Employment Status and Work-Related Difficulties among Family Members of Terminally Ill Patients Compared with the General Population

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Abstract

Background: Although caregiving to patients with terminal illness is known to be a stressful burden to family members, little attention has been focused on work-related problems. We aimed to investigate employment status and work-related difficulties of family caregivers of terminal cancer patients, comparing with the general population. Methods: Using structured questionnaires, we assessed family caregivers of 481 cancer patients determined by physicians to be terminally ill, from 11 university hospitals and the National Cancer Center in Korea. Results: Among 381 family caregivers of terminal cancer patients (response rate, 87.6%), 169 (43.9%) were not working before cancer diagnosis, but currently 233 (63.7%) were not working. Compared with the general population (36.5%), the percentage of not working among the family caregivers was higher (OR=2.39; 95% CI=1.73-3.29). A major reason for not working was to provide assistance to the patients (71.6%). 40.6% of those who continued working and 32.3% of those who were not working family members reported extreme fatigue. Caregivers of old age, those who were female, those with a lower household income, and those caring for patients with a low performance status were not working at a more significant rate. Conclusion: Family caregivers of terminal cancer patients suffer job loss and severe work-related difficulties, probably due to caregiving itself and to fatigue. We need to develop supportive programs to overcome the burden of caregivers of the terminally ill.

Key words: Terminal cancer patient - caregiver - employment status - work-related difficulty

Introduction

Although caregiving to patients with terminal illness is known to be a stressful burden to family members (Chochinov et al., 2011; Fairfield et al., 2012; Kimman et al., 2012; Tordoff et al., 2012), little attention has been focused on the impact of caregiving on employment status and work-related difficulties among family members of patients with terminal illness. Caregiver burden is closely connected to patient demands, and it might be related to the overall outcomes of the caregiving process (Dybiicz et al., 2011). For example, several studies have documented typically high levels of daily-living assistance, including help with transportation, shopping, homemaking, emotional support, nutritional care, nursing care, and personal care (Shahmoradi et al., 2009; O’Connor and Kumar, 2012; Stiel et al., 2012). As a result of daily-living assistance, many studies focused on family caregiver burdens such as high levels of stress, poor physical condition, emotional health, and family savings losses (Bukki et al., 2011; Duclos et al., 2012; Gomes et al., 2012; von Gunten, 2012).
As many caregivers reported spending over 40 hr per week providing care, it is not surprising that caregiving frequently interferes with employment (Pantilat et al., 2012). Employment status among family caregivers has especially important implications for society, the labor market, and family economics (Unroe et al., 2012). Although previous studies have focused on the return to work of cancer survivors (Knapp et al., 2011; Phipps et al., 2011; Flannelly et al., 2012; Unroe et al., 2012) and employment status among caregivers of cancer patients (Gomes et al., 2012; Pantilat et al., 2012), unfortunately, it is not fully understood how many family caregivers of terminal cancer patients maintain their employment status with caregiving. We aimed to evaluate employment status and work-related difficulties of family caregivers with terminal cancer patients, comparing with the general population.

**Materials and Methods**

**Study sample**

Family caregivers of terminal cancer patients. The Study to Understand Risks, Priority, and Issues at End-of-Life (SURPRISE), a multicenter study designed to identify important ethical issues, care burden, and quality of care at the end of life in Korea, recruited terminal cancer patients for this prospective cohort study from 11 university hospitals and the National Cancer Center, Korea; none had a stated policy about the disclosure of terminal illness. In SURPRISE, patients were eligible to participate if they were (1) aged 18 year or older, (2) diagnosed as terminal at an outpatient or inpatient facility, (3) capable of filling out questionnaires or communicating with an interviewer, and (4) competent enough to understand the intent of the study and provide informed consent. We defined a terminal cancer patient as someone with progressive advanced disease that, in a physician’s judgment, was refractory to conventional anticancer therapy (surgery, radiotherapy, chemotherapy, or hormone therapy) and who was likely to die within months.

Participants were given information explaining the study and were asked to participate. All patients and caregivers provided informed consent to participate in this study, and our institutional review boards approved the protocol.

Physicians identified 702 consecutive terminal cancer patients. Of those, 83 were excluded (11 continued conventional anticancer treatment after enrollment, 14 were of non-evaluable disease status in follow-up, 15 were lost to follow-up in front of treatment plan, and 43 had become physically or mentally incapacitated). Of the 619 remaining eligible participants, 481 (77.7%) gave written informed consent and completed the questionnaire.

Patients were asked about their primary family caregivers who provided them with the most assistance. We enrolled one caregiver per patient. The family caregivers were invited to participate in the study but were ineligible if they were (1) not aged 18 year or older, (2) not well enough to fill out questionnaires, (3) not able to communicate with an interviewer, (4) not able to understand the intent of the study well enough to provide informed consent, or (5) a patient with a history of cancer.

Of the 481 eligible patients, 30 had no caregivers, 13 had caregivers who were not competent enough to participate in the study, and 3 had caregivers who were not able to read the questionnaire. Of the 435 eligible caregivers, 58 declined to participate; the most common reasons given were inconvenience and lack of time. The remaining 381 caregivers completed the questionnaire (response rate, 86.7%). Details of the study population and data collection methods have been previously described elsewhere (Knapp et al., 2011).

**General population**

The survey was conducted in age and sex strata according to the guidelines of the 2000 Korean Census in 15 geographic districts. Probability proportional to size technique considers the size of individual groups and corrects for differences in the probability of larger and smaller groups being sampled. Criteria of eligibility included (1) being physically and mentally fit to fill out the questionnaire or communicate with the interviewer and (2) aged more than 18 year. The interviewers visited each person at home or in the workplace, evaluated eligibility, and explained the purpose of the study to the eligible person.

Of 2447 potentially eligible persons, 1447 refused to participate or did not complete the survey. The most frequent reasons people gave for refusing to participate were that they felt too busy to complete the questionnaire (N=734), the survey was inconvenient (N=356), they did not want to provide personal information (N=156), or other reasons (N =201). Of those who completed the survey, 6 had a history of cancer and were excluded. The final sample comprised 994 participants (response rate, 41%). The study population and data collection methods have been previously described elsewhere (Phipps et al., 2011).

**Study variables**

SURPRISE collected demographic data for the patients and the caregivers and clinical information for the patients. We administered the questionnaires by face-to-face interviews at an outpatient or inpatient facility to both groups at the same time within days of the baseline time point of the study, which was when the physician judged that the cancer was refractory to conventional anticancer therapy (surgery, radiotherapy, chemotherapy, or hormone therapy) and the patient was likely to die within months. The patient and family caregiver questionnaires were similar and took about 20 minutes to complete. We used a questionnaire to collect information on the employment status, work-related difficulties, and
sociodemographic characteristics of family caregivers of terminal cancer patients and the general population. Independent variables included gender, age, marital status, monthly household income, education, religion, health cost financing, family APGAR (a validated scale of family function, based on adaptability, partnership, growth, affection, and resolution), medical cost bearer, living together with family, Eastern Cooperative Oncology Group performance status (ECOG PS), relationship of patient, health status of patient, and terminal state recognized. Employment was delineated as either employed or not employed, where not employed included caregivers who were homemakers or retired.

If participants were currently working, they were asked what kind of work-related difficulties they were having. The question included the following five multiple-choice items for work: (1) reduced working hours, (2) lessened work-related ability than before cancer diagnosis, (3) easily fatigued and exhausted, (4) reduced opportunity for promotion, and (5) decreased wages. The question included the following multiple-choice items for not working: (1) physically limited, (2) easily fatigued and exhausted but not physically limited, (3) emotionally distressed (such as feeling depressed or anxious), and (4) for caregiving. If they were currently not working, they were asked why they were not working. The question included the same multiple-choice items used for homemakers. If the choice items were not applicable, participants were asked to write in the reason for not working. The design of this study has been used previously (Phipps et al., 2011; Flannelly et al., 2012).

Statistical analysis

We used propensity score to adjust for differences in characteristics between family caregivers of terminal cancer patients and the general population. Selected variables for propensity score included age, gender, education, marital status, religion, health cost financing, and monthly household income. Score adjustment did not correct for differences between family caregivers of terminal cancer patients and controls in unobserved characteristics. The propensity score is the estimated logistic regression model.

The primary outcome was the percentage of not working among 381 family caregivers of terminal cancer patients. We used a t-test for continuous variables and a chi-square test in univariate analysis to estimate the odds ratio (OR) for each independent categorical variable. For variables significantly associated in univariate analysis, we performed the multivariate logistic regression analysis with a stepwise selection method for each dependent variable to assess which of the independent variables best predicted not working because of caregiving. We set the significance level at P<0.05 and used SAS software, version 9 (SAS Institute, Cary, NC), for all analysis.

The study protocol was approved by the Institutional Review Board of the National Cancer Center and by the institutional review boards of all participating hospitals.

| Table 1. Sociodemographic Characteristics of Caregivers of Terminal Cancer Patients and the General Population Before and After Propensity Score Adjustment |
|---------------------------------------------------------------|
| Caregivers N=381 | General Population N=994 | P Value | P Value Adj. for Propensity |
| Sex Male | Female | Sex Male | Female | | |
| 127 (33.3) | 254 (66.7) | 497 (50.0) | 497 (50.0) | <0.0001 | 0.69 |
| Age 50-64 | 125 (33.1) | 206 (20.7) | <0.0001 | 0.57 |
| 65+ | 40 (10.6) | 77 (7.9) | | |
| Education Middle School | High school - | | |
| 91 (23.9) | 290 (76.1) | 161 (16.2) | 833 (83.8) | 0.0008 | 0.95 |
| Marital status Married | Widowed/divorced/separated/single | | |
| 306 (80.5) | 874 (19.5) | 706 (71.0) | 288 (29.0) | 0.0004 | 0.70 |
| Have a religion Yes | No | | |
| 252 (67.4) | 122 (32.6) | 532 (53.5) | 462 (46.5) | <0.0001 | 0.76 |
| Health cost financing Health insurance | Medical aid | | |
| 292 (77.4) | 85 (22.5) | 959 (96.6) | 34 (3.4) | <0.0001 | 0.72 |
| Monthly household income (US$) <2000 | ≥2000 | | |
| 218 (59.1) | 151 (40.9) | 243 (24.5) | 750 (75.5) | <0.0001 | 0.74 |
| Employment status Self-employed | Employed | Unemployed /retired | Homemaker | Other | Missing | | |
| 68 (18.0) | 144 (38.1) | 74 (20.2) | 133 (36.3) | 26 (7.1) | 27 (2.7) | | |
| ≥2000 | 264 (26.6) | 367 (36.9) | 60 (6.0) | 226 (22.7) | 27 (7.1) | | |
| Family APGAR | | | | | | |
| ≤3 | 47 (13.1) | NA | | | | |
| 4-7 | 154 (42.8) | NA | | | | |
| >7 | 159 (44.2) | NA | | | | |
| Relationship of patient Spouse | Other | ECOG PS | Health status | Terminal state recognized | | |
| 194 (50.9) | 187 (49.1) | 206 (69.6) | 90 (30.4) | 73 (20.0) | 286 (79.9) | | |
| 4 | 73 (20.0) | 90 (30.4) | 246 (71.4) | 83 (22.5) | | | |
| 50-64 | 125 (33.1) | 206 (20.7) | 246 (71.4) | 83 (22.5) | | | |
| ≥65 | 40 (10.6) | 77 (7.9) | | | | | |

*The propensity score summarizes the collection of different observable characteristics between caregivers of terminal cancer patients and the general population, including age, sex, education, marital status, religion, monthly household income, and health cost financing; ‡Lee MK, Lee KM, Bae JM, et al., (2008) Employment status and work-related difficulties in stomach cancer survivors compared with the general population. Bri J Cancer, 98, 708-15; †US$1=1,000won; ‡Employment status is the caregiver of a terminal cancer patient’s working status at the patient’s diagnosis compared to the general population’s current employment status. Family APGAR is a validated scale of family function based on adaptability, partnership, growth, affection, and resolution. *Eastern Cooperative Oncology Group performance status
### Results

#### Sample characteristics

Family caregivers of terminal cancer patients differed significantly from the general population in several sociodemographic characteristics before adjustment for propensity score, but not after adjustment for propensity score (Table 1).

#### Employment status of family caregivers of terminal cancer patients and the general population

Among 381 family caregivers of terminal cancer patients, 169 (43.9%) were not working at cancer diagnosis, but currently 233 (63.7%) were not working. Compared with the general population (36.5%), the percentage of not working among the family caregivers (63.7%) was higher (adjusted OR (aOR)=2.39; 95% confidence interval (CI)=1.73-3.29; Table 2).

| Table 4. Univariate Result of the Relationship to Employment Status among Caregivers of Terminal Cancer Patients |
|---------------------------------------------------------------|
| Characteristics                                    | Working | Not Working | P Value |
| Age ≤49                                             | 92 (44.4) | 115 (55.6) | <0.0001 |
| ≥65                                                 | 35 (29.9) | 82 (70.1)  |          |
| Sex Male                                            | 70 (56.9) | 53 (43.1)  | <0.0001 |
| Female                                              | 63 (25.9) | 180 (74.1) |          |
| Education < High school                             | 58 (29.0) | 142 (71.0) | <0.0001 |
| > High school                                      | 67 (53.2) | 59 (46.8)  |          |
| Marital status Married                              | 104 (35.0) | 193 (65.0) | 0.3403 |
| Widowed/divorced/ separated/single                   | 28 (41.2) | 40 (58.8)  |          |
| Health insurance                                    | 109 (38.6) | 173 (61.3) | 0.1374 |
| Medical aid                                         | 24 (29.6) | 57 (70.4)  |          |
| Have a religion                                     | 79 (32.0) | 168 (68.0) | 0.0159 |
| No                                                  | 51 (45.1) | 62 (54.9)  |          |
| Monthly household income (US$)*                     | <2000     | 54 (25.7)  | 156 (74.3) | <0.0001 |
| ≥2000                                               | 76 (52.4) | 69 (47.6)  |          |
| Living together as a family                         | Yes       | 46 (52.3)  | 42 (47.7)  | 0.0003 |
| No                                                  | 85 (31.1) | 188 (68.9) |          |
| Family APGAR <3                                     | 19 (41.3) | 27 (58.7)  | 0.6769 |
| >7                                                  | 52 (34.7) | 98 (65.3)  |          |
| Relationship of patient                             | Spouse    | 55 (29.3)  | 133 (70.7) | 0.0038 |
| Other                                               | 78 (43.8) | 100 (56.2) |          |
| Age ≤49                                             | 34 (42.5) | 46 (57.5)  | 0.2598 |
| ≥65                                                 | 55 (32.2) | 116 (67.8) |          |
| Sex Male                                            | 43 (37.7) | 71 (62.3)  |          |
| Female                                              | 73 (46.2) | 85 (53.8)  |          |
| Education < High school                             | 66 (38.4) | 106 (61.6) | 0.6047 |
| > High school                                       | 65 (35.7) | 117 (64.3) |          |
| Marital status Married                              | 105 (37.2) | 177 (62.8) | 0.6181 |
| Widowed/divorced/ separated/single                   | 27 (34.2) | 52 (65.8)  |          |
| Have a religion                                     | Yes       | 95 (37.0)  | 162 (63.0) | 0.8153 |
| No                                                  | 36 (37.5) | 65 (62.5)  |          |
| Employment status at patient’s diagnosis             | Working   | 64 (32.4)  | 132 (67.3) | 0.1382 |
| Not working                                         | 64 (40.2) | 95 (59.7)  |          |
| Current employment status                           | Working   | 12 (44.4)  | 15 (55.6)  | 0.3215 |
| Not working                                         | 110 (34.9) | 205 (65.1) |          |
| ECOG PS ≤3                                          | 81 (40.9) | 117 (59.1) | 0.0318 |
| 4                                                   | 24 (27.6) | 63 (72.4)  |          |
| Diagnosis Stomach cancer                            | 20 (29.0) | 49 (71.0)  | 0.369 |
| Lung cancer                                         | 17 (36.2) | 30 (63.8)  |          |
| Colon cancer                                        | 24 (44.4) | 30 (55.6)  |          |
| Other                                               | 71 (36.4) | 124 (63.6) |          |
| Health status Good                                  | 30 (41.0) | 43 (59.0)  | 0.2768 |
| Bad                                                 | 98 (27.3) | 188 (72.7) |          |
| Terminal state recognized                           | Yes       | 57 (37.2)  | 96 (62.7)  | 0.6977 |
| No                                                  | 73 (35.3) | 134 (64.7) |          |

*US$1=1,000 won; †Family APGAR is a validated scale of family function, based on adaptability, partnership, growth, affection, and resolution; ‡Eastern Cooperative Oncology Group performance status

### Table 3. Reasons for Work-Related Difficulties among Caregivers of Terminal Cancer Patients

| Reasons for not working (N=74) |
|-------------------------------|
| For caregiving                 | 53 (71.6) |
| Retired                        | 10 (13.5) |
| Limited in physical functioning| 2 (2.7)   |
| Other                          | 6 (8.1)   |
| Work-related difficulties      | 54 (72.9) |
| experienced by worker* (N=133)| 44 (33.1) |
| Easily fatigued and exhausted  | 44 (33.1) |
| Decreased wages                | 32 (24.1) |
| Reduced working hours          | 27 (20.3) |
| Missed an opportunity for promotion | 4 (3.0) |
| Housework-related difficulties | 21 (15.8) |
| experienced by homemaker* (N=133)| 11 (8.3) |
| For caregiving                 | 75 (56.4) |
| Easily fatigued and exhausted  | 43 (32.3) |
| but not limited in physical functioning | 21 (15.8) |
| Limited in physical functioning| 11 (8.3)  |
| Other                          | 12 (9.0)  |

*Items answered by multiple choices
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We found that not working was higher among caregivers of terminal cancer patients (63.7%) than among the general populations (36.5%). A major reason for not working was to provide assistance with care to the patients (71.6%), and in addition, caregiving itself (56.4%) was identified to be the most common difficulty for those doing housework. 40.6% of those who continually working and 32.3% of those who not working family members reported fatigability.

Our results were similar to the findings of previous studies of caregivers of cancer patients; that is, previous studies showed that 20% of caregivers provided full-time or constant care (Bukki et al., 2011), 5-20% of caregivers had quit their jobs or declined advancement as a result of caregiving (Dyibicz et al., 2011; Fairfield et al., 2012; Pantilat et al., 2012). Fatigability was also a major reason for not working among cancer survivors in previous studies (Phipps et al., 2011; Flannelly et al., 2012). However, our findings were specific to caregivers of terminal cancer patients because we focused on comparing caregivers of terminal cancer patients with the general population.

This study also discovered factors significantly associated with not working: old age, female, and low household income were significantly associated with not working. This is a natural result, according to previous studies, which showed that almost three quarters of all care for dying patients was provided by women (Duclos et al., 2012; Fairfield et al., 2012; Gomes et al., 2012; O'Connor and Kumar, 2012; Stiel et al., 2012). Caregivers with old age or who were female provided the majority of assistance with informal care of patients and commonly reported higher levels of personal burden than younger or male caregivers (Gomes et al., 2012; von Gunten, 2012). Our findings show that patient gender were significantly associated with not working in univariate analysis; however, it was insignificantly associated with not working in multivariate analysis. Therefore our findings confirm that caregiver gender is more significantly associated with not working than patient gender.

The low monthly household income is related to the lower employment status. Caregivers with low monthly household incomes cannot afford to buy high-cost assistive care (Herr et al., 2012; Pantilat et al., 2012). Providing care for terminal cancer patients instead of working worsens the economic conditions of family caregivers with lower monthly incomes. This study was limited by our data showing only the association between income and unemployment, which cannot assume direction or a causal nature. A prospective cohort study that includes a follow-up of family income and change direction or a causal nature. A prospective cohort study that includes a follow-up of family income and change employment status is needed.

We found that specific clinical characteristics can identify patients whose caregivers are more prone to reduced employment. ECOG PS was highly correlated with physical function (Smith et al., 2012) and is the

Table 5. Model-Based Adjusted Odds Ratio of Not Working by the Stepwise Method in Separate Logistic Regression Analyses in Caregivers of Terminal Cancer Patients

| Characteristic                                      | Caregiver (N=381) | P Value |
|----------------------------------------------------|-------------------|--------|
| OR* of Not Working (95%CI)                         |                   |        |
| Caregiver†: Age                                    |                   |        |
| ≤49                                                | 1 (Ref)           |        |
| 50-64                                              | 1.47 (0.75-2.91)  | 0.1511 |
| ≥65                                                | 7.32 (2.13-25.22) | 0.0039 |
| Sex                                                |                   |        |
| Male                                               | 1 (Ref)           |        |
| Female                                             | 4.92 (2.62-9.22)  | <0.0001|
| Monthly household income (US$)                     |                   |        |
| ≥2000                                              | 1 (Ref)           |        |
| <2000                                              | 0.46 (0.25-0.85)  | 0.0126 |
| Patient†: ECOG PS                                  |                   |        |
| ≤3                                                 | 1 (Ref)           |        |
| 4                                                  | 1.96 (1.01-3.82)  | 0.047  |

*Odds ratio estimates of not working vs. working, where “working” stands for the subjects who are self-employed or employed and “not working” stands for the subjects who are unemployed, retired, or homemakers; †Model-based odds ratios are from a series of logistic regression models with the stepwise method whose covariates were caregiver factors (age, sex, education, marital status, having a religion, relationship of patient, household monthly income, and living together with family) and the patient factor (sex, ECOG PS) that were significant (P < 0.05) in univariate analysis (Table 4)

Work- and housework-related difficulties among family caregivers of terminal cancer patients

A major reason for not working was to provide assistance with care to the patients (53, 71.6%). Those who continued working reported easier fatigability (54, 40.6%), decreased wages (44, 33.1%), less work-related ability (32, 24.1%), and reduced working hours (27, 20.3%). For those doing housework, caregiving itself (75, 56.4%) was identified to be the most common difficulty, followed by easy fatigability (43, 32.3%) and emotional distress (21, 15.8%; Table 3).

Associated factors of the work situations of family caregivers of terminal cancer patients

Among family caregivers, age, gender, educational level, having a religion, monthly household income, living together with family, and relationship of patient were associated with employment. Among terminal cancer patients, gender and ECOG PS were associated with employment (Table 4).

Table 5 shows the results of multivariable logistic regression. Among caregivers, the factors of older age (OR=7.32; 95%CI=2.13-25.22), female sex (OR=4.92; 95%CI=2.62-9.22), lower household income (OR=0.46; 95%CI=0.25-0.85), and low performance status of the patient (OR=1.96; 95%CI=1.01-3.82) were significantly associated with not working.

Discussion

This study focused on the determinants of one consequence of caregiving itself: reduced caregiver employment. This is, to our knowledge, the first study to examine caregivers’ work- and housework-related difficulties and the correlates of employment status in family caregivers of terminal cancer patients, as compared with the general population.
main correlate of not working (Phipps et al., 2011; Gomes et al., 2012; Pantilat et al., 2012). Poor ECOG PS of a patient would become a greater stressor for the caregiver (Tordoff et al., 2012) and family caregivers of terminal cancer patients who had poor ECOG PS scores were likely to need more assistance with patients dependent on care for activities of daily living or IADL including help with transportation, shopping, homemaking, emotional support, nutritional care, nursing care, and personal care (Baker et al., 2011; Chochinov et al., 2011; Cohen et al., 2012; Fairfield et al., 2012; Gomes et al., 2012; Pantilat et al., 2012; Tordoff et al., 2012).

This study had several limitations. First was possible selection bias. However, we could verify that there seemed to be no systematic differences between participants and subjects who did not participate. Because the study sample was drawn from 11 hospitals and the National Cancer Center, Korea, while the control sample was drawn from 15 geographic districts, the health care market might be different for each group (Phipps et al., 2011). We corrected for the different distributions of sociodemographic characteristics between the two groups by propensity score adjustment. We found no differences in variables between the two groups after adjustment. That allowed for better control than was evident in studies that matched groups one-to-one for only a few characteristics such as age and gender (Dybicz et al., 2011). Second, we do not investigate caregiving time, caregiving duration, and reduced working hours. Thus we were unable to confirm that changed employment status was because of the time required for caregiving. However, caregiving time might be closely related to the relationship with the patient, living together as a family, and patient health status. We included these variables in our study. Third, this study analyzed employment status with baseline characteristics. Therefore our results did not explain the causal relationship between variables in our study and employment status. A future study will need to make these consequences clear.

In spite of the preceding limitations, we found that when compared to the general population, family caregivers of terminal cancer patients have work problems such as not working and severe work- and housework-related difficulty, probably due to easy fatigue and caregiving itself. We need to develop supportive programs for reducing the work-related burden of caregivers of terminal cancer patients.

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