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Determinants of Caregiving Experiences and Mental Health of Partners of Cancer Patients

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BACKGROUND. Research regarding informal caregiving showed considerable individual variation in responses to cancer caregiving. The current longitudinal study examined determinants of caregiver outcomes in terms of caregiver experiences at 3 months and caregiver's mental health at 6 months after hospital discharge. It included both negative and positive dimensions of caregiving outcomes.

METHODS. One hundred forty-eight patients with newly diagnosed colorectal carcinoma and their partners were included. Caregiver experiences were assessed by the Caregiver Reaction Assessment Scale, which contains four negative subscales (disrupted schedule, financial problems, lack of family support, and loss of physical strength) and one positive subscale (self-esteem). The mental health of the caregiver was assessed in terms of depression and quality of life. Possible determinants of the caregiver's experiences and mental health were categorized according to characteristics of the caregiver, the patient, and the care situation. Caregiving experiences were studied as a fourth additional category of possible determinants of the caregiver's mental health.

RESULTS. Each domain of the caregiving experience was explained by different factors, with total explained variances ranging between 11–46%. Negative caregiver experiences were associated with a low income, living with only the patient, a distressed relationship, a high level of patient dependency, and a high involvement in caregiving tasks. Caregivers with a low level of education and caregivers of patients with a stoma were able to derive more self-esteem from caregiving. Although caregiving may lead to depression, especially in those experiencing loss of physical strength, caregivers may sustain their quality of life by deriving self-esteem from caregiving.

CONCLUSIONS. It is important that professionals involved in the ongoing care of cancer patients and their families be aware of the increasing demands made on caregivers and the specific problems and uplifts they perceive in caregiving. Professional caregivers are urged to involve informal caregivers with care explicitly and continuously. However, specific attention to those caregivers who live only with the patient, those with a low income, those with a distressed relationship, and those with a high level of patient dependency and care involvement is warranted.

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KEYWORDS: cancer, partners, caregiving experiences, depression, quality of life.

The diagnosis of cancer has not only a significant impact on the affected patients, but also on their families, and may cause emotional responses of shock, doubt, anxiety, and depression.^{1,2} With cancer rapidly developing into a continuous care problem because of increasing incidence rates, longer survival times, and a trend toward outpatient treatment, providing support and managing care has placed added responsibilities on caregivers. However, the consequences for these caregivers still are unclear. To differentiate the

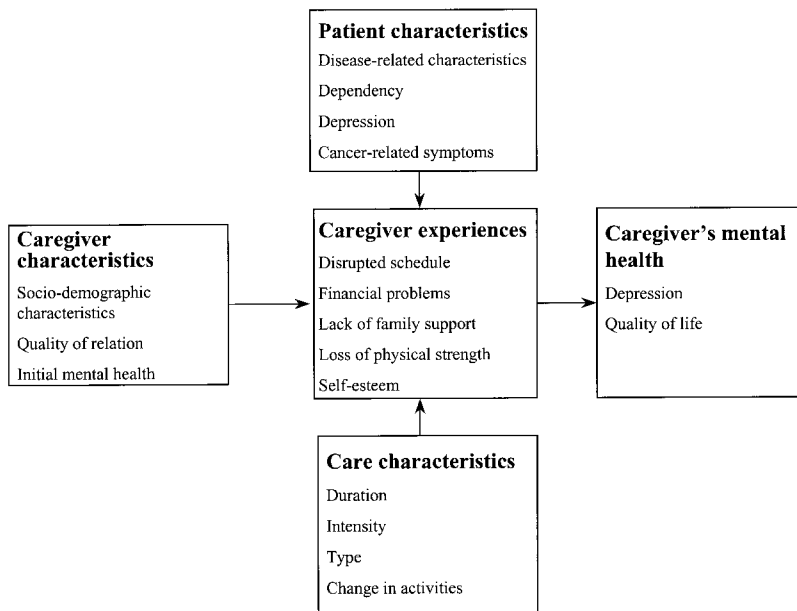


FIGURE 1. Conceptual research model for studying caregiver experiences and the mental health of partners of cancer patients.

impact of caregiving and to identify caregivers at risk, a thorough investigation of factors influencing caregiving consequences appears warranted.

Living with cancer can be conceived as a dynamic, ongoing process³ and providing care to cancer patients also can be seen as such.⁴⁻⁷ Three phases have been distinguished during the cancer patient's illness: the initial or "acute" phase, the "chronic" phase, and "resolution."⁸ During the acute phase the family is shocked, stunned, and frightened. In the chronic phase, when initial treatment has been endured and the patient has been released from the hospital, family members have to take on new and additional responsibilities. During the third phase, resolution, the family anchors itself in either survivorship or the bereavement process. All three periods may lead to considerable anxiety and perceived pressure in family members, particularly in the primary caregivers.⁹ Research into cancer caregiving is scarce, especially with regard to the chronic phase, on which to our knowledge hardly any information is available.

The majority of studies regarding caregiving are cross-sectional and involve family members of patients with mental disorders such as schizophrenia or dementia.¹⁰⁻¹² These studies revealed that interpretations of the relation between characteristics of the caregiving situation and caregiver outcomes may be guided by the cognitive stress theory of Lazarus and Folkman.¹³ According to this theory, contextual elements as well as personal perceptions of the situation play a major role in explaining variations in caregiver outcomes. Although caregiver experiences can be conceived as specific caregiver outcomes, the health of

the caregiver may be interpreted as a more generic caregiver outcome in the longer run.^{6,14} Factors that are mentioned to be associated with caregiver outcomes can be divided into three categories: 1) characteristics of the caregiver, 2) characteristics of the patient, and 3) characteristics of the care situation.¹⁴⁻¹⁶ Subsequently, caregiver experiences at 3 months may have an effect on the caregiver's mental health at 6 months. Thus, caregiver outcomes can be studied on the basis of a conceptual research model as presented in Figure 1.

Background characteristics of the caregiver that may influence caregiver outcomes include age, gender, living situation, socioeconomic status, and type and quality of the relationship between the care recipient and caregiver. Relatively consistent findings were reported regarding gender,¹⁷⁻¹⁹ age,^{20,21} coresidence, and the type of relationship between the care recipient and caregiver.^{22,23} Women, especially those at a younger age, tend to perceive caregiving as more negative than (older) men and report higher levels of psychologic distress,^{24,25} even when the quality of the patient's health and/or the amount of care provided is controlled for.²⁶ Compared with other informal caregivers, partners in particular are expected to bear a large proportion of the stresses and burdens that follow in the course of cancer.²⁷ A high quality patient-caregiver relationship (i.e., the absence of a distressed relationship) can be conceived as a necessity when care is provided over a longer period.^{28,29} Less consistent findings were reported for the association between socioeconomic status and caregiver outcomes. Although caregivers with a relatively low socioeco-

nomic status can be assumed to report a higher burden,²¹ Biegel et al.³⁰ did not find such a relation.

Although the caregiver's mental health often is studied as an outcome, their initial level of mental health may be an important resource that affects caregiver outcomes^{6,31} (e.g., negative caregiving experiences or health outcomes may be accentuated by caregivers who previously experienced depression).

Patient characteristics that have been cited in the literature as having an influence on caregiver outcomes include disease-related and treatment-related characteristics, dependency,³² and physical and psychologic symptoms.^{15,33} However, no consistent research findings have been reported, with some studies showing that patient characteristics are related to negative caregiver outcomes^{22,32} and others reporting no such relation.³⁴ In gerontologic studies, it generally was observed that the patient's mental health was associated with more negative responses in caregivers than the patient's physical health.^{15,35} Based on their research among caregivers of cancer patients, Given et al.^{36,37} reported that a patient's dependency and symptoms specifically have a negative impact on the caregiver's schedule. Another oncologic study regarding caregiving revealed that only a patient's dependency determined caregiver experiences (i.e., in terms of burden) and that other patient characteristics, such as disease-related and treatment-related symptoms, were not associated at all with caregiver experiences or mental health (e.g., mood).³³

Care characteristics may include duration of care,³⁸ intensity of care, and different types of care.²⁷ The more confining the care tasks are (i.e., the less time-flexible and the more disruptive they are to the caregiver's schedule), the more likely they are to create negative consequences.¹⁵ Personal tasks (e.g., feeding and washing the patient) appeared to be perceived as more difficult and burdensome than nonpersonal tasks (e.g., buying the groceries).²⁷ Moreover, because providing care requires time, the time available for other activities such as household chores, leisure, and visiting family and friends may be expected to decrease.^{22,32,39}

Caregiver experiences has been defined by a broad range of varying constructs, predominantly expressed as an overall measure, e.g., burden,³⁵ strain,⁴⁰ or role overload.⁴¹ The mental health of the caregiver also has been defined differently, e.g., psychologic distress,⁴² well-being,^{36,39} psychologic and physical symptoms,⁴³ depression, life satisfaction, and self-reported health.^{10,30,44} Findings from studies regarding the relation between caregiving experiences and the caregiver's mental health vary enormously. Given et al.¹ proposed that caregiver experiences can be de-

scribed according to five domains, including four negative domains (disrupted schedule, financial problems, lack of family support, and loss of physical strength) and a positive domain (caregiver's self-esteem). These five domains appear to represent the core set of caregiver experiences.^{1,15,32,45} In general, it is expected that greater perceived negative aspects of caregiving will be associated with decreased mental health. Caregivers may experience high levels of burden,³³ leading to increasing levels of depression^{9,38} or distress.⁷ Conversely, positive caregiving experiences also are reported^{1,4,9} that may help in maintaining the caregiver's mental health. As yet, the relation between positively perceived aspects of caregiving and health outcomes is unclear, but it can be hypothesized that more positive aspects of caregiving will be associated with a higher quality of life for the caregiver.

To summarize, to our knowledge, with a few exceptions, previous studies regarding caregiver outcomes used descriptive, cross-sectional designs and the majority of research was conducted among the caregivers of patients with cognitive disorders. In addition, previous research revealed that several characteristics may have an important influence on caregiver experiences and mental health, and can be categorized into caregiver characteristics, patient characteristics, and care characteristics (Fig. 1). The objectives of the current study were 1) to assess determinants of caregiving experiences in partners of cancer patients at 3 months after the patient's discharge from the hospital, both in terms of negative and positive domains (i.e., the impact of caregiving on daily schedule, finance, lack of family support, loss of physical strength, and self-esteem) and 2) to assess determinants of the caregiver's mental health at 6 months after the patient's discharge from the hospital in terms of depression and quality of life.

METHODS

Procedure and Subjects

Longitudinal data from the research project entitled "CAregiving of Spouses of cancer PATients" were used. This study was conducted in cooperation with ten hospitals in the Netherlands in the regions of Amsterdam and Groningen, and data were collected at three measurement points. The baseline measurement (T0) took place as soon as possible after the patient's surgery, either in the hospital or at home. The second measurement (T1) took place 3 months after baseline and the third measurement (T2) occurred again 3 months later (i.e., 6 months after baseline). Patients and partners were interviewed face-to-face by trained research assistants using structured questionnaires, and they also completed a self-report questionnaire.

Newly diagnosed colorectal carcinoma patients who recently underwent surgery, who had a survival prognosis of at least 6 months, and who lived with a partner were selected by surgeons of the 10 cooperating hospitals. The partner was defined as a relative by marriage or the person identified by the patient as a partner, and who resided in the patient's household. Of the 238 eligible cancer patients and their caregivers, informed consent was obtained from 181 at the onset of the study. The response rate was 76%. No response bias was found between participating patients and nonparticipants with respect to age, gender, diagnosis, and region. Longitudinal data (up to T2) were available for 148 couples (82%). Loss to follow-up occurred for the following reasons: serious illness of the patient ($n = 15$; 8%), refusal to report for follow-up ($n = 10$; 6%), and death of the patient ($n = 8$; 4%).

Measurements

Data were collected on caregiver characteristics (T0), patient characteristics (T1), care characteristics (T1), caregiver experiences (T1), and caregiver's mental health (T2).

Caregiver characteristics included sociodemographic characteristics, quality of the relationship, and the caregiver's initial mental health. The caregiver's sociodemographic characteristics were gender, age, level of education, income, major occupation, and living situation (i.e., either living only with the patient or together with patient and children), and were measured with single items.

The marital scale (ten items) of the Maudsley Marital Questionnaire (MMQ)⁴⁶ was used to estimate the quality of the relationship at baseline. The MMQ was designed to assess the degree of favorableness of attitudes towards one's own marriage or relationship. The scale was demonstrated to have a high internal consistency (Chronbach's $\alpha = 0.90$) and sufficient test-retest reliability and validity (Pearson correlation coefficient [r] = 0.70–0.80), and was shown to be only slightly related to social desirability.⁴⁷ The answering format was a nine-point scale (zero–eight). For clarity, the scores were reversed in the subsequent analyses and a total score was computed, with a high score indicating a high quality relationship.

The caregiver's initial mental health included two indices: caregiver's depression and caregiver's quality of life. The level of depression was measured by the 20-item Center for Epidemiologic Studies Depression Scale (CES-D).⁴⁸ The CES-D is comprised of a 20-item self-report scale that taps the level of depression during the week preceding hospital admission. Total scores can range from 0–60, with higher scores indicating a higher level of depression.⁴⁹ Chronbach's α

was 0.97. The caregiver's initial quality of life was measured with a one-item linear visual analogue self-assessment scale.^{50,51} Caregivers were asked to evaluate their quality of life during the week preceding hospital admission by marking a point on a 10-cm line, with 0.0 representing the lowest quality of life and 10.0 the highest quality of life.

Measures on patient characteristics included disease-related characteristics, dependency, cancer-related symptoms, and depression. Disease-related characteristics were assessed in terms of the duration of the patient's symptoms before hospital admission, the patient's diagnosis, and the presence of a stoma after surgery. The patient's dependency was measured by means of the Groningen Activity Restriction Scale.⁵² This hierarchical 18-item scale was used to assess the extent of (dis)ability to manage 1) activities of daily living (ADL) such as eating, dressing, bathing, using the toilet, grooming, and getting in and out of bed and 2) instrumental activities of daily living such as cooking, laundry, shopping, and housework. Each item was scored on a four-point rating scale. A dependency score was determined by summation of the item scores. The total score ranges from 18 (indicating the absence of dependency) to 72 (totally dependent). Chronbach's α was found to be 0.81.

Cancer-related symptoms was measured using the Rotterdam Symptom Check List.⁵³ Patients were asked to rate the severity of a symptom, either a physical (e.g., nausea) or a psychologic symptom (e.g., worrying), on a 4-point scale 3 months after hospital discharge. The internal consistencies of the two scales, "physical symptoms" and "psychologic symptoms," were 0.83 and 0.89, respectively. Like caregiver depression, patient depression was measured by the CES-D.

Care characteristics referred to involvement in care in terms of duration, intensity, performance of different types of care tasks, and changes in social activities. Apart from the duration of care tasks, which referred to the period before to the patient's hospital admission, the other care characteristics referred to the first 3 months after hospital discharge. Intensity of care was assessed in terms of the total of caregiving days and hours per week. The involvement in different care types was measured for personal tasks and household, organizational, and disease-related tasks. Personal tasks referred to assisting the patient with ADL (11 items [e.g., assistance with eating, dressing, and bathing]). Household tasks (seven items) included cooking, laundry, shopping, and housework. Organizational tasks (five items) focused on providing assistance with large expenses, transport, and providing odd jobs. Disease-related tasks (six items) referred to wound and stoma care, decision-making, and achiev-

ing and exchanging information. Task performance was dichotomized (0 = did not perform specific task; 1 = did perform specific task). For each type, a sum score was computed. A separate question was added concerning the total number of times the caregiver accompanied the patient to physician visits. Finally, change in social activities was assessed by asking the respondents to report on a four-point, six-item scale the actual change in time available for household, family, visits, hobbies, work, and relaxing.^{22,40} Chronbach's α was 0.74.

Caregiver experiences were measured by the Caregiver Reaction Assessment Scale (CRA) of Given et al.¹ The CRA is comprised of 24 items divided into 5 subscales, with each subscale representing a specific dimension of caregiving experiences. The subscale "disrupted schedule" (five items) measured the extent to which caregiving interrupted the usual activities of the caregiver. The subscale "financial problems" (three items) measured the financial strain on the caregiver as a consequence of the caregiving situation. The subscale "lack of family support" (four items) assessed the extent to which the caregiver perceived a shortage of family support and to what extent the caregiver felt abandoned by his/her family in taking on caregiving responsibilities. The subscale "loss of physical strength" (five items) assessed caregivers' reports of how caregiving impacted their ability and energy to provide care. The subscale "caregiver's self-esteem" (seven items) aimed to measure the extent to which caregiving contributed to individual self-esteem. Respondents were asked to rate the perceived impact of caregiving on each of the 24 items on a 5-point Likert scale. For each subscale, a total score was computed reflecting the mean item score, with a range between 1.00–5.00. A higher score represented a greater amount of the attribute. The subscales of the CRA were shown to be reliable (Chronbach's α coefficients ranged from 0.68–0.84) and valid.^{1,54}

Caregiver mental health at 6 months after discharge included caregiver's depression and caregiver's quality of life and were measured by the same instruments as at baseline.

Analyses

Descriptive statistics were computed for all relevant variables. The caregiver outcomes of the nominal variables such as gender, patient disease-related characteristics, and living situation were compared by chi-square tests. Analysis of covariance was conducted of the analogue comparisons of the outcomes on ratio level of measurement and scores on caregiver outcomes. Pearson product-moment correlations were used to examine the significance (with $P < 0.01$) of

associations between dimensions caregiver outcomes and all other characteristics. Significant variables, as identified by means of univariate analyses, subsequently were entered in blocks as defined by the research model (Fig. 1). Each set of variables was tested simultaneously and adjusted for all other variables entered. As such, the relative contribution of each set of variables could be determined. Model fit was evaluated by the adjusted R^2 and final adjusted B weights. Pairwise deletion of missing data was applied. Residual analyses were performed to ensure that the multiple regression assumptions of linearity, constant error variance, and normality were met adequately.

RESULTS

Sample

Table 1 presents descriptive characteristics of the 148 dyads who participated at all three waves. The majority of patients ($n = 96$; 65%) were diagnosed with colon carcinoma whereas 52 patients (35%) were diagnosed with rectal carcinoma. Approximately 33% of the patients had a stoma ($n = 49$) and 12–19% of the patients received chemotherapy and/or radiotherapy. The mean duration of the patients' cancer-related symptoms was 12.5 months (standard deviation [SD] = 43.3 months). The caregiver group was comprised of 54 men and 94 women, ranging in age from 25–89 years (mean age, 63 years; SD = 11 years). The majority of couples (89%) had children, and 18% still lived with their children at home. Sociodemographic characteristics are presented in Table 1.

Patients who dropped out during follow-up did not differ from patients who remained in the study with regard to gender, age, diagnosis, duration of symptoms, (co)morbidity, feelings of depression, and mental health. However, the proportion of patients with a stoma was slightly higher among those who dropped out of follow-up ($P < 0.10$) and the level of the patient's dependency was significantly higher ($P < 0.01$). These patients also reported more physical symptoms at baseline ($P < 0.05$) than patients who were followed for 6 months.

Caregivers of patients who dropped out of follow-up did not differ from those of patients who remained in the study with regard to gender, age, and baseline values of the majority of caregivers. However, participating caregivers reported a less negative impact on physical strength at baseline compared with those who dropped out over time (participants: mean score = 1.98; dropouts: mean score = 2.22; $P < 0.05$).

TABLE 1
Descriptive Characteristics of Patients and Partners Who Participated at All 3 Measurement Points (N = 148)

	Definition	No.	(%)
Patient characteristics			
Diagnosis	Colon carcinoma	96	(65)
	Rectal carcinoma	52	(35)
Stoma	No	99	(67)
	Yes	49	(33)
Radiation therapy	No	120	(81)
	Yes	28	(19)
Chemotherapy	No	130	(88)
	Yes	18	(12)
Duration of complaints (mos)	0-3	50	(34)
	4-6	43	(29)
	7-12	34	(23)
	>12	21	(14)
Caregiver characteristics			
Gender	Male	54	(36)
	Female	94	(64)
Age (yrs)	<50	18	(12)
	50-65	69	(47)
	>65	61	(41)
Educational level	Low	30	(20)
	Middle	85	(53)
	High	33	(22)
Income	< fl 40,000	38	(33)
	fl 40,000-60,000	51	(44)
	> fl 60,000	28	(24)
	Unknown	31	
Job	Low	28	(19)
	Low/middle	38	(26)
	Middle/high	51	(35)
Living situation	Upper	31	(21)
	With partner	122	(82)
Having children	With partner and children	26	(18)
	Yes	131	(89)
	No	17	(11)

Caregiver Experiences at 3 Months and Mental Health at 6 Months

Descriptive statistics of caregiver experiences at 3 months and caregiver's depression and quality of life at 6 months are presented in Table 2. The mean scores of the negative experiences were relatively low, indicating caregivers perceived a relatively low burden, whereas the mean scores of the self-esteem subscale were relatively high, indicating a highly positive perception of the caregivers' self-esteem. A high mean item score and a small SD were observed, especially with regard to Item 15, which addressed caregivers' feelings of resentment at having to care for their partner (item was reversed). The mean caregiver depression score was 9.04 (SD = 8.18), with 80% of the caregivers (n = 117) reporting a score below the cutoff score of the CES-D (i.e., < 16). The mean quality of life score was 6.77 (SD = 2.16), with approximately 76% (n = 113) reporting a score of ≥ 5 .

TABLE 2
Mean and SD of Caregiver Experiences at 3 Months and Mental Health at 6 Months after Hospital Discharge (N = 148)

		Subscale mean	SD
Caregiver experiences (T1)	Disrupted schedule	1.88	0.60
	Financial problems	1.82	0.51
	Lack of family support	2.10	0.60
	Loss of physical strength	1.98	0.62
Caregiver's mental health (T2)	Self-esteem (+)	4.19	0.41
	Depression	9.04	8.18
	Quality of life	6.77	2.16

SD: standard deviation; T1: second measurement (3 months after baseline); +: positive; T2: third measurement (6 months after baseline).

Further analyses examined correlations between caregiver, patient, and care characteristics, as well as caregiver experiences (T1) and mental health (T2). Variables that showed no significant relation to any of the criterion variables were patient's diagnosis; duration of symptoms; patient's cancer-related symptoms; caregiver's age, gender, and occupation; living situation; and household. Table 3 shows only those variables that were found to be significantly ($P < 0.01$) correlated with one of the subscales of caregiver experiences or with one of the two indices of caregiver's mental health. Caregiver characteristics were shown to correlate with all caregiver indices, except for the impact on disrupted schedule. Caregivers of patients with a stoma perceived a stronger impact of disrupted schedule and perceived an increased level of depression over time, although they also perceived a stronger positive impact on self-esteem. Patient's dependency and level of depression correlated with caregiver experiences and mental health outcomes in the expected direction. Finally, care characteristics appeared to be related to caregiver experiences in the expected direction, but no correlation was observed with caregiver mental health outcomes. Strong correlations were observed particularly between care characteristics and impact on disrupted schedule (Pearson's r range, 0.35-0.59) and to a lesser extent between care characteristics and impact on physical strength (Pearson's r range, 0.16-0.38). The majority of correlations between the subscales of the CRA appeared to be significant, and appeared to represent fairly independent dimensions of caregiving experiences, except for the subscales regarding loss of physical strength and disrupted schedule (Pearson's $r = 0.66$). With regard to caregiver's level of depression, all caregiver experiences were found to be related in the expected direction. With regard to caregiver's quality of life, only loss of physical strength and the impact on

TABLE 3
Correlation between Descriptive Characteristics and Caregiver Experiences and Mental Health (N = 148)

	Caregiver experiences (T1)					Mental health (T2)	
	Disrupted schedule	Financial problems	Lack of family support	Loss of physical strength	Self-esteem (+)	Depression	Quality of life
Caregiver characteristics							
Educational level	0.03	-0.14	0.04	-0.06	-0.23 ^a	-0.22 ^a	0.16
Income	-0.02	-0.24 ^a	-0.01	-0.05	-0.11	-0.16	0.19 ^b
Quality of relationship	-0.07	-0.01	-0.35 ^a	-0.09	0.18 ^b	-0.16 ^a	0.22 ^a
Initial depression	0.23	0.10	0.18 ^b	0.34 ^a	-0.02	0.55 ^a	-0.40 ^a
Initial quality of life	-0.05	-0.03	-0.03	-0.25 ^a	0.12	-0.39 ^a	0.50 ^a
Patient characteristics							
Stoma	0.23 ^a	0.06	-0.04	0.03	0.19 ^b	-0.21 ^b	0.04
Dependency	0.40 ^a	0.08	-0.06	0.17 ^b	0.10	0.08	-0.10
Depression	0.09	0.18 ^a	0.03	0.03	0.01	0.11	-0.22 ^a
Care characteristics							
Intensity	0.36 ^a	0.27 ^a	-0.02	0.22 ^a	-0.06	0.13	-0.08
Personal care	0.35 ^a	0.14	0.01	0.18 ^b	0.07	0.05	-0.02
Disease-related care	0.40 ^a	0.08	-0.01	0.17 ^b	0.10	0.04	0.08
Accompany on physician visits	0.38 ^a	0.08	-0.03	0.16	0.10	0.01	0.07
Change in activities	0.59 ^a	0.21 ^a	0.04	0.38 ^a	0.09	0.16	-0.04
Caregiver experiences							
Disrupted schedule	—	0.49 ^a	-0.05	0.66 ^a	-0.05	0.24 ^a	-0.12
Financial problems		—	0.24 ^a	0.47 ^a	0.30 ^a	0.18 ^b	-0.10
Lack of family support			—	0.36 ^a	-0.26 ^a	0.22 ^a	-0.16
Loss of physical strength				—	-0.27 ^a	0.44 ^a	-0.41 ^a
Self-esteem (+)					—	-0.21 ^b	0.29 ^a

T1: second measurement (3 months after baseline); T2: third measurement (6 months after baseline); +: positive.

^a $P < 0.01$; ^b $P < 0.05$.

the caregiver's self-esteem appeared to be related significantly, also in the expected direction. Caregiver's depression and quality of life were strongly negatively related (Pearson's $r = -0.66$; this correlation is not displayed in Table 3).

Determinants of Caregiver Experiences at 3 Months

Table 4 shows the results of the linear regression analyses that were conducted to explain caregiver experience in terms of five specific domains. Each domain of caregiver experience was explained by different factors with a total explained variance ranging from 11–46%. The highest degree of explained variance of the specific domains of caregiving experience was found on the subscale regarding disrupted schedule. Caregivers of patients who were highly dependent, those who were highly involved in caregiving (in particular, in performing disease-related tasks and accompanying the patient to physician visits), and those who reported more change in activities appeared to perceive a stronger (negative) impact on disrupted schedule.

The impact on financial problems was determined by two variables: income (6%) and intensity of

care (5%). Caregivers with a lower income reported a stronger negative impact on finance than those with a higher income, and caregivers who reported a high intensity of care perceived more financial strains as a result of caregiving.

Lack of family support was explained by caregiver characteristics only (18%). A distressed relationship and caregivers of patients who lived only with their partner perceived a greater lack of family support.

Twenty-three percent of the variance of loss of physical strength was explained by the proposed characteristics. Caregivers who reported more changes in social activities reported more loss of physical strength. Although the caregiver's initial level of mental health and the patient's dependency contributed 13% and 1%, respectively, of the variance on the caregiver's loss of physical strength, none of these variables strongly contributed to the final model. In addition some care specific characteristics (i.e., intensity of care, personal care tasks, and disease-related tasks) first showed a significant relation, but their B value dropped substantially and became insignificant when

TABLE 4
Determinants of Caregiver Experiences in Partners of Cancer Patients at 3 Months after Hospital Discharge: Results of Hierarchical Multiple Regression Analyses (Final β Weight and Adjusted R^2) (N = 148)

	Caregiver experiences at 3 months				
	Disrupted schedule	Financial problems	Lack of family support	Loss of physical strength	Self-esteem (positive)
Caregiver characteristics					
Gender (male = 0; female = 1)	0.11 ^a	—	—	—	—
Educational level	—	—	—	—	-0.25 ^b
Income	—	-0.20 ^c	—	—	—
Living situation (with partner = 0; with partner & children = 1)	—	—	-0.20 ^b	—	—
Quality of relationship	—	—	-0.36 ^d	—	0.17 ^a
Initial depression	0.04	—	0.12	0.18 ^a	—
Initial quality of life	—	—	—	-0.13	-0.17 ^a
Adjusted R^2	0.07	0.06	0.18	0.13	0.10
Patient characteristics					
Stoma (no = 0; yes = 1)	0.04	—	—	—	0.22 ^c
Dependency	0.21 ^c	—	—	-0.03	—
Depression	—	—	—	—	—
ΔR^2	0.15	—	—	0.01	0.05
Care characteristics					
Intensity of care	—	0.24 ^b	—	0.07	—
Personal care tasks	—	—	—	0.06	—
Disease-related tasks	0.16 ^c	—	—	0.04	—
Accompany on physician visits	0.17 ^c	—	—	—	—
Changes in activities	0.39 ^d	—	—	0.24 ^b	—
ΔR^2	0.24	0.05	—	0.09	—
Total R^2	46%	11%	18%	23%	15%

A dashed line indicates that the factor is not included in the model, within the column of the referring dependent variable, because of nonsignificant univariate associations.

^a $P < 0.10$; ^b $P < 0.05$; ^c $P < 0.01$; ^d $P < 0.001$.

the variable “change in activities” was entered into the model.

Finally, self-esteem was explained by both caregiver and patient characteristics. Caregivers with a lower level of education and those of patients with a stoma were able to derive more self-esteem from caregiving than other caregivers. In addition, both the quality of the relationship and the caregiver's initial quality of life tended to be related more to self-esteem, although these associations did not reach an adequate level of significance.

To summarize, caregivers with a low income, those who lived only with the patient, those with a distressed relationship, caregivers of highly dependent patients, those who provided a high amount of care, and those who reported more changes in activities were most likely to experience more negative consequences of giving care. A positive impact on self-esteem was determined by the caregiver's level of education and whether the patient had a stoma (i.e., caregivers with a lower level of education and those of

patients with a stoma were able to derive more self-esteem from caregiving).

Caregiver Experiences at 3 Months as Determinants of the Caregiver's Mental Health at 6 Months

Table 5 presents the results of the regression analyses aimed at establishing determinants of the caregiver's mental health (i.e., depression and quality of life). For caregiver depression, the total variance explained was 48%. The caregiver's initial score on depression and whether the patient had a stoma were related significantly to the caregiver's depression at 6 months. Caregivers who reported a relatively low quality relationship tended to report a higher level of depression. In the last step, perceived loss of the caregiver's physical strength accounted for an additional 6% of the variance. Additional regression analysis revealed that the predictive value of the impact of caregiving on self-esteem on the caregiver's depression was masked by whether the patient had a stoma (i.e., when the variable “stoma” was left out of the analysis, a higher

TABLE 5
Determinants of Mental Health in Partners of Cancer Patients at 6 Months after Hospital Discharge: Results of Hierarchical Multiple Regression Analyses (Final β Weight and Adjusted R^2) (N = 148)

	Caregiver's mental health at 6 months	
	Depression	Quality of life
Caregiver characteristics		
Gender	0.11	—
Educational level	-0.11	—
Income	—	0.15 ^b
Quality of relationship	-0.13 ^a	0.16 ^b
Initial depression	0.39 ^d	-0.11
Initial quality of life	-0.10	0.33 ^d
Adjusted R^2	0.36	0.34
Patient characteristics		
Stoma (no = 0; yes = 1)	-0.23 ^c	—
Depression	—	-0.09
ΔR^2	0.06	—
Caregiver experiences		
Lack of family support	-0.03	—
Loss of physical strength	0.24 ^c	-0.21 ^c
Self-esteem	-0.10	0.18 ^b
ΔR^2	0.06	0.09
Total R^2	48%	43%

Dashed line indicates that the factor is not included in the model, within the column of the referring dependent variable, because of nonsignificant univariate associations.

^a $P < 0.10$; ^b $P < 0.05$; ^c $P < 0.01$; ^d $P < 0.001$.

impact of caregiving on self-esteem was found to be significant at explaining the lower level of depression in caregivers at 6 months). The caregiver's quality of life at 6 months was explained predominantly by the caregiver's initial quality of life and to a lesser extent by the level of income and quality of the relationship, which together accounted for 34% of the variance. Caregiver experiences (i.e., loss of physical strength and self-esteem) accounted for an additional 9% of the variance in the caregiver's quality of life at 6 months.

DISCUSSION

The findings of this study indicated that different caregiver, patient, and care characteristics account for different types of caregiver experiences and mental health outcomes. With respect to caregiver experiences at 3 months after the patient's hospital discharge, it was shown that having a low income, living only with the patient, a distressed relationship, a high level of patient dependency, performing more care tasks, and reporting more changes in activities all increased negative experiences of giving care. Positive caregiver experiences were observed especially in

caregivers with a low level of education and those who took care of a patient with a stoma. With respect to the caregiver's mental health at 6 months after the patient's discharge from the hospital, the influence of patient characteristics and care characteristics was shown to be of minor importance compared with the way caregiving was experienced, especially in terms of the impact on physical strength and self-esteem.

The results of the current study are highly consistent with past research on caregiving and give support to the cognitive stress theory of Lazarus and Folkman.¹³ Although when studied as a group caregivers are likely to experience a number of negative and positive consequences, there are substantial individual differences in caregiver mental health outcomes. Care tasks clearly are a demanding and important part of caregiving, and their effect on the caregiver's mental health appears to act indirectly through caregiving experiences, in particular through perceptions of the caregiver's ability and energy to provide care.

With regard to sociodemographic characteristics of the caregiver, the influence of education on self-esteem is of particular interest. Caregivers with a high level of education derived less self-esteem in the course of giving care than those with a low level of education. This finding corroborates the findings of Kramer,⁵⁵ who reported the lowest level of gain among those caregivers who were highly educated. A possible explanation may be that caregivers in high socioeconomic classes perceive a more striking status differential between their current or prior professional role and their role as caregiver than those in low socioeconomic classes. In addition, the daily tasks of caregiving may be perceived as less rewarding by those with a higher education or those in high socioeconomic classes when compared with their professional, and possibly more intellectually stimulating, activities.

A higher level of self-esteem also was observed in caregivers of patients with a stoma, and these caregivers also reported a lower level of depression. Although negative caregiving experiences may have been expected to be most obvious in the caregivers of patients with a stoma, to our knowledge the positive effect on these caregivers largely has been unexplored in the past. In the field of oncologic practice, the primary caregiver appears to be explicitly and continuously involved whenever caring for a patient with a stoma. Therefore, it is likely that these caregivers perceive their caregiver role as more meaningful and worthwhile compared with other caregivers. This also may have an effect on depression in the longer term. In concordance with these findings, Kinney and Stephens¹¹ found that caregivers who were involved more intensely reported more uplifts; the authors ar-

gued that there were at least two possible explanations for this finding: 1) because these caregivers spend more time on caregiving, they have a greater opportunity for deriving satisfaction out of it and 2) caregivers may attempt to view providing care positively and try to focus on enjoyable aspects of caregiving because they often have little choice in carrying out their role. These explanations very well may apply to the situation of intensively involved caregivers of cancer patients in the current study.

Of all the patient characteristics measured, the level of the patient's dependency appeared to be particularly important in the determination of negative caregiver experiences, which is in agreement with the findings of earlier studies.^{33,37,38,42} Although no direct relation was observed between the patient's cancer-related symptoms or depression and caregiver outcomes, an indirect effect may be possible because symptoms may give rise to losses in mobility and function³ and more patient dependency.² It also is possible that patients have underreported symptoms⁵⁶ or anticipated that certain symptoms occurred within the fixed period of the study. The mutual effect that partners have on each other, as also was observed in several other oncologic studies,^{2,3,36,37,57} stresses the importance of a family-focused approach to the care of cancer patients and their significant others.

Our data emphasized the role of the quality of the relationship within the caregiving situation. For example, a low quality relationship was shown to be the most important determinant of a perceived lack of family support in taking on caregiving responsibilities; this is in keeping with other comparable research on caregiving.¹⁴ Moreover, relationship quality may influence the quality of care and, either directly or indirectly, the patient's quality of life as well. These results can be interpreted in the context of social support, because the quality of the relationship may be conceived as an indicator of social support. In general, social support is reported to be associated with less negative health outcomes, both for the caregiver^{10,58} and the patient.⁵⁹ Because primary caregivers are the main providers of support to the patient and because caregiving responsibilities may lead to social isolation,³⁴ caregivers and patients will have to depend mainly on each other.⁶⁰ Further research regarding the role and exchange of social support in the caregiving process is recommended.

Because this study and research by others^{57,61} have found that it is meaningful to make a distinction between negative and positive caregiver experiences, the question arises whether it is important to make a

distinction between negative and positive caregiver's mental health. Both the level of the caregiver's depression and quality of life were shown to be determined predominantly by baseline levels. Positive experiences appeared to result in a higher quality of life in caregivers, and these experiences may play an important role in compensating for the negative caregiver experiences. Because the role of positive experiences of caregiving could not be demonstrated clearly when studying negative caregiver outcomes alone, it therefore is recommended to make a distinction between positive and negative caregiver experiences as well as between positive and negative mental health outcomes.

However, in drawing overall conclusions, we must take notice of some limitations of this study. Compared with mean scores of both caregiver experiences and mental health as observed in other studies,^{2,4,9,37,51,53,60} results in the current study showed a relatively low score for negative caregiver outcomes and a relatively high score for positive caregiver outcomes. Selection bias may have occurred because of nonresponse and the selective dropping out of caregivers of cancer patients who were highly dependent (i.e., those lost to follow-up because of serious illness or death). Thus, it may be assumed that the results of this study are rather conservative or may even be optimistic because they are confined to partner caregivers of cancer patients with relatively good health and a good prognosis. However, although it is most likely that the strength of the relations between determinants and caregiver outcomes may have become more evident within a more heterogeneous sample, there is no reason to assume that the overall strength of the relations found will be different in a general population of caregivers. Moreover, although this study was longitudinal, the determinants found must be interpreted carefully because we did not examine the course of the caregiver's situation in relation to the course of the cancer. Therefore, further research focusing on the dynamics of caregiver outcomes is recommended to provide a more detailed understanding of the (changes in) consequences of cancer caregiving. Furthermore, the caregiver characteristics included in the study were restricted to sociodemographic characteristics, quality of the relationship, and initial scores on mental health whereas internal resources also are likely to play an essential role in caregiving.⁶² As shown in studies among caregivers of patients with various diseases, factors of the caregiver's personality such as optimism,^{9,37,30} neuroticism,¹⁶ self-efficacy,⁶³ and mastery⁶⁴ appeared to influence care-

giver outcomes, and future research may focus on the predictive value of personality characteristics on caregiver experiences and mental health outcomes in those caring for persons with cancer.

This study found that the mental health of caregivers primarily is related to how caregiving will be perceived and less to the amount or intensity of care tasks. It is important that health professionals involved in the ongoing care of cancer patients and their families be aware of the increasing demands made on caregivers and the specific problems and uplifts they perceive in caregiving. Professional caregivers are urged to involve informal caregivers with care explicitly and continuously; however, specific attention to caregivers who live only with the patient, those with a low income, those in a distressed relationship, those with a high level of patient dependency, and a those with a high involvement in care tasks appears warranted. Future research particularly may attempt to identify strategies that allow caregivers to derive more self-esteem, satisfaction, and meaning from caregiving. Identifying specific factors that have the greatest impact on caregivers of cancer patients, both negatively and positively, provides meaningful information for professional caregivers in the field of oncology.

REFERENCES

- 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 impairment. *Res Nurs Health* 1992;15:271-83.
- Kurtz ME, Kurtz JC, Given CW, Given B. Relationship of caregiver reactions and depression to cancer patients' symptoms, functional states and depression: a longitudinal view. *Soc Sci Med* 1995;40:837-46.
- Northouse L, Stetz KM. A longitudinal study of the adjustment of patients and husbands to breast cancer. *Oncol Nurs Forum* 1989;16:511-6.
- McCorkle R, Yost LS, Jepson C, Malone D, Baird S, Lusk E. A cancer experience: relationship of patient psychosocial responses to caregiver burden over time. *Psychooncology* 1993; 2:21-32.
- Oberst MT, James RH. Going home: patient and spouse adjustment following cancer surgery. *Top Clin Nurs* 1985;7: 46-57.
- Schulz R, Williamson GM. A two-year longitudinal study of depression among Alzheimer's caregivers. *Psychol Aging* 1991;6:569-78.
- Nijboer C, Tempelaar R, Sanderman R, Triemstra M, Spruijt RJ, Van den Bos GAM. Cancer and caregiving: the impact on the partner's health. *Psychooncology* 1998;7:3-13.
- Rait D, Lederberg M. The family of the cancer patient. In: Holland JC, Rowland JH, editors. *Handbook of psycho-oncology*. New York: Oxford University Press, 1990:585-606.
- Kurtz ME, Kurtz JC, Given CW, Given B. Predictors of post bereavement depressive symptomatology among family caregivers of cancer patients. *Support Care Cancer* 1997;5: 53-60.
- Haley WE, Levine EG, Brown SL, Bartolucci AA. Stress, appraisal, coping, and social support as predictors of adaptation outcome among dementia caregivers. *Psychol Aging* 1987;2:323-30.
- Kinney JM, Stephens MA. Hassles and uplifts of giving care to a family member with dementia. *Psychol Aging* 1989;4: 402-8.
- Pot AM, Van Dyck R. [The impact of providing care: a review.] *Tijdschrift Psychiatr* 1995;34:627-35.
- Lazarus RS, Folkman S. *Stress appraisal and coping*. New York: Springer Publishing Company, 1984.
- Stommel M, Given CW, Given B. Depression as an overriding variable explaining caregiver burdens. *J Aging Health* 1990;2:81-102.
- Given B, Stommel M, Collins C, King SS, Given CW. Responses of elderly spouse caregivers. *Res Nurs Health* 1990; 13:77-85.
- Vernooij-Dassen MJFJ, Persoon JMG, Felling AJA. Predictors of sense of competence in caregivers of demented persons. *Soc Sci Med* 1996;43:41-9.
- Barusch AS, Spaid WM. Gender differences in caregiving: why do wives report greater burden? *Gerontologist* 1989;29: 667-76.
- Miller B, Cafasso L. Gender differences in caregiving: fact or artifact. *Gerontologist* 1992;32:498-507.
- Zarit SH, Toseland RW. Current and future direction in family caregiving research. *Gerontologist* 1989;29:481-3.
- Mor V, Allen S, Malin M. The psychosocial impact of cancer on older versus younger patients and their families. *Cancer* 1991;74:2118-27.
- Montgomery RJV, Gonyea JG, Hooyman NR. Caregiving and the experience of subjective and objective burden. *Fam Relations* 1985;43:19-26.
- George LK, Gwyther LP. Caregiver well-being: a multi-dimensional examination of family caregivers of demented adults. *Gerontologist* 1986;26:253-9.
- Young RF, Kahana E. Specifying caregiving outcomes: gender and relationship aspects of caregiver strain. *Gerontologist* 1989;29:660-6.
- Blood GW, Simpson KC, Dineen M, Kauffman SM, Raimondi SC. Spouses of laryngeal cancer: caregiver strain and burden. *J Commun Disord* 1994;27:19-35.
- Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist* 1986;26:260-6.
- Horowitz A. Family caregiving to the frail elderly. In: Lawton P, Maddox GL, editors. *Annual review of gerontology and geriatrics*. New York: Springer Publishing Company, 1985: 194-246.
- Northouse L, Swain C. Adjustment of patients and husbands to the initial impact of breast cancer. *Nurs Res* 1987;36:221-5.
- Manne SL, Zautra AJ. Couples coping with chronic illness: women with rheumatoid arthritis and their healthy husbands. *J Behav Med* 1990;13:327-42.
- Triemstra M, Van der Ploeg HM, Smit C, Rosendaal FR. Hemophilia from the spouses' perspective: burden and impact on their lives. *Psychol Health* 1999;14:97-116.
- Biegel DE, Milligan SE, Putham PL, Song L. Predictors of burden among lower socioeconomic status caregivers of persons with chronic mental illness. *Community Ment Health J* 1994;30:473-94.
- Poulshock SW, Deimling GT. Families caring for elders in residence: issues in the measurement of burden. *J Gerontol* 1984;39:230-9.

32. Carey PJ, Oberst MT, McCubbin MA, Hughes SH. Appraisal and caregiving burden in family members caring for patients receiving chemotherapy. *Oncol Nurs Forum* 1991;18:1341-8.
33. Siegel K, Ravies VH, Mor V, Houts P. The relationship of spousal caregiver burden to patient disease and treatment-related conditions. *Ann Oncol* 1991;2:511-6.
34. Zarit SH, Reeve KE, Bach-Peterson J. Relatives of the impaired elderly correlates of feelings of burden. *Gerontologist* 1980;20:650-5.
35. Baillie V, Norbeck JS, Barnes LEA. Stress, social support, and psychological distress of family caregivers of the elderly. *Nurs Res* 1988;37:217-22.
36. Given CW, Stommel M, Given B, Osuch J, Kurtz ME, Kurtz JC. The influence of cancer patient symptoms functional states on patient depression and family caregiver reaction and depression. *Health Psychol* 1993;12:277-85.
37. Given BA, Given CW, Helms E, Stommel M, DeVoss DN. Determinants of family care giver reaction: new and recurrent cancer. *Cancer Pract* 1997;5:17-24.
38. Gilhooly ML. The impact of caregiving on care-givers: factors associated with the psychological well-being of people supporting a dementing relative in the community. *Br J Med Psychol* 1984;57:35-44.
39. Cantor MH. Strain among caregivers: a study of experience in the United States. *Gerontologist* 1983;23:597-603.
40. Robinson BC. Validation of a caregiver strain index. *J Gerontol* 1983;38:344-8.
41. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and measures. *Gerontologist* 1980;30:583-94.
42. Oberst MT, Thomas SE, Gass KA, Ward SE. Caregiving demands and appraisal of stress among family caregivers. *Cancer Nurs* 1989;12:209-15.
43. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990;30:583-94.
44. Cattanaach L, Tebes JK. The nature of elder impairment and its impact on family caregiver's health and psychological functioning. *Gerontologist* 1991;31:246-55.
45. Biegel D, Sales E, Schulz R. Family caregiving in chronic illness: Alzheimer's disease, cancer, heart disease, mental illness and stroke. Newbury Park, CA: Sage Publications, 1991.
46. Montgomery RJV, Stull DE, Borgatta EF. Measurement and the analysis of burden. *Res Aging* 1989;7:137-52.
47. Arrindell WA, Boelens W, Lambert H. On the psychometric properties of the Maudsley Marital Questionnaire (MMQ): evaluation of self-ratings in distressed and normal volunteer couples based on the Dutch version. *Personality Individ Diff* 1983;4:293-306.
48. Hendriks AAJ, Sanderma R, Ormel J. [The value of the Maudsley Marital Questionnaire (MMQ) as a measure of marital quality: a multitrail - multimethod analysis and confirmatory factor analysis] *Ned Tijdschrift Psychol* 1991;46:187-95.
49. Radloff LS. The CES-D Scale: a self-report depression scale for research in the general population. *Appl Psychol Measure* 1977;3:385-401.
50. Bouma J, Ranchor AV, Sanderma R, Sonderen van E. [Assessment of symptoms of depression by means of the CES-D. A manual.] Groningen, The Netherlands: Stichting Drukkerij Regenboog Co., 1995.
51. Andrews FM, Withey SB. Social indicators of well-being. New York: Plenum Press, 1976.
52. Witte De LP, Tilli DJP, Ticheler AJG, Winants BAC, Horst Van der FG, Linden vander Sj. [To live with rheumatoid arthritis]. Hoensbroek: Revalidation Institute, 1989.
53. Kempen GIJM, Miedema I, Ormel J, Molenaar W. The assessment of disability with the Groningen Activity Restriction Scale. Conceptual framework and psychometric properties. *Soc Sci Med* 1996;43:1601-10.
54. Haes de JCJM, Knippenberg FCE, Neijt JP. Measuring psychological and physical distress in cancer patients: structure and application of the Rotterdam Symptom Checklist. *Br J Cancer* 1990;62:1034-8.
55. Nijboer C, Triemstra M, Tempelaar R, Sanderma R, Van den Bos GAM. Measuring both negative and positive reactions to giving care to cancer patients: psychometric qualities of the Caregiver Reaction Assessment (CRA). *Soc Sci Med*. In press.
56. Kramer BJ. Differential predictors of strain and gain among husbands caring for wives with dementia. *Gerontologist* 1997;37:239-49.
57. Kurtz ME, Given B, Kurtz JC, Given CW. The interaction of age, symptoms, and survival status on physical and mental health of patients with cancer and their families. *Cancer* 1994;74(Suppl):2071-8.
58. Northouse LL, Dorris G, Charron-Moore C. Factors affecting couples' adjustment to recurrent breast cancer. *Soc Sci Med* 1995;41:69-76.
59. Schulz R, Tompkins CA, Decker S, Wood D. The social psychology of caregiving: physical and psychological costs of providing support to the disabled. *J Appl Soc Psychol* 1987;17:401-28.
60. Ruiter De JH. Social support and quality of life among patients with cancer. [Ph.D. Thesis]. Groningen: Krips, Meppel & computekst, 1995.
61. DesRosier M, Catanzaro M, Piller J. Living with chronic illness: social support and the well spouse perspective. *Rehabilitation Nurs* 1992;17:87-91.
62. Motenko AK. The frustrations gratifications and well-being of dementia caregivers. *Gerontologist* 1989;29:166-72.
63. Fingerma KL, Gallagher-Thompson D, Lovett S, Rose J. Internal resourcefulness, task demands, coping, and dysphoric affect among caregivers of the frail elderly. *Int J Aging Hum Dev* 1996;42:229-48.
64. Riemsma RP, Taal E, Rasker JJ, Klein G, Bryun GAW, Wouters JMGW, et al. The burden of care for informal caregivers of patients with rheumatoid arthritis. In: Riemsma RP [Thesis Challenging Arthritis]. Enschede, the Netherlands, 1998: 61-89.
65. Skaff MM, Pearlin LI, Mullan JT. Transitions in the caregiving career: effects on the sense of mastery. *Psychol Aging* 1996;11:247-57.