Caregiving to patients with colorectal cancer

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Summary

Colorectal cancer causes a stressful situation, both for patients and for those who provide care for them. Patients may experience multiple physical problems, intense emotional distress, such as anxiety and depression and complex care needs. The family and with the family the partner, if available, are often perceived as the most responsible for the care at home. As yet, research on the consequences for partners of patients with cancer shows inconsistent findings.

The main objectives of this thesis are 1) to describe the impact of caregiving on partners of colorectal cancer patients over time, in terms of caregiver experiences and health outcomes, and 2) to establish determinants of caregiver experiences and health outcomes of the cancer caregiving process. The cognitive stress theory of Lazarus and Folkman (1984) was proposed to guide interpretations of relations between caregiver’s aspects and outcomes. According to this theory, three key components are important within the caregiving process, namely stressors (such as the patient’s health and the care tasks), outcomes (caregiver experiences and caregiver’s health) and intermediate factors (social support and personality characteristics).

Data of this thesis were used from the study, entitled: "Caregiving among Spouses of Patients with cancer" (CASPA-study). Data were collected at three measurement points from 181 newly diagnosed colorectal cancer patients and their partners. The baseline measurement (T0) took place as soon as possible after the patient’s diagnosis, either in the hospital or at home. The second measurement (T1) took place 3 months after baseline and the third measurement (T2) again 3 months later (i.e., 6 months after baseline).
Chapter 2 provides an overview of the literature on the impact of caregiving over time and concerning cancer caregiving, in particular.
In the last decades, numerous correlates and effects of caregiving already have been reported. However, the majority of studies on caregivers concerned family members of frail elderly, or of patients with cognitive or psychiatric disorders. Research on informal caregivers of patients with cancer is scarce. Generally, a distinction was made into care tasks, caregiver experiences and caregiver’s health outcomes. Care tasks are categorized into type, duration and intensity. Types of care tasks are divided into assistance with patient’s self-care, household, organizational tasks and conducting disease-related tasks. Caregiver experiences are most frequently conceptualized as a multi-dimensional construct, including negative and positive aspects. Caregiver’s health, and caregiver’s mental health in particular, is generally conceived as an overall outcome. Long-term effects of caregiving on informal caregivers of patients with cancer were found to be scarce or inconsistent. It was suggested that the impact of caregiving over time might be related with the course of the patient’s illness or patient’s needs of care. Longitudinal research on the care situation of informal caregivers of cancer patients was recommended. Moreover, the importance to define and measure care tasks, caregiver experiences and health outcomes multidimensionally was stressed.

Because no instrument was available in the Dutch language to assess the negative and positive experiences of caregiving, we translated the Caregiver Reaction Assessment scale (CRA), which was developed in the United States of America. This instrument aimed to measure five core aspects of the caregiving situation, including negative and positive aspects. Moreover, this instrument was used previously among caregivers of patients with different diagnoses. In Chapter 3, the translated Caregiver Reaction Assessment scale (CRA-Dutch) was psychometrically evaluated, in terms of its feasibility, reliability and validity. The number of missing values appeared to be relatively low, indicating high feasibility of the instrument. By means of exploratory factor analyses five dimensions of caregiver experiences were distinguished, including four negative dimensions and a positive one: 1) disrupted schedule, 2) financial problems, 3) lack of family support, 4) loss of physical strength, and 5) care-derived self-esteem. All subscales showed sufficient reliability, in terms of internal consistency, varying from 0.62-0.83. Also the construct validity was supported. Therefore, the CRA-D was advocated as an instrument that could be applied among partners of cancer patients in order to assess multi-dimensional aspects of the caregiving situation, including both negative and
positive aspects. Each subscale can be used separately to measure the unique dimensions of caregiver experiences in more detail.

In Chapter 4 attention was given to the course of caregiver experiences over a period of 6 months after patient’s diagnosis. Five patterns of caregiver experiences (i.e., "disrupted schedule", "financial problems", "lack of family support", "loss of physical strength", and "care-derived self-esteem") were described separately. Direction and size of changes in caregiver experiences over time were analyzed both at a group and an individual level, and according to gender, age and socio-economic status. Patterns of caregiver experiences appeared to vary between type of caregiver experiences and between subgroups. Both the impact on schedule and on caregiver’s self-esteem decreased over time, while the patterns of the three other dimensions remained fairly stable over time. Moreover, women, younger caregivers and those with a higher socio-economic status experienced caregiving more negatively and less positively over time. In addition, the magnitude of the change differed between dimensions of caregiver experiences in terms of the individual variability i.e., the highest individual variability was observed at the impact on disrupted schedule and financial problems. For caregivers with the lowest socio-economic status, the highest individual variety was observed. The findings illustrated the value of studying each dimension of caregiver experience separately. Moreover, making a distinction between analyses at a group level and an individual level and between different subgroups was emphasized. Specific attention to women, younger caregivers, and those with a higher socio-economic status seemed warranted.

Chapter 5 presents patterns and determinants of the impact of informal caregiving in terms of three dimensions of caregiver’s health, i.e., physical functioning, mental health and social functioning. Change in physical functioning over a period of 6 months after patient’s diagnosis was predominantly predicted by initial level (i.e. baseline value), and to a lesser extent by caregiver’s gender, age and income. Female partners, those with a higher age and those with a lower income reported a decrease in physical functioning. Caregiver’s mental health improved over time and this pattern was predicted by initial level and a decrease in negative caregiver experiences. Also, social functioning improved over time. Patterns of social functioning were mainly predicted by a decrease in patient dependency. For male caregivers physical functioning remained stable and mental health improved over time, while for female caregivers less favorable patterns were observed, especially in those with a low income. Also among caregivers who
could derive more self-esteem from caregiving over time, only in male caregivers an improvement in mental health was observed. These findings suggest that the impact of caregiving, in terms of physical and mental health, is gender-specific. Moreover, results indicate that changes in caregiver experiences and the level of patient's dependency determine the course of mental and social health over time.

In Chapter 6 determinants of the impact of caregiving were examined, in terms of caregiver experiences 3 months after diagnosis and caregiver's mental health 6 months after diagnosis. The role of the following factors were examined: caregiver characteristics (demographic characteristics, quality of the partner relationship, and caregiver's initial mental health), patient characteristics (disease-related characteristics and level of patient's dependency and symptoms) and care characteristics (type, duration and intensity of care tasks). Also, the relation between caregiving experiences and caregiver's mental health was studied. Each domain of the caregiving experiences was explained by different factors. Negative caregiver experiences were associated with a low income, living only with the patient (i.e., no children living in the same household), a distressed relationship, a high level of patient dependency and a high involvement in care tasks. Caregivers with a low level of education and caregivers of patients with a stoma were able to derive more self-esteem from caregiving. Caregiver experiences 3 months after diagnosis influenced mental health 6 months after diagnosis to a large extent. Although caregiving may lead to depression, especially in those experiencing loss of physical strength, caregivers may sustain their quality of life by deriving self-esteem from caregiving. These findings implicate that caregiving may give rise to specific problems and uplifts perceived in caregiving. Professional caregivers are urged to involve informal caregivers explicitly, and specific attention seems warranted for caregivers who live only with the patient, those with a low income, those with a distressed relationship, those who take care for a highly dependent patient, and those with a high involvement in care tasks.

Chapter 7 presents the role of social support and personality characteristics within the caregiving process. The direct and moderating effects on changes in caregiver experiences and caregiver's depression over time of various aspects of social support and personality characteristics were examined. With respect to caregiver experiences, the direct effects of social support and personality characteristics was found to be small to absent. With respect to caregiver's depression, negative social interactions, mastery
and neuroticism showed to have direct effects on caregiver's depression over time; more negative social interactions, less mastery and more neuroticism were associated with a higher level of depression. Moreover, emotional support and mastery modified the relationships between caregiver experiences and caregiver's depression. Caregivers with a low level of emotional support, as well as those with a low score on mastery who also perceived caregiving in a more negative (or a less positive) way could be identified to develop more depression over time. These findings suggest that especially in circumstances where caregiving is experienced as burdensome or less positive, emotional support and acknowledgment or stimulation of caregiver's capacities to manage caregiving is beneficial, and may prevent depressive symptoms.

In Chapter 8, the main findings, general methodological issues, implications for health care practice and future directions for research are discussed. Future research on the impact of caregiving on informal caregivers has to be focused on caregiver experiences and the effects on caregiver's health. It is important to acknowledge the negative as well as the positive aspects of the impact of caregiving, and the changes in the impact on schedule, finances, family support, care-related physical strength and care-derived self-esteem, and changes in caregiver's health (physical, mental and social). Caregiver's health outcomes were indirectly related with patient's health and care characteristics. Caregiver experiences, social support and personality characteristics strongly influenced the impact on caregiver's health. Health professionals involved in the ongoing care for cancer patients and their families need not only to focus on reducing negative consequences of caregiving, but also on confirming the positive aspects of caregiving.