Caregiving to patients with colorectal cancer
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Introduction

In the Netherlands, 63,000 invasive tumors were registered in 1995, and the yearly incidence of cancer demonstrated to show about 1,000 extra cases per year.¹ In Western societies, it can be estimated that one in every three people 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 five years. With an incidence of more than 7,000 cases being diagnosed with colorectal cancer each year, representing 12% of all cases with cancer,¹ this disease is a major health problem in the Netherlands. If diagnosed in its early stages colorectal cancer is curable with an annual survival rate of 77%.³ However, when the tumor is localized in the rectum as compared to the colon, the survival rate drops dramatically. The prevalence of rectal cancer is higher among men than among women, whereas the prevalence of colorectal cancer is equally distributed among both sexes.

A disease like cancer may give rise to multiple physical problems, intense emotional distress manifested by anxiety and depression, and complex health care needs of both patients and families. For colorectal cancer patients, surgical intervention is the primary and most common treatment, unless the condition of the patient is very poor. Patients undergoing surgery (85%) may experience alterations in their functional ability, bodily functions, appearance, employment status, family and social role, and self-image.⁴ These patients may experience pain, bowel problems, nutritional adjustment problems and sexual functioning problems.⁵ In case a stoma is needed, problems may even be more pronounced. For example, the patient may experience feelings of stigmatization related to difficulty in attaining control and regulation of the stoma, which may lead to social isolation.⁶
From an acute disease with a prompt outcome, colorectal cancer has increasingly become a disease with long-term outcomes and a continuing need for care, with treatment often being implemented in home settings. Health care policy is shifting its focus from professional to informal care, a trend which is being exacerbated by the early discharge of hospital patients. Informal caregivers are often the major resource that prevents many ill or older persons from being admitted to an institution. With the changing policy, and with a high and still growing percentage of elderly and an increasing prevalence of chronic diseases, informal caregivers have become important actors in the health care system.

Informal caregivers can be defined as “primary care providers”, and are often being referred to as network members, such as the partner, parent, sibling or child. To a large degree, caregiving involves older patients, with many caregivers themselves being of high age with a broad range of physical, psychological and social needs of their own. Most research on caregivers concerns family members of frail elderly, or of patients with cognitive or psychiatric disorders, such as dementia, Alzheimer’s disease or schizophrenia. The number of Dutch studies on caregiving is increasing however, in the Netherlands no research has been focused exclusively on the cancer caregiving process.

Research reveals that, whereas some caregivers may perceive providing care as a burden, and are therefore more likely to be negatively affected, others may consider caregiving as quite a challenge, even in seemingly similar, difficult circumstances. Although most research on caregiving is focused on negative aspects of caregiving, studies increasingly report on the subjectively beneficial effects of caregiving. Also, studies have consistently reported that partners, in comparison to other informal caregivers, provide the most extensive and comprehensive care. In doing so, partners may have to re-evaluate their future, which may lead to changes in life goals. Because partners are less likely to receive assistance than other informal caregivers, they may be identified as the most vulnerable group of caregivers. They are more likely to experience strain, become ill themselves and experience higher rates of psychiatric symptoms than other types of caregivers.

As patients with cancer increasingly become chronic patients, and the hospital policy is to discharge patients “quicker and sicker”, and as caregivers may be negatively affected over time, it is essential to gain more insight into the cancer caregiving process. This thesis provides a perspective on caregiving by partners to newly diagnosed colorectal cancer patients.
Main research model and objectives

Numerous correlates and effects of caregiving have already been reported on, but the heterogeneity of the concepts studied hampers drawing overall conclusions with respect to the caregiving process. A theory that can be used to guide interpretations of relations between caregiver's aspects and outcomes is the cognitive stress theory of Lazarus and Folkman. According to this theory, three key components can be distinguished in the caregiving process, namely stressors, outcomes and intermediate factors. In general, stressors include contextual elements, such as the patient's health and care tasks. Outcomes refer to the enduring health effects in caregivers. Individual perceptions of the caregiver situation, i.e., caregiver experiences, can either be referred to as a stressor, an intermediate factor or as an outcome. Finally, social and psychological resources may act as intermediate factors in the caregiving process. These concepts may provide a useful framework for examining the caregiving process (Fig. 1.1).

![Conceptual model for studying the caregiving process](image)

Figure 1.1 Conceptual model for studying the caregiving process

The impact of caregiving can be described both in terms of caregiver experiences (including both negative and positive dimensions) and caregiver health outcomes. Caregiver experiences are directly related to the specific caregiving situation and play a central role in the caregiving process. Studying global health effects as outcomes may provide information about the general impact of caregiving on health by comparing the health characteristics of the study sample with those of the general population or non-caregivers.
Since the caregiving situation can be characterized as an ongoing, continuously changing situation, a longitudinal design is warranted to study this dynamic process. The impact of caregiving may change over time and changes may occur relatively rapidly in response to the changing situation of the patient. As yet, most findings on caregiving are based on cross-sectional data and only little longitudinal research has been conducted to examine caregiver experiences and health effects in caregivers of newly diagnosed patients with colorectal cancer.

The main objectives of this thesis are twofold:

- To describe the impact of caregiving on partners of newly diagnosed colorectal cancer patients over time, in terms of caregiver experiences and health outcomes.
- To establish determinants of caregiver experiences and health outcomes of the cancer caregiving process.

The results of the study will enhance our insight into the impact of cancer caregiving over time, and our understanding of why some persons adapt better than others to their caregiving role.

**Study design**

The study was conducted in cooperation with ten hospitals in the Netherlands, in the regions of Amsterdam and Groningen, and it was entitled: CAregiving by Spouses of cancer PAtients (CASPA). Newly diagnosed patients with colorectal cancer, who recently had undergone surgery, who had a survival prognosis of at least 6 months, and who lived with a partner, were selected to participate in the study. The partner was defined as the person who was/lived as married with the patient. At the onset of the study, approximately 150 couples were expected to enter.

The selection of the patient group was based on pragmatic and theoretical considerations. The incidence of colorectal patients is relatively high and almost equally divided among the sexes. In order to identify the role and effect of various multidimensional concepts in the caregiving process, a more or less homogeneous type of caregivers was selected, namely partners. Furthermore, studying caregiving in this specific patient group had the advantage that the (presumed) onset of caregiving could be identified as a marked point in time, i.e., the moment of hospital admission. Moreover, patients with these malignancies were selected because they were likely to experience certain problems (e.g., pain, appliance and equipment difficulties, skin and
drainage problems) and were to likely to need continuous medical, physical and psycho-social care following hospital admission. Subsequently, care involvement may include a broad spectrum of tasks. And, it was expected that care tasks as conducted by partners during the course of colorectal cancer were continuously changing in response to varying patients’ needs.

Patients and partners were interviewed face-to-face either at the hospital or at home by trained research assistants, using structured questionnaires. In addition, data were collected by self-report questionnaires. Data reflected on both the early phase of the disease, referring to two weeks prior to hospital admission, and the following chronic phase, i.e., 3 months and 6 months after patient’s diagnosis.

**Outline of this thesis**

Chapter 2 provides an overview of literature findings on the impact of caregiving over time and concerning cancer caregiving, in particular. 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. In Chapter 3, this instrument is psychometrically evaluated, in terms of its feasibility, reproducibility and validity. Chapter 4 provides a description of patterns of caregiver experiences over time. Direction and size of changes in caregiver experiences over time were analyzed both at a group level and at an individual level, and according to gender, age and socio-economic status. Patterns and determinants of health outcomes (i.e., in terms of physical, mental and social health dimensions) in caregivers of colorectal cancer patients are described in Chapter 5. In Chapter 6, determinants of caregiver experiences and mental health of partners over time are discussed, including characteristics of the caregiver, the patient, and the care situation. Chapter 7 focuses on the direct and moderating effects of social and psychological resources on caregiver experiences and caregiver mental health. Chapter 8 contains the general discussion, reflecting on the main findings, some methodological aspects and implications of the study, and it provides recommendations for future research.
References


