

Burdens and Quality of Life of Chronic Disease Patients' Family Caregivers: A Systematic Review

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Abstract - Chronic illness is a disease that requires long-term treatment and care. Chronic illnesses have a big impact not only on patients but also on family caregivers which can affect the quality of life and even become a burden on family caregivers. This systematic review aims to find out the view of burdens and quality of life of chronic disease patients' family caregivers. Qualitative research with a systematic review approach using content analysis with a search method was used. It also used an electronic data base consisting of ProQuest, PubMed, Google Scholar, science direct, and Springer. This research journals focused on the problems and quality of life of chronic disease patients' family caregivers that can be accessed in full text by the publishing year of 2010-2019. Research on the problems and quality of life of chronic disease patients' family caregivers has been carried out in several countries with different methods. The results of a systematic review illustrate that the majority of family caregivers are women and are patients' spouse. The problems of family caregivers in providing care to patients with chronic diseases are at moderate to high levels with factors that affect the level of education, patients' quality of life, relationships with patients, and family support. In addition, the quality of life of family caregivers is at moderate to low levels with factors that affect the relationship with the patient, the patient's age and condition, level of education, religion, emotional distress, and family and social support. The higher the problem of family caregivers is, the lower the quality of life will be. Family caregivers have high problems with low quality of life.

Future studies are expected to determine supportive care to ease the burden and improve the quality of life of chronic disease patients' family caregivers.

Keywords: family caregivers, chronic patients, quality of life, problems / burden of family caregivers

I. INTRODUCTION

Chronic illness is defined as a medical condition or health problem related to symptoms or disability that requires long-term management [1,2]. Based on World Health Organization data, the prevalence of chronic diseases in the world reaches 70% of cases that cause death. This percentage will increase from year to year. This is due to lifestyle changes, consuming foods high in fat, cholesterol, smoking and high stress. It is estimated that in 2030 around 150 million people will be affected by chronic diseases [3]. Types of chronic diseases that cause death are cardiovascular disease, stroke, cancer, chronic obstructive pulmonary disease, hypertension and diabetes mellitus [4]. The family as someone closest to the patient will take an important role in the care of

patients, especially patients with chronic diseases that requires long-term care (Given et al., 2001; Teschendorf et al., 2007) [5]. The role and function of the family in system theory is that one is a caregiver for sick family members[6]. Family caregiver is a term that refers to someone who cares for a relative or loved one[7]. Family caregiver or FCs are needed in providing a variety of assistance, including disease monitoring and treatment, symptom management, drug delivery, emotional support, assistance with personal and instrumental care, and also financial support (Given et al., 2001; Yun et al., 2005) [5]

A number of responsibilities that must be carried out causes family caregivers to experience various problems and difficulties that can cause stress and can affect their quality of life[8]. The problem or burden of family caregivers is defined as a feeling of distress or difficulty as a result of the process of treating patients with chronic illness (Given et al., 2001) [5]. Problems or burdens of family caregivers include physical, psychological, and financial burden[5]. The burden perceived by family caregivers can be influenced by several factors, including factors from patients, family caregivers and the environment (Chou, 2000; Goldstein, Concato, Fried, & Kasl, 2004; Papastavrou, Charalambous, & Tsangari, 2009, 2012; Rafiyah, 2011) [9].

Family caregivers especially from patients with chronic diseases, for example cancer tends to experience a decrease in quality of life due to the burden felt by the family caregiver (Song et al., 2011; Tang et al., 2008; Yun et al., 2005) [5]. Based on research, it was explained that the higher the family caregivers' burden in stroke patients, the lower the quality of caregiver life in all domains [10]. Factors influencing the quality of life of family

caregivers in addition to the burden felt by family caregivers, as well as economic status, education, and relationships with patients, and social support[11]. These factors need to be known to prevent the decline in quality of life. In addition, the quality of life in caregivers' families is important to consider because it is feared that it will affect the quality of care provided for cancer patients [8]. Research on the burden or problems and quality of life of chronic disease patients' family caregiver has been carried out in several countries. Therefore, this systematic review was conducted to find out the view of the problem or burden and quality of life of chronic disease patients' family caregiver, as well as the factors that influence the burden and quality of life of the family caregiver.

II. METHODOLOGY

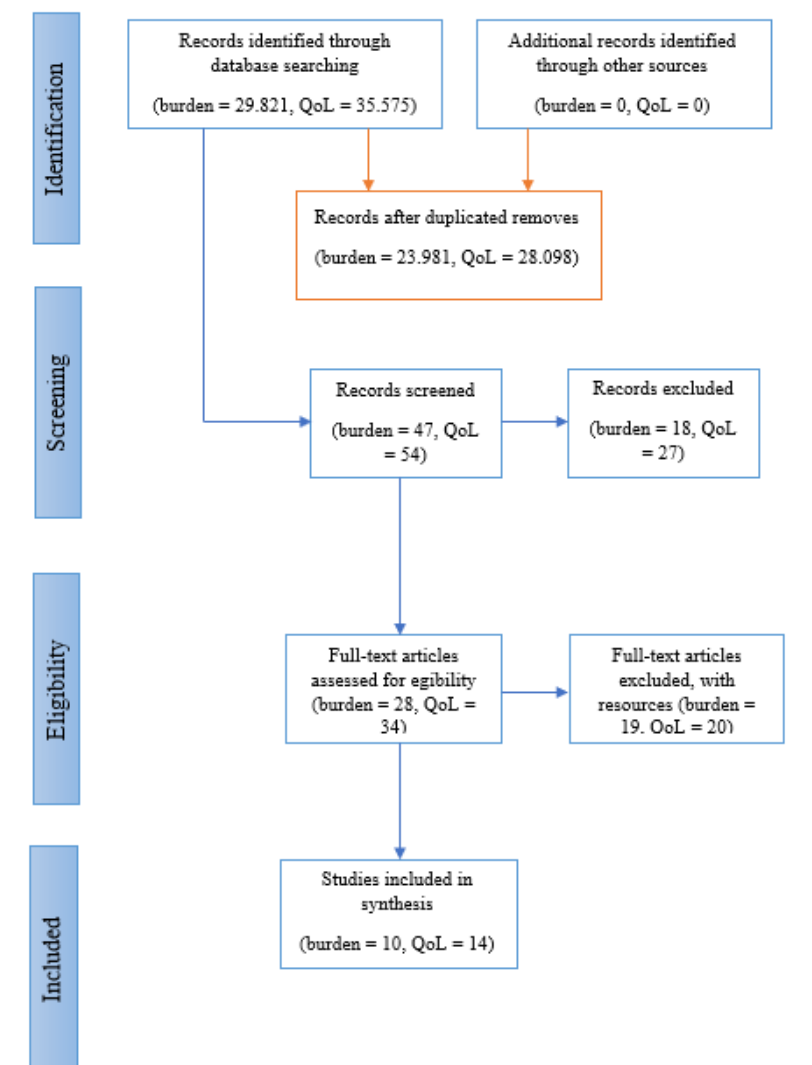
This systematic review is carried out through a review of research articles that have been published using content analysis. Research article searching methods used electronic data bases, namely ProQuest, PubMed, Google Scholar, Science Direct, and Springer. The research article was obtained using the keywords family caregiver, patients with chronic diseases, quality of life, and the burden or problems of family caregiver. There are 65.396 keyword-related research articles consisting of 29821 about family caregivers' burden or problems and 35.575 about family caregivers' quality of life. The inclusion criteria are research articles focusing on the burdens and quality of life of family caregivers' patients with chronic diseases that can be accessed in full text by the year of 2010-2019. Exclusion criteria are research articles containing only abstracts and not-good-enough article structures (abstract, introduction, methods, results, discussion, and references). There are 10 research articles that discussed about the burden or problem of family

caregivers in patients with chronic diseases, and 14 research articles that discussed the quality of life of family

caregiver of patients with chronic diseases. Articles found that fit in the criteria were then analyzed by using content analysis.

Table 1. Result of Literature Search

Databases	Number of articles according to keywords		Number of articles match the inclusion criteria	
	Burden FCs	QOL FCs	Burden FCs	QOL FCs
ProQuest	1890	2180	1	1
PubMed	454	651	1	2
Google Scholar	15.600	15.700	3	3
Science Direct	5570	8258	3	3
Springer	6307	8786	2	5
Total	29.821	35.575	10	14



III. RESULTS

Characteristics of Research Articles

After screening the articles, there were 10 research articles about the burden of chronic disease patients' family caregivers and 14 research articles on the quality of life of chronic disease patients' family caregivers that fit in the inclusion and exclusion criteria for content analysis. Based on the 24 research articles, research on the burden and

quality of life of family caregivers in patients with chronic diseases has been carried out in several countries, namely Indonesia, South Korea, Yunani, Iran, Brazil, Vietnam, India, Saudi Arabia, Italy, Japan, China, Thailand, Iceland and Germany (Table 2). The research design consisted of cross sectional studies, comparative studies and epidemiological studies (Table 3).

Table 2. Distribution of Research Sites

Place of Study	Number of Articles	
	Burden	QoL
Indonesia	1	
Korea Selatan	1	4
Italia	1	1
Yunani	1	
Iran	2	1
Brazil	1	
Vietnam	1	
India	2	
Saudi Arabia		1
Jepang		2
Jerman		1
China		2
Iceland		1
Thailand		1
Total	10	14

Table 3. Research Design

Research Design	Number of Articles
Cross-sectional study	20
Comparative study	3
Epidemiological study	1
Total	24

Characteristics of Family Caregivers

Based on 24 research articles, the characteristics of family caregivers in patients with chronic diseases include the ones over 40 years old, the majority of them were female (over 50%), having a relationship as a patients' spouses, and

having a high school educational background.

Family Caregivers' Burden or Problems

The results obtained from 10 research articles indicate that chronic disease patients' family caregiver have a burden or

problem in the level of moderate to high level.

Factors Affecting Family Caregivers' Burden

Factors affecting the burden of chronic disease patients' family caregiver can be divided into 3, namely factors originating from patients, from family caregivers, and from the environment. Factors originating from patients include gender, length of treatment, patient's condition, and type of treatment received by the patient. Factors derived from family caregivers include age, sex, relationship with patients, education level, and employment status. Environmental factors include family income, family support, family type, and social support.

Quality of Life of Family Caregivers

The results obtained from 14 research articles indicate that chronic disease

patients' family caregivers have a quality of life in the level of moderate up to low level.

Factors Affecting the Quality of Life of Family Caregivers

Factors that affect the quality of life of family caregivers in patients with chronic diseases can be divided into 3, namely factors originating from patients, family caregivers, and the environment. Factors originating from patients include age and condition of the patient. Factors originating from family care groups include age, level of education, relationship with patients, emotional distress, ability and readiness in caring for patients, and religion. Environmental factors include income, satisfaction with treatment services, family and social support, expenses during treatment.

Table 4. Article Summary about Family Caregivers' Burden

Author and Year	Place of Study	Study Design	Sample	Instruments	Findings
Rha et al., (2015)	South Korea	the cross-sectional descriptive study	212 family caregivers	The Korean version of the ZBI (Zarit Burden Interview)	FCs were mostly in the age of 46 years old and 79.2% of them werewomen. Half of the FCs were the patient's spouse and many FCs were the sole caregivers. 52.4% of FCs were highly educated but half of them did not work or stopped working because they wanted to look after these patients. FCs' burden was based on K-ZBI scores which were at moderate level although almost ¼ of them had high burden. Influencing factors include: Age, emotional burden, the patient's condition, living with the patient, and the length of time since given diagnosis. The greater burden of FCs is related to the poorer quality of life of FCs.
Spatuzzi et al., (2017)	Italia	Comparative study (active/cura tive group and hospice/pal	76 primary family caregivers of patients with cancer	The Caregiver Burden Inventory (CBI).	In both the majority groups of FCs were women and were on average of 46 years old, and had a high school level of education. There were no significant differences in CBI scores between the two groups. Factors

			liative care group)			influencing the burden of FCs in both groups were the amount of time spent caring for patients and the lack of social support.
Govina et al., (2015)	Yunani	Cross sectional study	100 pairs of patients and FCs at one radiotherapy centre.	Bakas Caregiving Out-comes Scale-Greek version (Greek BCOS) Oberst Caregiving Burden Scale (OCBC) Hospital Anxiety and Depression Scale-Greek version (G-HADS).		76% of FCs were women and 59% were patients' spouses. FCs who were female, faving from junior high school up to high school education, living with patients, having experience in caring for patients, not working, significantly having a heavier burden in caring for patients. The burden of FCs was caused by feelings of FCs depression, difficulties in performing care tasks, FCs family status, daily work hours or working status, and the patient's surgical history.
Masoudian et al., (2019)	Iran	Cross sectional study	62 informal home caregivers of the patients	Caregiver Burden Inventory		The average age of FCs is 63.76 years and 71% of FCs are women. 48.4% FCs are couples and 54.8% FCs are married. The average FCs load score is at a high level. The high burden of care is related to marital status and low levels of education. The increased burden on care by FCs reduces the quality of life in all aspects, especially FCs that provide care to their partners will experience more burdens.
Borges et al., (2017)	Brazil	Prospective cross sectional study	91 patient-caregivers	The Hospital Anxiety and Depression Scale (HADS), Medical Outcomes Study 36-item Short Form Health Survey (SF-36), The Caregiver Burden Scale (CBS)		The majority of FCs were younger than patients and 84% of them were women. 63% of high school FCs education levels and half of FCs were the patients' children. FCs from patients with end-stage cancer with poor patients' quality of life have a significantly higher burden, have a worse symptoms of anxiety or depression, and have a worse quality of life. In addition, FCs who treated patients with early-stage cancer and who had a good quality of life had a lower burden.
Thuy & Dan, (2015)	Vietnam	Descriptive Cross sectional study	107 family caregivers	The Zarit Burden Interview (ZBI), Activities of Daily Living		56.1% of FCs were male with an average age of 45 years. Most of the FCs work were farmers and employees. 68.3% FCs had a high school education and the majority were partners of patients. 55% of FCs had a poor burden on treating cancer patients and 17% had a very

				(ADL) and Instrumental Activities of Daily Living (IADL).	bad burden. A significantly higher burden was found in (1) female FCs with female patients, (2) FCs who treated the patients themselves without family or social support, (3) FCs from patients who were family's breadwinner, (4) FCs from patients who underwent radiotherapy and post-surgery, (5) FCs from newly diagnosed patients, and (6) FCs who were the patients' spouse rather than the patients' children. In addition, there was a positive relationship between the burden and age of FCs and the length of treatment provided.
Lukhmana, Bhasin, Chhabra, & Bhatia, (2015)	India	Cross sectional study	220 family caregivers	Hindi version of Zarit Burden Interview	Sociodemographic data show that 55% of FCs were female with an average age of 40 years. 51.5% FCs did not work, 57.5% FCs were spouses of patients, and 41% FCs lived with families and 88% FCs treated patients for 4 hours a day. Based on the ZBI score, 56.5% FCs had a minimal burden and 37.5% had a heavy burden, and 1% had a very heavy burden. Factors that influenced the burden of FCs in caring for patients include marital status, family type, patient occupation, and the type of treatment the patient receives, and culture.
Mirsoleyma ni, Rohani, Matbouei, Nasiri, & Vasli, (2017)	Iran	Cross sectional study	104 family caregivers	Caregiver Burden Inventory (CBI) and the Family Distress Index (FDI)	Sociodemographic data: 55.8% FCs were women with an average age of 40 years. 48.1% FCs had a high burden in treating cancer patients. Factors that influenced this were FCs who were souse of patients, patients being treated were male patients, inadequate monthly income, and patients newly diagnosed with cancer. FCs burdent was significantly related to family stress levels.
Srinivasago palan, Nappinnai, & Solayappan, (2015)	India	Cross sectional study and comparativ e study	62 family caregivers	Hospital Anxiety and Depression Scale (HADS) Burden Assessment Schedule (BAS) Presumptive Stressful Life Event Scale	Sociodemographic data: 41.9% of FCs of breast cancer patients were 20-30 years old while 35% of cervical cancer patients were 30-40 years old. The gender of FCs in breast cancer patients was 54.8% male and 58.1% female in FCs for cervical cancer patients. FCs education in both types of cancer dat high school education. Based on research, FCs burden more on male FCs with breast cancer cases. The closer the relationship between FCs and patients is, the higher the burden in both types of cancer will be. The

					higher the FCs burden is the higher the FCs stress level will be.
Sari et al., (2018)	Indonesia	Cross sectional study	178 family caregivers	The Caregiver Reaction Assessment (CRA) The family's Adaptability, Partnership, Growth, Affection, and Resolve (APGAR) The Palliative Performance Scale (PPS)	Characteristics of FCs: mean age of FCs was 44 years, 83.1% FCs were married, 59% were female, 47.2% were the patient's spouses, and 82% had high school education. Factors that significantly influenced FCs burden include FCs age, relationship with patients, level of education, family income, length of treatment, health status, family support, and patients' gender.

Table 5. Article Summary about Quality of Life Family Caregivers'

Author and Year	Place of Study	Study Design	Sample	Instruments	Findings
Rha et al., (2015)	Korea Selatan	The cross-sectional descriptive study	212 family caregivers	Korean version World Health Organization QOL-BREF (K-WHOQOL-BREF) The Eastern Cooperative Oncology Group (ECOG)	General characteristics of FCs: FCs were in the average age of 46 years, 79.2% of them were women accompanying cancer patients. Half of the FCs were spouse of cancer patients and many FCs were sole caregivers. In the study, 52.4% of FCs were highly educated but half of them did not work or stopped working because they wanted to care for or caregiving these patients. FCs had a moderate quality of life. Male FCs showed a better physical and psychological states. FCs who had a higher level of education showed better psychological and environmental conditions. Higher incomes contributed to creating a better quality of life environment. FCs that maintained cancer patients in hospitals had a worse quality of life in physical, psychological, and environmental aspects. FCs treating patients with functional damage experienced a higher burden. The greater burden of FCs is related to the poorer quality of life of FCs.
Almutairi, Alodhayan i, Alonazi, & Vinluan, (2017)	Saudia Arabia	A descriptive cross-sectional survey	289 Saudi caregivers	Short-Form Health Survey SF-36 (the RAND 36-item)	65.1% of FCs were women and 55.4% of FCs completed level 2 (junior high school) of education. The higher quality of life score indicates better function. Almost all domains of quality of life had scores above 50 except energy / fatigue levels. Physical role had the highest

					score followed by physical function. The age, sex, and type of cancer of the patient were predictors that significantly influenced the quality of life of FCs.
Spatuzzi et al., (2017)	Italia	Comparative study (active/curative group and hospice/palliative care group)	76 primary family caregivers of patients with cancer	The Medical Outcomes Study Short Form (SF-36)	In both groups the majority of FCs were women and were in average age of 46 years old, and had a high school level of education. There were significant differences between the 2 groups in terms of general health ($p = 0.048$), standard scale of physical components ($p = 0.026$) and mental ($p = 0.020$). The palliative care group had better general health and physical condition than the active / curative group did, but it had a worse mental state than the active / curative group.
Ito & Tadaka, (2017)	Japan	epidemiological study	262 family caregivers.	Japanese version of the CQOLC	There were 74 questionnaires that could be analyzed. Based on demographic data, 79.7% of FCs were women. The average age of FCs was 63.6 years. 35.1% of FCs were life partners and 28.4% of them were daughters of patients. 60.9% of FCs responded adequately or slightly to family budget/finance. Factors related to the quality of life of FCs are explained in four factors: depression, self-efficacy of family care, the presence or absence of an additional caregivers, and satisfaction with home care/treatment services. In contrast, social support and information accessibility were not significantly related to the FCs quality of life.
Morishita & Kamibepu, (2014)	Japan	A cross-sectional study	111 family caregivers	Short-Form 36 (SF-36; acute version), care evaluation scale (CES), satisfaction with care, and Japanese version of the caregiver reaction assessment (CRA-J)	The average age of FCs was 59 years with 75.7% of female FCs. The quality of life of FCs was lower than the national average. The score of the physical component was higher when the FCs age was lower, FCs had a better health, and when the patient's age was younger. The mental state of FCs would improve when the FCs were older and their health was good. Younger patients and FC's age and healthy feelings/mental state of FCs were associated with a better physical health of FCs, but satisfaction in caring for patients was not related to physical health. Although, mental health of FCs were associated with satisfaction in treating patients.
Cubukcu, (2018)	German	cross-sectional descriptive study	48 cancer patients who were served from home	The Katz Index of Independence in Activities of Daily	Characteristics of FCs: 83.3% of them were women and were in the average age of 51 years. The care/treatment given by FCs to cancer patients had an impact on the health

			care unit and 48 caregivers	Living, The Lawton Instrumental Activities of Daily Living Scale (IADL) Caregiver Quality of Life Index-Cancer (CQOLC).	of FCs in a negative direction: 91.2% of FCs stated that it gave impact on their psychological state and 8.8% of their physical health declined. 55.2% of FCs did not have enough time to fill their responsibilities during the cancer treatment process, 15.4% had poor family relationships. FCs that took care of patients diagnosed for more than 1 year were more depressed than those diagnosed less than 1 year. The quality of life of FCs was very low especially if FCs were not from the patient's family, or FCs did not have social insurance, or had a low income. Their health condition had also declined since starting to treat patients.
Choi et al., (2016)	Korea selatan	cross-sectional stud	299 FCs of terminal cancer patients from seven palliative care units	Korean Version of Caregiver Quality Of Life IndexCancer (CQOLC-K)	74.6% of FCs were women and were patients' life partners/spouses (41.1%). Factors affecting the quality of life of FCs were factors of the patient, FCs, and the environment. Patient factor, age was a factor that affected the quality of life of FCs (FCs of younger patients felt more burdened than older patients did). FCs factors, such as age, marital status, religion, relationship with patients and emotional distress that affected the quality of life of FCs, where emotional distress was the factor that mostly influenced the quality of life of FCs. Environmental factors that affected the quality of life of FCs were burden during care, level of social support, family functioning, satisfaction with care, and monthly household income.
Lee et al., (2016)	South korea	cross-sectional study	178 patient-family caregiver pairs	Korean version of the Caregiver QOL Index-Cancer (CQOLC-K)	The median of FCs' age was 50 years and 73.3% of FCs were women. The quality of life of FCs was not significantly related to the quality of life of terminal cancer patients. Factors that influenced the low quality of life of FCs were emotional distress, low social support, and FCs who had religion.
Lu et al., (2010)	China	A cross-sectional study	358 caregivers of cancer inpatients	QOL-Family Version offered by the American National Medical Center The Beckman Research Institute	The average value of the quality of life of FCs was 5.26. The very disturbing domains were psychological welfare and social conditions of FCs. Factors affecting the quality of life of FCs were relationships with life partners, the patient's condition and the patient's ability to carry out daily activities. A very strong relationship that affected the quality of life of FCs was a relationship with a spouse.

Masoudian et al., (2019)	Iran	Cross sectional study	62 informal home caregivers of the patients	SF-36 Questionnaire for assessing quality of life	The average age of FCs was 63.76 years and 71% of FCs were women. 48.4% of FCs were couples and 54.8% FCs were married. There was a negative and significant relationship between different aspects of quality of life and the burden of care. This study showed that increasing the burden of care in informal home care groups reduced the quality of life in all domains. The increased burden on care/treatment by FCs reduced the quality of life in all aspects, especially FCs that provided care to their partners would likely experience more burdens.
Song et al., (2011)	South Korea	A multicenter, cross-sectional survey	160 family caregivers (FCs) of inpatient palliative care	EQ-5D and Caregiver Reaction Assessment (CRA)	The relationship between health condition and the quality of life of FCs of terminal cancer patients were significantly lower than controls. Their depression experience happened more often than controls. Factors that influenced the relationship between health condition and the quality of life of FCs came from demographic factors and caregiver burden. Demographic factors consisted of religion and education level. Factors affecting mental health were age (older FCs felt less stress than younger FCs, but suicide thoughts commonly appeared), less family support (increased suicide thoughts). Financial problems increased feelings of depression and health effects increased stress of FCs.
Yu et al., (2017)	China	A cross-sectional study	90 FCs for leukemia patients	Chinese version of WHOQOL-BREF	The average FCs were women (54.7%), the majority of them were parents (44%) and patients' spouses (36.9%), married status (94.2%), workers / employees (77%) and did not have religious belief (85.1%). The quality of life scores of FCs were low in four domains, namely physical, psychological, social, and environmental. Social support had the greatest influence on the quality of life of FCs, followed by family functions. FCs who were older, had higher education, and did not have religious beliefs, felt higher emotional distress, and provided care to younger patients and patients without insurance had, a lower quality of life than others.
FRÍÐRIK SDÓTTIR et al., (2011)	Reykjavík, Iceland	Cross-sectional, descriptive and	223 family member	Quality of Life Scale (QOLS) Hospital	The majority of FCs were women (62%), were life partners/spouses of patients (64%), and the age range of FCs was 18-82 years. Overall the

		correlation al		Anxiety and Depression Scale (HADS).	quality of life of FCs was good. There was a positive but weak relationship between the important needs found with the quality of life of FCs. FCs who had experienced symptoms of anxiety and depression had a worse quality of life than FCs who did not experience these symptoms. A significant relationship between QOL and HADS was also observed and indicated an increase in quality of life by reducing emotional distress. Although in this study the quality of life of FCs was good, it is necessary to identify FCs who were at risk with the experience of psychological symptoms.
Waraporn mongkhon kul & Howteerak ul, (2018)	Thailand	Cross- sectional study	175 family caregivers	Thailand versionCQOL C, the generalized self-efficacy Scale, and social support using the multidimensio nal scale	79.8% of FCs were women and 86% of them were aged from 18-51 years. 52.8% of FCs had a good quality of life, 60.1% were at moderate level of self-efficacy, and 56.7% had a high level of social support in care delivery. FCs members who provided care to male cancer patients and were responsible for funding care had lower levels of self-efficacy and social support. They were also reported to have a worse quality of life. Patient characteristics were strongly related to the quality of life of FCs, then characteristics of FCs, perception of self-efficacy, and perception of social support. Factors that were significantly related to the quality of life of FCs were the sex of the patient, the cost of care, perception of self-efficacy and social support.

IV. DISCUSSION

Characteristics of Family Caregivers

Family caregivers of patients with chronic diseases are dominantly female and have a relationship as a patient's spouse and live in the same house[5,9,12,13]. According to the research of Wadhwa et al., (2013), 84% of family caregivers were partners of patients and 90% lived in the same house. Other characteristics of family caregivers are age and level of education. The mean age of family caregivers is over 40 years and high school education [5,9,10,15,16,17,18].

The results of the above study indicate that the majority of family caregivers are female and aged over 40 years due to the prevalence of chronic disease sufferers, especially cancer, found in many male patients and increases with age. This is supported by data from the World Health Organization, (2018), which states that 1 in 5 men and 1 in 6 women in the world experience cancer and 1 in 8 men and 1 in 11 women, die because of cancer.

According to data from the Indonesian Ministry of Health (2015)[8], the prevalence of cancer is higher in men

than women and risk factors increase along with increasing age. In addition, based on the review of the article above, most family caregivers are patients' spouse. Spouse is someone who has an important role in the treatment of cancer patients where the main factor is love that they owned [8]. Family caregiver is a term that refers to someone who is caring for a relative or loved one [7]. Family caregiver is needed in providing a variety of assistance, including disease monitoring and treatment, symptom management, drug administration, emotional support, assistance with personal and instrumental care, and financial support (Given et al., 2001; Yun et al., 2005) [5]

Burden of Family Caregivers

Chronic Disease Patients' Family Caregiver have burdens or problems in the moderate up to high levels. Research by Rha et al., (2015) explained that chronic disease patients' family caregiver had a moderate burden and almost $\frac{1}{4}$ of them have a high burden. In line with research conducted by Thuy & Dan, (2015), which states that 55% of family caregivers had a bad burden experience in treating cancer patients and 17% have a very bad burden. Research Borges et al., (2017); Masoudian et al., (2019); Mirsoleymani et al., (2017) explained that chronic disease patients' family caregivers had a high burden.

In contrast, research Lukhmana et al., (2015) explained that 56.5% caregivers had a minimal burden, and 37.5% had a heavy burden, and 1% had a very heavy burden. According to Lukhmana et al., (2015), this is due to cultural norms in India and Pakistan, where people who took care of sick patients should be their own relative, spouse or parents. It is considered the duty of the patients' healthy partner. Parents sacrifice for their children and adult children are required to care for them when one of them is sick and because of this, they continue to care for sick

members without clearly observing complaints or feeling burdened.

Factors that affect the burden of family caregivers in patients with chronic diseases can be divided into 3, namely factors originating from patients, family caregivers, and the environment. Factors originating from patients include gender, length of treatment, patient's condition, and type of treatment received by the patient. Research conducted by Rha et al., (2015) states that family caregivers with end-stage cancer experience more burdens. Supported by Borges et al., (2017), family caregivers of patients with end-stage cancer with poor patients' quality of life have a significantly higher burden, with worse symptoms of anxiety or depression, and have a worse quality of life.

According to the Thuy & Dan study, (2015), the burden of family caregivers was significantly higher found in family caregivers of patients undergoing radiotherapy and post-surgery. This result is supported by research Govina et al., (2015) which states the burden of family caregivers is caused by a history of patient surgery or the patient's condition.

According to the research of Sari et al., (2018), factors that significantly influence the burden of family caregivers include the sex of patients where family caregivers who take care of male patients experience a greater burden than to treat female patients. This is in line with research conducted in Yunani by Govina et al., (2015). The study stipulates that female patients will be more independent in fulfilling their own daily needs. In terms of social status, men are the heads of families. If he is sick or unable to support his family, of course this will be a burden for family caregivers.

Factors derived from family care groups include age, sex, relationship with patients, education level, and employment

status. The results of the study by Rha et al., (2015) showed that the age of family caregivers has a weak positive relationship with emotional burden. Research by Govina et al., (2015) explains that family caregivers who are female, having a junior or senior high school level, living with patients, having experience in taking care of patients, not working, significantly have a heavier burden in caring for patients. This is supported by Thuy & Dan's, (2015) study who mentioned that the burden of family caregivers was significantly higher found in female family caregivers with female patients being treated, and family caregivers who were the patients' spouse than their children.

In contrast, according to research by Srinivasagopalan et al., (2015) caregivers burden relied more on male caregivers. This happened because the study respondents were a partner of patients with breast cancer. The closer the relationship between caregivers and patients is, the higher the burden will be, and the higher the caregivers burden is, the higher the stress felt by caregivers will be.

According to the research of Masoudian et al., (2019), the high burden of care is related to marital status and the low level of education. The more often caregivers are associated with patients, the higher the burden of care will be. Besides, the higher the level of caregivers education is, the lower the burden of care will be. In line with the study of Sari et al., (2018), factors that significantly influence the burden of family caregivers include the age of family caregivers, relationship with patients, and education level. Supported by the research of Mirsoleymani et al., (2017), factors that influence the high burden of family caregivers are caregivers who are patients' spouse/ life partner.

Environmental factors include family income, family support, family type, and social support. According to

research by Thuy & Dan, (2015), the burden of family caregivers is significantly higher found in family caregivers who care for patients themselves without the support of family or social caregivers of patients who become the family's breadwinner. In line with the study of Sari et al., (2018), significant factors affecting family caregivers burden include family income and family support. Supported by research by Govina et al., (2015), caregivers burden is caused by caregivers family status.

Quality of Life of Family Caregivers

Family caregivers in patients with chronic diseases have a moderate to low quality of life. According to research by Rha et al., (2015), family caregivers of cancer patients have a moderate quality of life and burden. Morishita & Kamibeppu, (2014) state that the quality of life of family caregivers of cancer patients is lower than that of average score nationally. In line with the research of Song et al., (2011) and Yu et al., (2017) mentioning that the quality of life of the family caregiver of cancer patients is low.

In contrast, the research Almutairi et al., (2017) explained that almost all domains of quality of life have scores above 50 which means quality of life increased. It is also in line with the research of FRÍÐRIKSDÓTTIR et al., (2011) which states that overall the quality of life of family caregivers is considered good. These results indicated that the worst results often obtained for the burden and quality of life of family caregivers are reflections of the poorer patient performance status[26].

Decreased quality of life in family caregivers of cancer patients occurs in almost all domains. According to the study of Yu et al., (2017), the quality of life scores of family caregiver is low in four domains, namely physical, psychological, social, and environmental. This result is in line with the research of Liliana & Ciro,

(2012) which showed that family caregivers of cancer patients had negative perceptions on the quality of their lives with the most affected domains were the physical, psychological, and social welfare dimensions.

Factors that affect the quality of life of family caregivers in patients with chronic diseases can be divided into 3, namely factors originating from patients, from family caregivers, and from the environment. Factors originating from patients include age and condition of the patient. According to research of Choi et al., (2016) explained that age was a factor that affected the quality of life of family caregivers (family caregivers of younger patients feel more burdened than older patients). This is in line with the research of Morishita & Kamibeppu, (2014) mentioning that one of the factors that influenced the quality of life of family caregivers was age.

According to the study of Rha et al., (2015), family caregivers treating patients with functional damage experience a higher burden. It is in line with the study of Lu et al., (2010) arguing that factors influencing the quality of life of family caregivers are the patients' condition and the patients' ability to carry out daily activities.

Factors originating from family care groups include age, sex, level of education, relationship with patients, emotional distress, ability and readiness in caring for patients, and religion. According to the study of Rha et al., (2015), family caregiver factors, such as age, marital status, religion, relationship with patients and emotional distress affected the quality of life of family caregivers, where emotional distress is the most influencing factor in the quality of life of family caregivers and that in line with the research of Choi et al., (2016); Lee et al.,

(2016); Lu et al., (2010); Song et al., (2011); Yu et al., (2017).

According to research by Rha et al., (2015), male family caregivers showed better physical and psychological states. family caregivers who have a higher level of education showed better psychological and environmental conditions. The study was supported by Almutairi et al., (2017) who stated that age and sex were predictors that significantly affected the quality of life of family caregivers. Environmental factors that affect the quality of life of family caregivers are burden during treatment, level of social support, family function, satisfaction with treatment/care, and monthly household income[28,15,11]

The study is supported by the results of the Ito & Tadaka study(2017). They stated that the factors related to the quality of life of family caregivers are explained in four factors: depression, self efficacy family caregivers', the presence or absence of additional caregivers, and satisfaction with home care services. According to research conducted by Rha et al., (2015), family caregivers who maintained cancer patients in hospitals had a worse quality of life in physical, psychological, and environmental aspects, and a higher income contributed to creating a better quality of life environment.

V. CONCLUSION

Family caregiver is a term that refers to someone who treats a relative or loved one, especially in a state of illness that requires long-term care. The results of this systematic review show that family caregivers of patients with chronic diseases are prone to have a high burden and a low quality of life. Factors that influence the high burden include the sex of the patient, length of treatment, condition of the patient, type of treatment

received by the patient, age of family caregivers, sex of family caregivers, relationship of family caregivers with patients, level of education of family caregivers, family caregivers working status, family income, family support, family type, and social support. Factors affecting the low quality of life of family caregivers include age and condition of the patient, age and level of education of family caregivers, relationship of family

caregivers with patients, emotional distress of family caregivers, ability and readiness in caring for patients, religious side of family caregivers, family income, satisfaction of care services, family and social support and the burden during treatment. All of these factors are categorized into 3 categories: patient, family caregivers, and environmental category.

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