

University of Groningen

## Cancer and caregiving

Nijboer, C; Sanderman, R; Triemstra, M; Spruijt, RJ; Van den Bos, GAM

*Published in:*  
 Psycho-oncology

**IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.**

*Document Version*  
 Publisher's PDF, also known as Version of record

*Publication date:*  
 1998

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*

Nijboer, C., Sanderman, R., Triemstra, M., Spruijt, R.J., & Van den Bos, GAM. (1998). Cancer and caregiving: The impact on the caregiver's health. *Psycho-oncology*, 7(1), 3-13.

### Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

### Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

*Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.*

# CANCER AND CAREGIVING: THE IMPACT ON THE CAREGIVER'S HEALTH

CHRIS NIJBOER<sup>a,\*</sup>, REIKE TEMPELAAR<sup>b</sup>, ROBBERT SANDERMAN<sup>c</sup>, MATTANJA TRIEMSTRA<sup>a</sup>,  
ROB J. SPRUIJT<sup>a</sup> and GEERTRUDIS A.M. VAN DEN BOS<sup>a</sup>

<sup>a</sup> *Academic Medical Centre, University of Amsterdam, Institute of Social Medicine, Meibergdreef 15, 1105 AZ Amsterdam, The Netherlands*

<sup>b</sup> *Northern Centre of Health Care Research, Department of Health, University of Groningen, Groningen, The Netherlands*

<sup>c</sup> *Northern Centre of Health Care Research and Department of Clinical Psychology, University of Groningen, Groningen, The Netherlands*

## SUMMARY

A diagnosis of cancer affects not only the patient but also their significant others, especially when a lot of care tasks are involved. Some caregivers perceive the care as a burden, while others consider it a challenge. In this article, findings concerning the impact of cancer caregiving on informal caregivers will be described. No consistent results are reported, and little is known about patterns of caregiving changes in relation to the course of the patient's illness. Attention will be given to factors which have been identified as influencing the course and consequences of caregiving. These factors form the basis of a conceptual research model for caregivers of cancer patients. As cancer progresses, care tasks are generated, which can be perceived by the caregiver as either negative (i.e. burden) or positive. Furthermore, these caregiver experiences may lead to negative as well as positive effects on the caregiver's health and these relationships can be assumed to be bidirectional. © 1998 John Wiley & Sons, Ltd.

## INTRODUCTION

Recent health policy is shifting its focus from professional to informal care. An escalating trend is the early discharge of hospital patients. With a high and still growing percentage of elderly, and an increasing prevalence of chronic diseases, family members form a substantial part of the care system. Studies have shown that informal caregivers already provide an average of 55% of the care needed (SCP, 1994).

Cancer is a major disorder which affects many people, directly or indirectly. According to the 1993 report of the American Cancer Society, it was estimated that one in three people living in the USA will be diagnosed with cancer at some

point in his or her lifetime, and one in five deaths will be attributable to this disease (American Cancer Society, 1993). Nearly half of all the newly diagnosed cancer patients will survive longer than 5 years. The course of cancer is shifting from an acute disease with a prompt outcome, usually death, to a chronic disease with long-term treatment often implemented in home settings with a continuing need for care. Health policy, demographic trends and medical-technological developments will lead to an expansive involvement of the informal care system of cancer patients.

A diagnosis such as cancer influences not only the patient but also the significant others in many respects. Several studies have shown that patients and their partners reported higher levels of psychological distress as compared to the general population, and that patients and their partners did not differ significantly in their levels of distress (Northouse and Stetz, 1989; Oberst *et al.*, 1989). Not only the diagnosis itself, but also the subsequent course of the illness may influence the current level of health. Cancer includes multiple physical needs, intense psychological distress

---

\* Correspondence to: Academic Medical Center, University of Amsterdam, Institute of Social Medicine, Meibergdreef 15, 1105 AZ Amsterdam, The Netherlands.

Contract grant sponsor: Dutch Cancer Society; Contract grant number: AMC 95-1138

manifested by pain, anxiety and depression and restrictions in social and sexual functioning. Alterations in a patient's functional ability, bodily functions, appearance, employment status, sexual functioning, family and social role have a direct impact on the caregiver. Informal caregivers may face existential concerns that force them to re-evaluate their future, which may lead to changes in life goals. Cancer patients are a group in which care needs can be expected to increase over time, and as a consequence, problems raised by giving care as experienced by caregivers may change as the disease progresses (Northouse, 1984). Additional stress can be experienced by having to 'stand by' and observe the disease progress while being unable to alter or manage the illness (Stetz, 1987). It can be questioned to what extent caregiving to cancer patients is burdensome or may lead subsequently to feelings of depression.

Most research in the field of caregiving concerns family members of patients of frail elderly, or patients with mental disorders, such as dementia, or schizophrenia (Zarit and Toseland, 1986; Leff *et al.*, 1986; Baumgarten, 1989; Pot and van Dyck, 1995; Schulz *et al.*, 1995). In general, caregivers are defined as 'primary care providers', often referring to network members, such as the partner, parent, sibling or child. This article addresses available studies on the caregiving situation, with specific focus being placed on caregivers of cancer patients. Studies are traced by literature databases (PSYCHINFO and MEDLINE) for the period 1980–1996. At first, the main key words 'caregiving' and 'burden' were entered to select studies. Later the key word 'cancer' was included. Although this article does not claim to be exhaustive, it certainly includes the most important findings in the field of caregiving. Since research on caregiving to cancer patients is sparse, gerontological research will also be discussed to present the overall consequences of caregiving.

The aim of this paper is to develop a conceptual framework, which is meant to provide a guideline for examining the caregiving process. Special attention will be given to the definitions and operationalisations of two main concepts which play a central role within the caregiving situation, namely care tasks and caregiver experiences (i.e. burden and positive aspects).

## IMPACT OF CAREGIVING: CARE TASKS AND CAREGIVER BURDEN

Both objective and subjective components of the care situation can be distinguished (Montgomery *et al.*, 1985), with the former reflecting (changes in) *care tasks* and the latter reflecting the experience of (changes of) this situation (i.e. *caregiver burden*). Terms such as 'care involvement', 'care demands' and 'objective care activities' are used to refer to all different types of care tasks (Stetz, 1987; Given *et al.*, 1993). These tasks can be categorized into amount, frequency, duration and/or different types of care. Most frequently, types of care tasks are divided into: assistance with self-care, mobility, and symptom management of the patient, financial management and/or conducting medical care tasks. Emotional care tasks, such as providing social support, assistance with decision-making, and providing and seeking information, are seldom defined as a specific type of care task. 'Caregiver burden', 'strain', or 'role strain' are generally used to refer to the physical, psychological, social and/or financial reactions that can be experienced in giving care (Zarit *et al.*, 1980; Cantor, 1983; Robinson, 1983; Poulshock and Deimling, 1984; Given *et al.*, 1992). A multi-dimensional construct measuring this perceived impact of caregiving is most frequently used.

Findings suggest that the type of help provided may be a more salient predictor of burden than the total number of tasks or the care task hours. The more confining the care tasks are (i.e. the less time-flexible and the more disruptive they are to the caregivers' schedule), the more they create burden (Given *et al.*, 1990). Personal tasks (e.g. feeding and washing the patient) seem to be perceived as more difficult and burdensome than nonpersonal tasks (e.g. doing the groceries) (Horowitz, 1985). Specific care tasks may also have differential effects on burden. For example, providing emotional support to the patient proved to be the most time-consuming and difficult task to perform, and therefore this kind of task did receive the highest burden score in a study among family members of cancer patients receiving chemotherapy (Carey *et al.*, 1991).

## NEGATIVE AND POSITIVE ASPECTS OF CAREGIVING

Implicitly, the term 'burden' reflects a negative approach towards experiences of caregiving. Although most research has focused on negative experiences of giving care, more and more studies also report on the beneficial effects (Kinney and Stephens, 1989; Lawton *et al.*, 1989; Motenko, 1989). There are several reasons to believe that experiences of caregiving can also be positive and that it might be worthwhile to investigate their effects on health. Firstly, recognition of positive experiences, in terms of love, affection, rewards, challenge, meaning, commitment, purpose in life or joyful events (Horowitz, 1985; Oberst *et al.*, 1989; Carey *et al.*, 1991; Folkman *et al.*, 1995), may increase the caregivers feelings of pride in their ability to meet challenges and improve their sense of self-worth (Motenko, 1989). Secondly, caregiving may also define identity and involvement to one's society and thereby maintain well-being. Furthermore, understanding positive aspects and identifying predictors of positive outcomes may provide information to enhance theories, and clues as to how enhance or increase positive aspects or may identify caregivers who are less likely to need intervention.

The operationalisation of aspects of caregiving that are experienced as positive vary enormously. At first, positive aspects were part of more global burden scales (Zarit *et al.*, 1980; Poulshock and Deimling, 1984). In more recent studies, positive aspects were more explicitly defined and measured, such as uplifts (Kinney and Stephens, 1989), gratification (Motenko, 1989), caregiver self-esteem (Given *et al.*, 1992), appraisal, satisfaction, mastery and ideology (Lawton *et al.*, 1991). As yet, whether these positive experiences of caregiving lead to more positive or to less negative health effects is inconclusive. Kinney and Stephens (1989) argued that caregivers, who were most intensely involved in caregiving, might have greater opportunity to derive satisfaction from caregiving. Folkman *et al.* (1995) reported that caregiving may improve the quality of relationships between caregivers and care recipients, and this may contribute to self-esteem. They also showed that most caregivers are unlikely to experience positive and negative experiences at the same moment, but in many individual caregivers a shift in the direction of their feelings, reactions

and consequences of caregiving occurred. Lawton *et al.* (1989) reported that caregiver satisfaction was not strongly related to burden. However, as mentioned before, research concerning positive aspects of cancer caregiving is in its infancy. It is plausible that some positive aspects may decrease feelings of being burdened, and subsequently lead to a positive effect on health outcomes.

## CAREGIVING AND HEALTH

Since specific care tasks may have differential effects on burden, it is likely that specific care tasks may also have differential effects on health. Questions such as at what moment and to what extent (changes in) different types of care tasks relate to the caregiver's overall health outcome are an interesting topic of research. Although it seems evident that patient dependency is directly related to care tasks, the effect of (different types of) care tasks on caregiver health is less clear. Studies among the frail elderly have consistently shown that, as the level of functional and mental impairment of the care receiver increases, so does the amount of assistance provided by the caregiver (Horowitz, 1985). However, the majority of studies demonstrated that neither severity of patient impairment, nor type of illness, patient's symptoms, nor duration of caregiving are significantly related to negative effects on the caregiver's health (Stetz, 1987; Cattanach and Tebes, 1991; Wright *et al.*, 1993). For example, in the study of Gilhooly (1984) among persons caring for a demented relative, it was found that (1) level of patient's impairment was not associated with the caregiver's health and (2) the longer the duration of caregiving, the better the caregiver's health. The need to examine the role of conditioning or intervening variables is justified by the absence of consistent relationships between independent variables such as patient impairment (e.g. ability to perform tasks) and caregiver health. In this sense, the perception of care tasks, in terms of caregiver burden or positive aspects, may be worthwhile studying in order to explain overall health outcome in the caregiving situation.

Although, George and Gwyther (1986) argued that burden and health are actually the opposite sides of the same coin, current studies agree that it is important to make a distinction between the concepts of burden and health concerning the

impact of caregiving (Stull *et al.*, 1994; Stuckey *et al.*, 1996). Burden seems to represent a unique domain of the caregiving situation and is considered to be sensitive to caregiving specific demands, whereas health is considered to be an overall outcome, which can be viewed as the end result of the caregiving process. Evidently, the factors of burden and health are related to each other (Stuckey *et al.*, 1996). Whether the impact of caregiving burden leads to an effect on health or whether health leads to an effect on burden is unclear. Viewing the conceptual models which have been used to guide caregiving research, burden is generally stated as a predictor of health and likely to have an adverse impact on an caregiver's future (Lazarus and Folkman, 1984; Pearlin *et al.*, 1990). However, in the study of Stommel *et al.* (1990) among families of the demented elderly, no effect of burden on health was observed, but health, in terms of depression, was found to predict burden. This was also reported by Pruchno *et al.* (1990) in their study among spouses caring for the demented elderly. In the field of oncology, longitudinal studies on the caregiving situation concerning causal relations are scarce.

In studies on caregiving outcomes, two general dimensions of health are distinguished, namely psychological and physical health. Studies focusing on psychological health effects in caregivers show increases in psychological symptoms, such as depression, anxiety and emotional distress (Oberst and James, 1985; Schulz *et al.*, 1987; Holland, 1989; Northouse and Stetz, 1989; Given *et al.*, 1993). Schulz *et al.* (1990) reviewed the literature on the psychiatric and physical morbidity effects of caregiving. Their review indicated a higher level of psychiatric symptomatology and illness in caregivers when compared to population norms. In a study among cancer patients receiving chemotherapy, it was found that a patient's level of dependence and depression were related to the caregiver's daily schedule and depression. No relationship was found with the caregiver's physical health (Given *et al.*, 1993). Studies of the physical health effects of caregiving are less conclusive but suggest increased vulnerability. Generalized fatigue (Jensen and Given, 1991), and a wide variety of physical problems have been reported by partners of cancer patients, such as food intolerance, exacerbation of medical conditions, exhaustion and indigestion (Oberst *et al.*, 1989).

More studies are needed to examine the separate relations between the different type of tasks,

caregiver experiences (i.e. burden and positive aspects) and health dimensions. We suggest that these should include both the physical and the psychological dimensions of health.

#### CONTEXTUAL FACTORS IN THE CAREGIVING PROCESS

Numerous correlates and effects of caregiving have been reported (see for reviews Baumgarten, 1989; Wright *et al.*, 1993; Schulz *et al.*, 1995), which hampers drawing overall conclusions. Most studies include sociodemographic characteristics and social support within the caregiving situation, while a smaller group of studies has identified factors, such as patients' and partners' health prior to the care situation (Stommel *et al.*, 1990), quality of the relationship (e.g. marital satisfaction (Fuller and Swendsen, 1992) and personality factors, such as mastery (Pearlin *et al.*, 1990), optimism and neuroticism (Hooker *et al.*, 1992).

Sociodemographic characteristics include variables like age, gender, living situation, type of relationship, and socioeconomic status of both the care recipient and caregiver. Relatively consistent findings were reported regarding gender (Zarit and Toseland, 1986; Barusch and Spaid, 1989; Miller and Cafasso, 1992), age (Mor *et al.*, 1994), co-residence and the type of relationship between the care recipient and caregiver (Horowitz, 1985; George and Gwyther, 1986; Young and Kahana, 1989). Women, especially those at a younger age, tend to perceive caregiving as more negative than (older) men and report higher levels of psychological distress (Zarit *et al.*, 1989; Blood *et al.*, 1994), even if the amount of care provided and/or the level of patient's health is controlled (Horowitz, 1985). Compared to other informal caregivers, female caregivers and partners are identified as the most vulnerable group of caregivers. Moreover, partners are stated to provide the most extensive and comprehensive care (Horowitz, 1985) and are less likely to receive assistance. These caregivers often feel ultimately responsible for coordinating the care and make minimal use of professional services (Oberst *et al.*, 1989). Partners, as compared to other caregivers, are likely to experience more strain (Cantor, 1983), they may become ill themselves (Schulz *et al.*, 1987) and they may experience higher levels of psychiatric symptoms (George and Gwyther, 1986).

Caregivers with a relatively low socioeconomic status are assumed to report a higher burden, and subsequently a poorer health (Montgomery *et al.*, 1985). A negative relationship between income and caregiver outcomes has been observed for only certain types of caregivers (i.e. partners), whereas other types of caregivers report no relation (George and Gwyther, 1986). Biegel *et al.* (1994) did not find any relationship between socioeconomic characteristics and caregiver burden. For examining the role of socioeconomic status, the costs for providing care (Stommel *et al.*, 1993), time for job performance and time available for caregiving also need to be considered. Stommel *et al.* (1993) stressed that the costs for providing care are usually underestimated.

Attention to the role of social support within the caregiving process is growing extensively. In general, research shows that social support can have a positive effect on health (De Ridder and Scheurs, 1994). Studies revealed that the impact of support is related to its timing, its source (Ros, 1989; Hileman *et al.*, 1992), its type (Thompson *et al.*, 1993) and its perception (Dakof and Taylor, 1990). In particular, the support provided by the partner plays a major role in the patient's adjustment to cancer (De Ruiter, 1995). Likewise, support from the patient towards the partner may be assumed to play an important role too. Several authors stress the point of unhelpful support, especially within a marital relationship (Siegel *et al.*, 1991; Buunk and Hoorens, 1992). In studies of spouses of mastectomy patients, men were found to be deeply emotionally engaged, but they were hiding it, and were playing a protective, reassuring, minimizing role (Sabo *et al.*, 1986). These men assumed this to be the most supportive behaviour, but their wives interpreted this as rejection and insensitiveness. Well intended support from partners' attempts often fail to such a degree, that they actually increase health problems (Rait and Lederberg, 1990). However, the relationship between social support and health is not clear and it is likely that poor health and the perception of social support influence each other reciprocally. The role of social support within the caregiving process in particular is even more ambiguous. Caregiving can be very time-consuming and caregivers frequently lack the time to develop supportive relationships. If caregiving responsibilities lead to social isolation (Siegel *et al.*, 1991), caregivers will depend mainly on their care recipients for support (DesRosier *et al.*, 1992). In a

sample of frail elderly, the availability of social support and social contacts was found to be an important determinant of caregiver's well-being (Schulz *et al.*, 1987). In a study among family caregivers of frail elders the relationships between six different types of social support and five measures of caregiving burden was assessed (Thompson *et al.*, 1993). Not all types of social support were found to be equally associated with burden. Intimate interaction and confiding, positive feedback, as well as tangible assistance were observed to be unrelated with burden, while engaging in social interaction for fun and recreation appeared to be the most important in diminishing the burden of caregiving.

### CAREGIVING PATTERNS OVER TIME

Several studies show that caregiving is a dynamic, ongoing process, for which there may be several trajectories (Oberst and James, 1985; Schulz and Williamson, 1991; McCorkle *et al.*, 1993). Care tasks, caregiver burden and caregiver's health may fluctuate in response to changes in the patient's health. Caregiving-related health problems may steadily and uniformly increase, i.e. caregiver's physical and psychological stamina will be depleted along with the exposure to multiple and long-term stressors (Pearlin *et al.*, 1990). This basic idea has been described as the *downward-trajectory* or *wear-and-tear model* in a model of Williamson and Schulz (1993) (see Figure 1). This might suggest that personal and social resources are insufficient to maintain prior levels of the caregivers' health.

Alternately, it is possible that the gradual initial decrement in caregiver's health is followed by recovery to prior levels (*gradual decline and recovery*). This might be the case if caregivers are able to acquire skills and resources to cope effectively with demands of caregiving. Also, negative health effects may be high when cancer is diagnosed, and subsequently decrease and stabilize with time (*decline and stability*). These *adaptational trajectories* were found in correlation studies among persons caring for a demented relative, in which higher levels of caregivers' psychological health were associated with longer durations of caregiving (Zarit *et al.*, 1980; Gilhooly, 1984). Also probable is the situation in which the caregiver's health improves during the course of the patient's illness (*gradual*

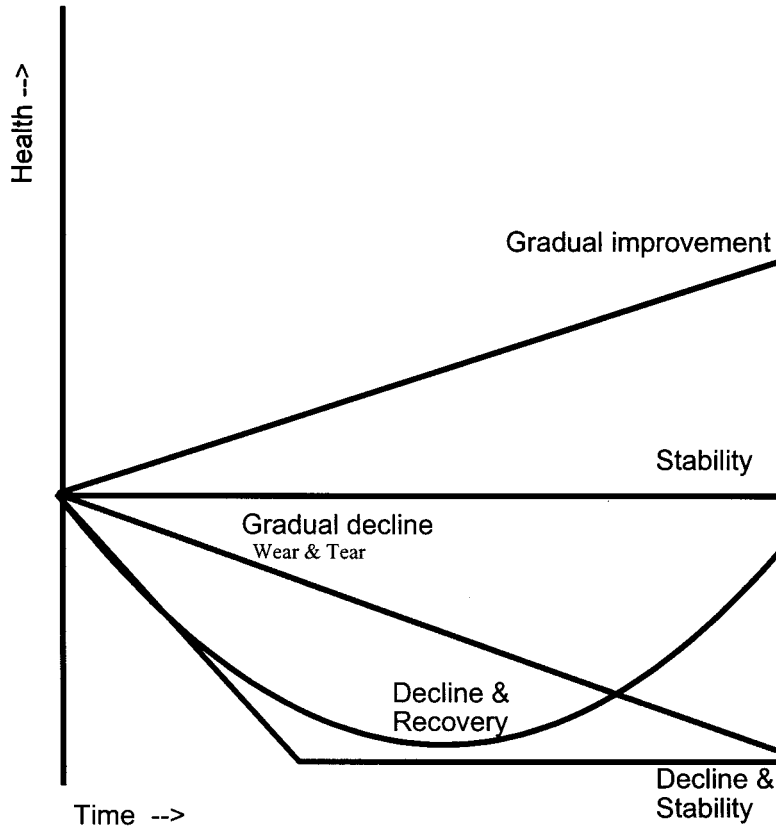


Figure 1. Patterns of partners' health in relation to the demands of caregiving (Source: Schulz *et al.*, 1990).

*improvement*). This can be a reflection of the positive effects of caregiving or an increased availability of social-support resources. Moreover, it could be assumed that caregivers who were coping poorly had their relatives institutionalized and only the 'best copers' persisted as primary caregivers. This pattern can be described as the *upward trajectory*. Most studies among caregivers of elderly or cognitively impaired persons showed no changes in caregivers' health at all (*stability*) (Pruchno and Resch, 1989; Schulz and Williamson, 1991).

Research on the responses of and consequences for caregivers of cancer patients reveals that health effects have to be examined in relation to the stage of illness the patient is going through (De Ruiter, 1995). Northouse and Stetz (1989) suggested that the course of cancer can be divided into three stages, the initial phase, the treatment phase and the adaptational phase. Although all three phases lead to considerable anxiety and

pressure for significant others (Blood *et al.*, 1994), the treatment phase is stated as the most stressful phase (Northouse, 1984). Directly after a diagnosis like cancer, emotional and informational support may be needed most. During periods of active treatment, assistance with patient's self-care, transportation, procedures, medication and symptom management seems to be needed (Given *et al.*, 1993). More and more researchers emphasize the importance of including the early phases of the illness in studying caregiver's health (Zarit and Toseland, 1986; Northouse, 1988; Given and Given, 1991; McCorkle *et al.*, 1993). Moreover, Schulz and Williamson (1991) stated that it would be ideal to obtain data from caregivers in advance to taking on the caregiving role, so that the effects on health of *becoming* a caregiver can be established. The moment of taking on the role as caregiver or in occupying other roles is not well-defined, and therefore hard to study. In the case of cancer, patients may be in need of care long

before diagnosed. Although not necessarily, in most studies the time-frame of the caregiving situation is usually fixed at the moment the diagnosis is made, and the primary caregiver also maintains their role during the process of cancer.

The present research on the consequences of cancer caregiving to caregivers is suggestive, rather than conclusive. In a review, Laizner and colleagues reported that at 3 months following the hospital discharge of cancer patients, 68% of the caregivers felt that they had to be available to patients for 24 h a day (Laizner *et al.*, 1993). In a study among laryngeal cancer patients and their partners, it was found that caregiver burden decreased as time since diagnosis increased. Changes in caregivers health were not reported, and burden was found to be unrelated to caregivers health (Blood *et al.*, 1994). In a study among terminally ill cancer patients and family members, no significant effects of the duration of caregiving were found on outcomes of caregiving (Yang and Kirshling, 1992). In a sample of patients who underwent surgery for either colon or bladder cancer, partners showed significantly higher levels of anxiety than patients. These emotional problems peaked 60 days after discharge and remained a problem for most partners up to 6 months after discharge (Oberst and James, 1985). In a similar patient population, it was found that the incidence of partners' somatic complaints, such as fatigue, aches and pains began to rise between 30 and 60 days after the patient returned home (Oberst and Scott, 1988). Baider and Kaplan De-Nour (1984) also noticed an increasing burden in spouse caregivers over time in addition to treatment. However, McCorkle *et al.* (1993) reported that even though patients improved in time, their caregivers continued to report similar levels of burden. Patients' health was strongly related to caregivers' financial impact, impact on schedule, and physical caregiving tasks.

As yet, there is no evidence to validate the precise effects of caregiving for cancer patients on caregivers over time. Primarily, it can be expected that giving care to patients with cancer depends on the phase of the disease and the needs of the individual patient. A possible assumption is that, immediately and shortly after diagnosis, caregivers may predominantly experience psychological symptoms, while in the long run (e.g. at 6 months) physical consequences of caregiving may also appear.

## A CONCEPTUAL FRAMEWORK OF THE CAREGIVING PROCESS

The cognitive stress theory of Lazarus and Folkman (1984) is frequently used in caregiving research. According to this theory, contextual elements, as well as perceptions of the situation, play a major role within a stressful situation, such as the caregiving process. The extent of the experienced stressful situation does not depend solely on the demands of the situation or on the personal and social resources of the person, but rather on the relationship between demands and resources as perceived by the individual. The assumption underlining this theory is that the individual's unique perceptions of the illness-caregiving situation are more likely to explain outcomes than sociodemographic or patient-illness characteristics alone. This theoretical approach may guide interpretations of relations between caregiving aspects and overall outcomes of caregiver's health. Following Pearlin *et al.* (1990), three key components of the cognitive stress theory are said to be involved in the caregiving process, namely (1) stressors, (2) outcomes, and (3) potential mediators. Stressors refer to the patient's physical and psychological health, and associated care tasks. Outcomes refer to the caregiver's physical and psychological health. Social support can be stated as a potential mediator. Caregiver burden can be seen either as a stressor or a mediator. These five concepts may provide a useful framework for describing the caregiving process and for explaining outcome differences in caregivers' burden and health (see Figure 2). It can be assumed that as the course of cancer proceeds, the patient's health changes and subsequently care tasks are generated. Here, the perception of these tasks is conceptualized as caregiver experiences, i.e. caregiver burden and positive aspects. Furthermore, it can be assumed that caregiver experiences may lead to an effect on the caregiver's psychological health and physical health or vice versa.

## CONCLUSIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH

Cancer can increasingly be characterized as a chronic disease with considerable, continuing and fluctuating specific needs and problems for pa-



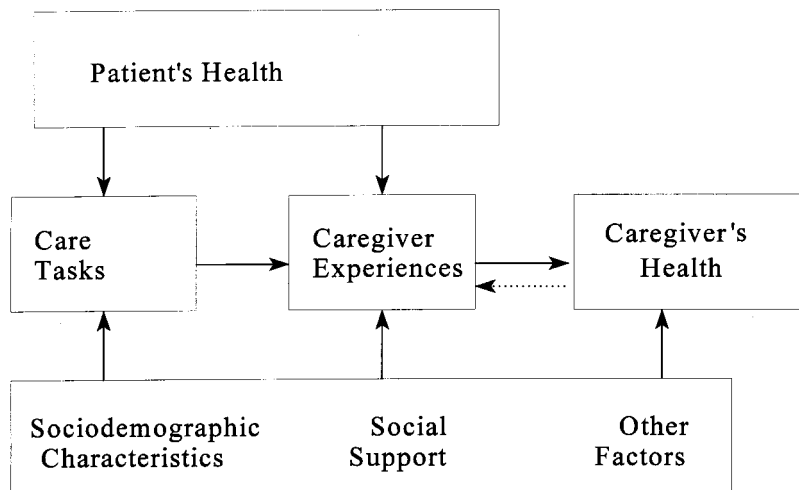


Figure 2. Conceptual framework of the caregiving process.

tients as well as their caregivers. Research focusing exclusively on the caregiving process involving cancer patients and their caregivers is scarce. Most research has been performed among family members of the frail elderly or cognitively impaired patients. There is a pressing need to study cancer patients and their caregivers concerning the caregiving process. Especially, when a lot of care tasks are involved, the health of the caregivers may both physically and psychologically change. Longitudinal studies that carefully follow patients and caregivers over the course of the illness can shed light on the long-term caregiving effects.

Contextual factors, personal characteristics, as well as perceptions are suggested to be related to caregiver's health outcomes. Specific types of care may lead to specific health outcomes. For example, in comparison to household activities, personal patient care and providing support may be expected to be a burdensome activity and may subsequently lead to a stronger negative effect on caregiver's health. However, because people may have an increased risk for poor health, this does not mean that they cannot experience positive health outcomes. It should be noted that intra- and inter-individual differences concerning circumstances, events, resources, and health outcomes exist. Also, positive and negative care experiences and health outcomes may coexist, but not necessarily at the same moment. Moreover, these experiences and circumstances are likely to be shifting throughout the day and during the

course of caregiving. Informal caregivers primarily need to be recognized as equivalent members of the health-care team. Once the physical and psychological states of caregivers are linked to the course of cancer and to the physical and psychological states of the patient, we may identify potential caregivers which are most vulnerable and in potential need of support.

As patients with cancer more often become chronic patients, and the trend of the health policy is to discharge patients 'quicker and sicker', it is essential to gain a better understanding of the consequences for caregivers of cancer patients. Numerous correlates and effects of caregiving have been reported, which hampers drawing overall conclusions. However, because partners are identified as the most vulnerable caregivers, and in order to obtain a more or less homogenous sample, the exclusion of family members other than partners is recommended when examining the role of the multi-dimensional concepts within the caregiving situation.

Describing the care situation from the perspective of the caregiver is passing questions related to the quality of care. Given the demographic, medical technological developments and health-care policy, this topic has and will become more and more serious. Altogether, an increasing involvement of, and a heavier demand on, the informal care system is expected to be most likely. Attention to the caregiver's experiences, whenever these are negative or positive, helps to ensure that better care will be given.

## REFERENCES

- American Cancer Society (1993) *Cancer Facts and Figures*. American Cancer Society, New York.
- Baider, L. and Kaplan De-Nour, A. (1984) Couple's reaction and adjustment to mastectomy. *Int. J. Psychiatry Med.* **14**, 265–276.
- Barusch, A.S. and Spaid, W.M. (1989) Gender differences in caregiving: Why do wives report greater burden? *Gerontologist* **29**, 667–676.
- Baumgarten, M. (1989) The health of persons giving care to the demented elderly: a critical review of the literature. *J. Clin. Epidemiol.* **42**, 1137–1148.
- Biegel, D.E., Milligan, S.E., Putham, P.L. and Song, L. (1994) Predictors of burden among lower socioeconomic status caregivers of persons with chronic mental illness. *Community Ment. Health J.* **30**(5), 473–494.
- Blood, G.W., Simpson, K.C., Dineen, M., Kauffman, S.M. and Raimondi, S.C. (1994) Spouses of laryngeal cancer: caregiver strain and burden. *J. Commun. Disord.* **27**, 19–35.
- Buunk, A.P. and Hoorens, V. (1992) Social support and stress: the role of social comparison and social exchange processes. *Br. J. Clin. Psychol.* **31**, 445–457.
- Cantor, M.H. (1983) Strain among caregivers: a study of experience in the United States. *Gerontologist* **23**, 597–603.
- Carey, P.J., Oberst, M.T., McCubbin, M.A. and Hughes, S.H. (1991) Appraisal and caregiving burden in family members caring for patients receiving chemotherapy. *Oncol. Nurs. Forum* **18**, 1341–1348.
- Cattanach, L. and Tebes, J.K. (1991) The nature of elder impairment and its impact on family caregivers' health and psychological functioning. *Gerontologist* **31**, 246–55.
- Dakof, G.A. and Taylor, S.E. (1990) Victims' perceptions of social support: what is helpful from whom? *J. Pers. Soc. Psychol.* **58**, 80–89.
- De Ridder, D.T.D. and Scheurs, K.M.G. (1994) *Coping en sociale steun bij chronisch zieken [Coping and social support of the chronically ill.] NCCZ-reeks, Zorg, opvang en begeleiding van chronisch zieken.*
- De Ruiter, J. (1995) *Sociale ondersteuning en kwaliteit van leven bij patienten met kanker [Social support and quality of life of patients with cancer]*, PhD Thesis, Rijksuniversiteit Groningen, The Netherlands.
- DesRosier, M., Catanzaro, M. and Piller, J. (1992) Living with chronic illness: Social support and the well spouse perspective. *Rehabil. Nurs.* **17**, 87–91.
- Fuller, S. and Swendsen, C.H. (1992) Marital quality of life and cancer patients and their spouses. *J. Psycho-Oncol.* **10**, 41–56.
- Folkman, S., Chesney, M.A. and Christopher-Richards, A. (1995) Stress and coping in caregiving partners of men with aids. *Psychiatr. Clin. North Am.* **17**(1), 35–53.
- George, L.K. and Gwyther, L.P. (1986) Caregiver well-being: a multi-dimensional examination of family caregivers of demented adults. *Gerontologist* **26**, 253–259.
- Gilhooly, M.L. (1984) The impact of caregiving on care-givers: factors associated with the psychological well-being of people supporting a cementing relative in the community. *Br. J. Med. Psychol.* **57**, 35–44.
- Given, B., Stommel, M., Collins, C., King, S.S., Given, C.W. (1990) Responses of elderly spouse caregivers. *Res. Nurs. Health* **13**, 77–85.
- Given, B. and Given, C.W. (1991) Family caregivers of cancer patients, in *Current issues in Cancer Nursing Practice*, J.P. Lippincott Company, Philadelphia, pp. 1–5.
- Given, C.W., Given, B., Stommel, M., Collins, C., King, S. and Franklin, S. (1992) The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairment. *Res. Nurs. Health* **15**, 271–283.
- Given, C.W., Stommel, M., Given, B., Osuch, J., Kurtz, M.E. and Kurtz, J.C. (1993) The influence of cancer patient symptoms, functional states on patient depression and family caregiver reaction and depression. *Health Psychol.* **12**, 277–285.
- Hileman, J.W., Lackey, N.R. and Hassanein, R.S. (1992) Identifying the needs of home caregivers of patients with cancer. *Oncol. Nurs. Forum* **19**, 771–777.
- Holland, J.C. (1989) Anxiety and cancer: The patient and the family. *J. Clin. Psychiatr.* **20**, 20–25.
- Hooker, K., Monahan, D., Shifren, K. and Hutchinson, C. (1992) Mental and physical health of spouse caregivers: the role of personality. *Psychol. Aging* **7**, 367–375.
- Horowitz, A. (1985) Family caregiving to the frail elderly, in *Annual Review of Gerontology and Geriatrics* (P. Lawton, G.L. Maddox Eds.) Springer, New York, 194–246.
- Jensen, S. and Given, B.A. (1991) Fatigue affecting family caregivers of cancer patients. *Cancer Nurs.* **14**, 181–187.
- Kinney, J.M. and Stephens, M.A. (1989) Hassles and uplifts of giving care to a family member with dementia. *Psychol. Aging* **4**, 402–408.
- Laizner, A.M., Yost, L.M., Barg, F.K. and McCorkle, R. (1993) Needs of family caregivers of persons with cancer: a review. *Semin. Oncol. Nurs.* **9**, 114–120.
- Lawton, M.P., Kleban, M.H., Moss, M., Rovine, M., and Glicksman A. (1989). Measuring caregiver appraisal. *J. Gerontol.: Psychol. Sci.* **44**, P61–71.
- Lawton, M.P., Moss, M., Kleban, M.H., Glicksman, A. and Rovine, M. (1991). A two-factor model of caregiving appraisal and psychological well-being. *J. Gerontol.: Psychol. Sci.* **46**, 181–189.
- Lazarus, R.S. and Folkman, S. (1984) *Stress, Appraisal, and Coping*. Springer, New York.

- Leff, J.P., Kuipers, L., Berkowitz, R., Eberlein-Vries, R. and Sturgeon, D. (1986) Controlled trial of social intervention in the families of schizophrenic patients, in *Treatment of Schizophrenia: Family Assessment and Intervention* (I. Hand, M.J. Goldstein and K. Hahlweg Eds.) Springer, Berlin, pp. 153–165.
- McCorkle, R., Yost, L.S., Jepson, C., Malone, D., Baird, S. and Lusk, E. (1993) A cancer experience: relationship of patient psychosocial responses to caregiver burden over time. *Psycho-Oncology* **2**, 21–32.
- Miller, B. and Cafasso, L. (1992) Gender differences in caregiving: fact or artifact. *Gerontologist* **32**, 498–507.
- Mor, V., Allen, S. and Malin, A. (1994) The psychosocial impact of cancer on older versus younger patients and their families. *Cancer* **74**(7) Suppl, 2118–2127.
- Montgomery, R.J.V., Gonyea, J.G. and Hooyman, N.R. (1985) Caregiving and the experience of subjective and objective burden. *Fam. Relat.* **43**, 19–26.
- Motenko, A.K. (1989) The frustrations, gratifications, and well-being of demented caregivers. *Gerontologist* **29**, 166–172.
- Northouse, L. (1984) The impact of cancer on the family: an overview. *Int. J. Psychiatr. Med.* **14**, 215–242.
- Northouse, L. (1988) Social support in patients' and husbands' adjustment to breast cancer. *Nurs. Res.* **37**, 91–95.
- Northouse, L. and Stetz, K.M. (1989) A longitudinal study of the adjustment of patients and husbands to breast cancer. *Oncol. Nurs. Forum* **16**, 511–516.
- Oberst, M.T. and James, R.H. (1985) Going home: Patient and spouse adjustment following cancer surgery. *Top. Clin. Nurs.* **7**, 46–57.
- Oberst, M.T. and Scott, D.W. (1988) Postdischarge distressing surgically treated cancer patients and their spouses. *Res. Nurs. Health* **11**, 223–233.
- Oberst, M.T., Thomas, S.E., Gass, K.A. and Ward, S.E. (1989) Caregiving demands and appraisal of stress among family caregivers. *Cancer Nurs.* **12**, 209–215.
- Pearlin, L.I., Mullan, J.T., Semple, S.J. and Skaff, M.M. (1990) Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* **30**, 583–594.
- Poulshock, S.W. and Deimling, G.T. (1984) Families caring for elders in residence: issues in the measurement of burden. *J. Gerontol.* **39**, 230–239.
- Pot, A.M. and van Dyck, R., (1995) Belastende factoren in de zorg voor een dement familielid: een literatuur overzicht [The impact of providing care: a review.] *Tijdschrift voor psychiatrie* **4**, 627–635.
- Pruchno, R.A. and Resch, N.L. (1989) Aberrant behaviors and Alzheimer's disease: mental health effects on spouse caregivers. *J. Gerontol.* **44**, S177–182.
- Pruchno, R.A., Kleban, M.H., Michaels, J.E. and Dempsey, N.P. (1990) Mental and physical health of caregiving spouses: development of a causal model. *J. Gerontol.: Psychol. Sci.* **45**, 192–199.
- Rait, D. and Lederberg, M. (1990) The family of the cancer patient, in *Handbook of Psycho-Oncology* (C. Holland, J.H. Rowland Eds.) Oxford University Press, Oxford, pp. 585–606.
- Robinson, B.C. (1983) Validation of a caregiver strain index. *J. Gerontol.* **38**, 344–348.
- Ros, W.J.G. (1989) *Sociale steun bij kankerpatienten [Social support at cancer patients]*, PhD Thesis, Rijksuniversiteit Utrecht, The Netherlands.
- Sabo, D., Brown, J. and Smith, C. (1986) The male group and mastectomy: support groups and men's adjustment. *J. Psycho-Oncol.* **4**, 19–31.
- Schulz, R., Tompkins, C.A., Decker, S. and Wood, D. (1987) The social psychology of caregiving: Physical and psychological costs of providing support to the disabled. *J. Appl. Soc. Psychol.* **17**, 401–428.
- Schulz, R., Vistainer, P. and Williamson, G.M. (1990) Psychiatric and physical morbidity effects of caregiving. *J. Gerontol.: Psychol. Sci.* **45**, 181–191.
- Schulz, R. and Williamson, G.M. (1991) A two-year longitudinal study of depression among Alzheimer's caregivers. *Psychol. Aging* **6**, 569–578.
- Schulz, R., O'Brien, A.T., Bookwala, J. and Fleissner, K. (1995) Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist* **35**, 771–791.
- SCP (1994) *Sociaal Cultureel Planbureau [Social and Cultural Report]*, Rijswijk.
- Siegel, K., Raveis, V.H., Houts, P. and Mor, V. (1991) Caregiver burden and unmet patient needs. *Cancer* **68**, 1131–1140.
- Stetz, K. (1987) Caregiving demands during advanced cancer: The spouse's needs. *Cancer Nurs.* **10**, 260–268.
- Stommel, M., Given, C.W. and Given, B. (1990) Depression as an overriding variable explaining caregiver burdens. *J. Aging Health* **2**, 80–103.
- Stommel, M., Given, C.W. and Given, B. (1993) The cost of cancer home care to families. *Cancer* **71**(5), 1867–1874.
- Stuckey, J.C., Neundorfer, M.M. and Smyth, K.A. (1996) Burden and well-being: the same coin or related currency? *Gerontologist* **36**(5), 686–693.
- Stull, D.E., Kosloski, K. and Kercher, K. (1994) Caregiver burden and generic wellbeing: Opposite sides of the same coin? *Gerontologist* **34**(1), 88–94.
- Thompson, E.H., Futterman, A.M., Gallagher-Thompson, D., Rose, J.M. and Lovett, S.B. (1993) Social support and caregiver burden in family caregivers of frail elderly. *J. Gerontol.: Soc. Sci.* **48**, 245–254.
- Williamson, G.M. and Schulz, R. (1993) Coping with specific stressors in Alzheimers' disease caregiving. *Gerontologist* **33**, 747–755.

- Wright, L.K., Clipp, E.C. and George, L.K. (1993) Health consequences of caregiver stress. *Med. Ex. Nutr. Health* **2**, 181–195.
- Yang, C.T., and Kirshling, S.M. (1992) Exploration of factors related to direct care and outcomes of caregiving. *Cancer Nurs.* **15**, 173–181.
- Young, R.F. and Kahana, E. (1989) Specifying caregiver outcomes: gender and relationship aspects of caregiver strain. *Gerontologist* **29**, 660–666.
- Zarit, S.H., Reever, K.E. and Bach-Peterson, J. (1980) Relatives of the impaired elderly, correlates of feelings of burden. *Gerontologist* **20**, 650–655.
- Zarit, S.H. and Toseland, R.W. (1986) Current and future direction in family caregiving research. *Gerontologist* **29**, 481–483.
- Zarit, S.H., Todd, P.A. and Zarit, J.M. (1989) Subjective burden of husbands and wives as caregivers. *Gerontologist* **26**, 260–266.

Copyright of Psycho-Oncology is the property of John Wiley & Sons Inc. and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.