

# Psychological Distress, Uncertainty Intolerance, and Quality of Life of Patients with Cancer and Their Caregivers: A Comparative Study

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## ABSTRACT

**Background:** Psychological distress and uncertainty intolerance in cancer patients are linked to various physical consequences and negative psychological impacts, such as increased symptom severity, disruption in daily life, and reduced quality of life (QoL). These issues also affect family caregivers of cancer patients. This study aims to describe the psychological distress, uncertainty intolerance, and quality of life in cancer patients and their family caregivers.

**Method:** This was a cross-sectional study with 57 cancer patients and 57 caregivers at Dr. Sardjito Hospital, Yogyakarta-Indonesia, in July to August 2023. Psychological distress was measured by using the Kessler Scale (K-10), uncertainty using the Intolerance Uncertainty Scale (IUS-12), and quality of life using the EORTC QLQ-C30 and SF-36. Data were analyzed using Mann-Whitney and Kruskal-Wallis tests.

**Results:** Psychological distress did not show a significant difference ( $p = 0.148$ ). However, significant differences were found in uncertainty intolerance between patients and caregivers ( $p = 0.001$ ) and caregivers' marital status ( $p = 0.045$ ). Quality of life varied among patients based on age, gender, marital status, cancer type, and treatment ( $p < 0.05$ ). Caregivers' quality of life differed by age in physical and emotional roles ( $p \leq 0.005$ ).

**Conclusion:** There is a significant difference between the intolerance uncertainty of cancer patients and family caregivers. Meanwhile, the quality of life of cancer patients and the quality of life of family caregivers have differences in each scale and domain in several of their demographic characteristics. Although no significant differences were found in psychological distress, longitudinal studies are needed to understand the trajectory of psychological distress and uncertainty intolerance over time.

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## INTRODUCTION

Cancer constitutes a significant public health challenge in Indonesia. It is widely recognized as a life-threatening illness with the potential to contribute substantially to the global oncological burden, alongside associated physical, psychological, and social adversities [1]. According to the Indonesian Ministry of Health,

cancer ranks as the third most common cause of mortality following cardiovascular diseases and cerebrovascular accidents. The national cancer prevalence rate stands at 51.5%, with an incidence rate reported at 136.2 per 100,000 individuals, where the province of Yogyakarta has the highest recorded prevalence of cancer within the country for the year 2021, with a total of 5,068 cases documented [2].

Individuals diagnosed with cancer experience elevated levels of psychological distress from the initial diagnosis onward. This distress is attributed to the fear and uncertainty surrounding the disease and its treatment modalities. Consequently, it is a common occurrence for both cancer patients and their family caregivers to seek clarity regarding their medical condition [3]. Illness uncertainty is characterized as the incapacity of an individual to comprehend the implications of disease-related events [4]. This uncertainty is palpable among cancer patients from the moment of diagnosis, through the commencement of novel treatments, during care transitions involving encounters with unfamiliar, intricate, and daunting experiences, and persists amidst concerns about long-term survival, potentially intensifying with the progression of the cancer [5].

The phenomenon of Intolerance of Uncertainty (IU) may be incited by a lack of adequate medical information [6], a deficient grasp of available treatment alternatives, or the standard progression of the illness, coupled with challenges in managing everyday life, all of which are compounded by perceived uncertainties [7]. Uncertainty among cancer survivors is associated with a spectrum of physical repercussions and exerts a detrimental psychological influence, manifesting as increased symptom severity, disruption of daily activities, pervasive fear, emotional turmoil, a diminished sense of control, and a consequent reduction in quality of life (QoL) [8].

A recent study suggests that intolerance of uncertainty can influence depression, anxiety, and the well-being of family caregivers, as evidenced by insomnia symptoms when caring for cancer patients [9]. Another study highlighted that during uncertain times, like the COVID-19 pandemic, healthcare professionals should assess cancer patients and survivors for emotional and instrumental support needs, identifying those with high intolerance of uncertainty as at risk for psychological distress [10]. Similarly, Vander and Etienne [11] discovered that a majority of parent groups experienced clinical psychological distress, with 64% reporting significant intolerance of uncertainty, akin to a generalized anxiety disorder.

Comprehending psychological distress and intolerance of uncertainty can aid in coping strategies and enhance the quality of life for both cancer patients and their family caregivers [10]. A high intolerance of uncertainty can alter the cognitive evaluation of anxiety and depression, which are related to changes in quality of life and end-of-life issues for both cancer patients and family caregivers [12]. Thus, the three measures of psychological distress, intolerance of uncertainty, and quality of life are interconnected when comparing these two groups. Although numerous studies have examined psychological distress and quality of life among cancer patients and family caregivers, research utilizing intolerance of uncertainty measures in Indonesian clinical

samples remains scarce. This gap was noted in the limitations of recent study, which calls for further research, particularly in clinical settings [13]. This study aimed to assess psychological distress, intolerance of uncertainty, and quality of life in cancer patients and family caregivers, providing insights for healthcare professionals to identify these factors as crucial for effective intervention strategies.

## METHODS

This research was a quantitative, cross-sectional study. The study took place across five wards at the Central Public Hospital in Yogyakarta from July 12 to August 30, 2023. It involved 57 cancer patients and 57 family caregivers, totalling 114 participants. Consecutive sampling was employed. The inclusion criteria for cancer patients were: undergoing chemotherapy, radiotherapy, or both, diagnosed with cervical, breast, ovarian, leukaemia, or lung cancer—these being the most common cancers at Dr. Sardjito Yogyakarta Hospital, aged 18 or older, and hospitalized for a minimum of two days. For family caregivers, the criteria included: extended family members such as spouses (wives or husbands), children (sons or daughters), parents, siblings, in-laws, or other relatives (e.g., grandparents, aunts, uncles) who are responsible for caring for the patient during hospitalization for at least two days or responsible for home care, aged 18 or older, and capable of communication. Exclusion criteria for patients encompassed those in emergency conditions unable to complete the questionnaire, with speech limitations that could lead to misinterpretation in sign language use, or uncooperative due to unstable emotions and communication difficulties. Family caregivers were excluded if they had hearing or speech impairments that could lead to misinterpretation in sign language use.

The variables collected in this study included demographic characteristics (age, gender, marital status, educational level, income, and cancer types), psychological distress, intolerance uncertainty, and quality of life in both cancer patients and caregivers. The independent variable was demographic characteristics, while psychological distress, intolerance uncertainty, and quality of life were dependent variables.

The Kessler Psychological Distress Scale (K10) of the Indonesian version, validated by Fananni [14], was used and utilized for cancer patients and family caregivers. The K10 questionnaire consisted of 10 questionnaire items, consisting of depression aspects in 4 question items and anxiety aspects in 6 question items. This questionnaire uses a 5-point Likert scale ranging from 1 (does not happen to me at all) to 5 (always happens to me). It demonstrated a Cronbach's Alpha of 0.868, categorizing mental disorder severity as mild (10–23), moderate (23–36), and severe (37–50).

The Intolerance of Uncertainty Scale-12 (IUS-12) was also employed, translated, and validated in Indonesian by Istiqomah et al. [13], with a Cronbach's Alpha of 0.867 and a median score indicating low intolerance of uncertainty ( $< 38$ ) and high intolerance ( $\geq 38$ ). The IUS-12 items use a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The IUS-12 items are arranged based on two dimensions, namely prospective anxiety (consisting of 7 question items), which focuses more on the cognitive domain, and inhibitory anxiety (consisting of 5 question items), which focuses more on the behavioral domain.

The quality of life for cancer patients was assessed using the EORTC QLQ-C30, translated and validated by Perwitasari et al. [15], showing internal consistency  $> 0.70$  and a correlation coefficient  $> 0.4$ , with scores ranging from 0 to 100. The questionnaire consisted of 30 items with 3 scales: general health scale (2 items), functional scale (15 items), and symptom scale (13 items). The general health scale consists of 2 items in questions 29 and 30.

For family caregivers, the Short Form (SF-36) was used, translated into Indonesian, and validated by Perwitasari et al. [16], with a Cronbach's Alpha between 0.619 and 0.867. This questionnaire consisted of 36 items that represent 8 dimensions of measurement, namely physical function, physical role, pain, general health, vitality, social function, emotional role, and mental health. The SF-36 questionnaire scores between 0 and 100, a score of 0 indicates that the respondent has poor health, while a score of 100 indicates that the respondent has good health.

The study was facilitated by two research assistants and initiated by screening potential participants through medical records. Those meeting the inclusion and exclusion criteria were then approached for consent to participate in the study.

The collected data were analyzed using IBM SPSS statistical software version 26 for Windows (IBM Corporation, Armonk, NY, USA). Descriptive statistics were used to analyze the demographic characteristics of the participants as independent variables. The results of the Kolmogorov-Smirnov normality test indicated a value of  $< 0.05$  for the questionnaire scale, suggesting that the data did not follow a normal distribution. Consequently, for dependent variables, the study employed the Mann-Whitney test for analyses involving two categories and the Kruskal-Wallis test for those with more than two categories, by showing the median and minimum-maximum results, respectively.

## RESULTS

### Sociodemographic characteristics

**Table 1** reveals that a significant portion of the study's participants, 33 respondents (57.9%), were

**Table 1.** Demographic characteristics of patients with cancer and family caregivers

Characteristics	Cancer Patients (n = 57)		Family Caregivers (n = 57)	
	N	%	N	%
Age (Years)				
18–44	33	57.9	30	52.6
$\geq 45$	24	42.1	27	47.4
Gender				
Male	16	28.1	17	29.8
Female	41	71.9	40	70.2
Marital status				
Not married/divorced	13	22.8	11	19.3
Married	44	77.2	46	80.7
Educational level				
Basic education	25	43.9	27	47.4
Secondary education	23	40.4	27	47.4
Higher education	9	15.8	3	5.3
Income				
None	18	31.6	11	19.3
$< 2,300,000$ IDR*	25	43.9	38	66.7
$\geq 2,300,000$ IDR*	14	24.6	8	14.0
Cancer types				
Cervix	9	15.8		
Breasts	19	33.3		
Ovary	7	12.3		
Leukimia	11	19.3		
Lungs	11	19.3		
Therapy types				
Chemotherapy	46	80.7		
Radiotherapy	11	19.3		

\*Yogyakarta City Regional Minimum Wage 2023

aged between 18 and 44 years. A substantial majority, 41 respondents (71.9%), were female, and most were married, accounting for 44 respondents (77.2%). Regarding educational background, less than half, 25 respondents (43.9%), had completed primary education. Similarly, 25 respondents (43.9%) reported incomes below the regional minimum wage. Among the types of cancer represented, breast cancer was present in less than half of the cases, with 19 respondents (33.3%), and the predominant treatment was chemotherapy, received by 46 respondents (80.7%).

In the family caregiver group, the majority also fell into the 18–44 age range, with 30 respondents (52.6%). Females were the primary caregivers, making up 40 respondents (70.2%), and the majority were married, similar to the patient group, with 46 respondents (80.7%).

**Table 2.** Overview of psychological distress and intolerance of uncertainty based on demographic characteristics in patients with cancer and family caregivers

Variable	n	Psychological distress		Intolerance uncertainty	
		Median (Min–Max)	p	Median (Min–Max)	p
Cancer patients					
Age (Years) <sup>a</sup>			0.923		0.663
18–44	33	3.38 (1.72–7.13)		7.75 (5.36–9.13)	
≥ 45	24	3.37 (1.22–10.0)		7.60 (4.84–10.0)	
Gender <sup>a</sup>			0.546		0.110
Male	16	3.16 (1.89–7.13)		7.38 (5.39–8.54)	
Female	41	3.38 (1.22–10.0)		7.70 (4.84–10.0)	
Marital status <sup>a</sup>			0.676		0.690
Not married/divorced	13	3.38 (1.72–10.0)		7.89 (5.36–8.79)	
Married	44	3.38 (1.22–7.13)		7.64 (4.84–10.0)	
Income <sup>b</sup>			0.676		0.360
None	18	3.60 (2.58–10.0)		7.89 (6.70–10.0)	
< 2,300,000 IDR*	25	3.24 (1.22–6.28)		7.65 (4.84–9.27)	
≥ 2,300,000 IDR*	14	3.33 (1.72–7.13)		7.41 (5.36–9.08)	
Education level <sup>b</sup>			0.615		0.932
Basic education	25	3.58 (1.22–10.0)		7.64 (6.11–10.0)	
Secondary education	23	3.24 (1.87–6.28)		7.68 (4.84–9.27)	
Higher education	9	3.37 (1.72–7.13)		7.69 (5.85–9.08)	
Cancer type <sup>b</sup>			0.600		
Cervix	9	3.24 (2.58–4.75)		7.36 (6.44–9.13)	0.119
Breast	19	3.38 (1.22–5.39)		7.89 (4.84–10.0)	
Ovary	7	3.80 (2.59–10.0)		8.33 (7.47–9.27)	
Leukimia	11	3.23 (2.19–4.88)		7.79 (5.39–8.54)	
Lung	11	3.09 (1.89–7.13)		7.08 (5.85–7.99)	
Treatment <sup>a</sup>			0.656		0.066
Chemotherapy	46	3.38 (1.22–10.0)		7.52 (4.84–10.0)	
Radiotherapy	11	3.51 (1.72–4.75)		7.90 (5.36–9.13)	
Family caregiver					
Age (Years) <sup>a</sup>			0.911		0.701
18–44	30	4.03 (1.17–7.70)		4.50 (1.10–9.13)	
≥ 45	27	4.17 (0.00–7.68)		4.25 (0.00–9.21)	
Gender <sup>a</sup>			0.121		0.062
Male	17	3.42 (0.78–7.43)		3.74 (1.10–7.52)	
Female	40	4.39 (0.00–7.70)		4.61 (0.00–9.21)	
Marital status <sup>a</sup>			0.968		0.045*
Not married/divorced	11	4.17 (1.17–7.43)		7.89 (5.36–8.79)	
Married	46	4.09 (0.00–7.70)		7.64 (4.84–10.0)	
Income <sup>b</sup>			0.815		0.654
None	11	4.69 (0.00–7.70)		4.78 (2.40–6.65)	
< 2,300,000 IDR*	38	4.18 (0.77–7.18)		4.24 (0.00–9.21)	
≥ 2,300,000 IDR*	8	3.39 (0.78–7.43)		4.27 (1.10–6.13)	
Education level <sup>b</sup>			0.771		0.297
Basic education	27	4.19 (0.00–7.68)		4.65 (0.00–9.21)	
Secondary education	27	3.54 (0.78–7.70)		4.44 (1.10–7.52)	
Higher education	3	5.40 (2.23–7.18)		3.74 (2.02–3.85)	

<sup>a</sup>Mann-Whitney U Test, <sup>b</sup>Kruskall-Wallis Test, \*p < 0.05

Most caregivers had attained primary or secondary education, totalling 27 respondents (47.4%), and a significant number, 38 respondents (66.7%), had incomes below the regional minimum wage.

Differences in psychological distress, intolerance uncertainty, and quality of life of patients with cancer and family caregivers based on sociodemographic characteristics

As shown in **Table 2**, statistical analysis of psychological distress among cancer patients, with respect to demographic factors, revealed no significant disparities. This was consistent across various categories, including age ( $p = 0.923$ ), gender ( $p = 0.546$ ), marital status ( $p = 0.676$ ), income ( $p = 0.676$ ), education level ( $p = 0.615$ ), cancer type ( $p = 0.600$ ), and therapy type ( $p = 0.656$ ). Similarly, an examination of family caregivers' demographic characteristics indicated no significant differences in psychological distress across age ( $p = 0.911$ ), gender ( $p = 0.121$ ), marital status ( $p = 0.968$ ), income ( $p = 0.815$ ), and education level ( $p = 0.771$ ). Furthermore, the analysis of intolerance to uncertainty in cancer patients showed no significant variation when considering demographic factors such as age ( $p = 0.663$ ), gender ( $p = 0.110$ ), marital status ( $p = 0.690$ ), income ( $p = 0.360$ ), education level ( $p = 0.932$ ), cancer type ( $p = 0.119$ ), and therapy type ( $p = 0.066$ ). However, for family caregivers, a significant difference in intolerance to uncertainty was observed based on marital status, with unmarried caregivers exhibiting a higher mean rank (38.00) compared to their married counterparts (26.85,  $p = 0.045$ ). No significant differences were found in relation to age ( $p = 0.701$ ), gender ( $p = 0.062$ ), income ( $p = 0.654$ ), and education level ( $p = 0.297$ ).

The analysis revealed that quality of life among cancer patients varies significantly in relation to demographic characteristics, with  $p$ -values less than 0.05 indicating statistical significance. Specifically, age was associated with differences in role function ( $p = 0.004$ ), cognitive function ( $p = 0.005$ ), and pain ( $p = 0.011$ ). Gender differences were noted in the experience of pain ( $p = 0.027$ ), while marital status influenced physical function ( $p = 0.047$ ) and appetite loss ( $p = 0.046$ ). Educational level was linked to global health ( $p = 0.048$ ) and cognitive function ( $p = 0.017$ ). The type of cancer impacted physical function ( $p = 0.040$ ) and appetite loss ( $p = 0.013$ ), and the type of therapy affected global health ( $p = 0.023$ ), emotional function ( $p = 0.022$ ), cognitive function ( $p = 0.011$ ), social function ( $p = 0.025$ ), and pain symptoms ( $p = 0.004$ ). Income status, however, did not show significant differences in any QoL aspect ( $p > 0.05$ ). In contrast, family caregivers' quality of life showed significant differences based on age in the domains of physical function ( $p = 0.001$ ), physical role ( $p = 0.005$ ), and emotional role ( $p = 0.003$ ), indicating that age is a determinant factor in these areas of quality of life (See supplementary file).

### Comparison of psychological distress and intolerance uncertainty between cancer patients and family caregivers

According to **Table 3**, the statistical analysis indicates that the difference in psychological distress between cancer patients and their family caregivers is not statistically significant, as the  $p$ -value is 0.148 ( $p > 0.05$ ). Conversely, there is a statistically significant difference in the levels of intolerance to uncertainty between cancer patients and family caregivers, evidenced by a  $p$ -value of 0.001 ( $p < 0.05$ ). The mean rank for intolerance to uncertainty is higher in cancer patients, at 82.32, compared to 32.68 in family caregivers.

**Table 3.** Comparison of psychological distress and intolerance uncertainty

Variable	Group	Median (Min–Max)	p
Psychological distress	Cancer patients	3.38 (1.22–10.0)	0.148
	Family caregivers	4.17 (0.00–7.70)	
Intolerance uncertainty	Cancer patients	7.68 (4.84–10.0)	0.001*
	Family caregivers	4.26 (0.00–9.21)	

\* $p < 0.05$

## DISCUSSION

In this study assessing the psychological distress and QoL in cancer patients and their family caregivers, the study found that psychological distress did not significantly differ across various sociodemographic factors for both groups. However, intolerance to uncertainty was notably higher in unmarried family caregivers compared to their married counterparts. When examining quality of life, this study observed significant differences among cancer patients, with age affecting role and cognitive functions, and pain; gender influencing pain experiences; marital status impacting physical function and appetite; education level correlating with global health and cognitive function; and both cancer and therapy types affecting multiple QoL domains. Interestingly, income level did not significantly affect any QoL aspect. For family caregivers, age was a significant determinant of physical and emotional roles. Overall, while psychological distress remained consistent, intolerance to uncertainty and quality of life varied based on specific demographic characteristics, highlighting the complex interplay between these factors and the well-being of individuals affected by cancer.

In this research, both cancer patients and their family caregivers exhibited a moderate increase in psychological



distress. This observation aligns with prior studies suggesting that cancer patients and caregivers may rely on each other when facing psychological challenges associated with cancer [17]. Individuals with chronic conditions like cancer often depend more on caregiver support, potentially heightening psychological distress for both parties. While mutual dependence is evident, each party has unique ways of managing psychological distress, a concept known as dyadic coping [18]. Cancer patients may hesitate to share their emotional struggles with caregivers and others, possibly due to a belief that their stress is inescapable or untreatable, and a desire not to burden others with their concerns. Research by Zhao and colleagues suggests that caregivers might underestimate the psychological distress of patients, a tendency also observed among healthcare professionals, who may not accurately assess patient distress levels [19]. Psychological distress is a critical issue that warrants increased focus. It can negatively impact the quality of life and mental health of both patients and caregivers, potentially hindering patient follow-up care and adversely affecting symptom management and treatment outcomes [20].

Our study reveals a notable difference in intolerance to uncertainty among family caregivers, influenced by their marital status. This aligns with research by Lu and colleagues, which found that unmarried caregivers often face caregiving as a novel and challenging experience, impacting their well-being negatively [21]. The absence of external support and understanding leaves them feeling isolated, overwhelmed, and trapped by their caregiving responsibilities. In our research, most unmarried caregivers were children of cancer patients. Indonesia, known for its strong familial bonds, culturally obligates families to provide care due to norms, moral duties, reciprocal responsibilities, and religious expectations. Furthermore, limited health services compel families to engage deeply in medical care and decision-making [3].

Recent finding shows that a significant disparity in uncertainty intolerance between cancer patients and their family caregivers. Several factors contribute to increased uncertainty intolerance in cancer patients. Firstly, it is linked to perfectionism and the fear of cancer recurrence [22]. It is also driven by excessive and uncontrollable worries about future events that affect daily life, such as finances, partner relationships, and employment [23]. Additionally, a low level of trust in physicians indirectly escalates uncertainty intolerance, and anxiety among cancer patients. Patients with heightened uncertainty intolerance exhibit increased worry, fear of cancer recurrence, anxiety, depression, and post-traumatic symptoms when facing uncertain situations like awaiting medical results or cancer prognosis. Patients with a low

tolerance for uncertainty may struggle to regulate their internal state, leading to experiential avoidance, affective, or behavioural attempts [9].

Our recent study highlights that age, gender, marital status, education, therapy, and cancer type affect the QoL for cancer patients and caregivers. Transitional nursing care is essential in addressing these factors, ensuring continuous care that improves QoL. It is particularly beneficial for older patients, providing tailored interventions for their unique challenges [24]. This care includes coordinating healthcare services, patient education, symptom management, and emotional support. Moreover, introducing palliative care early in the treatment process can markedly enhance the physical, emotional, and psychological health of patients [25]. These strategies are fundamental to improving life quality and streamlining the care experience throughout the cancer trajectory.

The study demonstrates strengths in its comprehensive approach, utilizing validated instruments to assess multiple variables in both cancer patients and their caregivers, which provides a holistic view of cancer's impact on families. The inclusion of various cancer types and wards enhances generalizability within the Yogyakarta context. However, limitations include the cross-sectional design, which precludes causal inferences, and the relatively small sample size from a single hospital, potentially limiting broader generalizability. The consecutive sampling method may introduce selection bias, and the exclusion of patients with communication difficulties or unstable emotions could omit data from a vulnerable subset. Additionally, reliance on self-reported measures may be subject to recall and social desirability biases. Recognizing these limitations, future research could focus on longitudinal studies with larger and more diverse samples. Moreover, the study offers valuable insights into the psychosocial aspects of cancer care in Indonesia.

## CONCLUSIONS

This study reveals significant differences in intolerance of uncertainty between cancer patients and caregivers, with caregivers, particularly those unmarried, showing higher levels. While psychological distress was uniform, quality of life varied among patients based on sociodemographic factors and cancer characteristics, and among caregivers by age. These findings emphasize the need for personalized care approaches that address uncertainty management, especially for caregivers, and consider diverse demographic factors in care planning. Future longitudinal research should explore the causal relationships between these variables and their impact on the cancer care experience.

## DECLARATIONS

### Competing interest

The author(s) declared that no conflicts of interest exist with respect to the research, authorship, and publication of this article.

### Ethics approval and consent to participate

Ethical clearance for this research was granted by the Ethics Committee of the Faculty of Medicine at UGM, reference number KE/FK/0882/EC/2023, dated May 29, 2023. This approval is crucial for nursing research involving human subjects, ensuring that the benefits derived from the research outweigh any potential harm. The ethical principles adhered to in this study include beneficence, respect for human dignity, and justice.

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