# Patterns of Caregiver Experiences Among Partners of Cancer Patients

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This study describes patterns of caregiving experiences in partners of patients with cancer (N=148) over a 6-month period. Caregiving experiences were assessed by means of the Caregiver Reaction Assessment Scale (CRA), which consists of four negative dimensions and one positive subscale: Disrupted Schedule, Financial Problems, Lack of Family Support, Loss of Physical Strength, and Self-Esteem. Subgroup analyses were performed according to gender, age, and socioeconomic status (SES). Type, size, and direction of changes in caregiving experiences over time were analyzed both at a group level and at an individual level. Patterns of caregiver experiences appeared to vary between the subgroups; women, younger caregivers, and caregivers with a higher SES experienced caregiving more negatively or less positively. The findings illustrate the value of studying inter- and intraindividual patterns across different subgroups, and stress that caregiver experiences should be regarded as a multidimensional concept that includes both negative and positive experiences of caregiving.

Key Words: Caregiver burden, Cancer, Health, Longitudinal patterns

Many types of cancer at the present time could be described as chronic diseases requiring long-term treatment and posing numerous demands on patients and their primary caregivers. Alterations in the patient's functional ability, bodily functions, appearance, employment status, family and social role, and self-image are reported to have a direct impact on the caregiver (Siegel, Raveis, Houts, & Mor, 1991; Stetz, 1987). With earlier diagnoses, advances in treatment, longer survival times, and a trend toward outpatient treatment, informal caregivers are likely to be involved in providing more complex care for a longer

period of time. Research in the field of caregiving has mainly concerned family members of patients with mental disorders such as schizophrenia or dementia (Baumgarten, 1989; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Zarit & Toseland, 1989). To date, however, only a few studies have specifically examined caregiver outcomes over time in the case of cancer. This study is an attempt to contribute to a more detailed insight into outcomes of caregivers of cancer patients over time.

One of the concepts that seems to play a central role within the caregiver situation is "caregiver burden," which refers to negative feelings that may be experienced when giving care (e.g., Vitaliano, Young, & Russo, 1991). Studies have consistently reported that partners, in comparison to other informal caregivers, are more likely to experience caregiver burden (Cantor, 1983), become ill themselves (George & Gwyther, 1986), and experience higher rates of psychiatric symptoms than other types of caregivers (Schulz, Visintainer, & Williamson, 1990). Because partners are less likely than other informal caregivers to receive assistance (Horowitz, 1985), they may be identified as the most vulnerable group of caregivers. More recent studies have stressed that experiences of caregiving should be studied as a multidimensional construct, referring to physical, psychological, financial, and/or social experiences to specific care demands (Given et al., 1992; Siegel et al., 1991). And, although caregiving is mainly addressed as being burdensome because of its unpleasant consequences, caregiving may also be perceived positively (Given et al., 1992; Kinney & Stephens, 1989; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Motenko, 1989). Therefore, the most balanced approach to measure caregiver experiences incorporates both the negative and positive aspects of giving care.

Also, in cancer caregiver research, caregiver experiences are defined over a broad range of varying constructs that can be regarded as positive, neutral, and/ or negative; subsequently, overall conclusions from studies are hampered by inconsistent findings. One of the first few longitudinal studies involving cancer patients and their spouses, conducted by Oberst and James (1985), revealed that the intensity of partner's

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distress did not change over time, whereas the amount of distress reported by patients systematically decreased over time. Keitel, Zevon, Rounds, Petrelli, and Karakousis (1990) reported similar patterns of distress in a study assessing the impact of the surgical treatment of cancer on the spouse. On the other hand, it was demonstrated that caregivers experienced high levels of burden when they first occupied the caregiver role, but these experiences dissipated with time (Blood, Simpson, Dineen, Kauffman, & Raimondi, 1994). Also, it was observed that caregivers continued to report similar levels of cancer caregiver's impact on financial problems, lack of family support, and loss of physical strength over time, but a decrease in impact on schedule over time and an increase on one positive dimension of caregiver experiences, caregiver's self-esteem (McCorkle et al., 1993). Evidently, these findings indicate a need to examine patterns of caregiver experiences more thoroughly.

Caregiving can be conceived as a dynamic, ongoing process for which there may be several trajectories (McCorkle et al., 1993; Nijboer et al., 1998; Oberst & James, 1985; Schulz & Williamson, 1991). Several researchers in the field of oncology stress that experiences of caregivers of cancer patients have to be examined in relation to the phase of illness the patient is going through (Northouse & Stetz, 1989). These phases have been divided into three stages: the initial or *acute* phase, the *chronic* phase, and the *res*olution (Rait & Lederberg, 1990). During the acute phase the family is shocked, stunned, and frightened. Patients and their family members may use this period to find ways to cope and deal with the crisis. In the chronic phase, when primary treatment has been endured and the patient has been dismissed 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 (Kurtz, Kurtz, Given, & Given, 1997). In order to gain insight into caregiver experiences over time, researchers increasingly emphasize the importance of including the acute and early chronic phases of the illness in studying caregiver experiences over time (Given & Given, 1991; McCorkle et al., 1993; Northouse & Swain, 1987).

Patterns over time can be examined by a number of different analyses, depending on the specific research question. These methods may distinguish themselves particularly with respect to the endpoint level of the outcome(s) under study, the overall rate of change over time, or overall changeability (Deeg, Smit, & Beekman, 1997). Preceding the question, Which factors influence change within the caregiving situation?, is the course of the pattern over time itself. In order to obtain a more specific insight into patterns of caregiver experiences, changes over time can be determined at two different levels, across different groups and within one person over time (Mulder, Ranchor, Sanderman, Bouma, & Van den Heuvel, 1998). As far as we know, longitudinal caregiving research has predominantly focused on overall variability (i.e., groups' variability), and no data are known about the proportion of cancer caregivers who perceive caregiving more negatively, more positively over time, or who remain stable.

Research into cancer caregiver experiences over time is rather scarce, but research into patterns among certain types of caregivers is even more sporadic. In cross-sectional studies, relatively consistent associations were reported on caregiver experiences and sociodemographic characteristics such as gender, age, and socioeconomic status (SES). Women, especially at a younger age and with a lower SES, tend to perceive caregiving as more negative than their counterparts (Barusch & Spaid, 1989; Blood et al., 1994; Oberst, Thomas, Gass, & Ward, 1989; Siegel et al., 1991; Young & Kahana, 1989; Todd, Zarit, & Zarit, 1986), even when this perceived impact is adjusted for the amount of care provided and/or the level of patient's health (Horowitz, 1985).

The aim of the current study is to describe overall patterns of caregiver experiences in partners of cancer patients over time; across different groups (i.e., according to gender, age, and SES), and within individuals over time. Data will reflect on the potential influence of the early and chronic phases of the disease (i.e., the 2 weeks prior to hospital admission, and to 3 and 6 months thereafter). Caregiver experiences are considered as a multidimensional construct, including negative and positive dimensions.

# Methods

# Procedure and Subjects

Longitudinal data were used from the research project entitled: "CAregiving of Spouses of cancer PAtients" (CASPA). This study was conducted in cooperation with 10 hospitals in The Netherlands in the regions of Amsterdam and Groningen. Newly diagnosed colorectal cancer patients who recently underwent surgery, who had a survival prognosis of at least 6 months, and who lived together with a partner were selected by surgeons of the hospitals. The partner was defined as a relative by marriage or person identified by the patient as partner, and who resided in the patient's household. Partners were recruited via the patients. The selection of this patient/partner group was based on pragmatic and theoretical considerations. The incidence of colorectal patients is relatively high and almost equally divided among men and women. Furthermore, studying caregiving in this specific patient group had the advantage that the (presumed) onset of caregiving could be identified as a marked point in time (i.e., the moment of hospital admission/surgery). Moreover, patients with these malignancies were selected because they were likely to experience certain problems (e.g., pain, appliance and equipment difficulties, skin and drainage problems) and were likely to need continuous medical, physical, and psychosocial care following hospital admission. Subsequently, care involvement may

include a broad spectrum of tasks, and caregiver experiences may change continuously during the course of colorectal cancer.

In order to describe patterns of caregiver experiences over the first period of time, representing the acute and early chronic phases of the patient's illness, and consistent with former research, three measurement points were chosen: the time of patient's diagnosis (T0), and 3 months (T1) and 6 months (T2) thereafter. Baseline measurement (T0) took place shortly after hospital admission and within 2 weeks after patient's surgery, with questions being asked retrospectively, referring to the period before hospital admission (i.e., the period before the caregiver role was likely to be taken on). The second measurement point (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 (e.g., CRA), and they also completed a self-report questionnaire.

### Measurements

Patient's Descriptive Variables.—In order to get information about potential selection bias, several descriptive variables of the patients were collected: patient's diagnosis, whether the patient had a stoma or not, cancer-related symptoms, comorbidity, and level of depression.

Cancer-related symptoms were measured using the Rotterdam Symptom Check List (RSCL; De Haes, Knippenberg, & Neijt, 1990). Patients were asked to rate the severity of a symptom, either a physical (e.g., nausea) or a psychological symptom (e.g., worrying), on a 4-point scale 3 months after diagnosis. The internal consistencies of the two scales, "physical symptoms" and "psychological symptoms," were 0.83 and 0.89, respectively.

Comorbidity was measured by asking the patient if he/she had a disorder of chronic nature in the preceding 3 months (e.g., stroke, serious heart problems, high blood pressure, diabetes). The short-form 16item list of the Central Bureau of Statistics was used (Centraal Bureau voor Statistik, 1989).

The level of depression was measured by the 20item Center for Epidemiological Studies Depression scale (CES-D; Bouma, Ranchor, Sanderman, & van Sonderen, 1995; Radloff, 1977). The CES-D comprises a 20-item self-report scale that taps the level of depressive symptoms during the week preceding hospital admission. Total scores can range from 0–60, with higher scores indicating a higher level of depressive symptoms. Cronbach's  $\alpha$  was 0.91.

Partner's Sociodemographic Variables.—Age, gender, and SES were used to define subgroups in order to study changes in caregiver experiences across different groups. The three age groups on the basis of age at baseline were: <50 years, 50–65 years, and >65 years. SES was operationalized as the highest level of education attained, and was categorized into three levels: low (primary school only), middle (lower/general secondary schooling and intermediate vocational schooling), and high (higher vocational schooling and university).

Caregiver Experiences.—Caregiver experiences were measured using the Caregiver Reaction Assessment scale (CRA), developed by Given and colleagues (1992). The CRA consists of 24 items that contain four negative dimensions and one positive dimension: Disrupted Schedule, Financial Problems, Lack of Family Support, Loss of Physical Strength, and Selfesteem. The subscale Disrupted Schedule (5 items) measures the extent to which caregiving interrupts the usual activities of the caregiver. The subscale Financial Problems (3 items) measures the financial strain on the caregiver as a consequence of the caregiving situation. The subscale Lack of Family Support (4) items) assesses the extent to which the caregiver perceives a shortage of family support and the caregiver's perception of being abandoned in their caregiving responsibilities. The subscale Loss of Physical Strength (5 items) assesses the caregiver's feeling of deterioration in physical health. The subscale Caregiver's Selfesteem (7 items) aims to measure the extent to which caregiving contributes to individual self-esteem. Respondents were asked to rate the perceived impact of caregiving on a 5-point Likert scale. For each subscale, a total score was computed reflecting the mean item, with a range between 1.00 and 5.00. A higher score represented a greater amount of the attribute. The subscales of the CRA were found to be valid and reliable (Cronbach's  $\alpha$ -coefficients ranged from 0.68– 0.90; Given et al., 1992; Nijboer, Triemstra, Tempelaar, Sanderman, & Van den Bos, 1999).

*Response.*—Of the 238 eligible cancer patients and their partners, informed consent was obtained from 181 at the onset of the study. The response rate was 76%. No response bias was found between participants and nonresponse with respect to the variables Age, Gender, Diagnosis, and Region. One hundred forty-eight (82%) couples participated in all three waves. Reasons for loss to follow-up were: serious illness (n = 15; 8%), refusal to report for followup (n = 10; 6%) and death of the patient (n = 8; 4%).

Patients who remained in the study did not differ regarding age, gender, diagnosis, comorbidity, and feelings of depression from dropouts. However, the proportion of patients with a stoma was slightly higher (p < .10), and they also reported more physical symptoms at baseline (p < .05) as compared to participants who were followed up to 6 months. Partners who remained in the study did not differ from dropouts regarding age, gender, and the baseline values of caregiver experiences: Disrupted Schedule, Financial Problems, Lack of Family Support, and Selfesteem. However, participating partners reported a significantly less negative impact on loss of physical strength at baseline, compared to those who dropped out over time (participants: mean score = 1.94; dropouts: mean score = 2.22; p < .05).

#### Statistical Analyses

Analyses were performed to examine changes in the five specific caregiver experiences domains over a 6-month period, starting from the time of diagnosis, referring to 2 weeks prior to patient's hospital admission (i.e., baseline, T0). Changes over time at group level were examined by means of General Linear Model (GLM) repeated measurement analyses of variances (ANOVAs) for the total group and across the separate subgroups. Post-hoc Scheffé tests for multiple comparisons of means were performed to gain insight into the actual differences between several groups. In addition, to indicate the relevance of the size of the difference between the average scores, Cohen's effect size statistic *d* for paired observations was calculated (Cohen, 1977). An effect size <0.20 indicates a small effect, 0.20-0.50 a moderate effect, and >0.80 a large effect (Cohen, 1992). Within each subgroup, caregiver experiences of the three waves were compared by means of paired t tests. The following comparisons were performed: wave T0 versus T1, T1 versus T2, and T0 versus T2.

Changes over time at individual level were assessed by means of calculating Pearson's correlation coefficients. Based on previous research concerning "change at an individual level" (Sanderman & Ranchor, 1994), the following rules for change were defined: no change at individual level was defined as a correlation coefficient of >0.70, coefficients between 0.70 and 0.50 indicated moderate change, and coefficients <0.50 were classified as highly dynamic.

Finally, the proportion and direction of changes in caregiver experiences were specified. The differences of the individual mean scores between the measurement points were calculated and subsequently classified as decrease, equal, or increase. For the four negative subscales, an increase indicated a more negative impact on the construct over time, whereas for the positive subscale Caregiver's Self-esteem, an increase indicated that more self-esteem was derived from caregiving. Again, there are no standard rules available to evaluate the size of a change as relevant. In order to correct for variability by chance (i.e., variability resulting from a slightly different answer), "change" was defined as a difference of at least half the baseline standard deviation of the subscale score between the two mean subscale scores (i.e., >0.5 imesSD baseline value).

## Results

#### Sample Characteristics

Table 1 presents disease-specific characteristics of the patients and sociodemographic characteristics of the partner caregivers who participated at all three waves. Most patients (n=96, 65%) were diagnosed with colon cancer, and 52 (35%) were diagnosed with rectal cancer. Thirty-three percent of all patients had a stoma. The caregiver group consisted of 54 men and 94 women ranging in age from 25 to 89 years (mean age = 63 years, SD = 11 years). Most

Table 1.	Sample Characteristics of Patients and Partners
	(148 Couples)

	Participants n (%)
Patient Characteristics	
Colon cancer	96 (65)
Rectal cancer	52 (35)
Stoma	49 (33)
Partner Characteristics	
Female	94 (64)
Age:	
<50 years	18 (12)
50–65 years	69 (47)
>65 years	61 (41)
Educational level:	
Low	30 (20)
Middle	85 (57)
High	33 (23)
Living situation:	
Living only with partner	122 (82)
Living with partner and children	26 (18)
Having children	131 (89)

couples (89%) had children, and 18% of all partners still lived with their children at home.

## Mean Scores of Caregiver Experiences Over Time

Overall, changes in caregiver experiences over time were small or absent (Figure 1). A decrease of the impact on disrupted schedule and self-esteem was observed over time, indicating less negative feelings of being interrupted in daily activities and a change in a less positive direction, respectively. Three out of the five domains of caregiver experiences remained stable over time (i.e., Financial Problems, Lack of Family Support, and Loss of Physical Strength).

# Group Variability Over Time for the Total Group and Among the Subgroups

Table 2 shows the mean scores at the three measurement points and group variabilities over time for the total group and among the subgroups, according to gender, age, and SES. Because changes between T0–T1 and between T1–T2 were in the same direction, but less substantial as compared to overall changes between T0-T2, only effect sizes based on differences between T0–T2 are presented. When first examining differences between the subgroups at each measurement point, no differences were observed regarding the impact on disrupted schedule, financial problems, and lack of family support. With respect to loss of physical strength, female caregivers reported a higher impact than male caregivers, and this difference was also observed over time. With respect to self-esteem, caregivers with a high SES reported a less positive score, indicating that they derived less self-esteem from providing care than other subgroups. Post-hoc analyses revealed that caregivers with a high SES differed significantly from those with



Figure 1. Scores for the subscales of the Caregiver Reaction Assessment Scale at baseline (T0), 3 months (T1), and 6 months (T2) after patient's hospital admission.

a middle SES (F = 8.37; p < .05); between low and middle SES no significant differences were observed.

Over time, the patterns of caregiver experiences differed between the subgroups regarding three domains, namely Disrupted Schedule, Financial Problems, and Self-esteem. In the youngest age group and those with the lowest SES, no significant time effect on Disrupted Schedule could be observed, whereas in the older caregivers and in those with a higher SES a less negative impact on Disrupted Schedule over time was found. Younger caregivers tended to report a higher (i.e., more negative) impact on Disrupted Schedule and continued to do so over time, whereas older caregivers appeared to experience caregiving as less negative over time. Given the effect sizes (varying between 0.47 and 0.93), the changes in impact on disrupted schedule over time appeared to be moderately to strongly relevant. For Financial Problems, caregivers with a low to middle SES reported a slightly stronger, but nonsignificant, impact on financial problems at baseline, indicating that they experienced rather more financial strain when providing care compared to caregivers with a high SES. However, over time caregivers with a low to middle SES reported a less negative impact on finance, while the opposite trend was observed in the highest SES group. Finally, with respect to Self-esteem, female caregivers, older caregivers, and those with a high SES reported a less positive impact of self-esteem over time, whereas men, those of younger ages, and those with a lower SES showed rather stable levels. The observed changes over time could be considered as small to moderate (effect sizes varied between 0.14 and 0.61).

#### Individual Variabilities and Proportional Changes Over Time

In Table 3, the variability at an individual level and proportional changes over time are presented for each subscale. Because changes between T0 and T1, and between T1 and T2 all pointed in the same direction, but were less substantial as compared to overall changes between T0 and T2, only changes between T0 and T2 are presented. As shown, the correlation coefficients of the subscales Disrupted Schedule and Lack of Family Support were relatively low, indicating a large individual variability. For Disrupted Schedule, variability was high within each subgroup. The frequency distribution of part B showed that most changes in the impact on disrupted schedule turned out to be in a less negative direction, indicating less negative impact on disrupted schedule over time. With respect to Lack of Family Support, individual caregivers reported a change in scores over time, even though no group variability was found (see Table 2). A closer inspection of the data revealed that the proportions of caregivers who reported a decreased, an equal, or an increased score 6 months after baseline were similar, and therefore the impact on Lack of Family Support remained stable at a group level. Particularly within the highest SES group, individual variability was large, and of all subgroups, those in the youngest age groups remained most stable at the individual level.

Individual variability over time was observed to a lesser extent for scores expressing the impact on financial problems and loss of physical strength, and it was least substantial for scores on self-esteem. Overall, approximately 50% of the caregivers reported equal scores on these subscales at baseline and 6 months later. Nevertheless, with respect to Financial Problems, especially caregivers with a low SES had varying scores. For Loss of Physical Strength, most individual variability was found in women, the younger age groups, and those with the highest SES. For Self-esteem, mainly caregivers in the lowest and middle SES groups reported different scores at the two measurement points.

	Total	Gender		Age Group			Socioeconomic Status		
Impact of Caregiving on:		Male	Female	<50	50–65	>65	Low	Middle	High
Disrupted Schedule									
то	2.41 (0.82)	2.38	2.43	2.52	2.41	2.35	2.23	2.40	2.62
T1	2.20 (0.85)	2.03	2.30	2.33	2.19	2.16	2.23	2.18	2.30
T2	1.99 (0.73)	1.96	$2.06^{+}$	2.17	1.89	2.04	2.01	1.90	2.19
Group variability	18.27***	9.84***	10.34***	1.52	13.44***	4.95**	0.79	15.74***	4.38*
Effect size	0.63	0.51	0.54	_	0.93°	0.47	_	0.76	0.69
Financial Problems									
ТО	1.88 (0.59)	1.89	1.87	1.83	1.97	1.79	1.88	1.95	1.69
T1	1.83 (0.54)	1.84	1.84	1.92	1.88	1.74	1.90	1.83	1.79
T2	1.82 (0.52)	1.87	1.82	1.70	1.93	1.74	1.81	1.82	1.84
Group variability	1.47	0.40	1.69	1.98	0.66	0.97	0.55	4.59*	1.27*
Effect size	—		—	_		—	_	0.37	_
Lack of Family Support									
ТО	2.11 (0.59)	2.02	2.16	1.93	2.12	2.16	2.17	2.10	2.10
T1	2.18 (0.59)	2.10	2.21	1.93	2.17	2.24	2.23	2.16	2.15
T2	2.17 (0.51)	2.13	2.18	2.09	2.14	2.23	2.15	2.17	2.19
Group variability	1.06	0.58	0.59	1.73	0.58	0.51	0.26	1.10	0.39
Effect size	—					—		—	
Loss of Physical Strength									
ТО	1.93 (0.61)	1.76	2.03**	1.82	1.89	2.01	2.02	1.93	1.87
T1	1.94 (0.61)	1.81	2.01	2.03	1.89	1.96	1.98	1.92	1.95
T2	1.87 (0.65)	1.75	1.96*	1.97	1.79	1.95	2.02	1.81*	1.95
Group variability	1.32	1.42	0.61	0.73	1.78	0.55	0.76	3.27*	0.28
Effect size	_			—		_	_	0.26	
Self-esteem									
ТО	4.22 (0.41)	4.16	4.24	4.26	4.16	4.26	4.29	4.24	4.10
T1	4.13 (0.40)	4.09	4.16	4.17	4.11	4.14	4.20	4.17	3.97*
T2	4.13 (0.43)	4.08	4.10	4.17	4.13	4.11	4.20	4.17	3.96*
Group variability	6.23**	1.60	4.90**	1.09	0.94	6.38**	1.63	1.81	4.35*
Effect size	0.49	_	0.35	_	_	0.14	_	_	0.61

Table 2. Means of Caregiver Experiencesa Over Time, Groups Variabilitiesb, and Effect Sizes, by Gender, Age and<br/>Socioeconomic Status

<sup>a</sup>A high score on impact on Disrupted Schedule, Financial Problems, Lack of Family Support or Loss of Physical Strength indicates a negative impact on caregiver experiences, whereas a high score on the impact on Self-esteem indicates a positive impact on caregiver experiences.

<sup>b</sup>GLM analyses of variances.

<sup>c</sup>Effect size > 0.80, indicating a large effect.

 $^{+}p < .10; *p < .05; **p < .01; ***p < .001.$ 

In sum, the largest individual variability was observed for the impact on Disrupted Schedule and Lack of Family Support, and the least individual variability was observed for the impact on Self-esteem. Within subgroups, individual variability depended predominantly on the type of impact. However, most individual variability was observed among caregivers in the lowest SES group.

#### Discussion

This study shows patterns of caregiver experiences in partners of cancer patients to vary over time and reports different patterns for several domains of experiences and according to subgroups of caregivers. It indicates that impact of caregiving on Disrupted Schedule and on Caregiver's Self-esteem both decreased over a period of 6 months postdischarge, whereas the impact on Financial Problems, Lack of Family Support, and Loss of Physical Strength remained constant over time. A decreasing score on Disrupted Schedule over time indicates that providing care was perceived as being less interruptive of daily activities 6 months after baseline. A decreasing score on Self-esteem over time indicates that caregivers were perceived to derive less self-esteem from caregiving over time. Distinctive patterns between male and female caregivers, and the age and SES groups were observed for specific caregiver experiences. Not all caregivers could be characterized by the overall patterns, because of a large individual variability.

Female caregivers perceived a more negative impact on Loss of Physical Strength as compared to male caregivers, and although Caregivers' Self-esteem did not change over time in male caregivers, female caregivers reported a less positive influence on selfesteem over time. Differences in social roles, in range of competing roles, and in role commitment may account for the observed distinctive patterns between female and male caregivers (Kramer & Kipnis, 1995). Also, differences in emotional attentiveness, in coping styles, or in occupying caregiving tasks may explain the observed gender differences (Rose-Rego,

		Gender		Age Group			Socioeconomic Status		
Impact of Caregiving on:	Total	Male	Female	<50	50–65	>65	Low	Middle	High
Disrupted Schedule									
Individual variability	0.26 <sup>a</sup>	0.28 <sup>a</sup>	0.26 <sup>a</sup>	0.39 <sup>a</sup>	0.42 <sup>a</sup>	0.21 <sup>a</sup>	13 <sup>a</sup>	0.37 <sup>a</sup>	0.19 <sup>a</sup>
% Decrease	13	11	14	17	10	15	17	12	12
% Equal	42	42	42	28	42	46	53	40	36
% Increase	45	47	47	56	48	39	30	48	52
Financial Problems									
Individual variability	0.53	$0.49^{a}$	0.56	0.72	0.50	0.46 <sup>a</sup>	0.16 <sup>a</sup>	0.65	0.43 <sup>a</sup>
% Decrease	24	25	23	17	26	23	27	19	33
% Equal	48	49	47	50	48	48	50	47	49
% Increase	28	26	30	33	26	29	23	34	18
Lack of Family Support									
Individual variability	0.27 <sup>a</sup>	0.31 <sup>a</sup>	0.21 <sup>a</sup>	0.68	0.17 <sup>a</sup>	0.24 <sup>a</sup>	0.37 <sup>a</sup>	0.43 <sup>a</sup>	0.03 <sup>a</sup>
% Decrease	35	42	31	33	26	44	33	32	43
% Equal	38	40	36	50	44	28	27	43	33
% Increase	28	19	33	17	30	28	40	25	24
Loss of Physical Strength									
Individual variability	0.46 <sup>a</sup>	0.59	$0.40^{a}$	0.44 <sup>a</sup>	0.41 <sup>a</sup>	0.53	0.48 <sup>a</sup>	0.52	0.33ª
% Decrease	16	13	18	33	13	15	13	14	24
% Equal	58	66	53	28	61	62	67	53	61
% Increase	26	21	29	39	26	23	20	23	15
Self-esteem									
Individual variability	0.58	0.68	0.51	0.73	0.57	0.55	0.49 <sup>a</sup>	0.46 <sup>a</sup>	0.79
% Decrease	31	30	32	33	25	38	30	28	39
% Equal	52	47	58	44	57	49	50	55	46
% Increase	17	23	14	22	19	13	20	17	15

Table 3. Individual Variabilities and Proportional Changes in Caregiver Experiences Between Time 0 and Time 2

<sup>a</sup>Pearsons correlation coefficient < 0.50 indicating a high variability.

Strauss, & Smyth, 1998). As female caregivers were found to be more attentive to their emotions, they were more likely to report negative effects of caregiving. Also, women have been found to use more emotion-focused coping strategies, which are associated with higher reported levels of negative health outcomes (Miller & Cafasso, 1992). Moreover, female caregivers traditionally are likely to perform more personal care and household chores, which may be more time-consuming, demanding, and ongoing than traditional male tasks (Rose-Rego et al., 1998). Our findings give support to the importance of making a basic distinction between female and male caregivers, rather than to analyze them as a homogeneous group of caregivers, but additional research is needed to interpret the observed gender differences in caregiving.

Younger caregivers tended to report a more negative impact on disrupted schedule and continued to do so over time, whereas older caregivers appeared to experience caregiving as less negative over time. A possible explanation may be that younger persons feel more restricted in performing outside activities, such as work and social activities, when they have to take on the caregiving role. Likewise, younger persons may experience more secondary role strains, such as work and child rearing; thus, caregiving may be a more easily accepted role at a later stage of life.

Regarding SES, no differences between the separate categories were found with respect to the negative caregiver experiences. However, scores for the impact on self-esteem in caregivers with a low SES were high and remained practically constant over time, whereas caregivers with a high SES derived substantially less and a decreasing amount of selfesteem from caregiving. As caregivers with a low SES derive self-esteem from caregiving activities—and they remain to do so over time—the caregiver role may be of greater importance to them compared to those with a high SES. It is plausible that caregivers with a high SES derive more self-esteem from outside activities (e.g., work) or from other resources.

Patterns of three out of five caregiver experiences were found to be stable. Findings of stable patterns of caregiver experiences have also been reported by other researchers (Collins, Stommel, Wang, & Given, 1994; Pruchno, Kleban, Michaels, & Dempsey, 1990). Hence, the moment at which someone takes on and perceives the role of caregiver is of great importance. In the current study, baseline has been defined as the period of 2 weeks before hospital admission. However, someone may have assumed the caregiver role long before this period, perhaps at the time of the first complaints. The implication to study patterns of caregiver experiences among carers of cancer patients at the moment of the first complaints (i.e., in most cases before the diagnosis is actually clear) is, however, unfeasible. In this study, the acute and early chronic phases of the cancer process were addressed. The fixed time period of 6 months after patient's discharge might be too short to test, however, if patterns in caregiver experiences have become manifest. Patterns in caregiver experiences may even become more pronounced over time,

when the patient's health is still deteriorating or improving and with ongoing changes in care demands or in caregivers' health (Kurtz, Kurtz, Given, & Given, 1995). Also, it might well be that the longer the chronic phase, the more caregivers' resources get depleted, and this may have an effect on how caregiving is perceived. As the consequences over a longer term are still largely unknown, future research should reflect on a longer period of time.

In order to explain the patterns observed, additional longitudinal analyses should be performed (Singer, 1998). The focus of this study was purely descriptive, and therefore implies reservation regarding the predictive value of time (i.e., whether a wearand-tear model or an adaptational model is most appropriate). However, the current findings gave little support to using only the wear-and-tear model, that is, a model which simply suggests that the longer care is provided, the more negative (or less positive) the outcomes will be, and which is supported by previous research (Townsend, Noelker, Deimling, & Bass, 1989; Walker, Acock, Bowman, & Li, 1996). Caregivers were shown to derive less self-esteem from caregiving activities over time, and this is in favor of the wear-and-tear model, but, on the other hand, the impact on disrupted schedule showed a decrease over time and this is consistent with an adaptational model. Apart from time and care characteristics, disease-specific characteristics, social support, personality characteristics, quality of the relationship, and caregiver's own health are likely to play an important role in caregiving (Biegel, Milligan, Putham, & Song, 1994; Bull, 1990; Intrieri & Rapp, 1994; Kurtz et al., 1995; McCorkle et al., 1993; Nijboer, Tempelaar, Triemstra, Sanderman, & Van den Bos, 1999; Walker et al., 1996; Wright, Clipp, & George, 1993).

Some issues need to be addressed with respect to the generalizability of the findings. First, only caregivers of cancer patients with relatively good health and a good prognosis were included and stayed in the study. Over the three waves, 13% of the patients died or had to withdraw because of deteriorating health, and especially in their partners the consequences of caregiving might have become very obvious. Second, a relatively high score on the positive domain of caregiver experiences and relatively low scores on the negative domains were observed as compared to reference studies involving caregivers of cancer patients (Given, Given, Helms, Stommel & DeVoss, 1997; Given et al. 1993; Kurtz, Given, Kurtz, & Given, 1994; Kurtz, et al., 1995, 1997; Mc-Corkle et al., 1993). It may be questioned whether high scores are due to a ceiling effect, and low scores to a floor effect, respectively. Furthermore, a general problem in the discussion on change scores is the phenomenon of "regression to the mean." In addition to studying caregiver experiences in other circumstances, the sensitivity of the CRA instrument needs to be further examined. Finally, the definition of the concept of change is rather arbitrarily defined, and one may wonder if the reported variability reflects actual changes or accidental fluctuations. Unfortunately, as yet, data concerning absolute changes in caregiver experiences as well as cutoff scores to detect caregivers at risk are unavailable. An external criterion is needed that is acceptable as a standard against which the instrument under study can be judged. The development of indicators for assessing clinically relevant changes of caregiving experiences should be encouraged.

In sum, this study shows the advantages of studying caregiver experiences as a multidimensional concept that includes both negative and positive experiences of caregiving and underlines the value of studying both inter- and intraindividual patterns across different subgroups. Women, younger caregivers, and those with a high SES were identified as subgroups that are most vulnerable as caregivers and perhaps in potential need of support. Further longitudinal research is needed to document the patterns of caregiver experiences over a longer period of time and for different groups of caregivers. Also, more research could reveal factors that differentiate caregivers who experience wear and tear from those who seem rather to adapt to the caregiving situation in order to develop specific interventions to support informal caregivers.

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