PAPER

WILEY

Trajectories of caregiver burden and related factors in family caregivers of patients with lung cancer

Yun-Hsiang Lee[1] ⬤ | Yu-Chien Liao[2] | Shiow-Ching Shun[1] | Kuan-Chia Lin[3] |
Wei-Yu Liao[4] | Pi-Hua Chang[5] ⬤ | Sin-Yuan Jhang[6] | Chong-Jen Yu[4] | Pan-Chyr Yang[4] |
Pei-Yin Hsieh[6] | Yeur-Hur Lai[1]

[1] School of Nursing, College of Medicine, National Taiwan University, Taipei, Taiwan

[2] Department of Nursing, Yuanpei University, Hsinchu City, Taiwan

[3] Institute of Hospital and Health Care Administration, Community Medicine Research Center, National Yang-Ming University, Taipei, Taiwan

[4] Department of Internal Medicine, National Taiwan University Hospital, Taipei, Taiwan

[5] Department of Nursing, Taichung Veterans General Hospital, Taichung, Taiwan

[6] Department of Nursing, National Taiwan University Hospital, Taipei, Taiwan

Correspondence
Yeur-Hur Lai, School of Nursing, College of Medicine, National Taiwan University, 1 Jen-Ai Rd., Sec. 1, Taipei 100, Taiwan.
Email: laiyhwk@ntu.edu.tw

Funding information
National Health Research Institutes of Taiwan, Grant/Award Number: NHRI-EX-100-980

Abstract

Objective: This study aimed to (1) identify the changes of 5 domains of family caregiver (FC) burden, overall burden, and its subtrajectories when caring for newly diagnosed advanced lung cancer patients during the first 6 months following cancer diagnosis; and (2) identify the FC-related and patient-related factors most associated with the overall FC burden and each of its subtrajectories.

Methods: A total of 150 newly diagnosed advanced lung cancer patient-FC dyads were recruited from a Taiwanese medical center. The overall FC burden was evaluated 4 times: before treatment, and 1, 3, and 6 months after treatment. The potential subtrajectory of the caregiver burden was investigated by latent class growth analysis. The FC-related and patient-related factors having the greatest effect on the overall FC burden and its subtrajectories over time were identified by generalized estimating equations.

Results: The highest level of burden domain was "Impact on daily schedule" over time. Generally, most of the FC reported a moderate level of overall burden over the investigation period. Three subtrajectories of the overall FC burden over time (% caregivers) were identified: high burden (34.7%), moderate burden (56.0%), and low burden (9.3%), respectively. The self-efficacy of FC was the strongest factor related to the changes of the FC's burden and burden in each subtrajectory.

Conclusion: The results support the existing and different types of subtrajectories of the FC's burden. Health care professionals should provide care based on those differences. Further research to test interventions which integrate those important factors related to FC's burden, particularly FC's self-efficacy, is strongly suggested.

KEYWORDS

cancer, caregiver burden, family caregiver, lung cancer, oncology, self-efficacy, trajectories

1 | INTRODUCTION

Lung cancer is the leading cause of cancer mortality.[1] Other than those in the terminal stages of cancer, or receiving surgery, most lung cancer patients are treated as outpatients. This increases the responsibility and care burden on family caregivers (FC). The burden is a dynamic multidimensional process which varies depending on how well the FC cope with their caregiving demands.[2] FC have to balance numerous care demands with the additional stress of watching a family member suffer from illness.[3] FC burden involves multiple physical, psychological, social, and financial dimensions,[2] which may impact the patient's

psychological status[4,5] and the FC's health.[4,6] Understanding the burden is essential in supporting patients and caregivers.

The FC burden varies depending on different cancers and disease-related conditions. Cancer caregivers face a consistently moderate burden after patient discharge.[7,8] Similar findings were reported in a Taiwanese study on caregivers of terminally ill cancer patients.[9] The informal caregivers of lung cancer patients experience high levels of burden and increasing demands over time.[10] Furthermore, of the 5 domains (lack of family support, impact on finance, impact on daily schedule, impact on health, and self-esteem) of overall burden,[11] the "impact on daily schedule" domain was the most severe burden in

caregivers of patients with lung cancer over time.[5] Thus, the FC burden of those caring for newly diagnosed advanced lung cancer patients is particularly severe due to the life-threatening nature and high mortality rate of advanced lung cancer.[1] In the first 6 months, a majority of those patients undergo anti-cancer therapy,[12] and the nature of the FC burden changes as the patient condition evolves.[13] Thus, to provide effective support to FCs and patients, a longitudinal study of the FC burden in this 6-month period is essential.

The human response to stress is highly varied.[14] In lung cancer care, different subtrajectories of FC burden may exist for particular FC-related and patient-related factors. Palos et al[15] identified 2 different symptom burden trajectories in FC caring for patients receiving chemotherapy treatment. Essentially, health care professionals should understand the factors related to FC burden and its subtrajectories and in devising personalized intervention solutions.

Based on the cancer family caregiving model,[4] this study hypothesizes that the caregiver burden is associated with 2 types of stressors: patient-related and FC-related factors. Patient-related factors include type of treatment, functional status, symptom severity, and depression. FC-related factors include employment status, financial problems, relationship with patient, previous caregiving experience, and caregivers' symptoms (eg, fatigue).[4] Based on the results of our previous study in FC anxiety and depression,[16] we also selected "FC's pain" and "FC caring for another sick family member (yes/ no)" as 2 other potential factors for examining their relationship to FC's burden.

This study also hypothesized an effect of FC's self-efficacy (confidence) in coping with cancer on their burden, because it provides important insight into the caregiver's confidence in adjusting their stress, motivation, and their capabilities to approach difficult tasks as challenges,[17] which has been integrated in this study for a potentially positive effect in helping caregivers care for cancer patients.[17,18] Thus, this study aimed to (1) the changes of 5 domains of FC burden, overall burden, and its subtrajectories when caring for newly diagnosed advanced lung cancer patients in the first 6 months; and (2) identify factors related to the overall FC burden and each of its subtrajectories.

2 | METHODS

2.1 | Design, sample, and setting

Patients with advanced lung cancer and their primary FCs were recruited from January 2011 to March 2014 from a Taiwanese medical center by consecutive sampling.[19] Patients were over 18 years old and diagnosed with non-small cell lung cancer at stage IIIb or IV. Eligible FCs were over 18 years old and identified by patients as their primary FCs. The patients and the FCs agreed to be interviewed at baseline (prior to initiating treatment, T0) and 1, 3, and 6 months post-treatment (T1, T2, and T3, respectively). The data-collection times were chosen to coincide with the follow-up appointments at these 3 intervals. Of the 174 patient-FC dyads (86.2%), 150 met the inclusion criteria and completed the first (T0) and second (T1) assessments. However, 15 participants and 10 participants dropped out at T2 and T3, respectively, due to a deterioration of the patient's condition.

2.2 | Procedure

The study was approved by the medical center's Institutional Review Board (Number: 200803079R). All patients were referred by physicians and approached as early as possible after diagnosis. Each participant signed informed consent forms and completed a set of questionnaires in 12 to 15 minutes at the 4 assessment points.

2.3 | Measures

2.3.1 | Participants' demographic and clinical characteristics

The participants' characteristics were measured using a researcher-designed and participant-completed background-information form. The clinical characteristics were obtained from medical records.

2.3.2 | Patients' physical functioning and symptoms

Physical functioning and symptoms were measured using the 30-item European Organization for Research and Treatment of Cancer QLQ-C30 (EORTC QLQ—C30). The physical function items were rated on a 4-point scale from 1 (not at all) to 4 (very much), and the scores were then transformed to a 0 to 100 scale, with a higher score indicating a better functional status. The symptom subscales included fatigue, nausea/vomiting, pain, dyspnea, insomnia, lack of appetite, constipation, and diarrhea; with a lower score indicating a reduced severity.[20] A Chinese version of the EORTC QLQ-C30 has been shown to provide both acceptable reliability and good validity.[21] The values of Cronbach's alpha for the EORTC QLQ-C30 physical function and symptom subscales in this study were 0.80 to 0.85 and 0.76 to 0.92, respectively.

2.3.3 | Patients' depression

Depression was assessed using the depression subscale of the Hospital Anxiety and Depression Scale (HADS).[22,23] HADS depression subscale comprises 7 items, scored from 0 (not at all) to 3, where a higher score reflects a greater depression level. The values of Cronbach's alpha for the depression subscale of HADS were 0.73 to 0.80.

2.3.4 | FCs' pain and fatigue

The FC perceived pain and fatigue levels were assessed using numerical rating scales, with scores ranging from 0 (no pain/fatigue) to 10 (worst pain/fatigue imaginable).

2.3.5 | FCs' self-efficacy for coping with cancer

The self-efficacy of the FC for coping with cancer was measured using a modified version of the Cancer Behavior Inventory-Brief (CBI-B).[24] The CBI-B scale is scored from 0 (no confidence at all) to 10 (totally confident). A 14-item Chinese version of the CBI-B was tested in a previous study involving Taiwanese cancer patients.[25] This study used this version but modified 2 items related to the dimension of "coping with treatment-related side-affects": (1) help patient manage symptoms such as nausea and vomiting, and (2) help patient cope with physical challenges. The remaining 12 items on the scale were retained without modification. Cronbach's alpha for the CBI-B scale varied from 0.90 to 0.94.

2.3.6 | Caregivers' subjective burden

The subjective burden of the FC was assessed using the 24-item Caregiver Reaction Assessment (CRA). 5 domains of CRA include positive caregiving experiences (self-esteem) and negative caregiving experiences (lack of family support, impact on finances, impact on daily schedule, and impact on health). The overall burden is the sum of these 5 domains of burden. The items were scored on a 5-point scale from 1 (strongly disagree) to 5 (strongly agree). For self-esteem, a lower score indicates higher caregiver burden, while for the 4 other domains, higher scores indicate higher caregiver burden.[11] However, Grov et al (2006) recorded the self-esteem domain, higher scores also reflected higher burden,[26] which was applied in this study. The Chinese-version CRA for Taiwanese FC of cancer patients has good reliability and validity.[9] Cronbach's alpha for the CRA and its subscales were 0.70 to 0.76.

2.4 | Data analysis

The participants' demographic, clinical characteristics, 5 domains of FC burden, and overall caregiver burden were analyzed in terms of their means, standard deviations (SD), number, and frequency using SPSS for Windows 20.0. The subtrajectories of the overall FC burden were identified by latent class growth analysis.[27] FC sharing similar trajectories of the overall FC burden over time were grouped together using semi-parametric, group-based trajectory modeling, which is an exploratory statistical analysis method that was used to identify the similar trajectories of overall caregiver burden over time. The fit of longitudinal data to a group-based model was analyzed using the Proc Traj macro of SAS (SAS, Version 9.2, Cary, NC). We also examined those potential categories of overall burden subtrajectories by goodness-of-fit tests based on Bayesian and Akaike criteria for model selection.[28] Finally, the factors most strongly related to changes in and trajectories of the overall FC burden and its subtrajectories were identified separately by generalized estimating equations (GEE).[29]

Potential factors for the GEE model were selected a priori by univariate analyses (independent t-tests, one-way ANOVA, and Pearson's correlation coefficients). Thus, potential factors included patient variables (gender; marital status; employment status; type of treatment; physical function; symptoms such as fatigue, nausea, vomiting, poor appetite, and diarrhea; and depression), FC variables (employment status, monthly household income, relationship with patient, caring for another sick family member, alternative care, pain, fatigue, and self-efficacy), and time (T0, T1, T2, and T3). Because the purpose of the study was to identify trajectories of the overall caregiver burden over time, the sample size of each group could not be estimated beforehand. Consequently, the observed power[30] was used to examine the sample size once data collection was completed.

3 | RESULTS

3.1 | Participant characteristics

The participants (n = 150) were 65.3% male with mean age of 60.0 years (SD = 11.4) and mean education of 10.1 years (SD = 4.8).

Most patients were married (78.7%), had a religion (70.7%) and were diagnosed with stage IV lung cancer (84.7%) (Table 1).

The participating FC (n = 150) were mainly female (70.0%), with mean age of 48.0 years (SD = 13.8) and mean education of 12.7 years (SD = 3.9); 75.3% of the FC were married, and half of the FC were patients' spouses (50.0%). Most had no caregiving experience (65.3%) and 61.3% had an alternative caregiver (Table 1).

3.2 | Changes in patient's depression over time

The patients' mean scores for depression at T0, T1, T2, and T3 were 5.9 (± 4.0), 5.1 (± 4.1), 5.4 (±4.5), and 4.6 (±4.0), respectively.

3.3 | Changes of five domains of FC burden (based on CRA five subscales) over time

Among the 5 domains of FC burden, the highest level of burden on average was "Impact on daily schedule" over time (range = 2.8-3.1). The second highest level of burden was "Impact on finances" over time (range = 2.5-2.6). On average, the other 3 domains of FC burden presented lower scores over time (Figure 1).

3.4 | Change of the overall FC burden and its subtrajectories over time

The mean scores (M ± SD) of the overall FC burden at T0, T1, T2, and T3 were 2.5 (± 0.4), 2.5 (± 0.5), 2.4 (±0.5), and 2.5 (±0.5), respectively. A 3-group solution for the model that best described the subtrajectories of FC burden was identified based on the smallest values of BIC (−2007.09) and AIC (−1984.51). This was achieved by Latent Class Growth Analysis. We defined the 3 subtrajectories based on their relative relationship to the overall FC burden and named them as high burden, moderate burden, and low burden. Most FC belonged to the moderate burden trajectory group (56.0%), with a moderate burden level (range = 2.3-2.4); 34.7% of the FC belonged to the higher burden trajectory group, with a high mean burden over time (range = 2.8-2.9); and 9.3% of the FC belonged to the lower burden trajectory group (range = 1.5-1.9), with a mild burden level which decreased at T2 and then increased slightly at T3 (Figure 2).

3.5 | Factors related to the changes in overall FC burden and FC burden subtrajectories

Changes in the overall FC burden over the 6-month follow-up period were significantly related to the FC self-efficacy (β = −0.042, P < .01), and to 5 other FC-related factors: the FC being the patient's spouse (β = 0.151, P < .05), having another sick family member (β = 0.189, P < .01), not having an alternative caregiver (β = 0.131, P < .05), FC pain (β = 0.020, P < .01) and FC fatigue (β = 0.017, P < .05) (Table 2).

The high FC burden subtrajectory was significantly related to changes in patient appetite (β = 0.002, P < .05), not having an alternative caregiver (β = 0.188, P < .01), FC pain (β = 0.024, P < .05), and FC self-efficacy (β = −0.048, P < .05).

For the moderate FC burden group, the FC burden was significantly related to the patient being male (β = 0.108, P < .01), changes

TABLE 1 Demographic and clinical characteristics of participants (N = 150)

Variable	Patients (n = 150) Mean (SD)	FCs (n = 150) Mean (SD)
Age (years)	60.0 (11.4)	48.0 (13.8)
Education (years)	10.1 (4.8)	12.7 (3.9)
Performance status (score)	1.1 (0.5)	-
	n (%)	n (%)
Gender		
Male	98 (65.3)	45 (30.0)
Female	52 (34.7)	105 (70.0)
Education level		
≦elementary school	48 (32.0)	14 (9.5)
Junior high school	27 (18.0)	22 (14.7)
Senior high school	32 (21.3)	41 (27.2)
≧college	43 (28.7)	73 (48.6)
Marital status		
Unmarried	32 (21.3)	37 (24.7)
Married	118 (78.7)	113 (75.3)
Religion		
No	44 (29.3)	33 (22.0)
Yes	106 (70.7)	117 (78.0)
Employment status		
Unemployed	79 (52.7)	-
Unemployed since sick	30 (20.0)	-
Employed	41 (27.3)	-
Cancer stage		
IIIb	23 (15.3)	-
IV	127 (84.7)	-
Histology		
Adenocarcinoma	132 (88.0)	-
Squamous cell	16 (10.6)	-
Other	2 (1.4)	-
Type of treatment (T1)		
Chemotherapy	96 (64.0)	-
EGFR-TKI (Iressa, Tarceva)	32 (21.3)	-
Radiotherapy	4 (2.7)	-
Chemotherapy and radiotherapy	18 (12.0)	-
Current employment status		
Full-time	-	59 (39.3)
Part-time	-	12 (8.0)
Unemployed	-	79 (52.7)
Previous occupational status		
Fulltime work		80 (53.3)
Part time work		15 (10.0)
Unemployed		55 (36.7)
Presence of health problems		
No	-	105 (70.0)
Yes	-	45 (30.0)
Monthly household income		
<expenses	-	48 (32.0)
Equal to expenses	-	57 (38.0)
>expenses	-	45 (30.0)
		(Continues)

TABLE 1 (Continued)

Variable	Patients (n = 150) Mean (SD)	FCs (n = 150) Mean (SD)
Relationship to patient		
Spouse	-	75 (50.0)
Child	-	53 (35.3)
Parents	-	2 (1.3)
Other relative		20 (13.4)
Caring for another sick family member		
No	-	128 (85.3)
Yes	-	22 (14.7)
Previous care experience		
No	-	98 (65.3)
Yes	-	52 (34.7)
Alternative care		
No	-	58 (38.7)
Yes	-	92 (61.3)

Abbreviation: EGFR-TKI, epidermal growth factor receptor-tyrosine kinase inhibitors.

in the level of patient depression (β = 0.013, P < .05), the FC being married (β = 0.101, P < .05), changes in the FC fatigue (β = 0.015, P < .05), and FC self-efficacy (β = −0.019, P < .05).

For the lower FC burden group, the FC burden was significantly lower at T2 and T3 than at T0 (β = −0.359, P < .05, and β = −0.236, P < .01, respectively). Furthermore, the FC burden significantly depended on only the FC self-efficacy (β = −0.042, P < .05).

4 | DISCUSSION

This study explored the FC burden issue over the first 6 months following the diagnosis of advanced lung cancer patients and considered both FC-related and patient-related factors. The results revealed important findings.

The "Impact on daily schedule" domain of FC burden was the most severe burden consistently over time which is similar as the previous study.[5] Among this burden domain, spending lots of time in care-giving and not being employed are identified. Similar as the previous study[31] that 19.6% of caregivers leave their jobs, 16% of the FCs quit their jobs before patients receiving first treatment in this study. Financial strain might become another burden following disruption of the FCs' schedule and job loss. In clinical settings, helping FC to develop effective problem-solving skills and providing resources in caring patients should be delivered to them.

Regarding the overall FC burden, most FC reported a consistent and moderate level of burden over the first 6-month investigation period. This finding is similar to that reported in previous studies.[7,8] However, it differs from the high burden reported for the FC of lung cancer patients.[10] The difference in findings might be 61.3% of the FC had alternative care, whereas in the study of Grant et al,[10] only 40% to 44% of the caregivers received help from friends and neighbors.
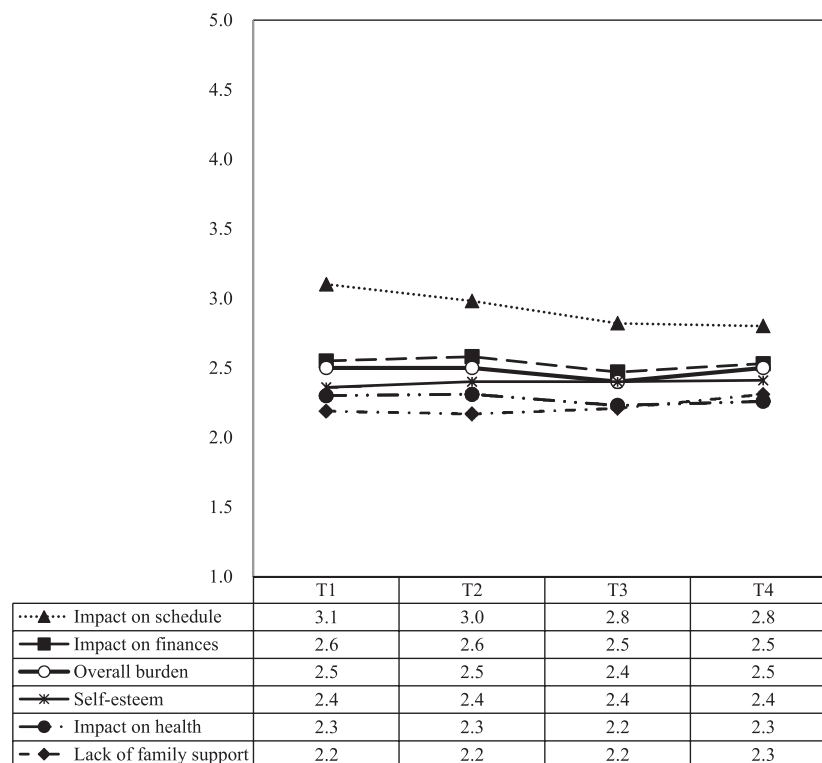
	T1	T2	T3	T4
····▲··· Impact on schedule	3.1	3.0	2.8	2.8
─■─ Impact on finances	2.6	2.6	2.5	2.5
─○─ Overall burden	2.5	2.5	2.4	2.5
─∗─ Self-esteem	2.4	2.4	2.4	2.4
─●· Impact on health	2.3	2.3	2.2	2.3
─ ◆ ─ Lack of family support	2.2	2.2	2.2	2.3

FIGURE 1 The changes and 5 domains of overall caregiver burden

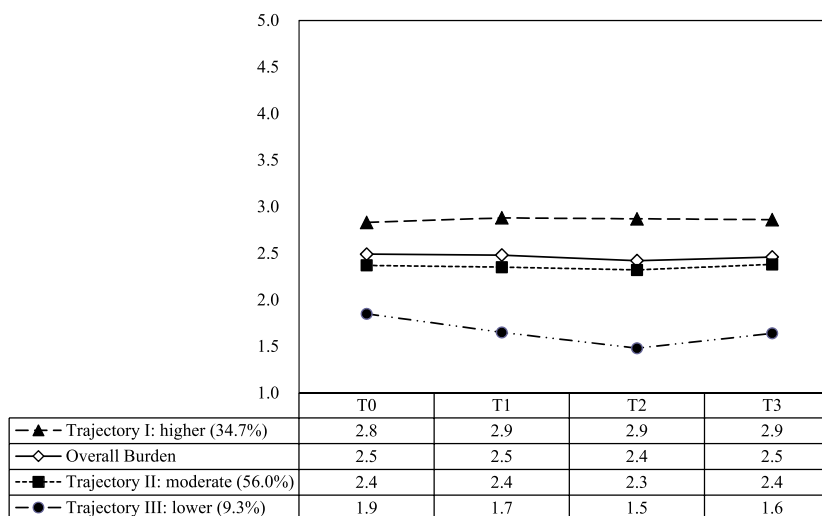|	T0	T1	T2	T3
─▲─ Trajectory I: higher (34.7%)	2.8	2.9	2.9	2.9
─◇─ Overall Burden	2.5	2.5	2.4	2.5
─■─ Trajectory II: moderate (56.0%)	2.4	2.4	2.3	2.4
─●─ Trajectory III: lower (9.3%)	1.9	1.7	1.5	1.6

FIGURE 2 Changes in and subtrajectories of FC burden. The effect of times was tested, and only "trajectory III: Lower" showed significant changes over time. T1/T0: $\beta = -0.188$, $P = 0.096$; T2/T0: $B = -0.359$, $P = 0.014$; T3/T0: $\beta = -0.236$, $P = 0.001$

Three subtrajectories of the FC burden were identified: high, moderate, and low. More than half of the FC (56%) perceived a moderate level of burden and did not change significantly during the study period, while 34.7% experienced a high level. Both FC groups (but particularly those with a high burden) require support from health care professionals. Some FCs in the low burden group (9.3%) reported mild burden and had significant changes over time. This finding was opposite to past studies.[7,8] All FCs in the low group who reported that they did not have another sick family member, had a higher percentage of alternative care, better household incomes, and higher education levels. These might be reasons for the lower caregiver burden in this group.

The different subtrajectories suggest that the FC burden varies with different FC-related and patient-related factors, which implies that they probably require different intervention strategies. The FC self-efficacy coping with cancer was the strongest factor related to overall FC burden and the various subtrajectories. Further analysis of the CBI-B subscale scores showed that FCs had lower confidence in affective regulation and seeking support. Thus, we recommend that clinicians help FCs of lung cancer patients to improve their skills for emotional management and support seeking.

"Not having alternative caregivers" is an important factor in determining the overall FC burden and is associated with the high burden group. The literature lacks longitudinal studies on FC alternative caregivers. One longitudinal study on perceived burden of US caregivers did consider the help provided to the FC by friends and neighbors; it was not made clear whether this help was related to caregiving tasks or caregiver burden.[10] Sharing the care burden for FC of cancer

TABLE 2 Significant factors related to changes in and subtrajectories of FC burden by GEE analysis

Variable	Estimate	Standard Error	95% CI Lower	95% CI Upper	Wald Chi-Square	P
Changes in overall FC burden						
Overall FC burden						
(intercept)	2.635	0.142	2.357	2.912	346.330	<0.001
FC variables						
Spouse (vs. child)	0.151	0.071	0.012	0.290	4.544	0.033
Another sick family member	0.189	0.055	0.082	0.296	11.970	0.001
No alternative care	0.131	0.053	0.028	0.235	6.153	0.013
Pain	0.020	0.008	0.005	0.035	7.173	0.007
Fatigue	0.017	0.007	0.004	0.031	6.612	0.010
Self-efficacy	−0.042	0.011	−0.063	−0.020	14.740	<0.001
Subtrajectories of FC burden						
Higher burden trajectory (34.7%)						
(intercept)	2.725	0.289	2.158	3.292	88.650	<0.001
Patient variables						
Poor appetite	0.002	0.001	0.000	0.004	4.393	0.036
FC variables						
No alternative care	0.188	0.070	0.052	0.325	7.298	0.007
Pain	0.024	0.010	0.005	0.044	5.808	0.016
Self-efficacy	−0.048	0.016	−0.079	−0.017	9.231	0.024
Moderate burden trajectory (56.0%)						
(intercept)	2.419	0.129	2.165	2.672	349.710	<0.001
Patient variables						
Male	0.108	0.034	0.041	0.175	10.040	0.002
Depression	0.013	0.005	0.003	0.023	6.355	0.012
FC variables						
Married	0.101	0.044	0.015	0.186	5.350	0.021
Fatigue	0.015	0.007	0.002	0.029	4.871	0.027
Self-efficacy	−0.019	0.010	−0.039	0.001	3.607	0.048
Lower burden trajectory (9.3%)						
(intercept)	1.548	0.370	0.822	2.274	17.480	<0.001
FC variables						
Self-efficacy	−0.042	0.022	−0.086	0.002	3.540	0.046
Time						
T2/T0	−0.359	0.146	−0.644	−0.073	6.069	0.014
T3/T0	−0.236	0.069	−0.371	−0.102	11.819	0.001

patients and devising intervention strategies merits further investigation. "Having another sick family member" is also associated with overall FC burden. Thus, further research to integrate both issues and test related interventions is important for providing effective solutions for this particular category of FC.

Being a spousal caregiver is also a significant factor of FC burden. This finding is similar to that of a study on spousal and adult-child informal caregivers of older adults.[32] Being married is also associated with moderate-burden trajectory and is probably due to having children or other family members' needs to meet, and more social and domestic responsibilities. The present results show that FC caring for male patients is likely to perceive a moderate burden than those caring for female patients. This may be due to male patients experiencing a more rapid and significant deterioration than female patients.[33] However, it may also be explained by male patients often being the main

family breadwinner, so having lung cancer may impact family income and increase FC burden.[34] Furthermore, Taiwanese females are expected to take care of the sick. Therefore, the FC burden may be increased by societal expectations.

FC physical pain and fatigue are significantly related to FC burden. FC pain is also related to the high burden subtrajectory. Similar to the result of our previous study,[16] the physical pain of FCs is a crucial factor that places them at a high risk of anxiety and depression. In this study, caregivers' own pain was still one of the major factors related to their burden over time. In addition, FC fatigue was also attributed as a major factor related to FC burden. Thus, the pain and fatigue of FCs should be simultaneously observed, and these conditions should be managed to decrease their care burden.

A poor patient appetite was a significant factor of the higher-burden FC trajectory. This finding has not been reported and cannot be

compared with other studies. However, the effect of poor patient appetite on FC burden is still very small, and more studies are needed, because previous research[35] indicated that the appetite loss can result in poor nutrition in lung cancer patients.

Patient depression is also a major factor in the FC moderate burden subtrajectory. This finding echoes a report that lung cancer patient distress (including depression) is strongly associated with caregiver burden at baseline and 3-month follow-up.[5] These findings suggest that difficulties when facing and handling patient depression contribute to the FC burden. Assisting FCs to acquire skills to cope with patient depression is a key requirement for health care professionals.

In contrast to the hypothesis, the results demonstrated that FC burden was not related to the functional status of the patient. This finding is inconsistent with previous studies,[36,37] and the reason for this is unclear. Future studies should further examine this issue to gain a deeper understanding of caregivers' burden.

5 | CONCLUSIONS

The results showed 3 subtrajectories of FC burden for FCs of advanced lung cancer patients in the 6-month period following cancer diagnosis. The FC self-efficacy has the greatest effect on the overall FC burden and each subtrajectory. The results provide evidence of the need for further related research and give a useful insight into the particular intervention strategies required to support patients and FC based on specific patient conditions and FC care burden concerns.[38]

6 | STUDY LIMITATIONS

The findings may not be applicable to the FC of extremely sick lung cancer patients because they were not recruited. Second, this study only investigated 150 patient-FC dyads in the first 6 months after diagnosis. Further studies are needed to validate the overall FC burden and its subdomains, subtrajectories, and factors identified in this study and to explore their changes over a longer follow-up period.

7 | CLINICAL IMPLICATIONS

Our results suggest that health care professionals should screen FC-related and patient-related factors shown to increase FC risk of burden. The screening results should inform further care.

CONFLICT OF INTEREST

None declared.

ORCID

Yun-Hsiang Lee http://orcid.org/0000-0001-7200-7373
Pi-Hua Chang http://orcid.org/0000-0003-1305-1854

REFERENCES

1. World Health Organization. Cancer fact sheet, 2015. Available from http://www.who.int/mediacentre/factsheets/fs297/en/. Accessed October 23, 2015.
2. Chou KR. Caregiver burden: a concept analysis. *J Pediatr Nurs*. 2000;15(6):398-407.
3. Raina P, O'Donnell M, Schwellnus H, et al. Caregiving process and caregiver burden: conceptual models to guide research and practice. *BMC Pediatr*. 2004;4(1).
4. Fletcher BS, Miaskowski C, Given B, Schumacher K. The cancer family caregiving experience: an updated and expanded conceptual model. *Eur J Oncol Nurs*. 2012;16(4):387-398.
5. Milbury K, Badr H, Fossella F, Pisters KM, Carmack CL. Longitudinal associations between caregiver burden and patient and spouse distress in couples coping with lung cancer. *Support Care Cancer*. 2013;21(9):2371-2379.
6. Perkins M, Howard VJ, Wadley VG, et al. Caregiving strain and all-cause mortality: evidence from the REGARDS study. *J Gerontol B Psychol Sci Soc Sci*. 2013;68(4):504-512.
7. McCorkle R, Yost LS, Jepson C, Malone D, Baird S, Lusk E. A cancer experience: relationship of patient psychosocial response to care-giver burden over time. *Psychooncology*. 1993;2(1):21-32.
8. Scherbring M. Effect of caregiver perception of preparedness on burden in an oncology population. *Oncol Nurs Forum*. 2002;29(6):E70-E76.
9. Lee KC, Chang WC, Chou WC, et al. Longitudinal changes and predictors of caregiving burden while providing end-of-life care for terminally ill cancer patients. *J Palliat Med*. 2013;16(6):632-637.
10. Grant M, Sun V, Fujinami R, et al. Family caregiver burden, skills preparedness, and quality of life in non-small cell lung cancer. *Oncol Nurs Forum*. 2013;40(4):337-346.
11. Given CW, Given B, Stommel M, Collins C, King S, Franklin S. The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Res Nurs Health*. 1992;15(4):271-283.
12. Scheff RJ, Schneider BJ. Non-small-cell lung cancer: treatment of late stage disease: chemotherapeutics and new frontiers. *Semin Intervent Radiol*. 2013;30(2):191-198.
13. Northouse LL, Katapodi MC, Schafenacker AM, Weiss D. The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Semin Oncol Nurs*. 2012;28(4):236-245.
14. Pearlin LI, Me G, Lieberman MA, Mullan JT. The stress process. *J Health Soc Behav*. 1981;22(4):337-356.
15. Palos GR, Mendoza TR, Liao KP, et al. Caregiver symptom burden: the risk of caring for an underserved patient with advanced cancer. *Cancer*. 2011;117(5):1070-1079.
16. Lee YH, Liao YC, Liao WY, et al. Anxiety, depression and related factors in family caregivers of newly diagnosed lung cancer patients before first treatment. *Psychooncology*. 2013;22(11):2617-2623.
17. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. *Psychol Rev*. 1977;84(2):191-215.
18. Havyer RD, van Ryn M, Wilson PM, Griffin JM. The effect of routine training on the self-efficacy of informal caregivers of colorectal cancer patients. *Support Care Cancer*. 2017;25(4):1071-1077.
19. Bowers D, House A, Owens D. Selecting samples for quantitative research. In: *Getting Started in Health Research*. Hoboken, NJ: John Wiley & Sone; 2011:47-55.
20. Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst*. 1993;85(5):365-376.
21. Chie WC, Yang CH, Hsu C, Yang PC. Quality of life of lung cancer patients: validation of the Taiwan Chinese version of the EORTC QLQ-C30 and QLQ-LC13. *Qual Life Res*. 2004;13(1):257-262.
22. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand*. 1983;67(6):361-370.

23. Chen PY, See LC, Wang CH, et al. The impact of pain on the anxiety and depression of cancer patients. *J Formos Med*. 1999;3:373-382.

24. Merluzzi TV, Nairn RC, Hegde K, Martinez Sanchez MA, Dunn L. Self-efficacy for coping with cancer: revision of the Cancer Behavior Inventory (version 2.0). *Psychooncology*. 2001;10(3):206-217.

25. Liao YC, Shun SC, Liao WY, Yu CJ, Yang PC, Lai YH. Quality of life and related factors in patients with newly diagnosed advanced lung cancer: a longitudinal study. *Oncol Nurs Forum*. 2014;41(2):E44-E55.

26. Grov EK, Fosså SD, Sørebø O, Dahl AA. Primary caregivers of cancer patients in the palliative phase: a path analysis of variables influencing their burden. *Soc Sci Med*. 2006;63(9):2429-2439.

27. Jones BL, Nagin DS. Advances in group-based trajectory modeling and an SAS procedure for estimating them. *Sociol Methods Res*. 2007;35(4):542-571.

28. Jones BL, Nagin DS, Roeder K. A SAS procedure based on mixture models for estimating developmental trajectories. *Sociol Methods Res*. 2001;29(3):374-393.

29. Zeger SL, Liang KY. Longitudinal data analysis for discrete and continuous outcomes. *Biometrics*. 1986;42(1):121-130.

30. Liu G, Liang KY. Sample size calculations for studies with correlated observations. *Biometrics*. 1997;53(3):937-947.

31. Kim SY, Chang YJ, Do YR, et al. Employment status and work-related difficulties among family members of terminally ill patients compared with the general population. *Asian Pac J Cancer Prev*. 2013; 14(1):373-380.

32. Oldenkamp M, Hagedoorn M, Slaets J, Stolk R, Wittek R, Smidt N. Subjective burden among spousal and adult-child informal caregivers of older adults: results from a longitudinal cohort study. *BMC Geriatr*. 2016;16(1):208.

33. Navidian A, Bahari F. Burden experienced by family caregivers of patients with mental disorders. *PJPR*. 2008;23(1-2):19-28.

34. Lin HR, Lin HC, Lin WC. Middle-aged female spouses of patients with metastatic cancer: lived experiences. *J Nurs Res*. 2015;23(2):135-144.

35. Xara S, Amaral TF, Parente B. Undernutrition and quality of life in non small cell lung cancer patients. *Rev Port Pneumol*. 2011;17(4):153-158.

36. Nelson MM, Smith MA, Martinson BC, Kind A, Luepker RV. Declining patient functioning and caregiver burden/health: the Minnesota stroke survey—quality of life after stroke study. *Gerontologist*. 2008;48(5): 573-583.

37. Hsu T, Loscalzo M, Ramani R, et al. Factors associated with high burden in caregivers of older adults with cancer. *Cancer*. 2014;120(18): 2927-2935.

38. Lai YH. Perspective on cancer survivorship: care and challenges. *J Nurs Res*. 2016;24(2):190-192.