

Assessment of Quality of Life Scores for Family Caregivers of Cancer Patients

Zakia Nurul Hikmah¹, Fitri Arofiati^{2,*}

¹Magister Keperawatan Universitas Muhammadiyah Yogyakarta, Indonesia

²Program Studi Magister Keperawatan Universitas Muhammadiyah Yogyakarta, Indonesia

Abstract

Family caregivers play a central role in providing care for cancer patients and may experience a decline in their quality of life. This study contributed to assessing quality of life scores among family caregivers of cancer patients. A literature review was conducted using PubMed, Scopus, and ProQuest databases. A total of 2,109 articles were identified and screened following the PRISMA guidelines, resulting in eight eligible studies included in the review. The findings showed that the quality of life of family caregivers was most significantly affected in the physical health domain. Demographic factors influencing caregivers' quality of life included age, gender, and marital status. In conclusion, family caregivers of cancer patients face substantial challenges that affect their quality of life. This review contributes to oncology nursing and palliative care by highlighting physical health as the most affected quality of life domain and identifying commonly used assessment instruments for family caregivers

Keywords: Cancer; Family Caregiver; Palliative Care; Quality of Life

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*) Corresponding author: Fitri Arofiati
E-mail: fitri.arofiati@umy.ac.id

1. Introduction

The increasing incidence of cancer has become a serious global health problem, causing high mortality and requiring long-term treatment (Ferlay et al., 2024). Due to the increase every year, cancer is becoming a big problem (L. Lin et al., 2021). Considered a non-communicable disease, Among the leading causes of death globally is cancer. Not only is it life-threatening, but the treatment and medication process is also costly (Kemenkes, 2024).

The World Health Organization (WHO) reported that the incidence of cancer continues to increase every year and is still a global health problem in developing countries. Cancer Disease noted that in 2022, around 9.7 million people, or 18.7% of all deaths worldwide, died from cancer. Colorectal, cervical, lung, and breast cancer are the four most common types of cancer in Indonesia. Cancer is the third highest cause of death after stroke and heart disease. The Global Cancer Observation Center, Globocan, recorded 408,661 and 242,988 fatalities and new cases of cancer in 2022. Lung cancer is more common in men, while breast cancer is more common in women.

According to the Global Cancer Observatory (Globocan), without a change in strategy, the burden of cancer cases and deaths in

Indonesia will increase by 63% between 2025 and 2040. As a result, cancer treatment must be a top priority throughout the country. With 4.86 incidents per 1,000 people, Yogyakarta has Indonesia's highest cancer rate. Lung cancer affects 19.4 out of every 100,000 males, and its average death rate is 10.9 out of every 100,000. An average of 7.6 liver cancer deaths and 12.4 liver cancer incidences per 100,000 individuals. Women are affected by breast cancer at a rate of 42.1 cases per 100,000, and the death rate is 7.6 cases per 100,000 (Kemenkes, 2024).

Cancer patients need palliative and supportive services throughout their disease journey, from the time of diagnosis to the end of their lives. With palliative and supportive care, patients are expected to feel more comfortable during treatment and have a better quality of life. Care involving family caregivers is essential to help cancer patients cope with the physical, psychological, social, and spiritual difficulties caused by the disease and its treatment (Rezaei et al., 2024). Patients who receive palliative care can participate in the care process and experience comfort, closeness, and safety. The closest person who usually cares for the patient is a family caregiver. A family caregiver is also considered someone with a personal relationship, such as a

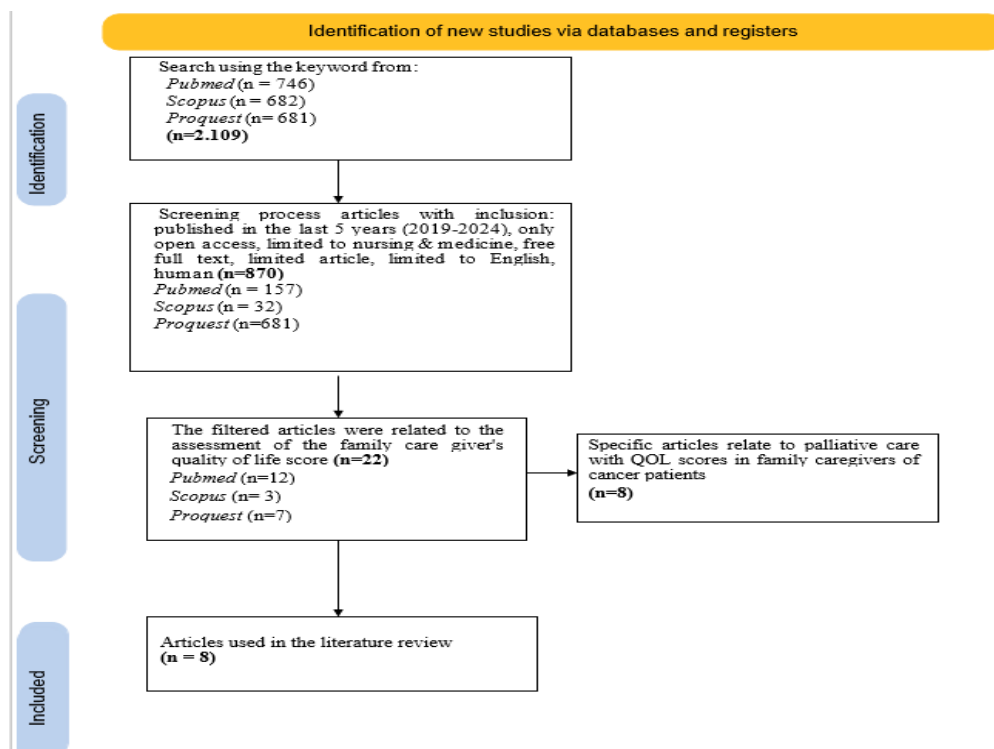
friend, family member, or relative, who is specifically willing to help someone suffering from a chronic illness or disability. Family caregivers are very important in helping patients with palliative illness. Family caregivers work with healthcare providers to improve the patient's health and quality of life, helping healthcare providers see how the patient's health condition and plan for care and treatment. Therefore, evaluating the patient's quality of life is essential to a comprehensive palliative care approach (Demuro et al., 2024)

Previous studies have shown that family caregivers of cancer patients experience high levels of caregiving stress, which results in fatigue, sleep disturbances, long-term exhaustion, and decreased emotional and cognitive functioning (Martin et al., 2023). In addition, there is a link between long-term caregiving responsibilities and a decrease in overall quality of life, as well as an increase in depression, anxiety, and psychological distress (Akter et al., 2023). Previous systematic research and meta-analyses have shown that psychosocial interventions for both patients and caregivers can improve caregivers' quality of life. However, physical, environmental, and spiritual aspects have received less attention, and most research still focuses on psychological and social aspects (Mathews et al., 2023). Previous research found that quality of life assessment instruments used by family caregivers of cancer patients (Chen, 2023). Furthermore, quality of life has never been comprehensively evaluated using a multidimensional approach, and quality of life has

not been consistently used as an external standard in oncology nursing practice. Furthermore, few studies have evaluated the overall quality of life of family caregivers of cancer patients (Rostami et al., 2023). Therefore, this literature review study assists oncology nursing by combining scientific evidence on the quality of life scores of family caregivers of cancer patients based on multidimensional domains and identifying the most common assessment instruments. The results of this study are expected to help create more standardized nursing assessments, develop family-centered interventions, and evaluate the effectiveness of support services for family caregivers of cancer patients.

2. Method

The literature review method was used to write this paper. A literature review is just one of many research methods available. The literature review will summarize how a particular issue has evolved. Researchers can identify the theory or approach through the literature review. The literature review method was used to write this paper. A literature review is just one of many research methods available. The literature review will summarize how a particular issue has evolved. Researchers will be able to identify the theory or approach through the literature review and identify differences between the theory and relevant research results (Luft et al., 2022). To gain a wealth of information and understanding about relevant research (Ebidor & Ikhide, 2024).



Picture 1. Prisma

Data collection was carried out through databases available on PubMed, Scopus, and ProQuest. The keywords used in this writing are "Quality of life," "Family caregiver," "family with cancer," and "Palliative Care". The selection of articles that have been searched and are based on the purpose of writing the article is to assess the quality of life score of family caregivers of cancer patients. Inclusion criteria are published in English, published in the last 5 years, 2019-2024, only open access, limited to nursing & medicine, free full text, limited to articles, human, and related to keywords and clinical questions.

3. Results and Discussion

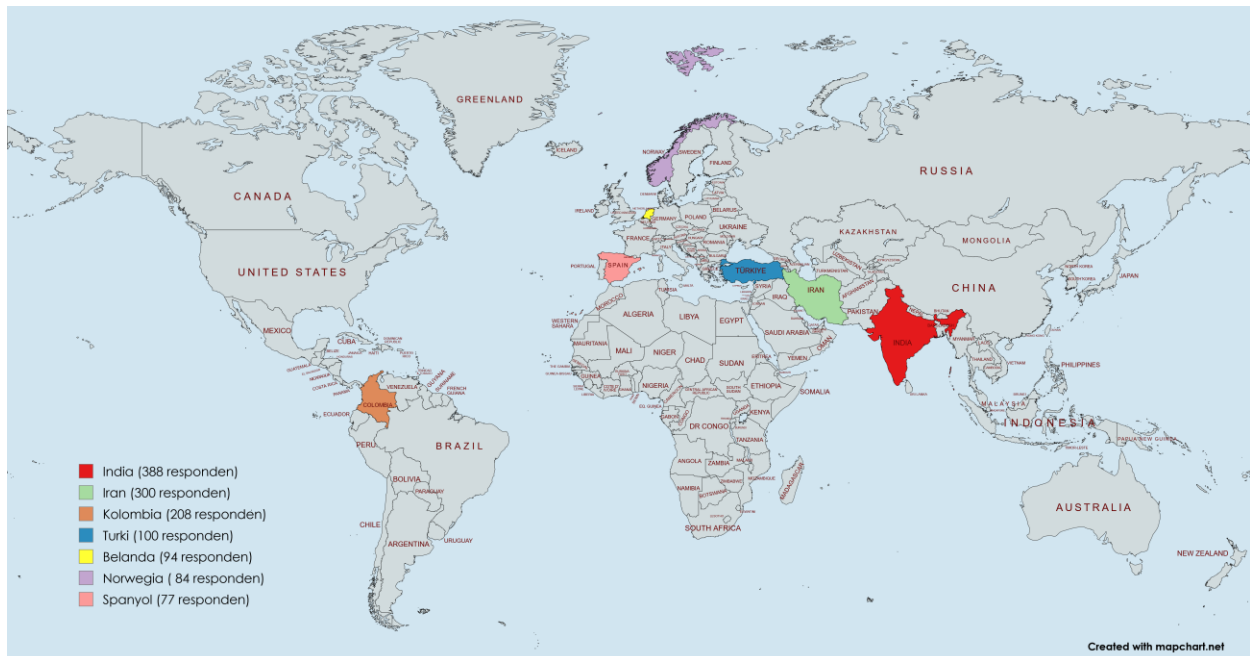
Conducted an article search from December 7, 2024, to December 10, 2024. The database search results obtained a total of 2,109 articles from 3 databases. A total of 870 articles that meet the inclusion criteria were obtained. Then, the filtered articles assessed the quality of life score of family caregivers in 22 articles. Then, the results of specific articles to family caregivers of cancer patients, getting the final results of 8 articles.

Figure 1 presents a PRISMA flowchart of the study selection process. A total of eight articles were included and analyzed to determine study characteristics and synthesize key findings. The characteristics of the included studies are summarized in Table 1.

Respondent characteristics are summarized in Table 2, while the geographic distribution of respondents is illustrated in Figure 2.

Based on the results, the overall data of the articles (n=8), the location of the research data collection in the articles used as reference sources was carried out abroad, with the most in the European continent, 50%, followed by the Asian continent 37.5% and the American continent, 12.5%.

The review findings showed that the total number of family caregivers was 1,369. There were more females, namely 713 (52%), while there were 656 males (48%); this aligns with research (Barzallo et al., 2024) that most family caregivers are women. This is due to social and cultural demands requiring women to care for sick family members. In addition, women more often take care of cancer patients because they care and are sensitive to their environment.



Picture 2, Respondent distribution map

In line with (Jabeen et al., 2024), Female caregivers have lower QoL scores than male caregivers. This may be because women have many societal responsibilities and are traditionally considered to have roles in all areas. Therefore, it is expected that female caregivers take on these responsibilities.

The review findings show that most family caregivers are adults with an average age of 39-50

years (50%). This is in line with research (Akter et al., 2023). Age hurts the quality of life score. Since there is a negative correlation between the caregiver's Age and a higher CQOLC score, it can be interpreted that for every one-year increase, there is a negative correlation between the caregiver's Age and his/her quality of life score, which will decrease by 3.989, while the caregiver's quality of life will increase. In addition, according

to the study (Dogan & Demirel, 2023), in adulthood, everyone begins to ignore their desires or rights and feels that their primary needs or interests are their family. As a result, more people work as caregivers at this Age. In addition, adult caregivers are considered to have sufficient life experience, are rational, able to control emotions, and are more tolerant of others.

Types of quality-of-life measurement instruments for family caregivers of cancer patients have been developed to evaluate various dimensions of quality of life for family caregivers. The instruments in this study were the SF-36, QOLLLTI-F, WHOQOL-BRE FTR, WHO BREF, CQOLC, FACIT-SP -12, HRQOL12 ITEM SF-36, CARER QOL. Each instrument has advantages and disadvantages, so the selection of instruments must be adjusted to the research context and the measurement objectives set by the researcher. On average, in several of these instruments, the aspects discussed are related to social interactions, environmental health, mental health, and bodily health. According to the study, caregivers experience burdens, not only physical ones. Care providers have physical, psychological, social, and financial challenges. Decreased sleep quality, fatigue, and pain are some physical consequences often experienced by family caregivers. Caregivers experience feelings of stress, depression, anxiety, and guilt as a result of caring for family members with cancer. The obligation of family caregivers to pay the high costs of caring for family members with cancer is a social burden for them. In addition, according to (Rezaei et al., 2024). Family caregivers of patients who show indications for palliative care experience significant psychological stress due to symptoms of depression and anxiety; this indicates that psychological support is vital not only for patients but also for their family caregivers. The family is part of the patient, so health workers must consider both needs. The family has several needs that need to be identified, including the need for understanding, involvement, support, intimacy, and knowledge regarding the patient's treatment. Therefore, to support the welfare of the patient and family, health workers play a critical role in identifying and supporting the fulfillment of these varied needs (Nysaeter et al., 2024).

The review findings showed that the majority of physical health and the quality of life of family caregivers decreased, with the criteria for the family caregiver being the patient's partner (husband or wife) (87.5%), which is in line with research (Bayafers et al., 2024). Which states that the majority of family caregivers are couples. Married couples must fulfill their three primary needs, namely psychological needs, sexual needs, and material needs, so that couples feel responsible

for caring for patients with cancer. Couples believe that providing care to patients is a primary value that is a cultural and religious value and strength. Couples know the patient's symptoms and participate in daily care, including physical, social, psychological, autonomous, spiritual, and economic problems. In addition, according to research (Yuliani et al., 2023) Almost all family caregivers live with the patient because cancer requires long-term care. When patients receive most of their care at home, most ongoing care responsibilities fall on the primary caregiver, family members (spouse, parents, children, or close relatives). According to (Y. Lin et al., 2020) Good relationships with family or family resilience and family support are significant in improving the Quality of Life (QOL) of Family caregivers of cancer patients, especially when patients receive most of their care at home. The nature of family members can influence the family's resilience as perceived by other family members, making this finding very important to assess family resilience and related factors in caring for cancer patients more efficiently (Cui et al., 2023).

The review results obtained from most articles on the level of quality of life of family caregivers showed that physical health results were very low. This aligns with research (Shin & Kim, 2022) that states that physical health or physical condition is essential to mental health. Over time, family caregivers can make adjustments to daily activities. Family caregivers can achieve self-acceptance, independence, and personal growth in good physical condition. Family caregivers face many challenges, but must be positive about themselves and their environment, and continue to live their lives by overcoming difficulties. In addition, family caregivers must also have independence in making decisions, such as determining what type of service should be given to cancer patients. For this reason, nurses must support family caregivers to ease their burden and improve their quality of life. In line with research (Shin & Kim, 2022), patients and their families may be impacted by cancer and its treatment. Praya Regional Hospital's description of the stress experienced by family caregivers of cancer patients reveals that family caregivers more frequently experience stress. Anxiety about losing a loved one, problems with the cost of care, and lack of rest are some sources of stress for family caregivers. This stress does not go away only when the patient is diagnosed with cancer but continues for years. In addition, family caregivers experience fatigue as a physical burden. The physical burden felt by family caregivers is fatigue. Providing treatment and meeting the client's basic daily needs, such as eating, drinking, and bathing, is part of family caregiver fatigue.

Table 1. Results of findings and extraction of selected articles according to inclusion criteria (n=8)

Writer	Year	Country	Objective	Age Range	Method	Sample	Research result	Conclusion
Mina Rostami, et.al	2023	Iran	Looking at significant predictors of Quality of Life along with the domain levels of Quality of Life of Family caregivers	Average 40.77 years	Cross-sectional.	300 <i>Family caregiver</i> (P=167 L=133)	Treatment methods most commonly used were chemotherapy (151, 50.3%) and chemotherapy plus radiation therapy (74, 24.7%). Physical function (74.88) ± 20.27 and bodily pain (76.50±16.67) were the two SF-36 domains with the highest scores.	Low QoL domains in cancer patient caregivers, namely emotional role, overall vigor, and health, had the lowest mean values—substantial variations in QoL domains between groups with patients' and their caregivers' fundamental and clinical traits. There are numerous essential predictors for QoL domains.
Edith Arredondo Holgin et al.	2021	Colombia	Explains quality of life and associated variables in a sample of Colombian nurses providing palliative care for cancer patients.	Average 49.72 years	Correlational descriptive and cross-sectional	208 <i>Family caregiver</i> (P=137 L=71)	Scores for quality of life ranged from 116.36 to 122.35 (95%CI). Patient Condition (2.4–3.2, 95%CI), Caregiver Condition (36.2–39.9, 95%CI), and Environment (14.4–15.7, 95%CI) were the dimensions with the lowest ratings.	Interventions to enhance the quality of life for nurses caring for patients with advanced cancer who are in the palliative stage must be developed. Examining how age affects caregivers' quality of life is crucial.
unny Nesteren, et.al	2021	Türkiye	To ascertain the burden and quality of life experienced by primary family caregivers of patients with advanced cancer undergoing inpatient palliative treatment.	Average 46.75 years	Prospective	200 <i>Family caregiver</i> (P=130 L=70)	Physical health had a standard deviation (SD) of 12.67, psychological status 59.21 (SD = 14.09), social interactions 56.83 (SD = 20.91), and the environmental domain 55.67 (SD = 14.13).	Caregivers of patients with advanced cancer experienced impairments in all quality-of-life subscales, with physical health being the most noticeable.
Seema Mishra et al.	2021	India	Assessing the stress and standard of living of family members who are caring for cancer patients	Average 38.98 years	Prospective observational	178 <i>Family care giver</i>	WHO BREF QOL assessment, scoreThe average general health score was 5.79 ± 1.84, The	70.22% of caregivers reported having a light to moderate burden, while 21.38% reported having a significant

Writer	Year	Country	Objective	Age Range	Method	Sample	Research result	Conclusion
			receiving chemotherapy in high dependency units or intensive care units.			(P=92 L=86)	scores for social relationships were 59.38 ± 21.43 , the environment was 58.73 ± 17.51 , psychological health was 51.85 ± 20.43 , and physical health was 49.65 ± 16.07 .	burden.
Ajay kumar condition and ambedkar yadala	2021	India	Recognizing the quality of life (QOL) disorders that arise from the responsibility of providing care maintenance.	>18 years	hospital-based cross-sectional	210 <i>Family care giver</i> (L=110 P=100)	54.42 ± 19.7 was the summative mean CQOLC score. FCs from below-poverty line (BPL) homes ($p=0.035$) and those residing in rural regions ($p=0.27$) had statistically significantly higher scores, indicating a lower quality of life.	The quality of life (QOL) of family caregivers from low-income and rural locations is poor.
Ingebrigt Roen et al.	2021	Norwegia	Investigating traits of patients and carers linked to spiritual quality of life in those who look for patients with advanced cancer.	Average 62.5 years	Prospective	84 <i>Family care giver</i> (P=52 L=32)	the average spiritual quality of life score was 23.3. ($R^2 = 0.34$) and showed a significant relationship to social support	Spiritual quality of life tends to be lower in caregivers with low levels of education and low social support, no children living at home, and also for caregivers of younger patients
Juana Perpina-Galvan, et al	2019	Spanyol	To know the level of burden borne by primary family caregivers, to identify the variables that influence prediction of the burden on family caregivers	Average 61.5 years	cross-sectional descriptive.	77 <i>Family care giver</i> (P=51 L=26)	Particularly noteworthy are the prevalence of excessive burden (41.6%), a high mean fatigue score of 23.0 (SD=8.5), and anxiety as a clinical concern (48.1%).	Characteristics of the palliative care patient nurse population, Considering the connection among PTG, weariness, melancholy, worry, and burden in this population. Anxiety and Depression is the variable that most predicts the level of burden on caregivers of patients undergoing palliative care.

Writer	Year	Country	Objective	Age Range	Method	Sample	Research result	Conclusion
Marloes E. Clarijs et al	2022	Belanda	Assessing the quality of life associated with care for patients with breast cancer, determining its possible predictors, and weighing its relationship to the patient's health-related quality of life (HRQoL).	Average 60.5 years	cross-sectional evaluation	112 <i>Family care giver</i> (P= 18, M=94)	8.0/10 was the average VAS Carer-QoL score, while 92.4/100 was the average CarerQoL utility score. There was a weak correlation between the EORTC QLQ-C30 score and the patients' EQ-5D-5L utility score (0.301, P=0.002) and EQ-VAS score (0.251, P=0.009), as well as between the CarerQol VAS score and the utility score (0.236, P=0.015) and the utility score (0.339, P<0.001).	There is a positive relationship between patient quality of life. Lower CarerQoL scores were found in caregivers of patients 6 months after surgery who received chemotherapy. This study focuses on the importance of including family caregivers in breast cancer patients.

The treatment chosen sometimes has to travel quite a distance and a long time outside the area of residence (Rezaei et al., 2024). Family

caregivers also tend to have more significant psychosocial stress (Kassir et al., 2021).

Table 2. Respondent Characteristics

Characteristic	Category	Number of cases	Frequency
Instrument	SF.-36,	1	12.5%
	QOLLLTI-F	1	12.5%
	WHOQOL-BRE FTR,	2	25%
	CQOLC	1	12.5%
	FACIT-SP -12	1	12.5%
	HRQOL12 ITEM SF-36	1	12.5%
	CARER QOL	1	12.5%
Family caregiver	Child	1	12.5%
	Couple (husband or wife)	7	87.5%
Age	>18 years	1	12.5%
	Average 39 - 50 years (Adult)	4	50%
	Average 60.5-62.5 Years (Seniors)	3	37.5%
Gender	Woman	713	52%
	Man	656	48%
Continent	Europe	4	50%
Location	Asia	3	37.5%
	American	1	12.5%

4. Conclusions and Suggestions

The assessment of the quality of life score of family caregivers of cancer patients concluded that the characteristics of family caregivers, such as gender and Age, can affect the quality of life of family caregivers. Family caregivers' most influential quality of life is the caregiver's physical quality. And assess the quality of life of family caregivers using various instruments, according to the results that researchers want. Future research is recommended to use standardized, multidimensional quality-of-life assessment instruments, including quality-of-life domain charts and culturally sensitive assessments. This approach is expected to provide a basis for designing and evaluating interventions that focus on family caregivers to simultaneously improve the quality of life of both caregivers and patients.

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