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Economic and Social Changes Among Distressed Family Caregivers of Lung Cancer Patients

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Abstract

Purpose—Although costs of lung cancer care have been documented, economic and social changes among lung cancer patients' family caregivers have yet to be fully examined. In addition, research has not focused on caregivers with greater need for support services. This study examined various economic and social changes among distressed family caregivers of lung cancer patients during the initial months of cancer care in the United States.

Methods—Lung cancer patients' primary family caregivers with significant anxiety or depressive symptoms were recruited from three medical centers within 12 weeks of the patient's new oncology visit. Caregivers ($N=83$) reported demographic and medical information and caregiving burden at baseline. Seventy-four caregivers reported anxiety and depressive symptoms and economic and social changes three months later.

Results—Seventy-four percent of distressed caregivers experienced one or more adverse economic or social changes since the patient's illness. Common changes included caregivers'

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Conflict of Interest

The authors do not have any conflicts of interest to disclose. The authors have full control of all primary data and agree to allow the journal to review their data if requested.

disengagement from most social and leisure activities (56%) and, among employed caregivers ($n=49$), reduced hours of work (45%). In 18% of cases, a family member quit work or made another major lifestyle change due to caregiving. Additionally, 28% of caregivers reported losing the main source of family income, and 18% reported losing most or all of the family savings. Loss of the main source of family income and disengagement from most social and leisure activities predicted greater caregiver distress.

Conclusions—Findings suggest that distressed caregivers of lung cancer patients experience high rates of adverse economic and social changes that warrant clinical and research attention.

Keywords

lung cancer; family caregiving; economic; financial; employment; psychological distress

Introduction

In recent years, the impact of cancer on the entire family has received greater research attention [1–2]. Given the decline in health care resources and the growth of outpatient care, family caregivers have increasingly assumed a central role in the patient's health care [3–4]. Family caregivers assist ill friends or relatives with personal or medical care tasks and provide informational, financial, or emotional support [5–6]. Family caregivers often face a range of stressors, including altered daily household routines, family role changes, personal health conditions, and financial and occupational strain [7–10]. These stressors help explain the high prevalence (20–50%) of clinically elevated distress among cancer patients' family caregivers [9,11–15].

The economic burden of cancer may have devastating effects on patients and families. One review of primarily American studies found that between 17% and 38% of families of terminally ill cancer patients lost most or all of their savings, and between 10% and 40% of families reported that someone had quit work in order to provide care [16]. A retrospective matched-cohort control analysis of United States (U.S.) databases and surveys of Medicare and private health insurance recipients also found substantial direct and indirect costs associated with having cancer [17]. These costs included deductibles, copayments, and reduced hours of employment among cancer patients and their caregivers. Loss of work productivity and financial strain, have, in turn, been associated with negative mental health and quality-of-life outcomes among cancer patients [18–19] and their caregivers [20–21].

Lung cancer has been found to have a greater economic impact on families than other cancers due to its high physical symptom burden and poor prognosis, resulting in expensive therapies and decreased workforce participation [17,22–23]. Among Americans with Medicare and private insurance, direct medical costs associated with lung cancer have been found to be higher than those of other prevalent cancers [17,22]. In addition, family caregivers of lung cancer patients appear to experience substantial economic burden. One recent study estimated that the average total economic burden for caregivers of lung and colorectal cancer patients in the U.S., including time and productivity costs and out-of-pocket expenditures, was \$14,000 over the first year following diagnosis [23]. Furthermore, in a large U.S. survey, caregivers of lung cancer patients were found to accrue higher time costs over the 2-year period following diagnosis than caregivers of patients with nine other cancer types [24].

Although researchers have estimated the costs of lung cancer care [17,22], little research has examined the extent to which caregivers of lung cancer patients experience vocational and social changes and major changes in family plans due to medical expenses. In addition, research has not focused on family caregivers of lung cancer patients with greater need for

support services. It is important to identify the specific economic and social changes experienced by distressed family caregivers of lung cancer patients in order to inform interventions to mitigate their distress. Therefore, the primary goal of this study was to determine the prevalence of various economic and social changes among distressed family caregivers of lung cancer patients during the early phase of cancer care at comprehensive medical centers. In addition, we explored the extent to which demographic characteristics, patient and caregiver medical factors, caregiving burden (i.e., degree to which the patient needed assistance with activities of daily living), and caregiver anxiety and depressive symptoms were associated with several economic and social changes (i.e., loss of the major source of income for the family, caregivers' reduced hours of employment, and caregivers' loss of involvement in most of their social and leisure activities).

Methods

Participants and procedure

Following institutional review board approval, family caregivers of lung cancer patients were recruited by contacting eligible patients from the oncology clinics at Memorial Sloan-Kettering Cancer Center (New York, NY), Indiana University Simon Cancer Center (Indianapolis, IN), and the Roudebush VA Medical Center (Indianapolis, IN). Eligible lung cancer patients were English speakers who were within 12 weeks of their first visit to the oncology clinic. Patients with lung cancer recurrence were ineligible for this study. Patient eligibility was assessed via medical record review followed by consultation with oncologists. A research assistant approached the patient during a clinic visit to describe the study and invite participation. Interested patients identified their primary family caregiver (i.e., the person who is responsible for the majority of their unpaid, informal care) and provided consent to contact their caregiver and collect information on their lung cancer and its treatment from their medical records. Eligibility criteria for caregivers were: (1) English fluency; (2) 18 years of age or older; and (3) elevated distress as indicated by self-reported scores exceeding the clinical cutoff (>8) on the Anxiety or Depression subscales of the Hospital Anxiety and Depression Scale (HADS) [25–26] at the time of recruitment. A research assistant assessed caregivers for eligibility and obtained informed consent in clinic or via telephone. All caregivers who completed the HADS received a brochure describing psychosocial support services available at the study site.

At baseline, enrolled caregivers completed telephone assessments of their demographic and medical information and caregiving burden with respect to helping patients with activities of daily living. Three months later, caregivers' anxiety and depressive symptoms and economic and social changes due to caregiving were assessed via telephone. Caregivers received \$25 for each completed assessment.

Measures

Demographics—Caregivers reported their demographic information and indicated whether they lived with the patient and the nature of their relationship with the patient (e.g., spouse/partner, adult child).

Patient medical information—Information regarding the patient's type and stage of lung cancer, weeks since diagnosis, and lung cancer treatment was obtained from medical records. At baseline and follow-up, caregivers also reported whether the patient had received chemotherapy, radiation, or surgery.

Caregiver medical conditions—A self-report version of the Charlson Comorbidity Index (CCI) [27–28] was used to evaluate caregivers' medical comorbidities at baseline.

This version of the CCI has been found to have adequate test-retest reliability and validity [28].

Economic and social changes due to caregiving—At follow-up, nine items from the Covinsky Family Impact Survey [29], used in the SUPPORT study [30], assessed economic and social changes due to caregiving. In addition, items from the Coping with Cancer Study [31–32] asked caregivers to indicate the number of hours worked per week before the patient’s diagnosis, any reduction in the number of hours worked per week since the diagnosis, and whether they ended involvement in most of their regular social and leisure activities since the diagnosis.

Caregiver anxiety and depressive symptoms—The 14-item Hospital Anxiety and Depression Scale [25] assessed caregivers’ symptoms of anxiety and depression during the past week at enrollment and follow-up. The HADS has been shown to be valid and reliable for use with the general population [26]. For the present research, coefficient alphas for Anxiety and Depression subscales were .69 and .76 at screening and .86 and .85 at follow-up, respectively.

Caregiving burden—Caregivers reported the extent to which the patient needed help with eight instrumental activities of daily living at baseline [33]. This valid measure of caregiving burden has been widely used with cancer patients’ caregivers [7,34]. Higher scores indicate less caregiving burden. Coefficient alpha for the present research was .79.

Statistical analyses

Descriptive statistics were computed to characterize demographic and medical information and caregivers’ anxiety and depressive symptoms, caregiving burden, and economic and social changes due to caregiving. Next, chi-square analyses and correlations were used to examine associations among demographic, medical, and psychosocial characteristics and three study outcomes (i.e., loss of the major source of income for the family, caregivers’ reduced hours of employment, and caregivers’ loss of involvement in most of their social and leisure activities). If multiple variables were significantly correlated with an outcome, we entered them into a logistic regression analysis with simultaneous predictor entry.

Results

Sample characteristics

Of the 234 potentially eligible lung cancer patients who were approached for this study, 97% ($n = 227$) identified a family caregiver. Most patients (97%, $n = 221$) provided consent for the research assistant to contact their caregiver and collect their medical information. The majority of caregivers (86%, $n = 189$) agreed to be screened for eligibility, 12% declined to participate, and 2% were unable to be reached via phone. The most common reasons for study refusal were personal stress, time constraints, and a desire to focus on the patient’s needs. Half of caregivers (50%, $n = 95$ of 189) met the clinical cutpoint (score ≥ 8) on the Anxiety or Depression subscale of the HADS. Most eligible distressed caregivers (95%, $n = 90$) provided informed consent for study participation. Eighty-three caregivers (92%) completed the initial phone assessment, and 74 caregivers completed the follow-up phone assessment (82% retention). Reasons for withdrawal prior to baseline or follow-up included time constraints, personal health problems, bereavement, and inability to reach the caregiver via phone.

Demographic and medical characteristics of the sample are presented in Table 1. Caregivers were, on average, 55 years old, married, female, Caucasian, and well-educated (mean = 15

years of education). The median annual household income was over \$50,000 with a range of <\$11,000 to over \$100,000. Over half of caregivers were employed at enrollment and follow-up, and 7% decreased their employment over this time period. Most caregivers were spouses/partners (62%) or adult children (27%) of the patient. The majority of patients (57%) were diagnosed with stage III or IV non-small cell lung cancer. At baseline, patients were, on average, 8 weeks from the lung cancer diagnosis. On average, caregivers reported that the patient required minimal assistance with eight activities of daily living ($M = 6.50$, $SD = 1.69$). Five of the caregivers were bereaved at follow-up.

Caregivers, on average, reported few medical conditions on the Charlson Comorbidity Index ($M = .89$, $SD = 1.85$). At follow-up, caregivers' mean level of anxiety exceeded the clinical cutoff (score = 8) ($M = 10.07$, $SD = 4.06$), whereas their mean level of depressive symptoms was below the cutoff ($M = 6.49$, $SD = 3.94$). Most caregivers (58/74, 78%) continued to meet the clinical cutoff for anxiety or depressive symptoms at follow-up.

Economic and social changes due to caregiving

Nearly three-fourths (55/74, 74%) of caregivers reported one or more adverse economic or social changes since the patient's illness (see Table 2). The most common changes included caregivers' disengagement from most of their regular social and leisure activities (41/73, 56%) and, among employed caregivers, hours of work lost due to the illness (22/49, 45%). The average number of hours of work lost each week due to the illness was 16 ($SD = 13$, range = 1–50). In addition, a sizable minority of caregivers reported that their family lost their major source of income (21/74, 28%) or made a major change in plans, such as delaying medical care for another family member or altering educational plans (16/74, 22%) because of the high cost of the illness. Nearly one-fifth of caregivers reported losing most or all of the family savings (13/73, 18%). Although 18% (13/74) of caregivers indicated that a family member made a major life change (e.g., quit work) to care for the patient, few caregivers reported that family members became ill or unable to function due to the stress of the illness (5/74, 7%).

We examined the extent to which caregiver characteristics (i.e., demographics, medical comorbidities, and anxiety and depressive symptoms) and patient medical factors were associated with loss of the major source of family income, caregivers' reduced hours of employment, and caregivers' loss of involvement in most of their social and leisure activities. Anxiety and depressive symptom subscales were combined into one scale for all analyses, as the subscales were highly correlated ($r = .73$). Losing the major source of family income was positively associated with the patient's receipt of surgery, (odds ratio = 3.07, 95% CI = 1.07 to 8.77; $\chi^2(1, N = 73) = 4.56$, $p < .05$), and caregivers' anxiety and depressive symptoms at follow-up, $r = .31$, $p < .01$. Logistic regression revealed that these two variables correctly classified 69% of the sample with regard to loss of the major source of family income and both variables uniquely predicted this outcome (see Table 3). None of the caregiver characteristics and patient medical factors were significantly associated with caregivers' reduced hours of employment. Finally, caregivers' loss of involvement in most of their regular social and leisure activities was associated with younger age, $r = -.28$, $p < .05$, greater anxiety and depressive symptoms at follow-up, $r = .56$, $p < .001$, and the patient's receipt of chemotherapy, (odds ratio = 3.21, 95% CI = 1.13 to 9.09; $\chi^2(1, N = 73) = 5.02$, $p < .05$). In the logistic regression, these three variables correctly classified 84% of the sample with regard to loss of involvement in social and leisure activities, but only greater anxiety and depressive symptoms was a significant unique predictor of this outcome (see Table 3).

Discussion

The majority (74%) of distressed family caregivers of lung cancer patients experienced one or more adverse economic or social changes since the patient's illness. The most prevalent changes included caregivers' loss of involvement in most of their regular social and leisure activities (56%) and, among employed caregivers, reduced hours of employment due to the illness (45%). In addition, a substantial minority of caregivers lost the main source of family income (28%) or made a major change (e.g., delaying medical care for another family member) (22%) in family plans due to the cost of the illness. Other caregivers reported that family members made major life changes (e.g., quit work) to care for the patient (18%), or that their family lost most or all of their savings since the patient's illness (18%). These hardships occurred even though most caregivers were middle to upper class and 92% had health insurance. The present findings are consistent with results from the SUPPORT study that showed prevalent caregiving and economic burdens among the families of hospitalized adults with cancer and other serious illnesses in the U.S. [29]. The current results also extend prior analyses of the costs associated with lung cancer [17,23,22] by documenting a range of adverse economic and social changes from the perspective of distressed caregivers of lung cancer patients. The high prevalence and severity of these changes and the association of some changes (i.e., loss of the major source of family income and loss of involvement in most social and leisure activities) with greater caregiver distress underscore the impact of lung cancer on the family's well-being and financial security.

Loss of the major source of family income also was associated with the patient's receipt of surgery. We did not collect data on patients' employment status and, thus, could not determine whether patients with resectable lung cancer were more likely to end their employment following the diagnosis than those with unresectable disease. Although caregivers' employment status and reduced hours at work were not associated with the patient's receipt of surgery (data not shown), other family members may have quit work in order to care for the patient following surgery. Caregivers' reduced hours of employment were not significantly associated with any caregiver characteristics or patient medical factors, which may be due to limited demographic variability. Further research is needed to examine the relationships among medical factors, socioeconomic variables, and vocational and economic changes in families coping with lung cancer.

Limitations of this study and directions for future research should be noted. First, the sample primarily consisted of Caucasian, middle class women with health insurance. Further research is needed to determine the extent to which these findings generalize to diverse populations. In addition, the relatively small sample size limited the statistical power for detecting significant correlates of study outcomes. Research with larger samples is required to replicate and extend the present results. Other study limitations include the cross-sectional assessment of economic and social changes and the subjective assessment of these changes. For example, although we assumed that loss of most or all of one's savings, regardless of the amount, would be a severe financial burden, we did not estimate the family's actual expenses and the extent to which these expenses were shared by the patient and caregiver. Future research may incorporate objective and subjective assessments of economic and social changes over the course of the illness. Such research may include the perspectives of multiple family members, as prior research has found only moderate agreement between seriously ill patients and their surrogates about the family's financial and caregiving burdens [29].

The present findings have significant implications for future research and clinical practice. First, findings point to high rates of clinically elevated distress and adverse economic and social changes among family caregivers of lung cancer patients. Research is needed to

further identify subgroups of caregivers who experience severe caregiving and financial burdens. The development and evaluation of interventions that are tailored to the economic and vocational needs of lung cancer patients' caregivers is another important direction for future research. Multidisciplinary efforts are warranted to address caregivers' practical concerns, health maintenance, and psychosocial needs. As a greater proportion of cancer care occurs at home [3–4], continued study of the burdens that home care places on the family will inform clinical care and health policy efforts.

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Table 1Sample characteristics ($N = 74$)

Variable	<i>n</i> (%)	<i>M</i> (<i>SD</i>)	Range
Caregiver Sex—Female	57 (77%)		
Type of Relationship			
Spouse/partner	46 (62%)		
Adult child	20 (27%)		
Sibling	5 (7%)		
Other relative	3 (4%)		
Caregiver lives with the patient	55 (74%)		
Caregiver Race/Ethnicity			
Non-Hispanic White	62 (84%)		
African American/Black	8 (11%)		
Other	4 (5%)		
Caregiver Age (years)		55 (12)	29 to 80
Caregiver Marital Status			
Married or marriage equivalent	61 (82%)		
Divorced	6 (8%)		
Single	7 (9%)		
Caregiver Annual Household Income (median)		>\$50,000	<\$11,000 to >\$100,000
Caregiver Education (years)		15 (3)	8 to 27
Caregiver Employment Status from Enrollment to Follow-up			
Increased employment	2 (3%)		
Decreased employment	5 (7%)		
Continued full or part-time employment	40 (54%)		
Continued to be unemployed	2 (3%)		
Not applicable (e.g., retired)	25 (34%)		
Caregiver has health insurance	68 (92%)		
Weeks since Patient's Diagnosis at Enrollment		8 (8)	.14 to 64
Non-small Cell Lung Cancer Stage ($n = 69$)			
I	15 (22%)		
II	10 (14%)		
III	19 (28%)		
IV	23 (33%)		
Missing	2 (3%)		
Small Cell Lung Cancer Stage ($n = 5$)			
Limited	2 (40%)		
Extensive	2 (40%)		
Missing	1 (20%)		
Type of Lung Cancer Treatment			
Surgery	31 (42%)		
Chemotherapy	51 (69%)		

Variable	<i>n</i> (%)	<i>M</i> (<i>SD</i>)	Range
Radiation	32 (43%)		
Treatment Center			
Memorial Sloan-Kettering Cancer Center (NY)	36 (49%)		
Indiana University Simon Cancer Center (IN)	31 (42%)		
Roudebush VA Medical Center (IN)	7 (9%)		

Table 2

Proportion of caregivers endorsing adverse economic and social changes

Question	% Yes (No./Total)
Caregiver worked fewer hours each week since the patient's diagnosis ^a	45 (22/49)
A family member made a major life change to care for the patient	18 (13/74)
Quit work or took time off from work	7 (5/74)
Other life change	11 (8/74)
Others in the family became ill or unable to function normally because of the stress of the illness	7 (5/74)
Most or all of the family savings were lost	18 (13/73)
A major source of family income was lost	28 (21/74)
A major change in family plans was made because of the cost of the illness ^b	22 (16/74)
Moved to a less expensive home	1 (1/74)
Delayed medical care for another family member	8 (6/74)
Altered educational plans for another family member	5 (4/74)
Other change	9 (7/74)
Since the patient's illness, the caregiver no longer engaged in most of his or her regular social/leisure activities	56 (41/73)
Reported any of the above adverse changes	74 (55/74)

^aOnly caregivers who reported working before the diagnosis responded to this question.

^bPercentages add to greater than 22% because more than one change in family plans could be reported per caregiver.

Table 3

Logistic regression analyses predicting loss of income and social or leisure activities

Outcome	Predictors	β	Wald Chi-square (<i>df</i> = 1)	Odds ratio	95% CI for odds ratio
A major source of family income was lost					
	Patient's receipt of surgery ^a	1.62*	6.70	5.07	1.48 to 17.36
	Caregiver anxiety and depressive symptoms	.13**	8.04	1.14	1.04 to 1.25
Since the patient's illness, the caregiver no longer engaged in most of his or her regular social/leisure activities					
	Patient's receipt of chemotherapy ^a	1.10	2.64	2.99	.80 to 11.23
	Caregiver age	-.04	1.77	.96	.91 to 1.02
	Caregiver anxiety and depressive symptoms	.23***	14.26	1.25	1.11 to 1.41

Note. *n* = 73. CI = confidence interval.

^aCoded 0 = no, 1 = yes.

* *p* < .05.

** *p* < .01.

*** *p* < .001.