



Trends of concerns from diagnosis in patients with advanced lung cancer and their family caregivers: A 2-year longitudinal study

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Abstract

Background: Both advanced cancer patients and their family caregivers experience distress and have a range of concerns after cancer diagnosis. However, longitudinal studies on this topic have been lacking.

Aim: To investigate concerns in both patients with advanced lung cancer and their family caregivers longitudinally from diagnosis.

Design: A multi-center prospective questionnaire-based study.

Setting/participants: We recruited patients with newly diagnosed advanced lung cancer and their family caregivers at 16 hospitals in Japan. We prospectively assessed the prevalence of their concerns using the Concerns Checklist and investigated the associations between their concerns and mental status as well as quality of life until 24 months after diagnosis.

Results: A total of 248 patients and their 232 family caregivers were enrolled. The prevalence of serious concerns was highest at diagnosis (patients: 68.3%, family caregivers: 65.3%). The most common serious concern was concern about the future in both groups at diagnosis (38.2% and 40.5%, respectively) and this remained high in prevalence over time, while the high prevalence of concern about lack of information improved 3 months after diagnosis in both groups. Approximately one-third of patient-family caregiver dyads had discrepant reports of serious concerns. The presence of serious concerns was significantly associated with anxiety and depression continuously in both groups.

Conclusions: The majority of advanced lung cancer patients and their family caregivers have serious concerns from diagnosis, which is associated with their psychological distress. The spectrum of concerns alters over the disease trajectory, warranting efficient tailored care and support for both groups immediately after diagnosis.

Keywords

Concern, advanced cancer, family caregiver, psychological distress, quality of life, needs

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What is already known about the topic?

- Not only advanced cancer patients but also their family caregivers experience physical burden and psychological distress.
- Several studies have reported characteristics of perceived concerns in advanced cancer patients, which were cross-sectional after some while from the time of diagnosis.

What this paper adds

- This longitudinal study provides real-world data for concerns of advanced lung cancer patients and their family caregivers from diagnosis.
- Both of them show highest prevalence of serious concerns at the time of diagnosis.
- The prevalence of concerns among family caregivers is high over time and comparable to that among patients.
- The presence of serious concerns is significantly associated with anxiety and depression continuously in both groups.

Implications for practice, theory, or policy

- This study suggests that real-life concerns in both advanced cancer patients and their family caregivers have considerable impacts on their psychological distress during the disease trajectory.
- Interventions better tailored for both of them through addressing their concerns are warranted.

Introduction

Patients with advanced cancer experience a wide range of problems, such as physical, psychosocial, and practical issues. Family caregivers of patients typically help the patient with symptom management, emotional support, personal care, finance, transportation, and communication with health care providers, during which they experience physical burden and psychological distress sometimes more intensely than the patient.¹⁻³ Wang et al.⁴ in a systematic review identified 12 unmet need domains among patients with advanced cancer and seven among informal caregivers.

The needs and burdens of patients and their caregivers are inter-related. The unsolved patient needs can increase the level of caregiver burden,⁵ while on the other hand, unsolved problems or unmet needs of the caregivers can affect the patient's health outcomes negatively in addition to impairing their own quality of life.^{6,7} Therefore, to improve care and support for both patients and caregivers together has been recognized as an important task in clinical practice.

The first step to improve quality of care is to identify needs or concerns of patients and their caregivers, and provide appropriate care and support based on such assessment of needs.⁸ Strategies to improve the care and support can be made utilizing the knowledge on what kind of concerns are common in patients and are associated with their quality of life. So far, there have been a few studies that have reported perceived concerns and needs in advanced cancer patients,^{4,9-11} however, almost all the studies were cross-sectional studies, where the assessment was conducted at a single time point after some while from the time of diagnosis. Concerns of patients and family at the time soon after they received the

diagnosis of advanced cancer and how their concerns change longitudinally have not been clear. Additionally, the domains of these assessments in the past studies have been biased toward biomedical perspectives rather than psychosocial effects.⁴

Since concerns vary from patient to patient, assessment of individual concerns enables personalized care and support, allowing available resources to be allocated as necessary.

Therefore, in this multicenter study, we aimed to investigate concerns in both patients with advanced lung cancer and their family caregivers longitudinally starting from their cancer diagnosis. We also examined the concordance rate of concerns between a patient and his/her caregiver, and associated factors: sociodemographic characteristics, self-reported quality of life, and mood symptoms of their concerns.

Methods

Study participants

Patient and family caregivers were recruited at 16 academic or medium/large hospitals in Japan from December, 2013 to March, 2016. Patients were eligible if they were (1) diagnosed with clinical stage IIIB or IV lung cancer (the seventh edition of lung cancer stage classification) that were diagnosed radiologically and clinically regardless of histological evidence, (2) 20 years of age or older, and (3) able to write and comprehend Japanese. Patients were excluded if they (1) had significant cognitive impairment, or (2) had already received anticancer treatments, including chemotherapy, radiation, surgery, or immunotherapy. Receipt of supportive therapy, and anticancer treatments for previous cancers other than lung cancer were

exceptions. Family caregivers were eligible if they were (1) identified by the patients as their primary family caregivers, (2) 20 years of age or older, and (3) able to write and comprehend Japanese. Family caregivers were not eligible if they had significant cognitive impairment. This study is part of a larger study, where various psychosocial aspects of patients with advanced lung cancer and their caregivers were longitudinally assessed, and the details of the study procedure have been described elsewhere.¹² This study was approved by the institutional review board of all participating hospitals, and all the participants submitted a written informed consent.

Self-reported outcomes

The Concerns Checklist, developed at Guys' and St. Thomas' Hospitals NHS Trust was used to assess the range of concerns of patients and family caregivers. The validity and acceptability of this checklist have been previously demonstrated.⁹ The Concerns Checklist (Appendix) comprises of fourteen items covering a range of non-physical concerns as follows. C1: lack of information about illness or treatment; C2: the way in which doctors and nurses communicate with you; C3: anything to do with treatment, side effects or care; C4: not being able to do the things you usually do; C5: caring for yourself; C6: lack of support from others; C7: your relationships with important people in your life; C8: worries or concerns about important people in your life; C9: worries or concerns about your appearance; C10: your marital or sexual problems; C11: your finance; C12: your work; C13: mental/spiritual issues; C14: worries or concerns about the future. In the current study, the authors modified an item of the list: "religious/spiritual issues" to "mental/spiritual issues", since most Japanese people do not identify themselves to a specific religion. Participants were asked to rate how much of a problem each item had been over the previous week using a scale ranging 0–3 (0: "not at all," 1: "a little," 2: "quite a bit," and 3: "very much"). In the current study, we defined that a patient and/or a family caregiver have a "serious" concern if they marked a 2 or 3 on any of the items on the Concerns Checklist.

Health-related QOL of patients was measured using the Functional Assessment of Cancer Therapy–Lung (FACT-L) scale. This scale measures multiple dimensions of QOL: physical well-being, social well-being, emotional well-being, functional well-being, and lung cancer symptom burden (lung cancer subscale: LCS) during the past week.^{13,14} Health-related QOL of family caregivers was measured with the Short-Form 8-Item Health Survey (SF-8).^{15,16}

Mood symptoms of patients and family caregivers were measured with the Hospital Anxiety and Depression Scale (HADS), a 14-item self-report questionnaire that contains two subscales measuring anxiety (HADS-A) and depression (HADS-D).^{17,18}

Patients' clinical characteristics were collected through reports from treating physicians at the same time points the participants were asked.

Procedure

Participants were prospectively recruited upon disclosure of their diagnosis of clinical stage IIIB or IV lung cancer (the seventh edition of lung cancer stage classification). Then, participants were asked to complete the questionnaires including the Concerns Checklist, health-related QOL and HADS promptly after submitting written informed consent, 3 months later, 6 months later, 12 months later, and 24 months later.

Statistical analyses

After descriptive analyses, bivariate analyses were conducted to compare variables of the participants with serious concerns with those of the participants without any serious concern. Fisher's exact tests were used for categorical variables and Mann-Whitney *U* tests for continuous and ordinal variables. Spearman's rank correlation coefficient was used to examine correlations between concerns and participants' variables. Proportions of missing data for the items of the Concerns Checklist were all lower than 5% except for C10 (10.4%) and C14 (8.2%) for patients (Supplemental Table 1) and the cases with missing values were excluded on an analysis-by-analysis or pair-by-pair basis. Additionally, considering the missing data, we performed mixed-effects model for repeated measures (MMRM) analyses for the prevalence of serious concerns and the associations between having serious concerns and mental status. An unstructured covariance structure was used to model the within-patient errors. Kenward-Roger correction was used to estimate denominator degrees of freedom. Dyadic analyses for patients and their caregivers were performed using data available for both of them. McNemar tests were conducted to examine differences in proportions between patients and family caregivers. All *p*-values were two-sided and *p* < 0.05 was considered statistically significant. Analyses were performed using SPSS 26.0 software (SPSS, IBM, Chicago, IL, USA) and Statistical Analysis Software version 9.4 (SAS Institute, Cary, NC, USA).

Results

Characteristics of the participants

Of approximately 340 newly diagnosed advanced cancer patients, 265 patients and their 257 family caregivers were eligible and approached. Of them, 248 patients and 232 of their family caregivers agreed to participate in this study. These patients included eight patients who did not have any caregivers and eight patients who had family or

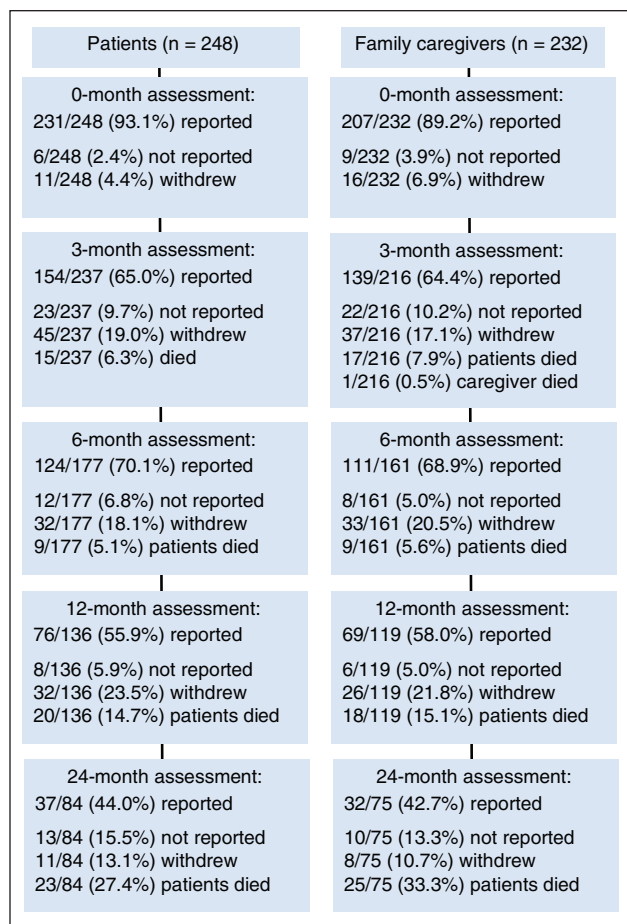


Figure 1. The participants flow diagram.

relatives but for whom we could not obtain their agreement to participate. The flow of the participants is shown in Figure 1. The participants' baseline characteristics are shown in Table 1. Briefly, most patients were over 60 years old, male, smokers, and had an Eastern Cooperative Oncology Group (ECOG) performance status of 0 to 2. Chemotherapy was scheduled for most patients (86.8%). Only several patients (2.6%) were scheduled solely to receive supportive care. The majority of family caregivers were spouses who were over 50 years old, female, and cohabiting with the patient. We examined the differences of variables between the participants who withdrew and those who remained in the survey at 3 months after the diagnosis. Poorer performance status, best supportive care, poorer QOL and higher HADS-D scores were significantly associated with the withdrawals (Supplemental Table 2).

Prevalence of concerns over time

Responses were obtained from 231 patients and their 207 caregivers (response rates: 93.1% and 89.2%, respectively) at the time of diagnosis (Figure 1). As shown in Figure 2, 68.3% of the patients and 65.3% of the family

Table 1. Sociodemographic and clinical characteristics of patients and family caregivers.

Variable	Patients (n = 231); n (%)
Age (year)	
Median	70
Lower-upper quartile	62–77
Sex	
Male	161 (70.0)
Female	69 (30.0)
Smoking status (pack year)	
Median	35
Interquartile range	5–54
Marital status	
Married	146 (66.7)
Single/widowed/divorced	53 (33.3)
Household size	
One person (living alone)	37 (16.7)
Two or more	185 (83.3)
Employment status	
Employed	54 (24.7)
Unemployed	165 (75.3)
Type of hospital	
Academic	72 (31.2)
Medium/large	159 (78.8)
ECOG performance status	
0	109 (47.6)
1	82 (35.8)
2	26 (11.4)
3	10 (4.4)
4	2 (0.9)
Clinical tumor-node-metastasis stage	
IIIB	41 (17.7)
IV	189 (82.3)
Planned initial treatment	
Chemotherapy	197 (86.8)
Radiation	1 (0.4)
Combined chemoradiation	23 (10.1)
Best supportive care	4 (2.6)
Variable	FCs (n = 207); n (%)
Age (year)	
Median	62
Lower-upper quartile	50–70
Sex	
Male	67 (32.8)
Female	137 (67.2)
Marital status	
Married	163 (79.9)
Single/widowed/divorced	41 (20.1)
Employment status	
Employed	111 (54.2)
Unemployed	94 (45.8)
Relationship to patient	
Mother	3 (1.4)
Spouse	109 (53.4)
Sibling	12 (5.9)
Child	68 (33.3)
Other	12 (5.9)
Resides with patient	
Yes	165 (80.9)
No	39 (19.1)

ECOG: Eastern Cooperative Oncology Group; FC: family caregiver.

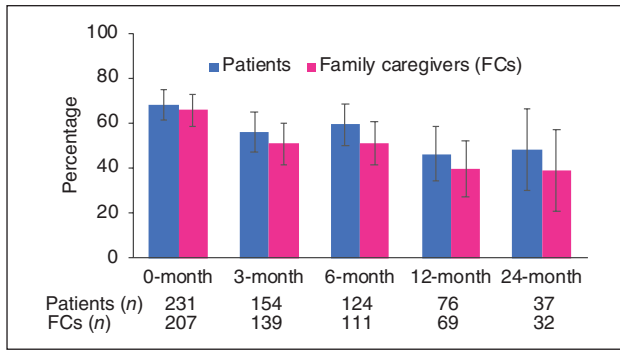


Figure 2. Proportions of participants having at least one serious concern at each time point. Error bars represent 95% confidence intervals. Number of participants assessed at each point is shown below the figure.

caregivers reported serious concerns (ratings of 2 or 3 on at least one item on the checklist) upon cancer diagnosis. These proportions were highest at diagnosis and showed a gradual decline (improvement) as time passed, however, the proportions remained high (higher than 40%) in both patients and family caregivers. The proportion of participants that reported experiencing some concerns for at least one item was more than 90% over time for both patients and family caregivers (Supplemental Figure 1). Estimates and associated confidence intervals of the prevalence of serious concerns over time were calculated as shown in Supplemental Table 3.

The prevalence of each concern at each time point is shown in Figure 3 and Supplemental Figures 2 and 3. The prevalence of “concerns about the future” (C14) was highest among serious concerns (rated as 2 or 3 on the checklist) in both patients and family caregivers at the time of diagnosis (38.2% of the patients and 40.5% of the family caregivers) and the prevalence remained high over time. Mental/spiritual issues (C13) ranked no. 3 in patients and no. 2 in family caregivers at diagnosis (28.8% and 33.3%, respectively) and remained relatively high in family caregivers. Lack of information (C1) ranked no. 2 in patients and no. 4 in family caregivers at diagnosis (29.1% and 30.2% rated 2 or 3, respectively) and reduced after 3 months. Concerns about treatment/care (C3) ranked high at diagnosis (no. 5 and no. 3, respectively) and continued to remain relatively high over time in both patients and family caregivers. Concerns about finance (C11) also remained high in prevalence over time in both patients and family caregivers. Of note, more than one-fourth of the patients reported serious concerns about work (C12) at diagnosis.

One-third of patient-family caregiver dyads had discrepant reports of serious concern at diagnosis and such discrepancies persisted over time (Figure 4). No differences in proportions of having serious concerns between patients and family caregivers were observed over time. When we looked into the concordance between the dyads

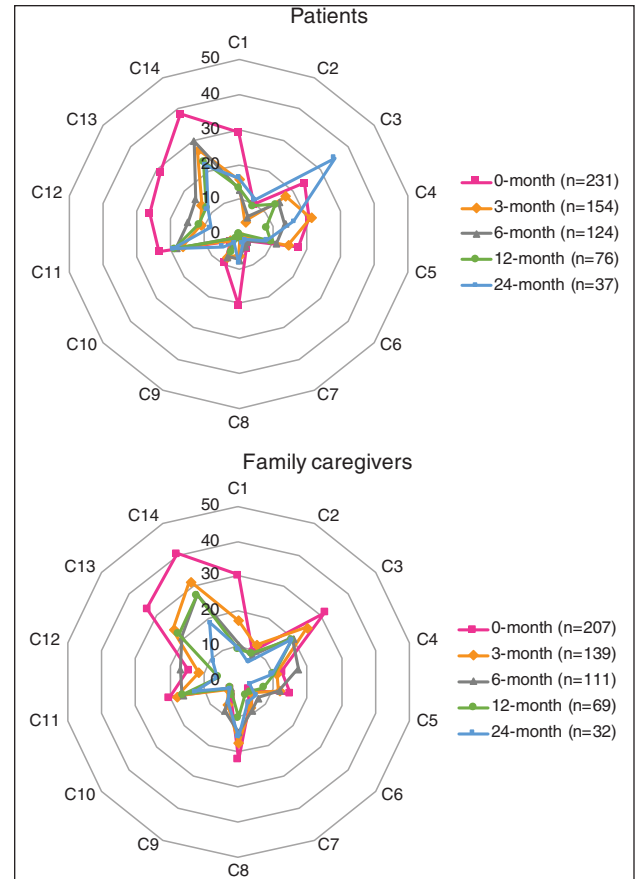


Figure 3. Radar charts showing percentages of participants rating each item as a serious concern at each time point. C1: Lack of information about illness or treatment. C2: The way in which doctors and nurses communicate with you. C3: Anything to do with treatment, side effects or care. C4: Not being able to do the things you usually do. C5: Caring for yourself. C6: Lack of support from others. C7: Your relationships with important people in your life. C8: Worries or concerns about important people in your life. C9: Worries or concerns about your appearance. C10: Your marital or sexual problems. C11: Your finance. C12: Your work. C13: Mental/spiritual issues. C14: Worries or concerns about the future.

for each item of the checklist (Supplemental Figure 4), proportions of the discordance for the concerns with high prevalence, such as concerns about the future (C14), mental/spiritual issues (C13) and concerns about treatment/care (C3), were relatively high over time. We further found that the proportion of having “worries or concerns about important people in your life” (C8) remained high in only family caregivers over time.

Associations between concerns and outcomes

To investigate whether the presence of concerns is linked to poor outcomes in patients and family caregivers, we examined the association between the presence of serious concerns and their mental status. As shown in Figure 5, anxiety and depression, measured by HADS-A and HADS-D

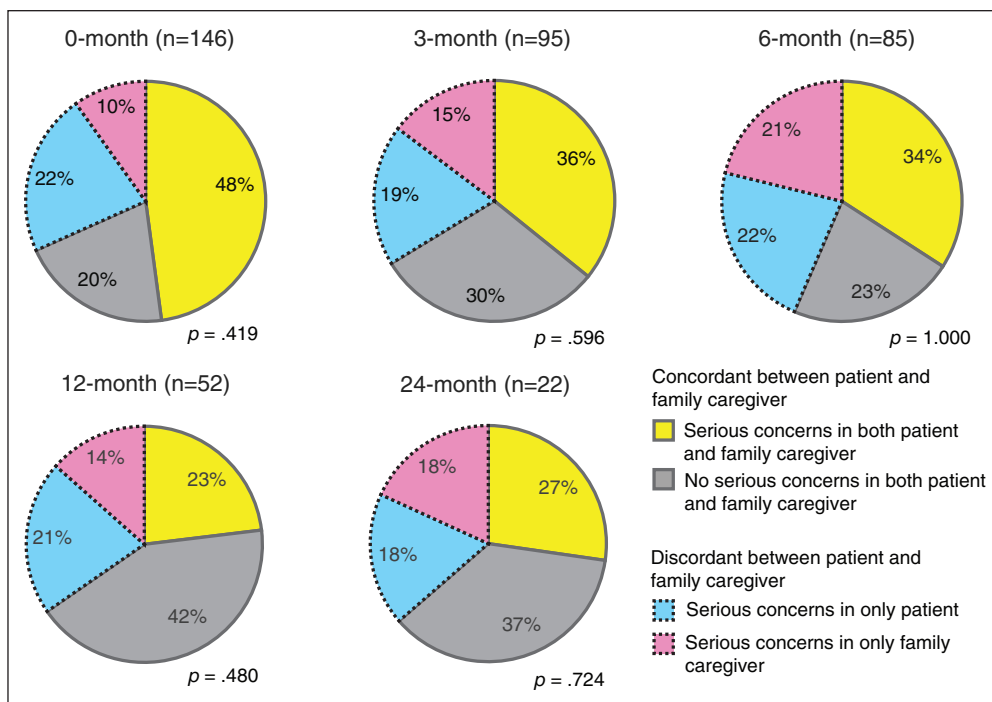


Figure 4. Concordance of having serious concerns between patient-family caregiver dyads at each time point. *p* Values compare differences in proportions of having serious concerns between patients and family caregivers using McNemar test.

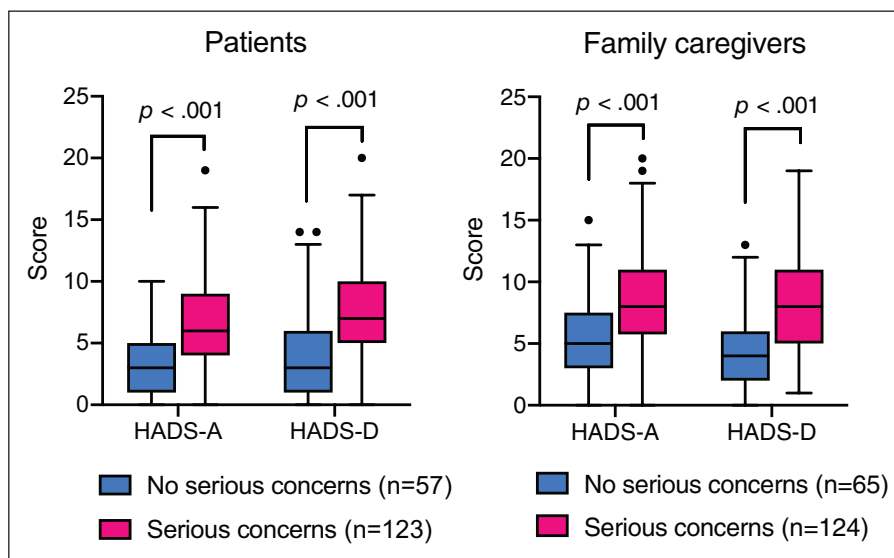


Figure 5. Associations between having serious concerns and mental status in patients and family caregivers at diagnosis. HADS-A: Hospital Anxiety and Depression Scale-Anxiety; HADS-D: Hospital Anxiety and Depression Scale-Depression. *p* Values compare levels of anxiety and depression between participants without any serious concern and those with serious concerns.

scores, were significantly higher among both patients and family caregivers with serious concerns as compared to those without any serious concerns at cancer diagnosis. This trend was observed over time (Supplemental Figure 5). Furthermore, when we performed longitudinal analyses using MMRM, the presence of serious concerns was significantly associated with both HADS-A and HADS-D

scores at all the time points in patients as well as in family caregivers (Supplemental Table 4).

There were no significant associations between the presence of serious concerns and the demographic background characteristics of the patients and family caregivers, except for patients' smoking history which was positively associated with the presence of serious concerns in

patients. In addition, patients' spouses tend to have serious concerns than the other family caregivers (Supplemental Table 5). Of note, we found that in case where the patient reported serious concerns, the family caregiver exhibited worse physical and mental status. We observed the reciprocal where the family caregiver had serious concerns, the patient showed poor physical well-being and higher levels of depression. In multivariate analyses, mental status measured by HADS total score was significantly associated with the presence of serious concerns in both patients and family caregivers (Supplemental Table 6).

We further examined the correlations between each score of the checklist item and the outcomes (quality of life and mental status in both patients and family caregivers) (Supplemental Table 7 and Supplemental Figure 6). For patients' concerns, we found moderate correlations between the concern of "being unable to do things" (C4) and physical well-being ($r = -0.404$), HADS-A ($r = 0.403$) and HADS-D ($r = 0.421$); between mental/spiritual issues (C13) and emotional well-being ($r = -0.522$), HADS-A ($r = 0.532$), and HADS-D ($r = 0.440$); between concerns about the future (C14) and emotional well-being ($r = 0.549$), HADS-A ($r = 0.523$), and HADS-D ($r = 0.412$). A strong correlation was observed between total scores of the checklist and HADS-A ($r = 0.662$). Noteworthy, there were weak correlations between the total scores of patients and the physical component summary of the SF-8 ($r = -0.202$), HADS-A ($r = 0.251$), and HADS-D ($r = 0.244$) of family caregivers, suggesting a relationship between patients' concerns and family caregivers' conditions. For family caregivers' concerns, moderate correlations were found between the concerns on "being unable to do things" (C4) and the mental component summary of the SF-8 ($r = -0.509$), HADS-A ($r = 0.414$), and HADS-D ($r = 0.417$); between the concerns on "self-care" (C5) and HADS-A ($r = 0.403$) and HADS-D ($r = 0.405$); between mental/spiritual issues (C13) and the mental component summary ($r = -0.470$), HADS-A ($r = 0.569$) and HADS-D ($r = 0.518$); between concerns about the future (C14) and the mental component summary ($r = -0.466$), HADS-A ($r = 0.501$) and HADS-D ($r = 0.514$).

Discussion

Main findings

In this multi-center longitudinal study, we found a high prevalence of concerns in both patients with advanced cancer and their family caregivers especially at the time of their cancer diagnosis. The prevalence of concerns among family caregivers was comparable to those among patients at diagnosis and remained high over time; adding to our knowledge about how concerns among both groups fluctuate along the illness trajectory. In addition, it is worth noting that this is the first study to demonstrate that the presence of serious concerns is associated with worse

mental status not only in patients but also in family caregivers, warranting additional efforts to support both patients and family caregivers.

Interpretation of results and implications

Nearly 70% of the patients reported serious concerns on at least one item at the time of diagnosis. Although the prevalence of serious concerns was highest at diagnosis, more than 90% of the patients consistently reported some level of concerns over time. When we looked into the detail of their concerns, the prevalence of each serious concern alters during the illness trajectory, especially from the diagnosis to 3 months after. "Worries or concerns about the future" was their major concern persistent over time, as reported in previous studies,^{9,11} suggesting the need for perspective-sharing among clinicians, patients and their family caregivers. "Lack of information about illness and treatment" was a prevalent concern soon after diagnosis, suggesting the need for immediate and efficient patient-clinician communication. A relatively high prevalence of "Mental/spiritual issues" at the time of diagnosis indicates that patients are generally aware of their psychological distress. The risk of suicide among cancer patients with poor prognosis is high, especially in the first 6 months after diagnosis.^{19,20} Thus, efforts to address the psychological distress of patients are warranted. We also found that finance was a major concern in patients over time as they would need to manage the financial impact of their cancer to afford medical care and treatment. Importantly, we found a high prevalence of concerns about work at the time of diagnosis among patients, warranting immediate interventions so as not to lose their employment after their cancer diagnosis.

The proportion of family caregivers who reported serious concerns since diagnosis was as high as that of the patients. An equivalent or higher proportion of family caregivers compared to patients reported serious concerns about the future, mental/spiritual issues, lack of information and treatment/care over time. These findings are similar to previous studies that reported the unmet needs of family caregivers.^{11,21-23} Their concerns included multiple aspects, suggesting that care and support for family caregivers should be provided by a multidisciplinary team. Additionally, we noticed a substantial discrepancy between patient-family caregiver dyads regarding serious concerns. This discrepancy teaches us that only assessing patients is not enough to support family caregivers, as care and support for family caregivers have been suboptimal in many situations compared with those for patients.²⁴ Interventions better tailored for family caregivers need to be provided effectively in both clinical and social settings.

In this study, we elucidated the associations between the presence of concerns and mental status (anxiety and

depression) in both patients and family caregivers. Of note, not only concerns regarding “mental/spiritual issues” and “the future” but also “being unable to do things they usually did” and “self-care” showed strong associations with anxiety and depression in both patients and family caregivers, suggesting that real-life problems have impacts on psychological distress for both of them. Although the causal relationship between concerns and mental status is unclear in this study, addressing their specific concerns may be an effective approach to reduce their psychological distress, which warrants further investigation.

In previous studies, the associations between sociodemographic and clinical variables including patients’ physical status and unmet needs of patients and their family caregivers have been pointed out, despite these efforts, the findings are inconsistent across studies.^{4,11,22,25–27} In our study, we found spousal caregivers tend to have serious concerns when compared with non-spousal caregivers. Fukui²⁶ reported that spousal caregivers presented more information needs. It is plausible that spousal caregivers may have more worries and concerns since they are usually in closer relationships with patients than others. Furthermore, we observed the associations between the presence of serious concerns in patients and family caregivers’ physical/mental status; in a reciprocal way, the presence of serious concerns in family caregivers was associated with patients’ physical/mental status. Chen et al.²² reported that poor physical performance and high levels of anxiety and depression of patients were associated with family caregivers’ supportive care needs. Although the causal relationships have not been confirmed, addressing concerns among both patients and family caregivers as a whole can be beneficial considering our findings indicate their mutual interactions.

Limitations

Our study has a few limitations. First, while there are other established needs assessment measures such as the Supportive Care Needs Survey (SCNS),²⁸ the Problems and Needs in Palliative Care questionnaire (PNPC),²⁹ and the Needs Assessment of Advanced Cancer Patients (NA-ACP),³⁰ we preferred the Concerns Checklist because it is simple while being comprehensive, for the participants to fill in with other questionnaires without feeling burdened. Although we used the Concerns Checklist that had been used and validated for cancer patients in previously published studies, the questionnaire has not been validated in the Japanese cancer population and for family caregivers. Second, although this was a longitudinal study, causal relationships of the associated variables cannot be inferred. Finally, the number of participants who completed the questionnaire decreased over time due to the nature of advanced cancer, therefore, the prevalence of

concerns the later time points are biased to those of longer-time survivors and their family caregivers.

Conclusion

In summary, this study is noteworthy in that it is the first study that comprehensively evaluated concerns of patients with advanced lung cancer and their family caregivers longitudinally from their cancer diagnosis. It elucidated that not only patients but also their family caregivers have a wide range of concerns from the time of diagnosis. We also highlighted association between the presence of concerns and psychological distress among both groups. Tailored care and support for both patients and family caregivers through addressing their concerns may help to improve their quality of life.

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Author contributions

T.S.: Conceptualization, methodology, formal analysis, investigation, visualization, supervision, and writing—original draft. D.F.: Conceptualization, methodology, and writing—review and editing. D.A.: Conceptualization, methodology, investigation, data curation, and writing—review and editing. I.N.: Resources, supervision, and writing—review and editing. M.T.: Conceptualization, methodology, and writing—review and editing. S.N.: Investigation, project administration, and writing—review and editing. K.K.: Investigation and writing—review and editing. Shinnosuke Ikemura: Investigation, project administration, and writing—review and editing. H.T.: Investigation, project administration, and writing—review and editing., H.Y.: Project administration and writing—review and editing. I.K.: Project administration and writing—review and editing. Y.S.: Methodology, formal analysis, and writing—review and editing. R.S.: Investigation and writing—review and editing. S.T.: Investigation and writing—review and editing. M.H.H.: Investigation and writing—review and editing. M.N.: Resources, supervision, and writing—review and editing. Y.O.: Resources, supervision, and writing—review and editing. T.T.: Resources, supervision, writing—review and editing. K.S.: Resources, supervision, writing—review and editing. F.S.: Resources, supervision, writing—review and editing. F.S.: Supervision and writing—review and editing. T.I.: Investigation, resources, supervision, and writing—review and editing. K.N.: Conceptualization, investigation, supervision, and writing—review and editing. K.F.: Resources, supervision, and writing—review and editing. K.S.: Conceptualization, methodology, investigation, supervision and writing—review and editing,

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