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## Introduction

Both from a scientific and common sense point of view, there are many ideas about how patients adjust to a life-threatening disease such as cancer. However, the empirical evidence on this topic is still elusive, especially about the consequences that patients may experience in the long term. The present thesis addresses patients' physical and psychosocial adjustment to cancer, in the first year after diagnosis onward to eight years after diagnosis. This introductory chapter starts with a description of the multiple consequences that cancer patients may experience as a result of the disease and its treatment. Next, the theoretical framework of the present study is presented, followed by the main research questions and the design of the present study. The chapter ends with a brief overview of the book.

### Cancer and its treatment

In the Netherlands, approximately 57,000 persons are newly diagnosed with cancer each year (Visser et al., 1998). The chance of receiving a diagnosis of cancer is about equally high for men and women, with about one out of three persons developing cancer during his or her life. Among men, the most common cancer types are lung cancer (21%), prostate cancer (19%), and colorectal cancer (12%), whereas among women, breast cancer is the most common type (32%), followed by colorectal cancer (14%) and lung cancer (6%).

Mainly as a result of the increase in the elderly population, changes in risk factors (e.g. smoking), and improvements in cancer screening and detection, there has been a gradual increase in the *incidence* of cancer in the last decades (Coebergh et al., 1995; Visser et al., 1998). At the same time, earlier cancer detection and/or more effective treatment have led to better five-year survival rates for most cancers. For instance, the five-year survival rate for breast cancer has increased from 52% to 76% in the period from 1955 to 1992. The expected chance of survival depends, amongst others, on cancer type, disease stage, and patients' age. For instance, certain types of cancer such as breast, cervix, and corpus cancer have a relatively good five-year survival chance (i.e. more than 70%). Moreover, patients with an early disease stage and those younger than 60 years at the time of diagnosis generally have a better chance of survival. On the whole, the risk of dying from cancer has decreased

only slightly over time and with 36,500 patients dying of cancer each year, cancer remains to be the second leading cause of death in the Netherlands.

Treatment for cancer depends, amongst others, on the cancer site, disease stage, and patients' age, and may consist of surgery, radiotherapy, chemotherapy, hormonal therapy, or a combination of these treatment modalities. Improvements in the quality of cancer treatment have led to less mutilating surgeries, more precise techniques in radiotherapy resulting in less damage to healthy cells and tissues, and a better management of physical side-effects such as pain, nausea, and vomiting. All together, these progresses have significantly improved the quality of life of cancer patients. However, cancer patients may still experience severely disabling, disfiguring, and painful side-effects while receiving cancer treatment (Jacobsen et al., 1998). For instance, surgery can be impairing and disfiguring, radiotherapy can cause fatigue, nausea, and a reddening and irritation of the skin, and chemotherapy often induces nausea, vomiting, hair loss, fatigue, temporary low blood cells counts, and suppression of the immune system. Most of these side-effects disappear after treatment has finished, but some physical problems may persist until years after treatment. For instance, cancer patients may have to face permanent changes to their body image, fatigue, impaired bowel, bladder, and sexual functioning, and infertility (Passik et al., 1998). Cancer patients are also at an increased risk of a recurrence of the primary tumour or the development of a second tumour.

In sum, as a result of better survival rates, many cancer patients are presently faced with a long period of uncertainty and the late consequences of cancer and its treatment. Therefore, cancer may be regarded as a chronic disease, which may bring along a series of stressful disease- and treatment-related situations and problems that vary in duration and severity.

## **Psychosocial aspects of cancer**

Besides the multiple physical sequelae, cancer patients may also experience a wide variety of psychosocial problems as a result of the cancer experience. The sudden and unexpected confrontation with a life-threatening and still stigmatised disease and its treatment can disturb patients' emotional balance. Patients may experience less confidence in their own body and feel uncertain, hopeless, and depressed (Moos & Schaefer, 1984). The disease may also affect patients' self-image, sense of autonomy and competence, their social activities and their relationships with their partner, children, other family members, and friends (Hoekstra-Weebers, 2001; Katz et al., 1995; Wortman, 1984).

With effective treatment and the support from members of the health care team and family and friends, the overwhelming impact of the diagnosis of cancer upon

patients' functioning will become less salient over time. In the phase of remission and rehabilitation, life will become more and more dominated by more mundane concerns associated with daily living. Still, long-term cancer survivors may have recurrent thoughts about the cancer event and experience a greater sense of uncertainty about their health, about their future, and fears of a recurrence of the cancer (Kornblith, 1998; Tross & Holland, 1989). Some cancer survivors may also have to face problems regarding re-entry into prior normal responsibilities and roles or difficulties regarding job discrimination and insurance.

Given the life-threatening nature of cancer and its chronic nature, it is not surprising that the focus of the literature in psycho-oncology has been on the negative consequences. However, recently, there is a growing realization that cancer may also have *positive* consequences. Being confronted with one's mortality may call into question basic values, beliefs, and goals and produce a heightened sense of vulnerability (Janoff-Bulman & Frieze, 1983). In such a period of loss and uncertainty, patients search for meaning (e.g. "Why me?") and reconsider their priorities and values (Taylor, 1983; Ten Kroode, 1990). Eventually, this may lead to positive changes in patients' life, prompted by and attributed to the cancer, such as a more positive self-image, more intimate and stronger relationships with family and friends, and a greater appreciation of life and its small pleasures (Andrykowski et al., 1996; David, 1999; Folkman & Greer, 2000; Justice, 1999; Petrie et al., 1999).

## Theoretical framework

Clearly, the cancer and its treatment may have multiple physical and psychosocial consequences for the patient, both in the short and in the long term. In order to increase our knowledge about patients' adjustment to the disease and its treatment, it is important to disentangle the various factors that are believed to play an important role herein, either as an *outcome* affected by the disease and/or as a *predictor* of (mal)adjustment.

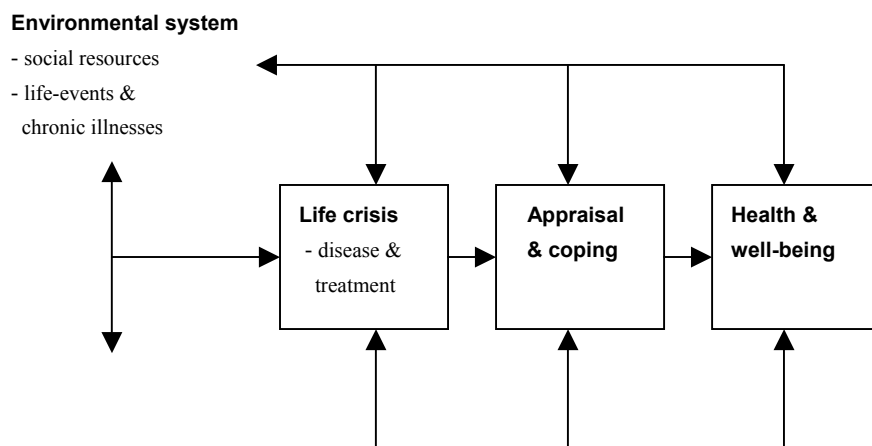
Moos and Schaefer have developed a model about how people adapt to a life crisis such as a serious physical disease (Moos & Schaefer, 1984; Moos & Schaefer, 1993). Their model can be used to classify the multiple factors into an overall conceptual framework. The use of such a stress-coping model in cancer research may lead to a better understanding of patients' adjustment to cancer and individual differences in the process of adjustment. Most patients cope relatively well with the cancer experience and seem to be able to control negative feelings and to retain a hopeful and meaningful outlook, a positive self-esteem, and satisfying relationships with others. Some cancer patients, however, suffer from severe psychosocial

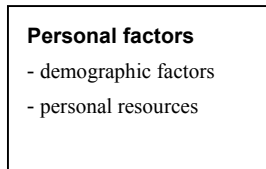
sequelae. Why do cancer patients adjust so differently from one another? Which factors affect patients' adjustment to cancer?

According to Moos and Schaefer (1993), three sets of factors influence people's appraisal and coping with a stressful event and ultimately their physical health and psychological well-being: (a) characteristics of the life crisis, (b) relatively stable personal factors (i.e. sociodemographic factors and personal resources), and (c) the environmental system (i.e. social resources, and other life events and chronic illnesses) (see Figure 1). The incorporation of cognitive appraisal and coping processes in the model emphasizes the importance of people's subjective perception of the meaning of the crisis and their choice of coping responses in the process of adjustment (Lazarus & Folkman, 1984).

In the case of cancer, objective disease characteristics, such as cancer site, disease stage, and type of treatment, are believed to affect patients' adjustment (Holland, 1989; Lipowski, 1970). At a later stage, a recurrence of the cancer may interfere with patients' functioning (Somerfield et al., 1999). Besides disease characteristics, patients' sociodemographic characteristics and personal resources (e.g. self-esteem, optimism, mastery, neuroticism, prior coping experience, and important goals, tasks, and beliefs) play a crucial role in the adjustment to cancer. Finally, patients' social resources (e.g. relationships with family, friends, and the medical team) as well as the presence of other life events and chronic diseases influence patients' adjustment. The bi-directional paths in the model indicate that reciprocal feedback can occur. For instance, patients' social resources can enhance their personal resources and vice versa. The model also incorporates the possibility that effectively coping with a stressor may lead to personal growth, in terms of enhanced personal and social resources and more effective coping skills (Schaefer & Moos, 1998). On the whole, the model emphasizes that cancer patients may simultaneously have to cope with the diagnosis and treatment of cancer, changes in personal and social resources

**Figure 1.** Stress-coping model of Moos and Schaefer





as a result of cancer, and/or other stressful life events and chronic diseases. All these factors may affect the process of adjustment.

The model of Moos and Schaefer does not explicitly make a distinction between short- and long-term adjustment. We believe, though, that the model is particularly useful to both forms of adjustment, since the model includes a wide variety of different components (also non-cancer related) and the possibility of personal growth. Such a meta-model of stress and coping can serve as a conceptual template for the development of more specific research questions and models, which define a less extensive and more manageable set of variables.

In the present study, we have used the model to categorize the main variables of interest and the hypothesized relationships among these variables. This has led to the formulation of the two main research questions:

- (a) what is the impact of a diagnosis of cancer and its treatment on patients' physical and psychological functioning and on their personal and social resources during the course of the illness?
- (b) what is the role of patients' sociodemographic and disease characteristics and their personal and social resources in the process of adjustment?

Numerous studies have examined these two issues among cancer patients, providing valuable information. However, when looking at the model, it becomes clear that an adequate methodological study design is needed to obtain a more comprehensive picture of the complex process of adjustment to cancer over time. Most importantly, the study should measure a wide variety of factors, should use a longitudinal design, and should incorporate a reference group of individuals without cancer from the general population. This is needed to distinguish the impact of cancer and its treatment from other factors that may influence patients' functioning, such as rather stable personal and environmental variables. Unfortunately, most previous studies among cancer patients used a cross-sectional design, did not include a healthy reference group, and studied a limited range of variables, focussing mainly on the negative consequences. Furthermore, most studies concentrate on the first year after diagnosis. Studies that did examine the long-term consequences of cancer often assessed patients at a wide variable time after diagnosis. Consequently, the

information about long-term adjustment is still elusive. As can be read more extensively in the section below, the present study attempted to fill in these gaps, through the use of a longitudinal, case-control design and the assessment of a wide variety of factors, using both quantitative and qualitative measures.

## The current research project

The data for the present study was collected as part of a longitudinal study that was initiated in 1990 on the role of social relationships in patients' quality of life (De Ruiter, 1995). A large group of 475 *cancer patients* were recruited from 12 hospitals in the three northern provinces of the Netherlands. The following types of cancer were included: breast, colon, rectum, lung, testis, corpus uteri, cervix, and ovarian cancer, thus representing the most common types of cancer. Patients had to be aware of the diagnosis of cancer and they had to have a relatively good prognosis, that is, a life expectancy of at least twelve months. Patients were assessed at four fixed points in time since diagnosis, that is, at 3 months, 9 months, 15 months, and 8 years after diagnosis. These points in the course of the illness were chosen to capture the period of crisis (3 months), intermediate adjustment (9 months), relatively short-term adjustment (15 months), and clearly long-term adjustment (8 years). In the present thesis, we have focused on the assessments at 3 months ( $n = 475$ ), 15 months ( $n = 403$ ), and 8 years after diagnosis ( $n = 206$ ).

Based on the gender and age distribution of the patient group, a *reference group* of 255 individuals without a history of cancer from the general population was selected from the register office of five townships in the same region as the patients. The reference group was also assessed at four points in time with similar intervals as the patient group. Again, we focused on the first assessment ( $n = 255$ ), the third ( $n = 225$ ), and the last assessment ( $n = 120$ ).

In order to obtain a comprehensive account of patients' adjustment to cancer, a wide range of variables were assessed by means of a self-report questionnaire and a semi-structured interview at the patient's home. Based on the model of Moos and Schaefer, these variables can be divided into three main groups:

- (a) physical functioning (i.e. physical symptoms and functional limitations in household and social activities);
- (b) psychological functioning (i.e. depressive symptoms and anxiety);
- (c) personal and social resources (i.e. neuroticism, extraversion, coping styles, satisfaction with life, self-esteem, meaning in life, social assertiveness, social comparison, social support, and marital satisfaction).

Information about the main sociodemographic characteristics (i.e. gender, age, education, and marital status) and the occurrence of other chronic illnesses and life events was collected during the semi-structured interview. Medical data (i.e. type, stage of disease, and treatment) were derived from the cancer registration from the Comprehensive Cancer Centre North Netherlands (CCCNN).

At eight years after diagnosis, a uniquely designed interview collected information about issues of particular concern to cancer survivors. This interview was based on the literature on long-term adjustment to cancer and the transcription of six lengthy pilot-interviews with long-term cancer survivors. In the interview, survivors were prompted to talk about the following issues: current quality of life and changes herein over the past eight years; current physical functioning, limitations in daily and social activities, and late physical effects of cancer or treatment; current psychological functioning, thoughts about the cancer (e.g. fear of recurrence, cause of the cancer, "Why me?"), and the experience of follow-up visits in the hospital; changes in activities and social relationships, current appreciation of activities and social relationships as well as changes herein in the past eight years; and finally, changes in the self as a person and life in general, current appreciation of the self and life in general, as well as changes herein in the past eight years. When cancer survivors reported a change, they were asked to indicate to what extent this change was due to cancer or due to other factors such as ageing. The interview ended with some general questions about the overall perception and impact of the cancer experience. The interview was also conducted in the reference group, with the exclusion of particular cancer-related issues. This has made it possible for us to draw comparisons between the group of cancer survivors and references.

The interview was conducted after respondents had completed the semi-structured interview. On average, the interviews lasted for about one hour in the reference group up till two hours in the survivor group (in addition to a semi-structured interview of about half hour). During the interview, survivors and references were encouraged to talk openly and at their own pace about the aforementioned issues. The interviewers were free to decide in which order to address the issues of the interview and to (re)formulate the questions. The interviews were recorded on tape. At home, while listening again to the interview on tape, the interviewers coded the open-ended responses on one or more response categories.

## **Overview of the book**

### **First part**

Depressive symptoms are the most frequently encountered psychological problem in the medically ill, including in cancer patients (Katon & Sullivan, 1990; McDaniel et

al., 1997). Therefore, the first part of the book focuses on the measurement and the presence and course of depressive symptoms in cancer patients in the year following diagnosis. Moreover, the factors associated with an increased risk of depressive symptoms are examined, using the model of Moos and Schaefer as a framework.

In *Chapter 2*, the psychometric characteristics of the Center for Epidemiologic Studies Depression (CES-D) scale are reported. The CES-D is one of the most widely used self-report questionnaires to measure depressive symptoms, both in the general population and in cancer patients (Beeber et al., 1998; Pasacreta, 1997). The scale consists of 20 items, 16 being negatively formulated items (e.g. "I felt sad") and four being positively formulated items (e.g. "I felt hopeful"). The total sumscore is based on the summation

of all 20 items. Little is known, however, about the function and the content of the four positively formulated items in a mainly negatively formulated measure of depressive symptoms. Do they measure the presence (or absence) of positive affect? Furthermore, to what extent are they related to the negatively formulated items? Some researchers believe that negative (depressed) affect and positive affect are the opposite poles of a single continuum (Ross & Van Willigen, 1997), while others argue that these two types of affect are largely independent of each other and may co-occur simultaneously (Folkman, 1997). In order to address these issues and to validate the use of the total sum score, we tested the validity and the reliability of the CES-D scale, both in the group of cancer patients and in the reference group.

*Chapter 3* explores into further detail the presence and course of depressive symptoms in cancer patients in the first year after diagnosis. The chapter also reports the results regarding the associations of patients' sociodemographic (i.e. gender, age, education, and marital status) and disease characteristics (i.e. site, stage, and treatment) with depressive symptoms. When examining the prevalence of depressive symptoms in cancer patients, it has to be taken into account that individuals without cancer from the general population may suffer also from depressive symptoms. Most previous studies among cancer patients, however, lack a reference group from the general population. Thus little is known about the extent to which depressive symptoms in cancer patients are the result of cancer or mainly reflect general psychological morbidity. Another important issue that has been overlooked by previous studies on the role of sociodemographic factors in depressive symptoms in cancer patients is that these factors have also been associated with depressive symptoms in the general population. If we want to know more specifically whether sociodemographic factors place cancer patients at a higher risk of developing depressive symptoms as a result of cancer *or* whether they primarily reflect general vulnerability, we need to compare the associations of sociodemographic factors with



depressive symptoms in cancer patients with those in references. In the present study, we compare the levels of depressive symptoms in cancer patients with those in a reference group of individuals without cancer from the general population, both at 3 months and 15 months after diagnosis. The study also examines the associations of sociodemographic factors with depressive symptoms, in cancer patients and references separately, and differences between the two groups in these associations. Finally, since patients' sociodemographic and medical characteristics are likely to be related to each other, we explore the associations among patients' sociodemographic and medical characteristics and examine whether both types of factors are independently of each other related to depressive symptoms.

Besides sociodemographic and disease characteristics, the model of Moos and Schaefer postulates that personal and social resources play an important role in patients' adjustment to cancer. *Chapter 4* focuses on two particular resources, that is, self-esteem and social support. Social support is the most frequently studied resource in stress-coping studies and is believed to be of crucial importance for psychological functioning (Thoits, 1995). According to the model of Moos and Schaefer, social resources (i.e. social support) are likely to be related to a person's personal resources. In the context of social support, self-esteem is considered to be an important personal resource, since one of the major functions of social support is to bolster or maintain self-esteem (Curbow & Somerfield, 1991). Therefore, we examine the interrelationships between self-esteem and social support and whether both resources, as measured at 3 months after diagnosis, are independently related to depressive symptoms at 3 months and 15 months after diagnosis. To investigate whether these resources are related to psychological functioning in *all* circumstances, or particularly in the face of adversity, the associations of social support and self-esteem with depressive symptoms in cancer patients are compared to those in references.

## **Second part**

In the second part of the book, we focus on the impact of cancer upon patients' functioning in the long term. Since the empirical evidence concerning the long-term adjustment to cancer is still limited, we broaden our scope of interest and examine, besides depressive symptoms, a wide variety of measures of physical functioning and personal and social resources.

*Chapter 5* presents the first results regarding survivors' long-term functioning at eight years after diagnosis. A major problem in the assessment of long-term adjustment to cancer is distinguishing the effects due to cancer from those due to ageing and comorbidities (Gotay & Muraoka, 1998). Many cancer patients are in the age of 60 years or older when they receive a diagnosis of cancer. Therefore, they are

likely to suffer from other physical problems (e.g. less energy and limitations in daily activities) and chronic diseases, which may affect their functioning and resources. In order to differentiate the impact of cancer and its treatment from ageing, the present study compares cancer survivors and references on a wide variety of aspects of physical functioning (i.e. physical symptoms and functional limitations), psychological functioning (i.e. depressive symptoms and anxiety), and personal and social resources (i.e. self-esteem, global sense of meaning in life, life satisfaction, marital satisfaction and emotional support). Since functioning may fluctuate over time, comparisons between survivors and references are made at 3 months, 15 months, and 8 years after diagnosis. We also examine differences between the two groups in changes (i.e. difference scores) in these outcomes measures over time. These longitudinal quantitative data were supplemented with the data from a qualitative interview at eight years after diagnosis. Additional analyses were performed to examine to what extent a cancer recurrence or a new primary tumour affects survivors' long-term functioning.

In *Chapter 6*, we zoom in on the role of age in long-term adjustment to cancer. There are several indications that patients' age at the time of diagnosis affects their adjustment to cancer, both in the short and in the long term. As mentioned in the previous paragraph, older cancer patients are more likely to suffer from other physical problems that may impair their functioning. Age is also believed to influence the psychological impact of the cancer experience, by its effect on patients' appraisal of the meaning of the cancer experience. That is, younger cancer patients may be less anticipated, have less prior coping experience, and may perceive a greater sense of loss as a result of the illness. In *Chapter 3*, we started off with the examination of the role of age in the course of depressive symptoms in the first year after diagnosis. In *Chapter 6*, we continue our research by examining age differences in various aspects of survivors' physical and psychological functioning at 3 months, 15 months, and 8 years after diagnosis. At the latter point in time, we also look at age differences in a global sense of meaningfulness in life, positive consequences of illness, and more qualitative aspects of adjustment to cancer. In addition, to take the role of ageing into account, we compare levels of functioning in cancer survivors with those in similar-aged references.

A summary and general discussion of the meaning and implications of the results is presented in *Chapter 7*. This is followed by a Dutch summary.

