

Impact of Cancer on Primary Caregivers of Patients Receiving Radiation Therapy

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The main objective of this study was to assess the consequences of caregiving on primary caregivers of Greek cancer patients receiving radiotherapy. Sixty-five caregivers participated in the study and data were collected through structured interviews. Our results pointed to a lack of association concerning extent of patients' disease, treatment schedule, performance status or awareness of diagnosis. However, female caregivers with low qualifications, partners, and those living with the patient were more likely to report heightened symptoms of anxiety and depression, severe impact of caregiving on their lives, poor health and low quality of life. In addition, it was shown through multivariate analyses that psychological distress was the sole predictor of overall health and global quality of life. In conclusion, Greek caregivers are to a great extent affected by the disease. Caring for significant others is essential to promoting quality of life for the family and the patient.

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In recent years, research on the impact of cancer on family members—mainly on those who are involved in caregiving—has been a major area of interest for psychosocial oncology (1, 2). There are two possible reasons for this growing interest in conducting research on the informal caregiver. First, it has been suggested that family members' responses to the illness can play a central role in the patient's outcomes (3, 4). Therefore, in order effectively to help the patient cope across the disease continuum and achieve the best quality of life, it is imperative to address at the same time the problems and needs of the whole family (5, 6). Second, advances in the detection and treatment of cancer have led to significant prolongation of life, increased administration of different therapies on an outpatient basis, and decrease in the length of hospitalization (4). Consequently, caregivers are becoming increasingly responsible for providing physical and emotional care over longer periods (7, 8).

The general pattern that emerges from the literature is that the disease imposes considerable demands upon informal caregivers. That is, in addition to the financial constraints, cancer caregivers report restrictions on social roles and leisure activities, the physical burden of actually providing care, and are likely to experience heightened levels of emotional distress, diminished physical health and low quality of life (4, 9–11).

However, the existing evidence on the consequences of caregiving is suggestive rather than conclusive, as there are still conflicting findings about who is in fact affected the most and to what extent (12, 13). To take just a few examples: in a review by Biegel and colleagues (14) it was asserted that caregivers coped well with the strain of diagnosis and treatment, and returned to normal functioning once immediate caregiving subsided. In contrast, Ell and colleagues (15) reported a decline in personal well-being and an increase in psychological distress among significant others of cancer patients between diagnosis and one year post-treatment. Most studies have suggested that female caregivers—especially partners—are the most likely to report a higher burden and lower health status, and tend to experience as much, if not more, anxiety and depression as the patients (13, 16). However, two recent studies indicated no gender differences in psychological distress among partners of cancer patients (17, 18). Yet, another investigation found husbands of breast cancer patients to be even more depressed than their wives (19). With respect to level of education attained, a number of studies have shown that the less-educated caregivers were more distressed (20) and had poorer overall physical health (21) than the better educated. In contrast, McMillan found that as the educational level of the caregiver increased, quality of life decreased (22). Finally, some

studies have suggested that poor prognosis, metastatic disease, poor physical status and palliative treatment are negatively related to caregiver outcomes (21, 23), whereas others have suggested no such relationships exist (19, 22).

In the remainder of the article we report our own investigation on the effects of caregiving on primary caregivers of cancer patients receiving radiotherapy. The present study can be seen as a first attempt to delineate the profile of the Greek cancer caregiver, because this issue has hardly ever been examined in Greece.

The first objective of the study was to assess the extent to which caregiver demographic and patient clinical characteristics affect the caregiver's psychological distress, the impact of caregiving on life, overall health status and global quality of life. The second objective was to examine the associations between psychological distress, impact of caregiving on life, on the one hand, and health status and quality of life on the other. Most studies have considered psychological distress to be an outcome, whereas we see it as a potential predictor of overall outcome.

MATERIAL AND METHODS

Subjects and procedure

The study took place at the University of Patras Medical School, in South-West Greece, between January and June 2000. Caregivers of cancer patients receiving radiotherapy were approached at routine treatment appointments in the radiotherapy clinic and invited to take part in the study. The criteria were that they should have a relative with cancer, should be the identified primary caregiver, should be at least 18 years of age, should be native speakers of Greek, and should be able to communicate effectively. Caregivers were told that it was hoped that the study would improve healthcare provision and that it concerned their needs and feelings. Seventy caregivers were approached, and 65 agreed; of the 5 who refused, 2 said that they lacked the time, and 3 gave no reason.

Data were collected by means of structured individual interviews administered by the first and second authors. Interviews rather than questionnaires were used so that a good rapport would be built up and participants would be encouraged conscientiously to answer the sometimes sensitive and searching questions. Many questions required responses to be given on scales, and response cards were therefore used. The interviewer would read out the question, show the card, and record the response on the protocol. All the interviews took place in an office, set aside for the purpose, and typically lasted 15 min. Information regarding the patient's diagnosis, stage of the malignancy, treatment status, and performance status was obtained from the doctors or from the hospital charts.

Interview measures

Demographic characteristics. Caregivers' gender, age, level of education, relationship to the patient, and living situation were all recorded. Caregivers were also asked whether the patient was aware of the true diagnosis.

Psychological distress. Psychological distress was assessed using the Hospital Anxiety and Depression Scale (HADS; (24)), a measure we have used in previous research (25). The HADS consists of 14 items, 7 for anxiety and 7 for depression. The original 4-point scales were adopted for our study, and Cronbach's alphas were 0.90 for the anxiety subscale and 0.88 for depression. A composite score of overall psychological distress produced a Cronbach's alpha of 0.93.

Impact of caregiving on life. To measure impact of caregiving on life, we used a questionnaire that we ourselves devised for the study. There were seven 5-point items ranging from 1 (Not at all) to 5 (Very much), each designed to tap impact on a different dimension of the caregivers' lives: 'During the past week, to what extent has caring affected: your social life; your leisure activities; your finances; your daily schedule; your profession; your physical strength (fatigue); and, your emotions?' The seven items were combined into a single scale and Cronbach's alpha was 0.81.

Overall health status and global quality of life. Caregivers were asked to rate their overall health status and global quality of life on two 100 mm visual analogue scales (VAS, 0–100), the extremes of which represented the worst possible and best possible scores for each parameter.

Statistical analysis

Data were analysed using SPSS 7.5 for Windows. Pearson's correlation coefficients were calculated for possible relationships among continuous measures, and one-way analysis of variance was used to compare means of continuous variables between groups. Multiple regression analyses were conducted to predict the dependent variables by certain independent measures.

RESULTS

Sample

The demographic characteristics of the caregivers and the clinical characteristics of the patients are listed in Table 1. Before we proceeded to the main analyses, we examined the consequences of caregiving on the sample as a whole. Table 2 presents the means, standard deviations, and ranges of the psychosocial measures. There are two points to be made. First, on average the 65 caregivers experienced significant levels of psychological distress. In accordance with the HADS scoring instructions, ratings on both the anxiety and the depression subscales ranging from 0 to 7 are considered as 'non-cases', from 8 to 10 'doubtful cases' and from 11 to 21 'definite cases'. For the anxiety subscale,

Table 1*Caregiver demographic and patient clinical characteristics*

Gender	
Males	28 (43.1%)
Females	37 (56.9%)
Age	
<45	31 (47.7%)
>46	35 (52.3%)
Mean 47.6 yrs, Range 21–80, SD 15.7	
Educational level	
Low	23 (35.3%)
Middle	30 (46.2%)
High	12 (18.5%)
Mean 9.5 yrs, Range 0–18, SD 4.5	
Relationship to patient	
Partners	27 (41.6%)
Adult children	30 (46.1%)
Other	8 (12.3%)
Living situation	
Living with patient	48 (73.8%)
Not living with patient	17 (26.2%)
Awareness of diagnosis (patient)	
Yes	23 (35.4%)
No	42 (64.6%)
Cancer diagnosis	
Lung	16 (24.6%)
Breast	11 (16.9%)
Head and neck	8 (12.3%)
Colorectal	7 (10.8%)
Other	23 (35.4%)
Disease extent	
Early disease (stages I, II)	23 (35.4%)
Advanced disease (stages III, IV)	42 (64.6%)
Treatment status	
Radical radiotherapy	37 (57%)
Palliative radiotherapy	28 (43%)
Karnofsky performance status	
50	5 (7.7%)
60	6 (9.2%)
70	7 (10.8%)
80	21 (32.3%)
90	15 (23.1%)
100	11 (16.9%)
Mean 80.5, range 50–100, SD 14.5.	

10 caregivers (15.4%) were 'non-cases', 13 (20.0%) were 'doubtful cases', and 42 (64.6%) were 'definite cases'; for the depression subscale, the figures were 13 (20.0%), 11 (16.9%), and 41 (63.1%), respectively.

Second, caregivers reported relatively high values on impact on life, moderate values on overall health status, and low values on global quality of life.

Effects of caregiver and patient background characteristics

In the first part of our main analysis we investigated whether there were differences in psychological distress, impact of caregiving on life, overall health and global quality of life according to caregiver and patient background characteristics. Univariate analyses revealed no significant effects for age, disease extent, treatment status or awareness of diagnosis. However, there were reliable main effects for gender, level of education, relationship to the patient (recoded into a dichotomous variable, 1 = partners or 2 = others) and living situation (Table 3). First, female caregivers were significantly more anxious and depressed than male caregivers, reported a more severe impact of caregiving on their lives, and had lower scores for overall physical health and global quality of life. Second, caregivers with higher education were significantly less anxious and depressed than those with a lower level of education, and reported significantly lower scores on impact of caregiving on life and higher scores on overall health status. Third, partners were found to be significantly more depressed than non-partners. Fourth, caregivers living with the patient experienced a greater impact on their lives than those who were not living with the patient. There were no interaction effects among variables. Finally, the KPS (Karnofsky performance status) of the patient was unrelated to any of the psychosocial measures of concern.

Predicting overall health status and global quality of life

In the next stage of our analysis we used Pearson's correlations, and tested for all possible relationships between psychological distress and caregiving impact on life, on the one hand, and overall health status and global quality of life on the other. This time a clear constellation of associations emerged (Table 4), and there are three points to

Table 2*Means, standard deviations, and ranges of scores of different measures*

Measures	M	SD	Potential range	Observed range
HADS—Anxiety	12.9	5.6	0–21	0–21
HADS—Depression	12.1	5.2	0–21	0–21
Overall psychological distress (total HADS)	25.0	10.1	0–42	0–40
Impact of caregiving on life scale	22.6	6.7	7–35	7–35
Overall health status ¹	53.1	25.2	0–100	0–100
Global quality of life ¹	45.0	25.6	0–100	0–100

¹ Higher scores indicate better health and quality of life.

Table 3

Main effects of caregiver background characteristics: one-way analysis of variance

Characteristic	HADS—Anxiety			HADS—Depression			Impact of caregiving on life			Overall health status			Global quality of life		
	Mean	SD	F	Mean	SD	F	Mean	SD	F	Mean	SD	F	Mean	SD	F
Gender															
Male	10.6	5.6	9.6**	9.9	5.2	9.1**	20.4	7.0	5.7*	63.3	24.9	9.3**	56.8	23.7	11.4***
Female	14.7	4.9		13.7	4.7		24.3	5.9		45.3	22.6		36.5	23.8	
Education															
Low	14.9	5.1	3.9*	14.0	4.7	3.6*	26.3	6.3	7.1**	41.3	22.1	5.8**	35.5	22.1	2.8 n.s.
Middle	12.7	5.0		11.7	5.2		21.4	6.0		55.8	24.2		48.8	26.2	
High	9.6	6.5		9.3	5.3		18.7	5.8		68.7	24.1		54.5	26.9	
Relationship to patient															
Partners	13.7	6.2	1.0 n.s.	13.8	5.7	5.1*	24.6	5.7	3.8 n.s.	49.0	26.3	1.2 n.s.	39.1	22.1	2.4 n.s.
Others	12.3	5.1		10.9	4.6		21.3	6.9		55.9	24.3		49.1	27.3	
Living situation															
Living with patient	13.4	5.5	1.4 n.s.	12.7	5.2	2.6 n.s.	23.6	6.2	4.0*	52.6	25.3	0.1 n.s.	43.3	25.6	0.9 n.s.
Not living with patient	11.5	5.9		10.3	5.2		19.9	7.2		54.4	25.3		49.9	25.7	

n.s. = not significant. * $p \leq 0.05$; ** $p \leq 0.01$; *** $p \leq 0.001$.

make. First, feelings of anxiety and depression correlated positively and significantly with impact of caregiving on life but negatively with overall health status and global quality of life. Second, impact of caregiving on life was also significantly associated with overall outcome and the relationships were inverse. Third, the moderate correlations observed between health status and quality of life suggested that caregivers perceived the two measures as being conceptually distinct.

Our final step in examining overall health and global quality of life was to perform a separate multiple regression analysis for each measure. In both analyses, the total score of the HADS was used as a composite psychological distress measure, because the anxiety and the depression subscales were strongly correlated ($r = 0.73$, $p < 0.001$). With the exception of psychological distress and impact of caregiving on life, the caregiver's age, disease extent, treatment status and awareness of diagnosis were also entered into the equation. As can be seen in Tables 5 and 6, psychological distress was the sole predictor of both overall health status and global quality of life. By contrast, the impact of caregiving on life and background characteristics failed to reach significance.

DISCUSSION

Concerning the consequences of caregiving, our data indicated that, overall, Greek primary caregivers were affected by the disease, as evidenced by the elevated scores on anxiety, depression and impact of caregiving on their lives and the relatively low scores for global quality of life. Their overall health status was perceived as moderate.

Our next step was to examine whether and to what extent certain caregiver and patient background characteristics influenced caregivers' experiences. Our results, contrary to other reports, indicated lack of associations with patients' disease extent, treatment status, physical functioning, and awareness of diagnosis. A possible explanation for this might be that, on average, patients exhibited a high KPS, thus suggesting limited physical dependency. Progressive disease and palliative treatment do not necessarily equate with an immediate deterioration in physical functioning, so that it could have been too early for the demands of caregiving to have manifest themselves. Perhaps, a sample of more physically debilitated patients might have produced more definite effects.

Table 4

Intercorrelations (Pearson's r) among measures

Measures	1	2	3	4
1. HADS—Anxiety				
2. HADS—Depression	0.73 ***			
3. Impact of caregiving on life scale	0.61 ***	0.70 ***		
4. Overall health status	-0.49 ***	-0.63 ***	-0.48 ***	
5. Global quality of life	-0.55 ***	-0.59 ***	-0.52 ***	0.49 ***

*** $p \leq 0.001$.

Table 5*Predicting overall health status: multiple regression*

Predictors	Beta	t
Age (yrs)	-0.12	-1.1 n.s.
Disease extent (early = 0; advanced = 1)	0.08	0.6 n.s.
Treatment status (radical = 0; palliative = 1)	0.04	0.3 n.s.
Awareness of diagnosis (aware = 0; not aware = 1)	-0.02	-0.2 n.s.
Overall psychological distress (total HADS)	-0.46	-3.1**
Impact of caregiving on life scale	-0.15	-1.0 n.s.

Adjusted R² = 0.30 df 6, 56 F = 5.5***

n.s. = not significant. **p ≤ 0.01; *** p ≤ 0.001.

With respect to caregiver demographic characteristics, marked effects were found for gender, level of education, type of relationship and living situation. First, as to gender, female caregivers appeared to be more affected by their situation than their male counterparts. Our results are in line with previous research, which has identified women as being the most vulnerable group of caregivers. This may partly be attributable to the fact that women are still the traditional family caregivers, and as a result, they carry out most of the tasks of caregiving (16). Another explanation may be that women have generally been found to be more susceptible than men to chronic physical illness and mood disorders, particularly when confronted with stressful life events (26, 27).

As noted in the introduction, level of education has produced inconsistent findings across studies. In our investigation, caregivers with lower levels of educational attainment suffered significantly more emotional distress than those with higher education, and reported a greater impact on their lives and poorer physical health. It may be that less education is positively associated with lower socioeconomic status and therefore with fewer available resources to deal with the demands of caregiving (21).

In accord with previous research, our findings showed that partners were most likely to develop severe depressive symptomatology. Not surprisingly, caregivers living with the patient were more likely to report a greater impact of caregiving on their lives than were non-residents.

With respect to our second objective, it was found that increased rates of anxiety, depression and impact of caregiving on life were positively linked to lower overall health and global quality of life. Finally, the findings of multivariate analyses showed that psychological distress was the strongest predictor of both overall health and global quality of life, whereas impact of caregiving on life and background characteristics played no part. Similar results have been reported in a recent study where increased overall mental health was related to a better quality of life,

Table 6*Predicting global quality of life: multiple regression*

Predictors	Beta	t
Age (years)	-0.04	-0.4 n.s.
Disease extent (early = 0; advanced = 1)	0.25	1.8 n.s.
Treatment status (radical = 0; palliative = 1)	-0.20	-1.4 n.s.
Awareness of diagnosis (aware = 0; not aware = 1)	-0.03	-0.3 n.s.
Overall psychological distress (total HADS)	-0.49	-3.4**
Impact of caregiving on life scale	-0.17	-1.2 n.s.

Adjusted R² = 0.36 df 6, 55 F = 6.6***

n.s. = not significant. **p ≤ 0.01; *** p ≤ 0.001.

while more psychological distress was associated with a poorer quality of life (28). However, we must add a note of caution here. In our study, data on all measures were collected at the same point in time, and therefore conclusions about causality cannot be addressed. That is, we can say little about the paths of influence from one set to the other, but the simplest would be that psychological distress affects both indices of outcome directly. Through path analysis, it will be possible to explore this issue in detail, using larger numbers and a prospective longitudinal design.

There is another point that we have to make about our research, and this concerns generalization. It might have been easier to draw conclusions if the sample had been more homogeneous, i.e. consisting of adult children and partners only and if the patients had been either curatively or palliatively treated, not mixed.

Nonetheless, our research has led to one issue for policy and practice, namely the proper screening and management of caregivers' psychological distress. In our study, a significant proportion of caregivers experienced levels of anxiety and depression sufficient to warrant further evaluation and management. The rates of symptomatology observed were higher than those reported in other countries (8, 29) and this is among the first steps in drawing the psychological profile of the Greek caregiver, to date a largely neglected area. High levels of emotional distress, beyond their harmful effects on health status and quality of life, may undermine quality of care, because a distressed caregiver is less likely to assimilate important illness-related information and provide comprehensive patient care. There is thus a need to further assess the psychological morbidity of Greek caregivers and to come up with well-evaluated and cost-effective interventions that will help caregivers maintain their psychological hygiene. For example, it is well documented that experimental interventions designed for adult and paediatric cancer patients have been successful in alleviating psychological distress and

promoting quality of life (30–32). In all likelihood, similar programmes of research might also prove beneficial for family members, but until further empirical data become available, we can do no more than speculate.

In summary, the present exploratory study met its objective of shedding more light on the effects of cancer caregiving in a different cultural setting. Greek significant others were found to be affected by the disease, especially women, those with low qualifications, partners, and those living with the patient. Moreover, the presence of anxiety and depression was the key factor in determining overall health and global quality of life.

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