but the most common caregiving tasks in cancer survivors are household tasks, emotional support, and managing money. In addition to assisting cancer patients with their activities of daily living, caregivers provide them with cancer-specific care such as observing their treatment side effects, helping manage their pain, nausea, or fatigue, administering medicine, deciding to call a doctor, deciding when they need their medicine, and changing bandages. Much assistance for cancer patients is delivered in the home by informal caregivers, often without desired training, with a significant minority having limited resources and high additional demands [6]. Caregiving activities in long-term cancer care may influence the FCG's QOL due to various reasons such as lack of readiness in caregiving, limited resources available, new role adjustment, high demand for care provision, etc. The subjective demands that increased significantly over time and the perceived skills which decreased over time have led to a deterioration in psychological well-being and overall QOL over time in FCGs of cancer patients [7].

In 2014, breast cancer occupied the first position as the leading cause of death, followed by cervical cancer in second place [8]. In 2017, breast cancer still became the first position as the highest number of new cases and deaths in Indonesian cancer statistics [9]. Caregivers of patients diagnosed with breast cancer and cancer in the female reproductive organs predicted lower QOL [10]. With a high number of women living with cancer globally and nationally, it is expected to find many male spousal caregivers in home-based palliative care in a community context. A prior study of 258 FCGs of cancer patients who took care of outpatient treatment in Singapore showed that male FCGs who cared for advanced-stage cancer patients were found to have impaired QOL [11].

FCG's QOL of individuals with cancer varies along the illness trajectory. Therefore, it is important to assess the FCGs' ongoing adjustment toward caregiving activities over time [12]. QOL is a multidimensional construct of an individual's perception of his or her position in life in the cultural context and value system adopted at his or her place as well as his or her relationship with life goals, expectations, standards, and shares/roles. World Health Organization (WHO) stated that this is a broad concept that has a complex influence on a person's physical health, psychological status, level of independence, social relations, and the relationship of these things with the salient characteristics of his environment [13]. The caregiving activity has a significant impact on FCG's QOL. This study aimed to analyze the best predictor of FCG's QOL of female cancer patients in a community setting. The findings of this study may enable the health care professional (HCP) and health researchers to formulate and develop a suitable and effective intervention to improve FCG's QOL in a community setting.

METHODS

There are 63 public health centers spread all over Surabaya today. This cross-sectional study involved five PHCs or 7.94% of all PHCs in Surabaya, Indonesia. They were selected by a one-stage cluster random sampling and consisted of PHCs of Pacar Keling, Pucang Sewu, Klampis, Mulyorejo, and Pakis. There were 60 FCGs of breast and cervical cancer patients who participated in this study (n = 60). There are no specific criteria for sample recruitment. As long as the PHC confirmed the cancer diagnosis of the care recipient and the patients confirmed that the individual is the primary FCG then he or she is eligible to be a study respondent. Regarding the capability in filling in the instrument, a good educational background was very supportive, but it was not compulsory. The Exclusion criteria were rejection on filling out the consent form.

Data were collected from February to March 2020. The Caregiver Quality of Life – Cancer (CQOLC) was a valid and reliable instrument that was used to collect the data. Instrument testing procedure towards this study respondents before data analysis proved that CQOLC had good validity and reliability value (r = 0.361–0.734; Chronbach Alpha = 0.934). CQOLC scale is a 35-item cancer-specific instrument that assesses the carer/caregiver of a cancer patient's QOL, that is, some of the physical, social, emotional, and financial aspects of wellbeing, and functioning. It consisted of five domains, burden (12 items), disruptiveness (11 items), positive adaptation (4 items), financial concern (3 items), and social support (5 items) [14]. It takes only approximately 10 minutes to complete this scale. For each item of CQOLC, respondents are asked to indicate how true each statement has been for them during the past seven days as a result of cancer caregiving at home, using the following response options: "not at all" (score 0), "a little bit" (score 1), "somewhat" (score 2), "quite a bit" (score 3), and "very much" (score 4). Based on the above score for each item (Likert scale of 0 to 4), the researchers then divided the level of FCG's QOL into three categories. They are low (total score: 0-46), moderate (total score: 47–93), and high (94–140). Linear regression and oneway ANOVA tests were used in the data analysis (α <.05). SPSS 19.0 was used to proceed with the statistical tests.

RESULTS

There were 48 spousal caregivers and 12 other family members participated in this study. Most respondents were middle-aged married men with sufficient educational backgrounds according to Indonesian standards and still actively working with adequate income. **Table 1** below explains the demography characteristics of the study respondents in detail.

The results of the study showed that there were 98.33% of respondents reported impaired QOL due to caregiving activities. Most respondents reported a moderate level of QOL (85%). The descriptive statistics showed that the Mean value was 62.57 (moderate) and the standard deviation value was 16.23. **Table 2** below explains the level of FCG's QOL in detail.

Furthermore, researchers tried to identify which domains becoming the significant predictors of FCG's QOL. One-way ANOVA test result showed that burden ($p < 0.000$), disruptiveness ($p = 0.001$), and financial concern ($p < 0.000$) were significantly different between the three levels of FCG's QOL. Positive adaptation and social support were relatively similar among respondents ($p > \alpha$). **Table 3** below explains the results of statistical test in detail.

The linear regression test result showed that the best predictor of FCG's QOL of female cancer patients in a community setting was disruptiveness (R2 = 0.622; $p < 0.000$) compared to burden (R2 = 0.531; $p < 0.000$) and financial concern (R2 = 0.184; $p = 0.001$). The disruptiveness domain accounted for a 62.2% variance of FCG's QOL ($p < 0.000$). Therefore, the best predictor of FCG's QOL existed in the domain of disruptiveness. Item 35 about the disinterest of the other family members in caregiving was proved to be the best predictor of FCG's QOL in this population (R2 = 0.539; $p < 0.000$). It accounted for a 53.9% variance of FCG's QOL ($p < 0.000$). Item 26 concerning the responsibility of cancer care at home and item 32 concerning the need to manage cancer pain were the only items in the disruptiveness domain that insignificantly predicted the FCG's QOL in this study ($p > \alpha$). **Table 4** below explains the results of the statistical test in detail.

DISCUSSION

The results showed that almost all respondents reported impaired QOL. There was only one respondent who claimed to have a high level of QOL while most of the rest reported a moderate level of QOL. QOL of FCGs is a multidimensional concept including the assessment of caregivers' burden, disruptiveness, positive adaptation, financial concerns, and social support. The moderate level of QOL found in the majority indicates fewer caregivers' burden and disruptiveness, better adaptation due to resiliency, adjusted finance, and more social support. The general concept of life standard which determines the individual QOL may not be applicable in this study context. A moderate level of QOL was found in most respondents potentially due to most of their caring for short-term cancer survivors. This rationale was supported by a study of 215 FCG – cancer patient dyads (in their last six months) which showed that FCGs of patients in the worst symptomfunctional states (advanced stage or end of life/terminal

Table 1. Demography characteristics of patients

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		
Primary school	6	10.00
Secondary school	8	13.33
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
Jobless/retire	4	6.67
Gross Domestic Product (GDP) in 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	15.00

Table 2. The level of family caregivers quality of life of female cancer patients in a community setting

Characteristic	Frequency	Percentage
Low (0–46)	8	13.33
Moderate (47–93)	51	85.00
High (94–140)	1	1.67

Table 3. Predictors of family caregivers quality of life: Domain analysis

Domain	Sum of Square	Mean Square	F	Sig.
Burden	2768.363	1384.182	15.438	0.000
Disruptiveness	973.520	486.760	8.060	0.001
Financial concern	98.944	49.472	10.290	0.000
Positive adaptation	4.736	2.368	0.256	0.775
Social support	18.525	9.262	0.560	0.574

Table 4. Predictors of family caregivers quality of life: Item analysis

No.	Item	R Square	% of Influence	Sig.
Domain: Burden		0.531	53.1	0.000
Domain: Disruptiveness		0.622	62.2	0.000
1	It bothers me that my daily routine is altered	0.332	33.2	0.000
2	My sleep is less restful	0.480	48.0	0.000
3	My daily life is imposed upon	0.457	45.7	0.000
4	It is a challenge to maintain my outside interests	0.296	29.6	0.000
5	It bothers me, limiting my focus to day-to-day	0.163	16.3	0.001
6	I have difficulty dealing with my loved one's changing eating habits	0.509	50.9	0.000
7	It bothers me that I need to be available to chauffeur my loved one to appointments	0.414	41.4	0.000
8	The responsibility I have for my loved one's care at home is overwhelming	0.030	---	0.184
9	The need to protect my loved one bothers me	0.130	13.0	0.005
10	The need to manage my loved one's pain is overwhelming	0.046	---	0.101
11	It bothers me that other family members have not shown interest in taking care of my loved one	0.539	53.9	0.000
Domain: Financial concern		0.184	18.4	0.001

condition) reported the worst QOL because they had the worst subjective caregiver burden and depressive symptoms [15]. Therefore, if FCGs take care of shortterm cancer survivors, there will be a high chance for them to have a moderate level of QOL. In addition, the result of this study supported the finding.

The fact that most respondents of this study are the cancer patients' spouses can be another possible cause. This rationale was supported by a study of 358 patient-caregiver pairs which showed that most cancer patients rated FCG's high QOL in accordance with their spousal caregivers than with non-spousal caregivers [16]. Another study of 110 male spouses of breast cancer patients also showed that male spousal FCG's QOL was significantly related to their age and the patient's QOL [17]. Therefore, patients' and caregivers' mental and physical health were interdependent [18].

In this study, the burden was proved to be one of the predictors of FCG's QOL because it was significantly different among the three levels of FCG's QOL. Caregiver burdens such as the impact on health, financial problems, and lack of family support did not influence the QOL and mental health [19]. The caregiver burden and their QOL are two multidimensional concepts that have a causality relation. The negative change in QOL is one of the consequences of the caregiver burden, together with decreased care provision, physical, and psychological health deterioration [20]. This study's finding was supported by a study of 167 FCGs of terminally ill cancer patients which showed that caregiving for them causes a significant QOL deterioration over time and this is caused by the increased subjective caregiving burden, especially when the patient's death approaches [21]. This study finding was also supported by a study of 212 FCGs of cancer patients which showed that caregiver burden was the influential and the negative factor for the QOL; it was responsible for 30.3% of QOL variance [22]. Another study of 300 FCGs of cancer patients over the first five years of diagnosis also showed that caregiver burden was one of the factors associated with low or deteriorating QOL together with depression, unmet needs, coping, and social support [23]. By reducing the FCG's burden it can be considered that the QOL of both family members and cancer patients may increase [24].

Financial concern was also proved to be one of the predictors of FCG's QOL because it was significantly different among the three levels of FCG's QOL. A qualitative study of eight dyads of cancer patientcaregivers showed that cancer triggered financial hardships [25]. Financial concerns were more likely to happen in married FCGs, FCGs with less social support, or FCGs with low incomes [26]. A study of 100 pairs of cancer patients and their spouse-caregivers showed that monthly household income and cigarette smoking status were associated with financial concern [27]. This study finding was supported by a study of 284 FCGs of advanced cancer patients which showed that most respondents who had moderate QOL reported financial concerns [28]. Financial concern/problem is one aspect of caregiver burden as explained by Song et al. [19]. Another study of 193 FCGs showed that most spousal caregivers carried a heavy caregiving burden if they had financial insufficiency [29]. Another study of 103 FCGs of outpatient cancer patients also showed that the absence of financial support was significantly associated with high-level burden and psychological morbidity in male FCGs [30]. Therefore, HCP should provide counseling for FCGs regarding ways to obtain financial support to improve their QOL [31].

Disruptiveness was proved to be the best predictor of FCG's QOL in this study. This study finding was supported by a study of 284 FCGs of advanced cancer patients which showed that most respondents with low QOL reported disruptiveness [28]. Another study of 299 FCGs of terminal cancer patients also showed that disruptiveness was strongly associated with FCG's emotional distress, together with burdensomeness and total QOL, in which FCG's emotional distress was the most important factor determining the overall and negative aspects of FCG's QOL [26].

Among all items in the disruptiveness domain, the disinterest of the other family members in caregiving was proved to be the best predictor of FCG's QOL in this study. This study finding was supported by a study of 191 FCGs of cancer patients which showed that when most respondents were the spouse of the patients then their QOL was predicted by more hours spent in caregiving and change in the caregiver's work situation [32]. If the other family members have not shown interest in caregiving then there is a high possibility for the FCGs to spend more hours in caregiving and experience changes in their work situation as the consequence. This disrupted schedule positively influences the FCG's QOL and mental health [19]. Another study of 120 FCGs of outpatient cancer patients also showed that FCGs who took care of their spouses and spent 21 hours daily taking care of their spouses had the worst QOL [24]. A study of 100 pairs of cancer patients and their spouse-caregivers showed that family function was significantly associated with the total QOL score [27]. Therefore, the involvement of all family members in caregiving, within the context of family duty/role/function without considering their interest or disinterest in caregiving, is highly important to equally spread the caregiving hours to all family members. A study of 139 FCGs of terminally ill cancer patients showed that those who shared caregiving responsibilities were less prone to be negatively affected by cancer caregiving activities [33]. Therefore, sharing the caregiving burden with the other family members is important.

However, this study has limitations. The sample's criteria were not strict and specific. Therefore, some conditions influencing FCG's QOL other than the cancer caregiving activities may exist but were ignored in this study. For instance, the patient's condition related to cancer treatment; whether they were under, just started, or off treatment; may influence their dependence on FCGs at home. In addition, deteriorating FCG's QOL sometimes becomes hidden morbidity, especially when the HCP ignores this aspect. Due to the complexity of the QOL concept, the continuous assessment of FCG's QOL by using a certain instrument may not be adequate in practice because of the continuous changes in the QOL aspects. Therefore, further studies need to be conducted to explore the multidimensional concept of FCG's QOL in cancer management at home more deeply and identify the other predictors of FCG's QOL. Thus, that proper intervention may be developed and given towards FCG of female cancer patients in order to improve their QOL, especially in a community context.

CONCLUSIONS

FCG's QOL of female cancer patients in a community setting is at a moderate level. It seems that it is a bit difficult to achieve a high QOL level while caring for a cancer patient at home. The domains of disruptiveness, burden, and financial concern could predict FCG's QOL significantly. The other family members' disinterest in caregiving which belongs to the disruptiveness domain is the best predictor of FCG's QOL of female cancer patients in a community setting which accounted for a 53.9% variance of QOL in this population. Health care professionals, especially community nurses, may formulate strategies to increase the other family members' interest in cancer caregiving at home, so that this duty may not only be one person's duty in the household. Their interest may be influenced by various factors, personally or conditionally. Community nurses may give interventions e.g. training activities to the adult family members of cancer patients in order to increase their care competencies, despite the fact that they are informal caregivers. Consequently, the personal barrier related to limited care competency can be eliminated successfully.

DECLARATIONS

Ethics Approval

Ethical clearance was issued by the Faculty of Medicine, Widya Mandala Surabaya Catholic University, with certificate number 080/WM12/KEPK/DOSEN/T/2020.

Competing of Interest

We declare that there are no known conflicts of interest associated with this publication, and there has been no significant financial support for this work that could have influenced its outcome.

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