Caregiving to patients with colorectal cancer
Nijboer, C.

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Cancer and caregiving: the impact on the caregiver's health

Abstract
A diagnosis of cancer affects not only the patient but also their informal caregivers, especially when it results in a lot of care tasks. Some caregivers perceive giving care as a burden, while others consider it as a challenge. In this chapter, literature findings concerning the impact of cancer caregiving on informal caregivers will be described. No consistent results have been 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 identified as influencing the course and consequences of caregiving. These factors serve the basis for 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.


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 make up a substantial part of the care system. Studies have shown that informal caregivers already provide an average of 55% of the care needed.\(^1\)

Cancer is a major disorder that affects many people directly or indirectly. In the 1993 report of the American Cancer Society, it was estimated that one in three people living in the United States of America will be diagnosed with cancer at some point in his or her lifetime, and one in five deaths will be attributable to this disease.\(^2\) 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.\(^3,4\) Not only the diagnosis itself, but also the subsequent course of the illness may influence the level of health. Cancer includes multiple physical needs, intense psychological distress 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 have to 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.\(^5\) Additional stress can be experienced by having to "stand by" and observe the disease progress while being unable to alter or manage the illness.\(^6\) It can be questioned to what extent caregiving to cancer patients is burdensome and 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. In general, caregivers are defined as "primary care providers", often referring to network members, such as the partner, parent, sibling or child. This chapter addresses available studies on the caregiving situation, with specific focus being placed on caregivers of cancer patients. Studies were traced in literature databases (PSYCHINFO and MEDLINE) for the period 1980 to 1996. At first, the main key words "caregiving" and "burden" were entered to select studies. Later the key word "cancer" was included. Although this chapter 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, gerontologic research will also be discussed to present the overall consequences of caregiving.

The aim of this chapter is to describe a conceptual framework, that 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, with the former reflecting (changes in) care tasks and the latter reflecting the experience of (changes of) this situation (i.e., caregiver burden). Terms like "care involvement", "care demands" and "objective care activities" are used to refer to all kinds of care tasks. 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 tasks. "Caregiver burden", "strain", or "role strain" are generally used to refer to physical, psychological, social and/or financial problems that can be experienced in giving care. 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 to the caregiver’s schedule), the greater the burden. Personal tasks (e.g., feeding and washing the patient) seem to be perceived as more difficult and burdensome than non-personal tasks (e.g., doing the groceries). 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 obtained the highest burden score in a study among family members of cancer patients receiving chemotherapy.

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. 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, may increase the caregivers feelings of pride in their ability to meet challenges and improve their sense of self-worth. Secondly, caregiving may also define identity and involvement in 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 help to identify caregivers who are less likely to need intervention.

The operationalisation of aspects of caregiving that are experienced as positive vary enormously. Initially, positive aspects were part of more global burden scales. In more recent studies, positive aspects were more explicitly defined and measured, such as uplifts, gratification, caregiver self-esteem, appraisal, satisfaction, mastery and ideology. As yet, it is inconclusive whether these positive experiences of caregiving lead to more positive or less negative health effects. Kinney and Stephens argued that the caregivers who were most intensely involved in caregiving might have greater opportunity to derive satisfaction from caregiving. Folkman et al. reported that caregiving may improve the quality of relationships between caregivers and care recipients, and that this may contribute to caregiver’s self-esteem. They also showed that most caregivers are unlikely to experience positive and negative experiences
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simultaneously, but that in many individual caregivers a shift in the direction of their feelings, reactions and consequences of caregiving occurred. Lawton et al.\textsuperscript{24} reported that caregiver satisfaction was not strongly related to burden. However, as mentioned before, research concerning positive aspects of caregiving is in its infancy. It is plausible that some positive aspects may decrease feelings of being burdened, and subsequently lead to positive effects on health outcomes.

Caregiving and health

Since specific care tasks may have different effects on burden, it is likely that specific care tasks may also have different effects on health. Questions such as at what moment and to what extent (changes in) different type of care tasks relate to 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's 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.\textsuperscript{20} However, the majority of studies demonstrated that neither severity of patient impairment or type of illness, patient's symptoms, or duration of caregiving are significantly related to negative effects on caregiver's health.\textsuperscript{6,27,28} For example, in the study of Gilhooly\textsuperscript{29} 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’s 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\textsuperscript{30} 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.\textsuperscript{31} 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 burden and health are related with each other.\textsuperscript{32} Whether
the impact of caregiving burden will have an effect on health or whether health will have 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 caregiver's future.\textsuperscript{32,34} However, in the study of Stommel et al.\textsuperscript{35} among families of 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.\textsuperscript{36} in their study among spouses caring for 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.\textsuperscript{4,13,37,38} Schulz et al.\textsuperscript{39} 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 patient's level of dependence and depression were related to the caregiver's daily schedule and depression. No relationship was found with caregiver's physical health.\textsuperscript{13} Studies of the physical health effects of caregiving are less conclusive but suggest increased vulnerability. Generalized fatigue\textsuperscript{40} 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.\textsuperscript{3}

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 and intermediate factors in the caregiving situation**

Numerous correlates and effects of caregiving have been reported (see e.g.,\textsuperscript{9,11,28}), which hampers drawing overall conclusions. Most studies include socio-demographic 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,\textsuperscript{35} quality of the relationship (e.g., marital satisfaction\textsuperscript{41}) and personality factors, such as mastery,\textsuperscript{33} optimism and neuroticism.\textsuperscript{42}
Socio-demographic characteristics include variables like age, gender, living situation, type of relationship, and socio-economic status of both the care recipient and caregiver. Relatively consistent findings were reported regarding gender, age, co-residence and type of relationship between care recipient and caregiver. Women, especially those at a younger age, tend to perceive caregiving as more negative than (older) men and report higher levels of psychological distress even if the amount of care provided and/or the level of patient's health is controlled for. 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 and are less likely to receive assistance. These caregivers often feel ultimately responsible for coordinating the care and make minimal use of professional services. Partners, as compared to other caregivers, are likely to experience more strain, they may become ill themselves and they may experience higher levels of psychiatric symptoms. Caregivers with a relatively low socio-economic status are assumed to report a higher burden, and subsequently a poorer health. A negative relationship between income and caregiver outcomes has been observed for only certain type of caregivers (i.e., partners), whereas other types of caregivers report no relation. Biegel et al. did not find any relationship between socio-economic characteristics and caregiver burden. For examining the role of socio-economic status, the costs for providing care, time for job performance and time available for caregiving also need to be considered. Stommel et al. 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. Studies revealed that the impact of support is related to its timing, its source, its type and its perception. In particular, the support provided by the partner plays a major role in the patient's adjustment to cancer. 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. 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. These men assumed this to be the most supportive behavior, 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. 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, caregivers will
depend mainly on their care recipients for support. 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. In a study among family caregivers of frail
elderly the relationships between six different types of social support and five measures
of caregiving burden was assessed. 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. Care tasks, caregiver burden and caregiver's health may
fluctuate in response to changes in the patient's health. Care-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. This
basic idea has been described as the downward trajectory or wear and tear in a model
of Williamson and Schulz (1993) (see Fig. 2.1). 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 duration of caregiving.
Also probable is the situation in which the caregiver's health improves during the course
of the patient's illness (gradual 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 (*stability*).\(^{64,66}\)

![Figure 2.1 Patterns of caregiver's health in relation to the demands of caregiving\(^\text{39}\)](image)

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.\(^{56}\) Northouse and Stetz (1989)\(^4\) 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,\(^{47}\) the treatment phase is stated as the most stressful phase.\(^5\) 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.\(^{13}\) More and more researchers emphasize the importance of including the early phases of the illness in studying caregiver's health.\(^{7,62,67,68}\) Moreover, Schulz and Williamson\(^{64}\) 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 his 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 et al.\textsuperscript{59} 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 hours a day. 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.\textsuperscript{47} 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.\textsuperscript{70} 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.\textsuperscript{63} 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.\textsuperscript{71} Baider and Kaplan-de Nour\textsuperscript{72} also noticed an increasing burden in spouse caregivers over time in addition to treatment. However, McCorkle et al.\textsuperscript{62} 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 for the caregiving process

The cognitive stress theory of Lazarus and Folkman\textsuperscript{34} 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 socio-demographic 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., 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 or health (Fig. 2.2).

![Conceptual framework of the caregiving process](image)

**Figure 2.2 Conceptual framework of the caregiving process**

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 be increasingly characterized as a chronic disease with considerable, continuing and fluctuating specific needs and problems for patients 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 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 most likely. Attention to the caregiver’s experiences, whenever these are negative or positive, helps to ensure that better care will be given.

References

Chapter 2


Cancer and caregiving

Chapter 2