

ORIGINAL**Relationship between Uncertainty and Emotions in Advanced Lung Cancer Patients after Initial Therapy**Tomoko Sasai¹⁾ and Chiemi Onishi²⁾¹⁾Tokushima University Hospital, Department of Nursing, Tokushima, Japan, ²⁾Tokushima University Graduate School, Institute of Biomedical Sciences, Tokushima, Japan

Abstract : Purpose : We investigated the relationship between uncertainty and emotions in advanced lung cancer patients after initial therapy. **Methods :** Fourteen advanced lung cancer patients participated in this study. A survey was conducted using the Universal Uncertainty in Illness Scale (UIIS) and the Profile of Mood States-Brief Form (POMS-Brief Form), Japanese Version. **Results :** The total UIIS score of each participant ranged from 42 to 109, with a mean±SD of 70.7±20.9. The T-scores for the 6 factors of the POMS-Brief Form were 50.2±11.9 (mean±SD) for tension-anxiety (T-A) ; 49.6±12.2 for depression-dejection (D) ; 40.4±4.9 for anger-hostility (A-H) ; 41.8±9.3 for vigor (V) ; 44.2±5.8 for fatigue (F) ; and 52.7±15.2 for confusion (C). In terms of the correlation between the total UIIS score and the respective T-scores of the six POMS-Brief Form factors, a strong correlation was seen between total UIIS score and D ($r=0.735$, $p=0.003$). A substantial correlation was also seen between total UIIS score and T-A ($r=0.694$, $p=0.006$). **Conclusions :** In advanced lung cancer patients after initial therapy, uncertainty had an effect on emotions. *J. Med. Invest.* 64 : 96-100, February, 2017

Keywords : Advanced Lung Cancer, Uncertainty, Emotions

INTRODUCTION

According to a summary of joint surveys on survival rates by the Japanese Association of Clinical Cancer Centers (1), the 5-year survival rate, which is the medical standard for evaluating recovery, exceeded 62.5% in all sites.

Majority of cancers are viewed as chronic diseases. However, lung cancer is usually not discovered early and is characterized by rapid progression and metastasis. With a 5-year survival rate of less than 5% for stage IV disease, lung cancer has been perceived as an intractable disease that accounted for the highest rate of mortality among all cancers (Ministry of Health, Labour and Welfare) (2).

Lung cancer patients tend to have a large number of psychological, physical and daily living unmet needs, compared with patients with cancer of other organs (3). They also undergo illness-related emotions during diagnosis and at the beginning of therapy (4), which might be the reason for their strong emotional needs (5). Over the course of therapy, patients with lung cancer in the advanced stage experience an overlap of cancer-associated symptoms, as well as side effects of chemotherapy, surgery, and radiation therapy. These myriad of symptoms cause emotions, such as fear and internal conflict (6). As a consequence, these emotional problems of advanced lung cancer patients have been linked to reduced quality of life (QOL) (7, 8). The lung cancer patients had lower QOL scores than patients suffering from other malignancies (8, 9). This also suggests that lung cancer patients have serious emotional problems.

At the same time, uncertainty is defined as the inability to determine the meaning of illness-related events (10). Advanced lung cancer patients also experience uncertainty about death (11). The period from diagnosis to the start of therapy has been acknowledged

by patients as a time of unbearably strong uncertainty. Uncertainty can also lead to anxiety, which reduces QOL (12). Uncertainty about what will happen next and about the consequences of an event and what it means are important to a person with any illness (10). Managing uncertainty associated with an illness and its treatment may be an essential task in adaptation (10). Adaptation is defined as biopsychosocial behavior occurring within a persons' individually-defined range of usual behavior (10).

The emotional needs of advanced lung cancer patients are strong, especially during the period from diagnosis to the start of therapy. As patients experience wavering emotions due to their symptoms, their strong uncertainty about death further affects their emotions and can reduce their QOL. To address this issue on uncertainty, it is important to understand first the degree of uncertainty and its effects on an individual patient's emotions. However, it is not known about relationship between uncertainty and emotions in advanced lung cancer patients. In this study, we investigated the relationship between uncertainty and emotions in advanced lung cancer patients after initial therapy.

METHODS*1. Study participants*

The present study was conducted from May 2013 to July 2014. Selection criteria were (a) being an adult, (b) being diagnosed with advanced lung cancer, and after initial treatment ; chemotherapy or/and radiation therapy, (c) being explained about diagnosis and treatment, (d) being not evaluation of the response to initial therapy, (e) being judged by a physician to have no physical, psychological, cognitive (i.e., mental illness), or language disorders. Participants were given written and verbal explanations on the study purpose, objectives, and methods ; that participation was voluntary ; that refusing to give consent or withdrawing consent halfway through the study would not negatively affect their treatment or nursing care ; and that their personal information would be protected. After consenting to participate in the study, the patients

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were asked to sign a consent form. Eligible consenting participants were investigated about uncertainty and emotions after initial therapy. Because this study involved advanced cancer patients who were at the stage after initial therapy, and before evaluation of the response to initial therapy, consideration was given to voluntary participation and to the health and mental well-being of participants by establishing a support system for times of physical and mental unease during the study. The study was performed in accordance with the Declaration of Helsinki and the study protocol was approved by the Institutional Review Board of Tokushima University Hospital (approval number : 1500, approval date : 2012/8/20).

2. Methods of data collection

1) Participant attributes

Data on age, sex, disease, histologic type, disease stage, treatment regimen, occupation, and family composition were collected from medical records.

2) Measuring uncertainty

The Universal Uncertainty in Illness Scale (UIIS) (13) was used to measure uncertainty, with the approval from its developers. The UIIS (Cronbach's α 0.79-0.93), which was developed by Nogawa, can provide an understanding of uncertainty in both inpatients and outpatients. The scale comprised 6 factors, including ambiguity of characteristics of illness (characteristics of illness), complexity of interpretation of information (interpretation of information), unpredictability recovery from illness (recovery from illness), unpredictability of daily life (daily life), instability of self-confidence in carrying on a struggle against illness (carrying on a struggle against illness), lack of cues finding meaning in illness (meaning in illness). Each factor contained 3-8 questions for a total of 26 questions. Participants answered each question by choosing one option from a 5-point scale, as follows : false (1 point), somewhat false (2 points), no opinion (3 points), somewhat true (4 points), and true (5 points). The score for each factor and the overall score were added to a cumulative score. The overall score ranged from 26 to 130 points. A higher score indicated a stronger feeling of uncertainty.

3) Measuring emotions

The Profile of Mood States-Brief Form (POMS-Brief Form), Japanese Version was used to measure various moods and emotions in the participants (Cronbach's α 0.57-0.88). It is available commercially and the necessary parts were purchased for this study (Kaneko Shobo Co., Tokyo, Japan). POMS-Brief Form comprised 6 factors, including tension-anxiety (T-A), depression-dejection (D), anger-hostility (A-H), vigor (V), fatigue (F), and confusion (C). Each factor had 5 question items for a total of 30 questions. Participants answered each question by choosing one option from a 5-point scale, as follows : not at all (0 points), a little (1 point), moderately (2 points), quite a bit (3 points), and extremely (4 points). The total score for each factor was calculated as the base score and was then converted to a standardized score (T-score), according to the instructions (14). A high T-score meant that the person had many negative moods with low vigor (14). A T-score of 40-60 indicated a healthy state (14).

3. Data analyses

1) Analyses of uncertainty

A complete set of answers to all questionnaire items was considered a valid response. The scores and means \pm SD for all question items in the UIIS, as well as those for the six-factor scores and the overall scores, were calculated. Differences in the total UIIS score were tested according to participant attributes using the Mann-Whitney U test.

2) Analyses of emotions

A complete set of answers to all questionnaire items was considered a valid response. The respective T-scores and the mean score

of the 6 factors of the POMS-Brief Form were calculated. A healthy T-score range of 40-60 was used as the indicator for analysis (14). Differences in T-scores among the 6 factors were tested according to participant attributes using the Mann-Whitney U test.

3) Analyses of the relationship between uncertainty and emotions

The relationship between the total UIIS score and the T-scores of the 6 factors of the POMS-Brief Form was analyzed by Spearman's rank correlation coefficient.

The software SPSS Ver. 23 for Windows was used for statistical analyses. A p value < 0.05 was considered significant.

RESULTS

1. Participant attributes (Table 1)

Of the 15 patients who consented to participate in the study, 14 gave valid responses to both the UIIS and POMS-Brief Form. The mean age of patients was 60.5 years (range 47-71 years) and 57% were male. Twelve participants were non-small cell lung cancer, others were small cell lung cancer. All participants had stage IV. Eight participants received chemotherapy/radiotherapy, others received chemotherapy.

Table 1. Demographic data of the study participants

Characteristics	n = 14
Sex	
Male	8
Female	6
Age	60.5 \pm 6.2 (47-71)
Histological type	
non-small cell lung cancer	12
small cell lung cancer	2
Clinical Stage	
IV	14
Therapy	
chemotherapy/radiotherapy	8
chemotherapy	6

2. Uncertainty

1) UIIS scores

Participants reported levels of UIIS after initial therapy. The total UIIS score of each participant ranged from 42 to 109, with a mean \pm SD of 70.7 \pm 20.9. The score of all 26 UIIS items was 2.7 \pm 1.5 (mean \pm SD). In addition, the score of each of the 6 factors were 3.3 \pm 1.5 for characteristics of illness ; 2.6 \pm 1.3 for interpretation of information ; 2.2 \pm 1.4 for recovery from illness ; 2.9 \pm 1.5 for daily life ; 2.7 \pm 1.4 for carrying on a struggle against illness ; and 2.4 \pm 1.5 for meaning in illness (Figure 1).

The percentage of participants who indicated that they felt uncertain by answering "true" or "somewhat true" to any of the items among the 6 UIIS factors were 71.4% (10 participants) for characteristics of illness ; 57.1% (8 participants) for interpretation of information ; 35.7% (5 participants) for recovery from illness ; 64.3% (9 participants) for daily life ; 42.9% (6 participants) for carrying on a struggle against illness ; and 57.1% (8 participants) for meaning in illness.

More than half of the participants answered that they had feelings of uncertainty with regard to 4 question items, including "I cannot see what course my illness will take (characteristics of illness)"; "I do not know how serious my illness is (characteristics

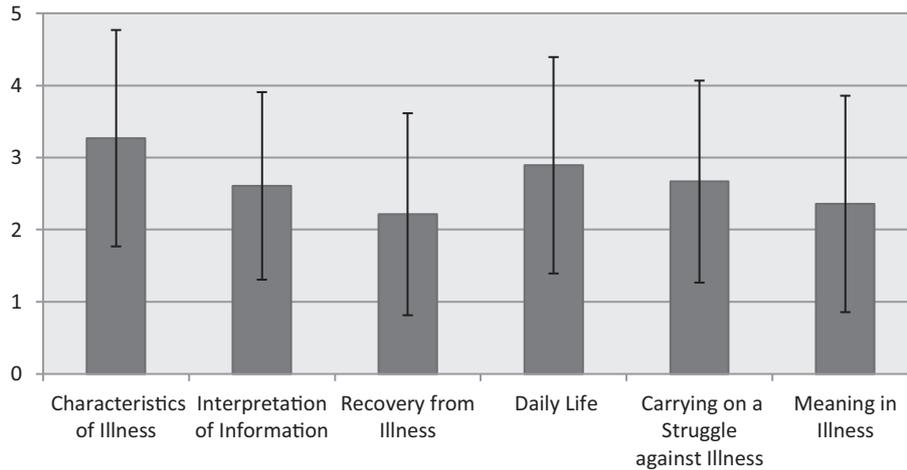


Figure 1. Mean of each factor of UUIS
 The score for the 6 factors of UUIS were 3.3 ± 1.5 (mean \pm SD) for characteristics of illness ; 2.6 ± 1.3 for interpretation of information ; 2.2 ± 1.4 for recovery from illness ; 2.9 ± 1.5 for daily life ; 2.7 ± 1.4 for carrying on a struggle against illness ; and 2.4 ± 1.5 for meaning in illness.

of illness)” ; “I think about how much burden will be placed on my family in the future (daily life)” ; and “I wonder about what caused my illness (meaning in illness).”

2) Differences in UUIS scores according to participant attributes

UUIS scores did not differ significantly according to sex, occupation, and cohabitating family members. Furthermore, using the mean age of 60.5 years as a reference, no significant difference was seen between the groups aged ≤ 60 and ≥ 61 years.

3. Emotions

1) Scores for the POMS-Brief Form

Participants reported levels of POMS-Brief Form after initial therapy. The T-scores for the 6 factors of the POMS-Brief Form were 50.2 ± 11.9 (mean \pm SD) for T-A, 49.6 ± 12.2 for D ; 40.4 ± 4.9 for A-H ; 41.8 ± 9.3 for V ; 44.2 ± 5.8 for F ; and 52.7 ± 15.2 for C (Figure 2).

The number of participants who was outside the healthy overall T-score range of 40-60 was 4 ; whereas the number of participants who was outside the healthy range was 3 for T-A, 2 for D, and 4 for C.

2) Differences in the 6 factors of the POMS-Brief Form according to participant attributes

No significant differences in scores were seen according to sex,

occupation, and cohabitating family members. Furthermore, using the mean age of 60.5 years as a reference, no significant difference was seen between the groups aged ≤ 60 and ≥ 61 years.

4. Relationship between uncertainty (UUIS) and emotions (POMS-Brief Form)

In terms of the correlation between the total UUIS score and the respective T scores of the 6 factors of the POMS-Brief Form (Figure 3), a strong correlation was seen between total UUIS score and D ($r=0.735$, $p=0.003$). A substantial correlation was also seen between total UUIS score and T-A ($r=0.694$, $p=0.006$). On the other hand, total UUIS score was not correlated with A-H, V, F, or C.

DISCUSSION

1. Relationship between uncertainty and emotions

In this study population of patients who were diagnosed as advanced lung cancer and after first-line therapy, a correlation was seen between total UUIS score and the respective T-scores of the 6 factors of the POMS-Brief Form. When a participant’s uncertainty about illness was strong, the statuses of “D” and “T-A” were also particularly strong. In lung cancer patients, uncertainty during

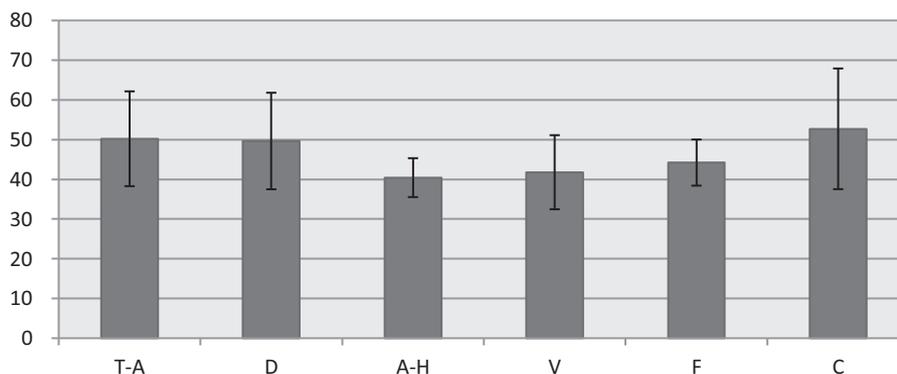


Figure 2. Mean of each factor of POMS-Brief Form
 T-A : tension-anxiety, D : depression-dejection, A-H : anger-hostility, V : vigor, F : fatigue, C : confusion
 The T-scores for the 6 factors of the POMS-Brief Form were 50.2 ± 11.9 (mean \pm SD) for T-A, 49.6 ± 12.2 for D ; 40.4 ± 4.9 for A-H ; 41.8 ± 9.3 for V ; 44.2 ± 5.8 for F ; and 52.7 ± 15.2 for C

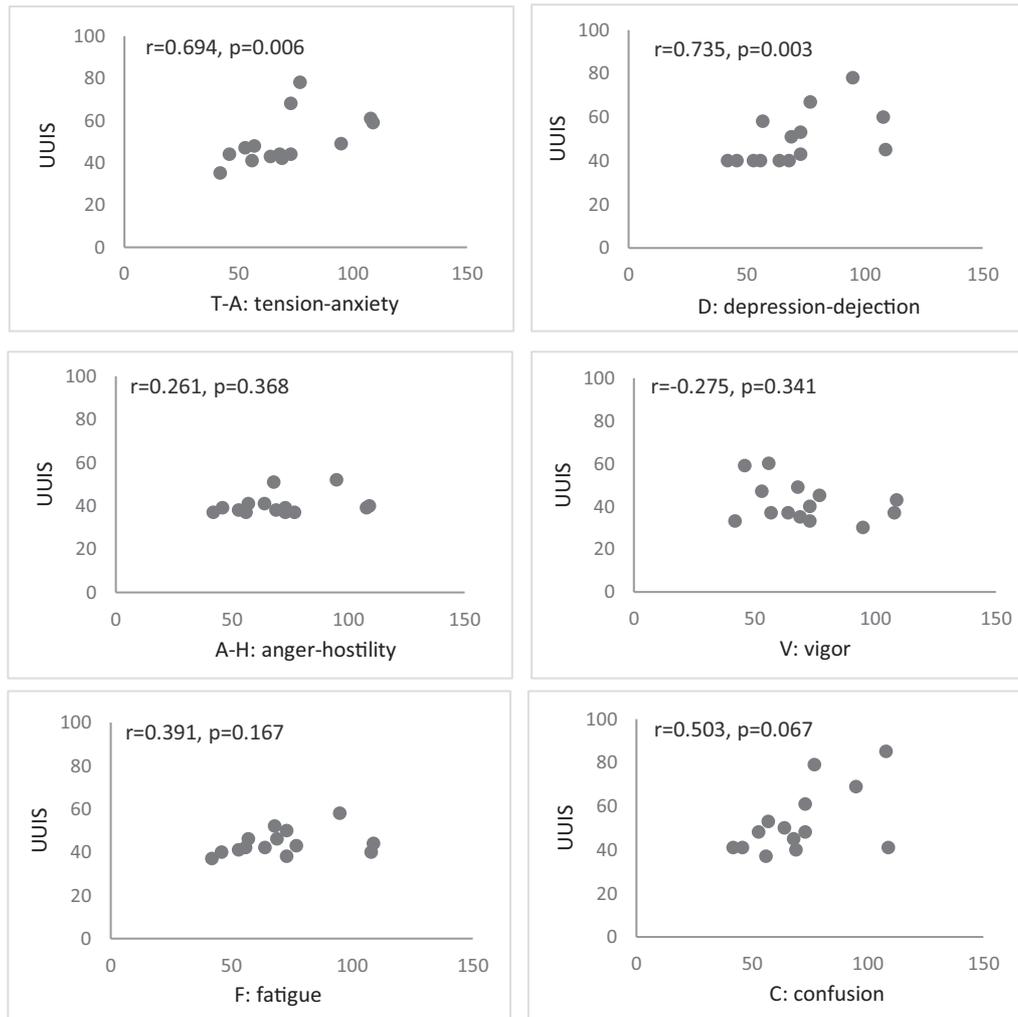


Figure 3. Correlations between UUIS and POMS-Brief Form

In terms of the correlation between the total UUIS score and the respective T scores of the 6 factors of the POMS-Brief Form, a strong correlation was seen between total UUIS score and D ($r=0.735$, $p=0.003$). A substantial correlation was also seen between total UUIS score and T-A ($r=0.694$, $p=0.006$).

the stage between diagnosis and start of therapy can result in anxiety and reduced QOL (12). However, the results of this study suggested that uncertainty caused depression and dejection, as well as anxiety. Anxiety has core symptoms of fear, anticipated concern, and autonomic symptoms; whereas the core symptoms of depression are sadness, hopelessness, and diminished joy and interest. Anxiety and depression easily prolong recovery, when these intermingle and simultaneously manifest (15). When uncertainty is strong, both anxiety and depression are thought to manifest for a prolonged period of time. Furthermore, despite the lack of a clear relationship of uncertainty with confusion and vitality, prolongation of anxiety and depression can result in confusion and decrease in vitality. Confusion signifies a decline in thinking power (14), which can be a factor that hinders patients from taking on an individually-defined biopsychosocial behavior during usual daily living.

A healthy T-score range of 40-60 was used as the indicator for analysis (14). In this study, a cumulative T-score of 40-60 from the factors of the POMS-Brief Form was considered a healthy range, suggestive of emotional stability. In the period between diagnosis and the start of therapy, patients with advanced lung cancer manage uncertainty through efforts in finding a way to live amidst this state of confusion (16). Management of uncertainty between diagnosis and initial therapy may be important cause of emotional

stability of patients with advanced lung cancer after therapy.

More than half of the participants felt uncertain about at least 1 of the 4 UUIS factors, including characteristics of illness, interpretation of information, daily life, and meaning in illness. We were able to interpret the situations of patients, including their thoughts on how the serious status of their advanced lung cancer would develop, their difficulty in understanding information on their illness, their lack of outlook on daily life, and their wavering resolve on the meaning of life with illness. Furthermore, in 4 participants, the POMS T-score from some factors, such as T-A, D, and C, fell outside the healthy range. If persistent throughout the subsequent course of therapy, this state could have a significant effect on emotions; therefore, it is critical to support patients in managing their own uncertainty while verifying the details of a patient's uncertainty.

2. Suggestions for nursing

Cancer experiences, particularly at the stage between diagnosis and therapy, do not encompass a binary notion of cure versus non-cure; the vagaries, phases, and syndromes of survival are far more complex than that simple idea and patients are commonly confronted with their own deaths (17). Anxiety and depression are related to the QOL of patients with lung cancer (9). The level of anxiety often increases during therapy, which is related to decrease

in QOL (9). Patients with advanced lung cancer particularly suffer strong uncertainty over their potential death, which can lead to strong expression of negative emotions, including anxiety and depression, and subsequent reduced QOL. The concept of a “cancer survivor” was based on the experience on the cancer continuum—living with, living through, and living beyond a cancer diagnosis (18). It signifies a strong resolve to perceive one’s self as a person who lives in the present; for this to happen, a lot of support is necessary, especially after receiving a diagnosis of cancer (19).

The results of this study revealed a relationship between uncertainty and emotions in patients with advanced lung cancer after initial therapy, which can make it difficult for these patients to stand themselves as people who live in the present. This was because their strong uncertainty greatly affected their emotions. Studies on support systems that allow individuals to manage uncertainty on their own are available for patients with other cancers (20); a similar study for advanced lung cancer patients is needed. Support systems of the uncertainty management could help maintain and improve the QOL of patients by allowing them to control their emotions and to move forward as survivors living with cancer.

3. Study limitations

This study had two limitations. First, it was the small number of subjects who participated in this study. However, we believe that the result shows an intriguing fact: it suggested that uncertainty caused depression and anxiety. We need to increase the number of samples, and validate these results. Another limitation, this study investigated uncertainty and emotions only after initial treatment. Therefore, changes at the time when diagnoses were received and the subsequent course of treatment require investigation. A future study will also be needed to examine the relationship between uncertainty and its management by patients.

CONCLUSIONS

In patients with advanced lung cancer after initial therapy, uncertainty had an effect on emotions and can reduce QOL. Support that encourages patients to manage their uncertainty on their own while verifying the details of a patient’s uncertainty is important.

CONFLICT OF INTERESTS

None of the authors have any conflicts of interest to declare.

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