UNCERTAINTY IN ILLNESS FOR PATIENT WITH LUNG CANCER: A LITERATURE REVIEW

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ABSTRACT

Background: Lung cancer is a disease that is one of the leading causes of death worldwide. Some patients experience psychological problems due to uncertainty in disease management, which can affect the treatment process and outcomes. This study analyzes the uncertainty, impact, and prevention strategies of lung cancer management. **Methods:** a systematic review using the PRISMA protocol and JBI critical appraisal tool to determine eligible articles. The five electronic databases used (Science Direct, PubMed, Scopus, IEEE Explore, and Google Scholar). The inclusion criteria included research on lung cancer published in English in the last ten years (2013 -2023). **Result:** The results showed that 11 articles met the inclusion criteria. The review results show several factors related to uncertainty related to lung cancer, including perceived physical symptoms, disease experience, cognitive factors, self-authority, social support, education, adaptation control, uncertainty inference buffering strategies, and the presence of health information. The impact of disease uncertainty is a lack of emotional control, increased stress, lifestyle changes and maladaptive behavior in health management. Nurses can implement prevention strategies by providing precise and comprehensive information, patient-centered palliative care services, improving coping through increasing family support or other social support, using positive emotional experiences of patients, evaluating service systems and planning continuous care programs. **Conclusion:** Patients' uncertainty in managing lung cancer can negatively impact disease management and disease management outcomes. Nurses can use appropriate strategies to improve adaptive coping abilities must be carried out to prevent adverse impacts and positively impact patient management and treatment outcomes.

Keywords: Illness, Lung Cancer, Patients, Uncertainty

INTRODUCTION

Cancer is a disease that is the leading cause of death worldwide. The prevalence of cancer continues to increase from year to year. In 2020, the number of new cancer cases was 19.2 million, estimated to grow to 27 million new cases in 2040. The increase in the number of cancer cases is in line with the rise in the number of deaths from cancer, as many as 10 million deaths, of which 1/ 8 males and 1/11 females will die from cancer (GLOBOCAN, 2020d, 2020b, 2020c; Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, 2021). While the number of cancer cases in Indonesia in 2020 reached 396,914 cases

with the number of death being 234,511 (GLOBOCAN, 2020a).

Lung cancer is the second highest type of cancer in the world, with a total of 2.21 million new cases of all cancer cases in the world (11.4%). However, it is the leading cause of death from cancer, with a total mortality rate of 1.8 million patients (18%). In Indonesia, lung cancer ranks 3rd after breast and cervical cancer, with 8.8%. However, the leading cause of death is caused by cancer, namely lung cancer (GLOBOCAN, 2020a). It is because lung cancer has the worst prognosis compared to other types of cancer. The incidence of lung cancer is very low for those aged less than 40 years, but it will continue to increase until the age of 70. Several factors can lead to mortality, including the type of cancer, the stage of the disease at the time of initial diagnosis, general appearance and the therapy given. These factors can be caused by uncertainty about the condition before getting a precise diagnosis from a doctor (GLOBOCAN, 2020d, 2020b, 2020c; Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, 2021).

Uncertainty related to disease substantially affects how individuals understand, integrate and communicate about the condition. The patient can ease uncertainty about the illness through cure or treatment. Still, some diseases pose unique challenges to individuals because of doubt and can persist or become cyclical over time (Mishel, 1988). Uncertainty related to disease certainly does not occur in various conditions or illnesses because each disease has variations in symptoms, complications, treatment plans and regimens (Chen *et al.,* 2018). Factors that affect uncertainty include stimulus consisting of pattern consistency, perceived symptoms, and

experience of illness or health procedures. Mishel also suggested that evaluating and assessing these antecedents could be moderated by a person's cognitive capacity, level of education, availability of credible medical services and social support (Zhang, 2017).

The theory of disease-related uncertainty provides a comprehensive framework for viewing the experience of illness and serves as a form of optimal adjustment. This theory helps explain the relationship between stress caused by the results of diagnosis and treatment therapy, disease experience, the individual's process of assessing uncertainty related to disease experience and the importance of providing care by providing information in understanding uncertainty related to disease (Mishel, 1988). Therefore, this literature review aims to discover the uncertainty of the disease process in lung cancer patients, its impact, and prevention strategies.

METHODS

The research design is a systematic literature review using the PRISMA protocol and JBI Critical Appraisal tools. Inclusion criteria for articles in the literature review in this study include 1) articles in English; 2) Publication between 2000-2023 (last 10 years); 3) related to the uncertainty of the disease process specifically for lung cancer. Exclusion criteria include 1) more than 2000 publications, 2) research that deviates from the topic under study, and 3) non-specific studies for lung cancer uncertainty. The author read each identified article in full and assessed for relevance to the review according to the inclusion criteria by which the article must provide information about

the uncertainty of the disease process in lung cancer patients.

A literature search was conducted from February to April 2023 using five electronic databases: Science Direct, PubMed, Scopus, IEEE Explore, and Google Scholar 2013 to 2023. Keywords used include "lung,"; "lung cancer,"; "uncertainty,"; "illness,"; and "uncertainty in illness ." authors only include articles published in English (a well-accepted universal language) in the review. The protocol for the literature review was followed systematically, including quotations, theoretical basis, methodology, findings and conclusions. The search yielded 1,206 articles. Study selection was made through four stages using the Preferred Reporting Items for Systematic

Reviews and Meta-analysis (PRISMA) flowchart (Figure 1). In the first stage, the initial search obtained 1,206 articles: Science Direct (28), PubMed (32), Scopus (202), IEEE Explore (3) and Google Scholar (941). The second stage examines the abstract according to the inclusion criteria. One thousand one hundred twenty-four articles based on the topic but excluding the theme of uncertainty in illness for patients with lung cancer were rejected. In the third stage, from the remaining 82 articles, we selected 15 for review based on the full-text arrangement. The reference list of 11 articles is presented in Table 1. Meta-synthesis analyzed data with the compare, contrast, criticize, and synthesis approaches.
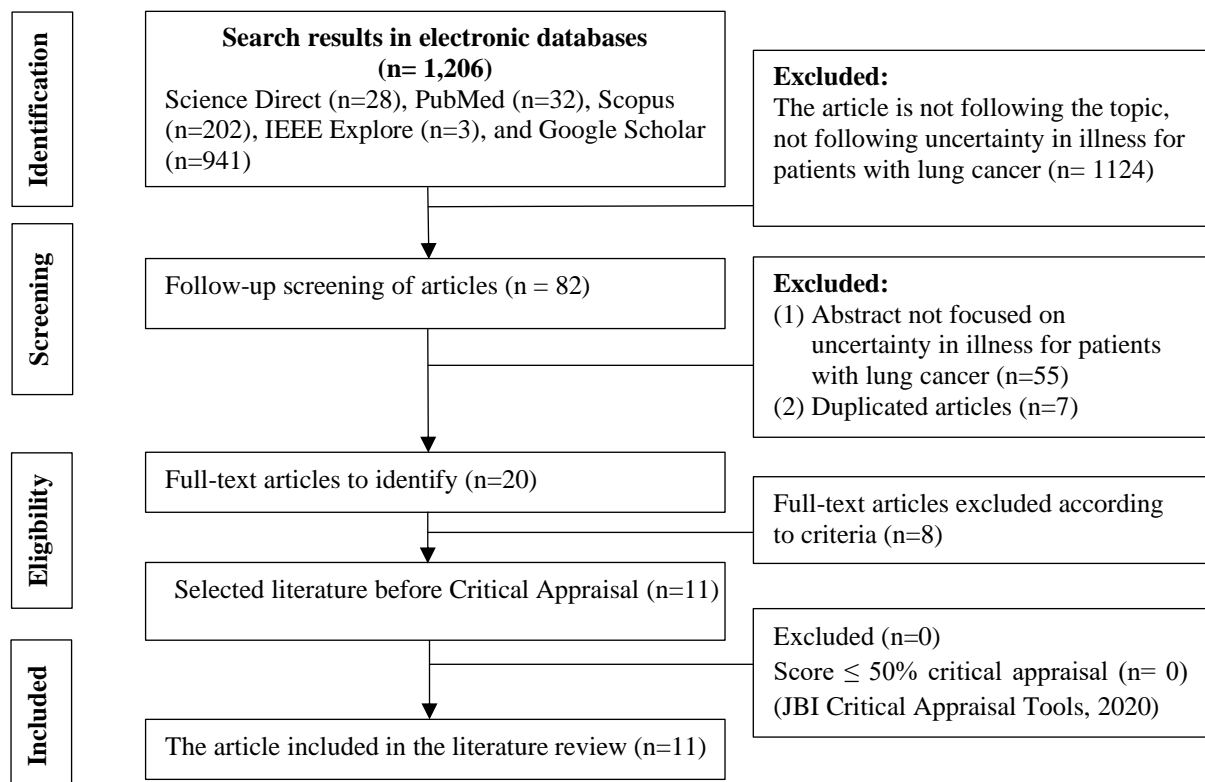

Figure 1. Study Selection based on the PRISMA flow chart

RESULTS

This literature review identified twelve articles that fit the inclusion criteria. The presentation of results of a study of articles about uncertainty in illness for patients with lung cancer is presented in Table 1. Three of the eleven articles used a cross-sectional design to analyze factors that influence disease uncertainty in lung cancer patients. Nine other articles used a qualitative method to analyze the emotional level patients and their families felt related to uncertainty in their lung cancer illness. The influence of disease uncertainty on the emotional status of patients and patient members, perceived disease symptoms, disease experience, inference support strategies, and health information (Arias-Rojas et al., 2019). Patients' and families' knowledge about the disease and plans for treatment and therapy also influence uncertain conditions (Refsgaard & Frederiksen, 2013; Sajjadi et al., 2014). The results of research in Iran show that states of uncertainty increase emotional problems, including increased stress (Sajjadi et al., 2014). The impacts of disease uncertainty were common dynamic control, lifestyle and maladaptive behavior in health management (Cypress, 2016; Hendriksen et al., 2015; Kendall et al., 2015; Li et al., 2022; Mosher et al., 2013; Sparla et al., 2017).

Several other studies related to evaluating service systems and planning ongoing care programs showed the experience and acceptance felt by patients and their families (caregivers) with metastatic lung cancer in the future, identifying unmet needs for supportive care, the role of nurses in providing appropriate and comprehensive information and treatment through improving coping through increased family support or other social support (Shilling et al., 2017; McDonnell et al., 2019; Petrillo et al., 2021).

Table 1. Study of Uncertainty in Illness for Patients with Lung Cancer

No.	Author (s)	Purpose of study	Methods	Main Finding
1	Refgaard, B., Frederiksen, K. (2013)	Describe disease-related knowledge related to patients' emotional experiences with incurable lung cancer.	D: A qualitative meta-synthesis S: 10 Qualitative research between 1995 - 2011 V: Emotional experience of lung cancer I: Sandelowski dan Barroso instrument A: Metasyntesis	Eight emotional experiences arise in connection with lung cancer, namely: (1) guilt, blame, shame, and stigmatization; (2) hope and despair; (3) lonely; (4) changes in self-image and self-esteem; (5) uselessness and dependence; (6) uncertainty and worry; (7) anxiety and fear; and (8) loss. The findings show that this study supports patients with lung cancer who are related to the patient's emotional level. The results of these findings can be used as a reference for nurses in providing emotional care.
2	Mosher, C.E., Jaynes, H.A., Hanna, N.,	Explore caregivers' key challenges coping with their family member's lung cancer.	D: Single, semistructured qualitative interviews S: 21 participants (distressed family caregivers of lung cancer patients)	Caregivers experience three significant challenges in managing their family member's cancer, namely: (1) a deep sense of uncertainty about the future when they try to understand the patient's

No.	Author (s)	Purpose of study	Methods	Main Finding
	& Ostroff, J.S. (2013)		V: Distress dan kanker paru I: Hospital Anxiety and Depression Scale A: Thematic analysis with Atlas.ti software	prognosis and potential functional decline (38%); (2) time-consuming effort to manage the patient's emotional reactions to the illness (33%); and (3) practical tasks, such as coordinating patient medical care (14%). The findings show that the efforts needed by caregivers are emotional handling by health services and emotional support for patients and their caregivers
3	Hendriksen, E., Williams, E., Sporn, N., (2015)	Identify causes and manifestations of anxiety experienced by patients with stage IV non-small cell lung cancer (NSCLC) and their primary caregivers	D: Qualitative, in-depth semistructured interviews S: 21 participants V: Level of anxiety and causes of anxiety in lung cancer patients and their families I: Hamilton Anxiety Rating Scale (HAM-A) A: Grounded theory methodology	Eight themes emerged characterizing shared causes and manifestations of anxiety: (1) uncertainty, (2) loss and impending loss, (3) changing roles, (4) conflict outside the dyad, (5) finances, (6) physical symptoms, (7) fears of decline and death, and (8) life after the patient's passing. Patients and caregivers shared all themes. The findings show that uncertainty is one of the factors causing anxiety in patients with advanced lung cancer.
4	Kendall, M., Garduff, E, Lioyd, A., Kimbell, B., Gavers, D., et al., (2015)	To understand how patients with different advanced conditions and their families and professional caregivers view their deteriorating health and the services they require	D: Narrative framework to synthesize eight methodologically comparable, longitudinal, and multiperspective interview studies S: 440 respondents (156 patients, 114 families and 170 health workers) V: Disease experience and treatment outcomes I: Qualitative, longitudinal, and multiperspective interviews A: Riess man's model of thematic narrative analysis	Cancer patients gave a well-rehearsed account of their illness, hoping for recovery alongside the fear of dying. In contrast, people with organ failure and their family caregivers struggled to pinpoint when their condition began, or to speak openly about death, hoping instead to avoid further deterioration. Frail older people tended to be frustrated by their progressive loss of independence, fearing dementia or nursing home admission more than dying. Explanation of the disease, the experience of the disease, and the fears felt by the patient and family. The necessary services are in the form of palliative care.
5	Cypress, B.S. (2016)	To explore, describe, and understand the concept of uncertainty among patients and family members during critical illness in the ICU	D: Descriptive analytics S: 9 Qualitative phenomenological study V: Uncertainty concept I: - A: van Manen's wholistic	Uncertainty is a patient-specific theme illuminated in this qualitative phenomenological study not noted among the family members. The patients perceived that they "do not know what is going to happen," "if they are progressing or not," or "if they will make it or not." The concept of disease uncertainty can assist health workers in explaining related illnesses to patients and their families. This concept relates to plans for providing information and therapy to patients so that patients and their families are assisted in making the right

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				decisions. The concept of uncertainty can change the mindset based on the experience of the disease so that it can have a positive impact.
6	Shilling, V., Starkings, R., Jenkins. V., Fakkowfiel d. L., (2017)	To explore the impact of extended cancer survival on broader aspects of life and well-being for patients with advanced cancer and their informal caregivers.	D: Qualitative study S: 24 participants (dyads; patients and caregivers) V: The concept of uncertainty I: Open-ended question, NVivo 11™ software A: Thematic analysis	Uncertainty related to disease, covering various issues including (1) future planning; (2) provide for the family; (3) work; (4) finance; and (5) uncertainty related to the timescale and trajectory of the disease and lack of control or ability to plan. There are differing views regarding the uncertainty between patients and their families. However, nurses rarely discuss these problems with each other.
7	Sparla, A., Flach-Vorgang, S., Villaloos, M., Krug, K., Kamradt, M. *et al.*, (2017)	To explore and compare reflections arising from the context of diagnosis and how patients and their relatives try to handle advanced lung cancer.	D: Qualitative study S: 18 participants (nine patients and nine relatives) V: Disease reflection and treatment strategies in lung cancer I: Open-ended questions A: Qualitative content analysis	Reflection aspects were : (1) thoughts about the cause; (2) meaning of belief; and (3) experience of inequity. Patients often experienced the diagnosis as inequity and were more receptive to believing in treatment success. The main strategies used by patients are (1) repression; (2) positive attitude; (3) intense focus on the present; and (4) adjustment to living conditions. The findings showed that the strategies used by family members are similar to those of patients. The result needs to be more reflective. The results of patient interviews mostly believed that the success of treatment recovery and repression of the future comes from oneself
8	Arias-Rojas, Mauricio (2019)	To describe the level of disease uncertainty in the patient's family (caregivers) of palliative patients and to analyze the relationship between caregiver profile and level of uncertainty.	D: Descriptive, cross-sectional study S: 300 respondent V: Level of uncertainty, symptoms of treatment, service distance, perception of support from health workers, family and religious support I: Edmonton Symptom Assessment Questionnaire, Uncertainty in Illness Scale. A: Spearman's Rho correlation test	There were high levels of uncertainty among caregivers about their patient's illnesses. These levels are associated with the health condition and symptoms of the patient who is cared for, the length of service as a caregiver and the perceived support from health professionals, family, and religion.
9	McDonnell, K.K., Owens. O.T., Messias, D.K.,	To identify factors associated with receptivity and preferences for lifestyle behavior change	D: Deskriptif kualitatif S: 26 participants V: Health status and health behavior	Four major themes: (1) family members and survivors both resisted the caregiver role; (2) dramatic changes evoked by the diagnosis of lung cancer were facilitators and barriers to lifestyle choices; (3)

No.	Author (s)	Purpose of study	Methods	Main Finding
	Heiney, S.P., Friedman, D.B., Campbell. C., Webb, L.A., (2019)	among family members of African-American survivors of lung cancer	I: Behavioral Risk Factor Surveillance System Questionnaire A: thematic analysis method	leaning on faith was the primary source of support; and (4) families live with a constant threat of multiple cancers. Findings emphasize the importance of meaningful conversations among healthcare providers, survivors, and family members during diagnosis, treatment, and recovery so that family members are better prepared to cope with anticipated changes. This study highlights the stressors that affect family members and sheds light on their unique needs. The stressors limit their ability to change health behaviors. Family members need primary education, skills training, and support for lung cancer diagnosis and other cancers. Current methods to provide these services are limited in accessibility, availability, and effectiveness.
10	Petrillo, L.A., Traeger, L.N., Sommer, R.K., Zhou, A.Z., Temel, J.S., Greer, J.A., (2021)	To describe how these metastatic cancer survivors and their caregivers experience an uncertainty about the future and identify their unmet supportive care needs	D: a qualitative study S: 39 lung cancer patients and 16 patient families V: Experience and support needed by lung cancer patients with uncertainty I: Primary data (structured interviews), secondary data (clinical data from electronic health records). A: Framework approach	The findings show that patients with metastatic lung cancer who receive therapy and care experience problems related to disease uncertainty, need more coping support, relationships with friends/relatives, provide information and provide healthy lifestyle guidelines.
11	Li, J., Sun, D., Zhang, X., Zhao, L., Zhang, Y., Wang, H., Ni, N., and Jiang, G. (2022)	To explore the relationship between anticipatory grief and illness uncertainty among Chinese family caregivers of patients with advanced lung cancer and to determine the factors influencing anticipatory grief.	D: a descriptive cross-sectional study S: 254 respondent V: Anticipate grief, uncertainty about illness, lack of information, monthly income, and family burdens I: Anticipatory Grief Scale (AGS), Uncertainty in illness scale family caregiver version, self-compiled general information questionnaire A: One-way ANOVA	The findings showed that disease uncertainty is one of the important factors influencing anticipatory grief. Excessive caregiving causes a burden on the patient, increasing the high level of anticipatory grief. Increased disease uncertainty and the burden of caregiving will be effective in reducing anticipatory grief in family caregivers in China

DISCUSSION

According to Mishel's theory, research related to uncertainty due to disease has been widely applied, one of which is for lung cancer patients (Kurita et al., 2013; Mishel, 1988). The series of uncertainties in cancer patients is caused by several factors, including perceived symptoms, disease experience, cognitive factors, credible authority, social support,

education, mobilization, the influence of control strategies overcoming adaptation, and uncertainty inference buffering strategies. (Mishel, 1988; Shaha, M., Cox, C.L., Talman, K., & Kelly, 2008). Uncertainty is higher in lung cancer patients with physical symptoms than without (Kim, S.H., Lee, R., & Lee, 2012; Wong, C.A., & Bramwell, 1992; Zhang, 2017).

The analysis results show that disease uncertainty was influenced by several factors, including low information related to disease, which needs to be more accurate and comprehensive, and low knowledge about plans for care programs and therapies (Petrillo et al., 2021). Some of these factors cause high uncertainty in patients, causing a lack of emotional control, thereby increasing stress. Patient stress is also caused by a lack of support from family and other social support (Liao, M.-N., Chen, M.-F., Chen, S.-C. & P.-L., 2008; Lien, C.-Y., Lin, H.-R., Kuo, I.-T., & Chen, 2009; Petrillo et al., 2021).

The impact of the uncertainty of the disease is a lack of emotional control (Vos *et al.,* 2011; Kurita *et al.,* 2012; Refgaard and Frederiksen, 2013; Sajjadi *et al.,* 2014; Arias-Rojas, 2019), sadness (Cypress, 2016; Mosher et al., 2013; Petrillo et al., 2021; Refsgaard & Frederiksen, 2013; Hendriksen, 2015). High levels of stress so unable to change lifestyle and healthy behavior (McDonnel *et al.,* 2019). The long-term impact is a feeling of uncertainty about the illness (Shilling *et al.,* 2017).

Several factors that affect disease uncertainty and the impact felt by patients can be material in strategic planning. Nurses can provide precise and comprehensive information (Vos *et al.,* 2011; Kurita *et al.,* 2012; Refgaard and Frederiksen, 2013; Sajjadi *et al.,* 2014; Arias-Rojas, 2019), provide patient-centered palliative care (Kendal *et al.,* 2015), improve coping in the form of support from family or other social support (Kurita et al., 2013), utilize the patient's emotional experience that is considered capable of dealing with stress problems

(Refsgaard & Frederiksen, 2013), evaluate service systems and plan ongoing care programs related to services and providing therapy (Petrillo et al., 2021).

Comparison of the findings with Michel's theory has similarities, where disease uncertainty was caused by factors including perceived symptoms, disease experience, cognitive factors, credible authority, social support, education, mobilization, the influence of control strategies overcoming adaptation, uncertainty inference buffering strategy has similarities with several studies regarding the uncertainty of disease related to lung cancer. Following up on this, if the nurse has understood the influencing factors, impacts and treatment strategies can prevent and overcome the problem of disease uncertainty, especially in lung cancer patients. Thus, proper treatment can prevent problems from arising and adverse effects on patients.

CONCLUSION

Disease uncertainty, according to Mishel's theory, is supported by several findings of the articles reviewed in this study. Patients' uncertainty in lung cancer management can harm disease management and disease management outcomes. Nurses can use appropriate strategies to improve adaptive coping skills to prevent adverse effects and positively impact patient management and treatment outcomes. The results of this literature review are expected to be reference material for education and health agencies in treating lung cancer patients. Follow-up research should measure the level of anxiety the patient feels, forms of coping that have been received from both family and other social groups, and the patient's knowledge regarding the disease received so that the treatment strategy obtained is in accordance with the patient's condition and needs.

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