Caregiving to patients with colorectal cancer
Nijboer, C.

Link to publication

Citation for published version (APA):

General rights
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), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: http://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
General discussion

Due to improvements in medical treatments and diagnostics, some types of cancer have evolved from a fatal disease into a chronic disease. Continuing and fluctuating health care needs in patients may imply considerable consequences for patients as well as their partners. Longitudinal studies that carefully follow informal caregivers during the course of illness can shed light on the long-term effects of caregiving in the home environment.

In our CASPA study, newly diagnosed colorectal cancer patients and their partners were followed from the moment of hospital admission till 6 months after patient's diagnosis (N = 148). This study aimed to 1) to describe the impact of caregiving over time and 2) to establish the determinants of the caregiving process. This chapter provides a brief recapitulation of the main findings of this study, in line with these two main research objectives. In addition, some methodological aspects of the study are discussed. Finally, implications and recommendations for further research are addressed.
Main findings

Objective 1: to describe the impact of caregiving on partners of newly diagnosed colorectal cancer patients over time, in terms of caregiver experiences and health outcomes

The literature study (Chapter 2) revealed no consistent research findings regarding the impact of caregiving on caregivers, and showed that only little information exists on patterns of caregiving effects in relation to the course of the patient’s illness. A multi-dimensional approach was advocated to measure caregiver experiences. This includes not only measuring the impact of caregiving on specific aspects of life, but also differentiating between negative and positive dimensions of caregiving. Because no appropriate instrument was available in the Dutch language, the Caregiver Reaction Assessment scale (CRA) was translated and evaluated (Chapter 3). The CRA-D proved to be a feasible, reliable and valid instrument for assessing five specific caregiver experiences of partners of cancer patients, including negative aspects (i.e., disrupted schedule, financial problems, lack of family support, loss of physical strength) and one positive aspect (i.e., care-derived self-esteem).

Over the first 6 months after patient’s diagnosis, the impact of caregiving on both disrupted schedule and self-esteem showed a decline, whereas the impact on financial resources, family support and physical strength appeared to remain constant (Chapter 4). Women, younger caregivers and caregivers with a higher level of education experienced caregiving more negatively and less positively over time as compared to their counterparts.

To study caregiver’s health over time, a distinction was made between physical, mental and social health dimensions (Chapter 5). Physical functioning deteriorated over time in female caregivers, while no change was found in male caregivers. For mental health and social functioning, an improvement was observed over time in both male and female caregivers. Changes in caregiver’s physical functioning were associated with gender, age, and income, and these changes were mainly determined by the initial (baseline) level of physical functioning. Changes in mental health and social functioning were predicted by (changes in) patient dependency, caregivers’ impact on self-esteem and changes in impact on schedule. Least favorable patterns were observed in female caregivers, particularly in those with a low income. In those who were able to derive
more self-esteem from caregiving over time, mental health improved in male caregivers, while this was not the case in female caregivers.

Conclusions

In general, the findings demonstrate that caregiving may have negative as well as positive consequences. Most caregiver experiences were quite stable over time, while caregiver health outcomes were likely to change. Female caregivers, and caregivers of a younger age, those with a higher level of education and those with a lower income were most likely to be negatively affected. These caregivers can be seen as the most vulnerable and in need of extra support in the care-setting at home. Furthermore, the results regarding caregiver experiences and health indicate that caregivers may return to their previous levels they had at an earlier point in their caregiving career, e.g., before baseline. These changes are likely to be attributable to the stressors or resources of caregiving.

Objective 2: to establish determinants of caregiver experiences and health outcomes of the cancer caregiving process

Findings regarding this objective were based on the general research model, as presented in the introduction (Chapter 1, Fig. 1.1). Potential determinants of caregiver outcomes, either in terms of caregiver experiences or caregiver health outcomes, could be categorized into stressors and caregiver’s resources. Stressors were defined as characteristics of the caregiver, the patient and the care situation (Chapter 6). Caregiver’s resources included various aspects of social support and of personality (Chapter 7). Furthermore, the effect of potential determinants on initial scores and change scores of caregiver outcomes were examined. As some potential determinants (such as resources) may be subject to change too, the effects of changing values of these variables on changes in caregiver outcomes also was investigated (Chapter 7).

With respect to determinants of caregiver experiences, negative caregiver experiences were found to be associated with a low income, living alone with the patient, a distressed relationship, a high level of patient dependency and a greater involvement in care tasks. Positive caregiver experiences were especially seen in caregivers with a low level of education and in those who took care of a patient with a stoma. Negative
caregiver experiences could have been expected in caregivers on the basis of previous research, but positive experiences have remained largely unexplored till now. In line with Kinney and Stephens,\(^2\) we may conclude that more intensely involved caregivers reported more uplifts and that there are at least two possible explanations for this finding: 1) because these caregivers spend more time on caregiving, they have a greater opportunity deriving satisfaction out of this, and 2) caregivers may attempt to view providing care positively and try to focus on enjoyable aspects of caregiving, because they often have no choice but to take on and play their role. These explanations may very well apply to the situation of deeply involved partners who provide care to patients with a stoma and caregivers with a relatively low level of education.

With respect to determinants of caregiver's health, the influence of patient and care characteristics seemed to be of minor importance in predicting caregiver's health over time (in particular mental health), compared to the way in which caregiving was perceived. Moreover, social and psychological resources (i.e., negative social interactions, mastery and neuroticism) and changes in these resources showed to have substantial direct effects on caregiver's depressive symptoms over time. Daily emotional support and mastery ameliorated relationships between caregiver experiences and caregiver's depressive symptoms. Caregivers with a low level of daily emotional support and those with a low score on mastery, who also perceived caregiving in a more negative and/or a less positive way showed elevated levels of depressive symptoms over time.

**Conclusions**

Results show that the general research model needed to be elaborated more explicitly. Different factors showed to be related with different types of impact of caregiving impact. On the one hand, caregiving could be perceived as burdensome, when patient dependency and care demands increased, especially in female caregivers, those with a distressed relationship, a relatively low income or those who lived alone with the patient. On the other hand, caregiving could be perceived as uplifting, especially by caregivers of patients with a stoma or those with a low level of education. It is very likely that the group of caregivers with a low education largely coincides with the group of caregivers with a low income.

Since negative as well as positive experiences were observed in caregivers in particular in those with a low income and education, it seems that both negative and positive
experiences may very well appear in one individual, although not necessarily at the same time.

Moreover, caregivers’ health outcomes were primarily related to the way in which caregiving was perceived, and less to the presence of stressors (i.e., patient’s health indices or care tasks). Some persons adapted better than others to their caregiver role, as they perceived caregiving as less burdensome and more positively over time, and this showed to be partly due to the availability of social and psychological resources (e.g., less negative interactions, more daily social support and a high mastery).

Findings suggest that it is important to acknowledge both the negative and positive aspects of the impact of caregiving, and to make a distinction between the concepts “caregiver experiences” and “health outcomes”, and between the various aspects of social and psychological resources.

**Methodological considerations**

**LONGITUDINAL DESIGN**

One of the major advantages of the study presented is its longitudinal study design. Numerous researchers on caregiving have stressed the importance of longitudinal studies. The number of longitudinal studies on the impact of informal caregiving in relation to the course of the patient’s illness is limited, especially regarding cancer caregiving. Only a few longitudinal studies on caregivers of cancer patients have been conducted. The study presented here is the first longitudinal study on cancer caregiving in the Netherlands. Subjects were measured three times: at baseline, and 3 and 6 months thereafter. This enabled us to describe and evaluate changes over time in caregiver experiences and health outcomes and to investigate the predictive value of stressors and resources during a 6 months period of follow-up.

However, caution is required in interpreting the longitudinal results. As outlined in Chapter 4, "actual" change can be questioned, because the baseline measurement point (T0) can be criticized. It took place shortly after hospital admission and within two weeks after patient’s surgery, but questions were asked retrospectively, referring to the period before hospital admission. To most patients and their partners, this period may be characterized as shocking, stunning and frightening and this might have influenced the reliability of the answers (i.e., recall bias). In theory, the most preferable choice of a baseline measurement point would be before the caregiver role is taken on. But practical reasons hampered the recruitment of potential caregivers at an earlier moment.
Furthermore, a follow-up period of 6 months may be too limited to reveal lasting changes over time. It may be considered worthwhile expanding this study with more assessments, covering one to two years after baseline.

**THE COMPOSITION OF THE SAMPLE**

Another advantage of this study is the composition of the sample. A relatively homogeneous group of patients and caregivers was chosen for recruitment, namely newly diagnosed colorectal cancer patients who recently had undergone surgery, and their partners. However, we acknowledge the difficulty of assessing the onset of caregiving, since a definite point of onset is hardly conceivable. This was also notified in earlier studies among other samples.\(^5\)\(^1\)\(^3\) In the current study, the onset of caregiving was estimated to start in the two weeks period before patient’s hospital admission (Chapter 1). However, the transition to providing care to a cancer patient, particularly to the partner, is often a gradual one without a clear beginning. Providing care, support or help may be interchangeable, in particular with a life-threatening disease such as cancer in a sample of partner caregivers. By questioning the patient about the duration of months of complaints, we were able to estimate the actual onset of patient’s needs. The mean duration of complaints was observed to be approximately 13 months, but the onset varied widely (SD = 44 months). Subsequently, the onset of caregiving could have started much earlier than in the two weeks before patient’s hospital admission.

Due to the sample’s composition, the generalization of the findings is limited to a certain extent. For example, the response rate was relatively high (i.e., 76%), but only caregivers of cancer patients with a relatively good health and good prognosis have been included, and remained in the study. Over the three waves, 13% of the patients died or had to withdraw because of deteriorated health. Especially in partners of patients with a bad prognosis and deteriorating health, the consequences of caregiving might have become more obvious. Because of the selective drop-out, we may have overestimated the positive effects and underestimated the negative effects. Thus, it may be assumed that the results of this study are rather conservative or even optimistic, as they are confined to partner caregivers of cancer patients with a relatively good health and prognosis. However, although it is most likely that the strength of the relationships between determinants and caregiver outcomes may have become more evident within a more heterogeneous sample, there is no reason to assume that the overall strength of the relationships found will be different in a general population of caregivers.
MEASUREMENTS

To evaluate the research model as presented in the introduction, concepts of stressors, caregiver experiences, resources and health outcomes were operationalized by use of multi-dimensional or various measures. For example, stressors were assessed by patient dependency, patient’s depressive symptoms or involvement in care, and caregiver’s health included dimensions of physical, mental and social aspects. Making a distinction between different indices of concepts (e.g., of various aspects of social and psychological resources, of negative and positive caregiver consequences), between the role of initial and changing scores over time, and between direct and moderating effects provided a detailed insight into the variables which influenced the caregiver process and its underlying mechanisms.

If available, existing valid and reliable instruments to assess patient dependency, and caregiver’s health were preferred and used in this study, such as the GARS,\textsuperscript{14} CES-D,\textsuperscript{15} RSCL\textsuperscript{16} and RAND-36.\textsuperscript{17} Since no Dutch instrument was available to assess multidimensional aspects of caregiver experiences, including negative and positive aspects, we translated and evaluated the Caregiver Reaction Assessment Scale (CRA) of Given et al.\textsuperscript{1} (Chapter 3). In our study, a relatively high score on the positive domain and relatively low scores on the negative domains were observed as compared to studies from other countries that also used the CRA among caregivers of cancer patients.\textsuperscript{9,10,18,20} Therefore, it may be questioned whether caregiver experiences are also culture-related, not only regarding differences in interpretations of the CRA-items, but also regarding differences in e.g., health policy, organization of professional (home) care and informal care, and geographical distance to family members. Using the CRA, international research could reveal these cross-cultural differences. Moreover, negative and positive domains showed different effects on caregiver’s health outcomes, but no thorough research has explored the moderating, independent or multiplicative health effects of caregiver experiences. More analyses are needed to examine these pathways. Research on (the meaning of) positive caregiver experiences is still in its infancy and further investigation into the CRA and related multidimensional instruments on caregiver experiences is needed.

Implications for health care

It is important that health professionals involved in the ongoing care of cancer patients and their families are aware of the increasing demands made with respect to informal
care, and the specific problems and uplifts they may perceive in caregiving. Positive and negative care experiences and (changes in) health outcomes may coexist in individuals, but not necessarily at the same moment. 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 important members of the health care team. Professional caregivers should involve informal caregivers explicitly and continuously in the care process. Specific attention seems warranted to female caregivers, those who live only with the patient, those with a low income, those with a distressed relationship, who have to deal with a high level of patient dependency and those with a high involvement in care. Professionals should help caregivers to obtain and maintain feelings of mastery and positive social interactions.

If the relationships between the determinants on the impact of caregiving can be confirmed in caregivers of patients with a worse condition or prognosis, they point to a potentially increasing problem. Given a growing need for home care due to the aging of the cancer population, early discharge from hospitals, and the continuing trend toward smaller households, the important policy question is whether we can continue to rely on informal caregiving to meet these needs. Therefore, possibilities to support informal caregivers must be expanded. As yet, in the Netherlands, informal caregivers of patients with cancer can join support groups. Most of these support groups are informative and may offer immediate emotional comfort or psychological help. Other ways of support to caregivers, e.g., stimulation of patient’s self-care, the provision of extra home care, and specific education/training or financial compensation, are less common. Some caregiving stressors can be reduced or made manageable by these types of support. Other ways of providing support to informal caregivers is e.g., to bolster positive and reduce negative social interactions, or stimulate person’s capacities to manage caregiving. As such, caregiver’s personal resources might be made better use of.

**Recommendations for further research**

Although most research has focused on negative aspects of caregiving, a growing number of studies focus on the positive aspects of caregiving. The fact that so few gerontologic studies report positive outcomes may reflect that positive outcomes are infrequently found or generally overwhelmed by the negative aspects. It may be expected that in caregiving studies involving patients with cognitive disorders or frail elderly, in which the course of the illness is usually one of steady decline with no
expectations for improvement, the impact of caregiving in these cases may lead primarily to negative consequences. In cancer caregiving, however, many cancer patients may improve over time leading to (more) positive consequences of the impact of caregiving. In the study presented, caregivers of patients with a stoma and those with a low education perceived caregiving as more positive than their counterparts. While negative caregiver experiences may have been expected to be most obvious, a positive effect on these caregivers has remained largely unexplored up till now. The mechanism(s) underlying a more positive perception of caregiving as well as of the effects of positive experiences on caregiver’s health, needs to be examined more thoroughly. In this respect, more instruments measuring positive aspects in caregiving should be developed.

Priorities in intervention studies to diminish negative caregiver effects or to maintain or improve positive caregiver effects may be based either on determinants that influence the caregiving process, or on specific subgroups. Most intervention studies focused on caregivers in general without making a distinction for gender. This study showed that an intervention should be gender-specific. While for female caregivers, financial support may help to reduce negative health effects, for male caregivers strengthening the skills and coping strategies directed at deriving self-esteem from caregiving might be indicated.

Describing the care situation from the perspective of the caregiver is ignoring questions related to the quality of care. Also the role of professional caregivers has not been investigated in this study. Further research should examine the effect of informal care on the overall quality of care for the patient in relation to the professional care provided. Findings from this thesis emphasize the need to take the course of the illness into account in studying the impact of caregiving. Future longitudinal (prospective) studies are needed to confirm the observed associations between stressors, caregiver experiences, resources and health outcomes in different types of caregivers, in caregivers of patients with different types and phases of cancer, and in caregivers of different diseases, and if possible over a longer period of follow-up. More research into the mechanisms underlying the caregiving process will help in identifying tools to assure the quality of (informal) care, and to improve quality of life of patients and their caregivers.
References


