

Research Article

Incidence of Anxiety and Depression and Its Related Factors in Family Caregivers of Cancer Patients

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Abstract

Cancer patients' family caregivers are critical in supporting and caring, particularly in developing countries with limited resources. However, little is known about the incidence of anxiety and depression among cancer patients' caregivers in Indonesia. This study aimed to identify the incidence of anxiety and depression and explore the related factors among cancer patients' family caregivers at Soehadi Prijonegoro Public Hospital Indonesia. A cross-sectional study was conducted from November 2022 to January 2023, involving 85 caregivers. The Hamilton Anxiety and Depression Rating Scale were used to assess anxiety and depression levels, respectively. The study revealed high anxiety (3.5%) and mild to moderate anxiety levels (89.4%) among family caregivers. Additionally, approximately half of the caregivers (45.9%) experienced depression, with mild depression being the most common (35.3%). Significant correlations were found between anxiety and age ($p=0.007$), length of patient's sick time ($p=0.010$), and family care time ($p=0.009$). Age was negatively correlated with anxiety and depression. Moreover, the caregiver who lived with the patient correlated with anxiety ($p=0.005$) and depression ($p=0.016$). This study highlights the significant burden of anxiety and depression among cancer patient caregivers. Healthcare professionals should consider the identified factors when developing tailored interventions.

Keywords: anxiety, cancer, depression, family caregivers, mental health.

Insidensi Kecemasan dan Depresi serta Faktor-faktor Terkait pada Pengasuh Keluarga Pasien Kanker

Abstrak

Pengasuh keluarga pasien kanker memiliki peran penting dalam memberikan dukungan dan perawatan, terutama di negara-negara berkembang dengan sumber daya terbatas. Namun, masih sedikit yang diketahui tentang insidensi kecemasan dan depresi di kalangan pengasuh keluarga pasien kanker di Indonesia. Penelitian ini bertujuan mengidentifikasi insidensi kecemasan dan depresi serta menjelajahi faktor-faktor terkaitnya di antara pengasuh keluarga pasien kanker di Rumah Sakit Umum Soehadi Prijonegoro Indonesia. Studi potong lintang dilakukan dari bulan November 2022 hingga Januari 2023, melibatkan 85 pengasuh. Skala Penilaian Kecemasan dan Depresi Hamilton digunakan untuk menilai tingkat kecemasan dan depresi. Studi ini mengungkapkan insidensi tingkat kecemasan yang tinggi (3,5%) dan tingkat kecemasan sedang hingga ringan (89,4%) di kalangan pengasuh keluarga. Selain itu, sekitar setengah dari pengasuh (45,9%) mengalami depresi, dengan depresi ringan menjadi yang paling umum (35,3%). Korelasi signifikan ditemukan antara kecemasan dengan usia ($p=0,007$), lama sakit pasien ($p=0,010$), dan waktu perawatan keluarga ($p=0,009$). Usia berkorelasi negatif dengan kecemasan dan depresi. Selain itu, pengasuh yang tinggal bersama pasien dikaitkan dengan tingkat kecemasan ($p=0,005$) dan depresi ($p=0,016$). Penelitian ini menyoroti beban signifikan kecemasan dan depresi di kalangan pengasuh pasien kanker di Indonesia. Para profesional kesehatan perlu mempertimbangkan faktor-faktor yang teridentifikasi tersebut ketika mengembangkan intervensi yang disesuaikan.

Kata kunci: kecemasan, kanker, depresi, pengasuh keluarga, kesehatan mental.

Introduction

As the leading cause of morbidity and mortality worldwide, cancers reached 19.3 million new cases and almost 10 million deaths in 2020, or nearly one in six deaths.^{1,2} Of these, 1.8% (348,000) of new cancer cases and 2% (200,000) of cancer deaths occurred in Indonesia.³ In developing countries, most new cancer cases are frequently diagnosed at an advanced stage. Also, treatment options are limited and expensive.⁴ With an increase in cancer cases, there has been a concurrent rise in the need for family members to take care of their family members, what is known as a family caregiver, which refers to spouses, children, parents, or other relatives thrust into the role providing support to the patients.⁵ This disease is chronic and requires lengthy treatment. Family caregivers need to support all the patient aspects of life; thus, caregivers and patients presented similar mental health conditions, especially depression, and the symptoms worsened with time.⁶ According to Geng et al,⁷ a considerably high incidence of depression and anxiety is found in cancer patient caregivers. Several factors may affect depression and their quality of life.⁷ Anxiety can lead to physical health issues like sleep problems, heightened risk of cardiovascular conditions, weakened immune system, and increased mortality rates in caregivers.⁸ The global incidence of anxiety in 2013 was 7.3%, meaning 1 in 14 individuals may experience an anxiety disorder, and 1 in 9 individuals will experience an anxiety disorder each year. According to the World Health Organization (WHO), it is estimated that 323 million people worldwide experience depression, with the highest number in the Southeast Asia region. In Indonesia, approximately 6% of the population aged 15 years and above, around 14 million people, experience emotional and mental disorders manifested as anxiety and depression.^{8,9} The Basic Health Research on adults in Indonesia shows an increase in emotional disorders, with an incidence of 6% in 2013 and 9.8% in 2018. It is estimated that there are 19 million people with mental disorders in Indonesia, and approximately 11.6%, or around 2.2 million out of 19 million individuals with mental disorders, suffer from anxiety disorders or depression.^{10,11} In 2018, it was found that the incidence of depression in Sragen Regency is 3.77%, whereas the average incidence in Central Java is higher at 4.40%. The highest occurrence of depression was observed among the elderly population, women, and individuals residing in

urban areas. In terms of emotional and mental disorders, the incidence in Sragen Regency was documented at 7.37%, closely reflecting the average rate of 7.71% in Central Java.¹²

Cancer is a stressor that can heighten anxiety levels in patients and caregivers due to its status as one of the leading causes of death globally, with a growing number of cases each year. Anxiety disorders occur in approximately 7-30% of oncology patients and 20-40% of oncology caregivers. Based on these findings, it can be inferred that caregivers experience higher anxiety levels than patients. However, no definitive data is currently available in Indonesia regarding the incidence of anxiety disorders among cancer patients' caregivers.⁸ Furthermore, no study shows the incidence of anxiety and depression and related factors in cancer family caregivers at Soehadi Prionegoro Regional Public Hospital (RSSP).¹³ As one of the secondary referral hospitals, RSSP plays an essential role in managing cancer patients in Central Java, especially in the Sragen region. It also provides access to Indonesian Health Insurance, ensuring that cancer patients with lower incomes are referred to RSSP.¹⁴ This study aimed to know the incidence of anxiety and depression and related factors in cancer patient caregivers at the hospital to screen their mental health and give proper management for them to improve their quality of life.

Methods

This cross-sectional study was conducted from November 2022 to January 2023 among family caregivers of cancer patients at Soehadi Prijonegoro Regional Public Hospital in Sragen, Indonesia. The estimated sample size was determined using the rule of thumb formula based on the recommended minimum sample size. We used the rule of thumb in our sample size for practical and feasibility reasons, considering the study's exploratory nature, the availability of participants, and resource constraints. Thus, a total of 85 respondents were required. The inclusion criteria for respondents, the family members of cancer patients, are over 18 years old and can read and write. Respondents were required to provide informed consent, complete the questionnaire, and participate in the study voluntarily. Caregivers diagnosed or treated with mental disorders were excluded.

Respondents were selected using a quota/consecutive sampling technique. The study instruments included the Indonesian translation of the Hamilton Depression Rating Scale (HAM-D

or HDRS) and Hamilton Anxiety Rating Scale (HAM-A). The questionnaire comprised a personal data section and two other sections: HAM-A and HAM-D. The HAM-D, consisting of 17 items, is a widely used instrument for evaluating symptoms of depression, and it has been employed in numerous significant studies related to depression and its treatment. On the other hand, the HAM-A is a psychological questionnaire consisting of 14 items, which clinicians use to assess the severity of a patient's anxiety.

Data analysis involved univariate analysis for all variables, presenting categorical and numerical data. Bivariate analysis was performed using the Spearman and chi-square test, and variables with a p-value < 0.25 were selected for multivariate analysis. Statistical analysis was conducted using Statistical Package for the Social Sciences software (SPSS) version 25 by the International Business Machines Corporation (IBM). Ethical approval was obtained from the Ethics Committee of the Soehadi Prijonegoro Regional Public Hospital, and the study was conducted with voluntary participation and confidentiality of the respondents' data (Ethics Committee approval No: 078/Etik-Crssp/XI/2022).

Results

This study obtained 85 participants aged between 20 to 77 years old. Most were male (65.9%), while 34.1% were female. The majority worked as employees (44.7%), and only a few were students (5.9%). High school education has the highest number (40%). Half the caregivers were the patients' spouses (51.8%), and nearly all lived together (88.2%). Both patients' sick time (82.4%) and caregivers' time (83.5%) for accompanying patients were above three months mostly. Breast cancer (64.7%) was the highest number of cancer patients in this population (Table 1).

In the assessment of the Hamilton rating scale, anxiety and depression, we found that most family caregivers have mild to moderate anxiety (89.4%) and moderate to severe (3.5%), as shown in Figure 1. While for depression, almost half of them don't have depression symptoms (54.1%), but those who have depressive symptoms showed mild (35.3%), moderate (8.2%), and severe (2.4%) depression (Figure 2).

Table 1. Characteristics of the Family Caregivers of Cancer Patients

Characteristics	Frequency	%
Age		
Young adult (20-39)	41	48.2
Middle adult (40-64)	41	48.2
Elderly (>64)	3	3.5
Gender		
Male	56	65.9
Female	29	34.1
Job		
Labor	25	29.4
Homemaker	17	20
Employee	38	44.7
Student	5	5.9
Education		
Elementary	19	22.4
Middle school	27	31.8
High school	34	40
Bachelor/diploma	5	5.9
Family caregiver status		
Child	31	36.5
Parent	5	5.9
Spouse	44	51.8
Sibling	5	5.9
Living together		
Yes	75	88.2
No	10	11.8
Patient sick time		
≤ 3 months	15	17.6
>3 months	70	82.4
Caregiver time		
≤ 3 months	14	16.5
>3 months	71	83.5
Type of cancer		
Thyroid	16	18.8
Salivary gland	3	3.6
Breast	55	64.7
Melanoma	1	1.2
Nasopharynx	7	8.2
Oral	3	3.6

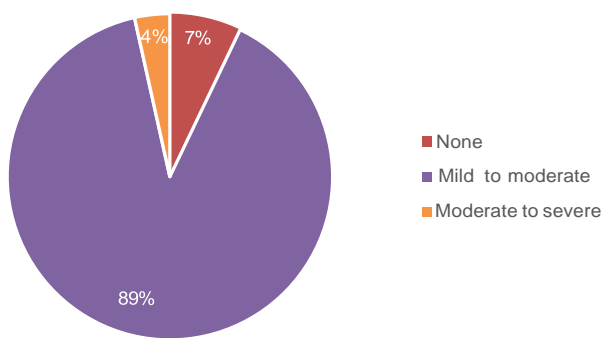


Figure 1. The Proportion of Anxiety in Family Caregivers

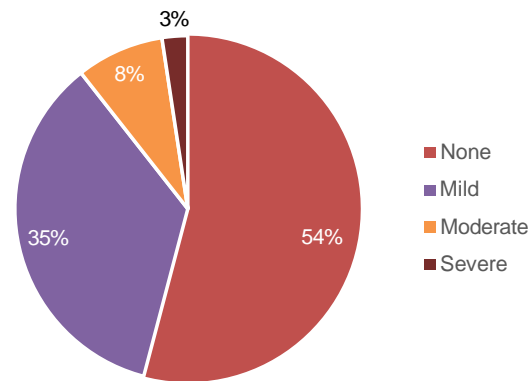


Figure 2. The Proportion of Depression in Family Caregivers

In numeric variables, we compare the mean of the characteristic variable with the score of anxiety and depression. We found that there's a significant correlation between age ($p=0.007$), the length of the

patient's sick time ($p=0.010$), and family care time ($p=0.009$), with the rate of anxiety in family caregivers (Table 2). Also, a significant correlation was found between age and the rate of depression ($p=0.011$).

Table 2. Correlation of the Family Caregivers' Numerical Characteristics with Depression and Anxiety

Characteristics	Anxiety		Depression	
	P value	Correlation coefficient	P value	Correlation coefficient
Age	0.007	-0.290**	0.011	-0.274**
Patient sick time	0.010	0.277*	0.740	0.037
Caregiver time	0.009	0.281*	0.423	0.088

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

Notably, patient sick time and caregiving time were in the positive correlation coefficient. Thus, the longer the duration of the patient sick time and family care time, the more likely the anxiety appears and worsen. Age has a negative correlation, which means the older the family caregiver age has, the less anxiety the caregiver has.

We also analyze the characteristics of the nominal variables related to anxiety and depression (Table 3). There's a significant relationship between anxiety ($p=0.005$) and

depression ($p=0.016$) with family caregivers living with the patient, with both positive correlations. Before, we considered the high value of those living with the patients in data input; thus, the caregiver who lives with patients has a higher chance of anxiety and depression development. The level of education also has a significant correlation with depression ($p=0.001$) with a positive correlation, meaning the higher education the caregiver has, the more related to depression, while anxiety was found not related.

Table 3. Correlation of the Family Caregivers' Ordinal Characteristics with Depression and Anxiety

Characteristics	Anxiety		Depression	
	P value	Correlation coefficient	P value	Correlation coefficient
Gender	0.104	-0.152	0.750	0.035
Job	0.469	-0.080	0.888	-0.016
Education	0.322	0.109	0.001	0.340**
Living together	0.005	0.301**	0.016	0.262*

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

Discussion

Globally, approximately 10 million cancer patients died in 2020, and caregivers play a crucial role in reducing mortality rates and providing palliative care.¹⁵ In the United States, most caregivers are female (58%), and most caregivers for cancer patients are family members (88%), with around 60% being non-family caregivers.¹⁶ In our study, most family caregivers are male (65.9%) because the majority of cancer in this hospital are female with breast cancer (64.7%).

Based on a national survey carried out in the United States, it was found that the primary caregivers for patients are typically family members. Specifically, around 40% are spouses, 40% are adult children, and the remaining 20% fall into the broader category of "others," which includes individuals such as friends, neighbors, or grandchildren. We also found that most family caregivers are the patient's spouse (51.8%). These caregivers offer support in various areas, ranging from functional tasks associated with daily activities to psychological, social, and economic assistance.^{17,18}

A global epidemiological study using systematic review and meta-analysis indicated that 42.3% of caregivers experience depression and 46.55% experience anxiety.¹⁵ A study conducted at the Oncology Clinic of Dr. Saiful Anwar Regional General Hospital (RSSA) in Malang, East Java, found that 36% of caregivers experienced anxiety and 8% experienced depression.¹⁹

Almost all our subjects have anxiety (93%), with most of them in mild to moderate severity (89%), while half of our subjects have depression (51%) and 3% in severe depression. Insufficient social support, ineffective family communication, conflicts, and religious beliefs within the family contribute to stress among caregivers.¹⁷ The emotional burden caregivers face is a matter of concern, as it can harm the caregivers themselves and the patients they care for. When caregivers experience high levels of anxiety, it can exacerbate the patient's anxiety, and additionally, it may hinder their ability to provide optimal care and support for the patients.²⁰

Caregivers are particularly susceptible to mental health issues as they often neglect their feelings and fail to address their personal needs and emotions. Moreover, when caring for patients in the terminal stage, caregivers face additional physical and psychological burdens. Studies have found that family caregivers experience anxiety

in 46% of cases and depression in 39% within a year before the cancer patient's death.²¹ The risk of anxiety and depression can be further exacerbated by family problems, the duration of the cancer illness, and financial difficulties.²²

The emotional pressure experienced by caregivers varies across different phases of the patient's illness. These phases include prediagnosis, diagnosis, treatment, survival, recurrence, and end of life. Caregivers play an important role in supporting the patient but may face challenges managing their emotional well-being. For instance, during the prediagnosis phase, caregivers gather information about the disease and plan strategies to prevent its recurrence. Anxiety may arise after genetic testing. In the diagnosis phase, caregivers help patients navigate the emotional challenges of understanding their condition and determining the next steps. The treatment phase can be particularly demanding for caregivers as they worry about treatment effectiveness and potential side effects. Monitoring the patient's condition becomes their responsibility. The survival phase brings a sense of relief and improved emotional well-being, although some caregivers may still worry about cancer recurrence. In the recurrence phase, different reactions can be observed among patients and caregivers, ranging from reduced anxiety due to prior knowledge to despair and decreased life expectancy. Finally, in the end-of-life phase, caregivers may experience clinical symptoms of depression influenced by strained family relationships, feelings of abandonment, and financial stressors.²⁰

Our study shows that the younger age of family caregivers was significantly related to lower anxiety ($p=0.007$) and depression ($p=0.011$) severity. A study by Price et al²³ found that being younger was associated with higher anxiety levels among caregivers but not with depression. Interestingly, the findings also indicated that individuals caring for a patient who was their child reported lower levels of depression than those caring for a partner.²³

Nearly all of the family caregivers in our study lived together with patients (88.2%), and it showed a significant relationship with both anxiety ($p=0.005$) and depression ($p=0.016$). Cancer requires long-term care. When patients receive most of their treatment at home, most of the responsibility for ongoing care falls on the primary caregiver, usually a family member. The family's role becomes crucial in providing care for the patient. Primary caregivers, often spouses, parents, children, or close relatives,

care for and serve the patient. Their responsibilities include staying close to the patient, preparing meals, administering medication, shopping, assisting with daily activities, running errands, making decisions, assisting with home medical care, and providing social-emotional support.²⁴

Caring for a cancer patient over an extended period is a challenging task. It can evoke feelings of fear of losing the person being cared for, anxiety about the future of the patient and one's future, and concerns for the family members dependent on them. Some caregivers may even experience depression or a sense of hopelessness regarding the future.²⁵

Caregivers' tasks are difficult, and many must spend more than 12 hours with the cancer patient. The burden on family caregivers becomes even heavier when caring for hospitalized cancer patients, as in Indonesia, where patients are accompanied by family members almost 24 hours a day, impacting the caregivers' daily activities. Long durations of caring for cancer patients can have financial and psychological implications for family caregivers due to the lack of support from the surrounding environment.²⁶ Long-term caregiving can have physical and emotional consequences for caregivers. Research suggests that nearly all caregivers experience challenges in adapting to the demands of caring for cancer patients, leading to heightened levels of anxiety and depression among caregivers.²⁷ In line with this study, family caregiving time and patient sick time, nearly >80%, are above three months and significantly correlated with anxiety.

The duration of caregiving for cancer patients can influence the level of anxiety experienced. Providing care for patients in the terminal stage of illness can intensify psychological stress and reduce the overall quality of life, leading to various life burdens such as fatigue, frustration with the caregiving situation, feelings of helplessness, and a sense of despair towards the prolonged caregiving process, all contributing to heightened anxiety levels.²⁸ Correspondingly, a study conducted in Vietnam highlights that as the duration of caring for a cancer patient increases, so does the likelihood of experiencing elevated levels of anxiety and depression, manifesting in symptoms like sleep difficulties, elevated blood pressure, and increased heart rate.²⁹ Individuals who care for cancer patients in advanced stages may dedicate 11-20 hours per day to caregiving, resulting in limited time for other activities, which can further contribute to

heightened susceptibility to anxiety.³⁰

Patients who need prolonged cancer treatment undergo multiple treatments, such as radiation and chemotherapy. As a result, these patients require increased support and assistance from caregivers. Caregivers play a crucial role in fulfilling the daily living needs of cancer patients, including tasks related to food, transportation, personal care, and providing social support.³¹

Limitations of this study include the study's sample size was relatively small, and it was conducted in a single hospital, limiting the generalizability of the findings to other settings and populations. Moreover, excluding caregivers diagnosed or treated with mental disorders might have impacted the sample's representativeness and introduced selection bias. Future research should consider a more diverse range of caregiving settings to understand better the dynamics and complexities of caregivers' mental health in cancer care.

Conclusion

Most family caregivers in the study had mild to moderate anxiety, while nearly half of them showed symptoms of depression. The duration of the patient's illness and the length of time the caregivers spent providing care were positively correlated with anxiety levels. On the other hand, age had a negative correlation with anxiety, indicating that older caregivers experienced lower anxiety levels. Furthermore, caregivers living with the patients were more likely to experience anxiety and depression. These findings highlight the emotional burden faced by family caregivers of cancer patients and the need for support and intervention to address their mental health. Caregivers play a vital role in the well-being of cancer patients, and their well-being should not be overlooked.

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