

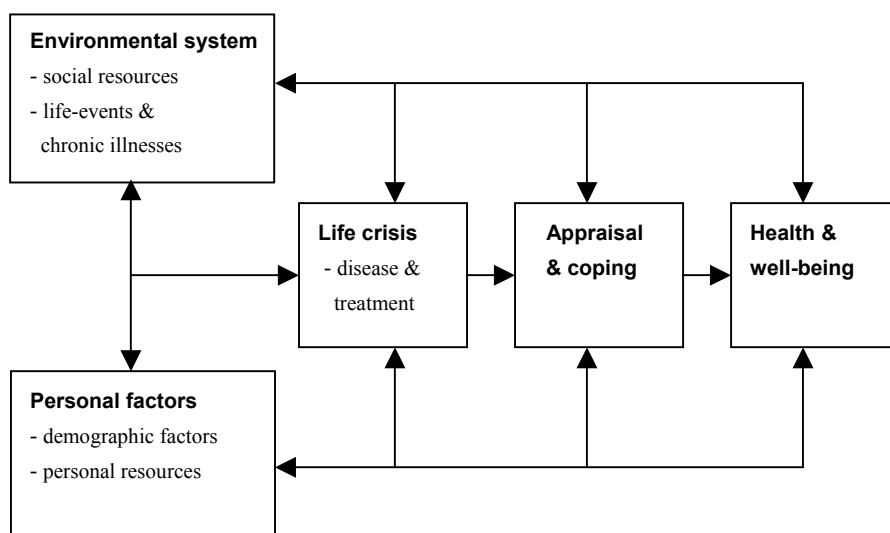
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General discussion

The thesis started off with the statement that, both from a scientific and common-sense point of view, there are many ideas about how patients adjust to cancer, yet that the empirical evidence on this topic is still elusive. Having carried out the present study, where do we stand now? In this final chapter, the main findings of the study are reviewed and conclusions are drawn about the two main research questions. In addition, some overall methodological considerations regarding the design of the present study are addressed in order to evaluate the conclusions drawn. This chapter will end with some theoretical reflections and the implications for future research and clinical practice will be outlined.

Main findings

The Introduction described the multiple physical and psychosocial consequences that cancer patients may experience as a result of the disease and its treatment. In the period following the diagnosis of cancer, patients must come to terms with the diagnosis of a life-threatening and still stigmatised disease and the often painful, disfiguring, and disabling treatment and side-effects. Patients may also experience emotional problems as a result of cancer and its treatment and changes in their self-image, sense of autonomy and competence, social activities and relationships with others. In the long term, most cancer patients adapt remarkably well to the cancer experience and are able to continue their lives. Some survivors even feel that cancer has improved their life in a certain way.

Figure 1. Stress-coping model of Moos and Schaefer

In order to organize the main variables of interest and to reach a clearer understanding of the adjustment to cancer and the individual differences herein, the stress-coping model of Moos and Schaefer was introduced (see Figure 1). The model proposes that three sets of factors influence patients' health and psychological well-being: (a) characteristics of the life crisis (e.g. disease characteristics such as cancer site, stage, and treatment), (b) more or less stable personal factors (i.e. sociodemographic characteristics and personal resources), and (c) the environmental system (i.e. social resources and other life events and chronic illnesses). The bi-directional paths in the model indicate that reciprocal feedback can occur. For instance, patients' social resources (e.g. social support) can enhance their personal resources (e.g. self-esteem) and vice versa. Furthermore, the process of adjustment to cancer may lead to personal growth, in terms of enhanced personal and social resources and more effective coping skills. Based on the model, two main research questions can be formulated:

- (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?

First part

The first part of the book (Chapter 2, 3, and 4) focused on depressive symptoms in the year following diagnosis. Specifically, we explored the extent to which cancer patients develop such symptoms shortly after diagnosis and whether these symptoms persist in the year following diagnosis. In addition, the associations of patients' sociodemographic and medical characteristics and personal and social resources with depressive symptoms in the year following diagnosis were investigated. First, however, we examined the psychometric properties of the self-report questionnaire that was used in the present study to measure depressive symptoms, the Center for Epidemiologic Studies Depression (CES-D) scale.

The main interest of *Chapter 2* was to examine the content and function of the four positively formulated items in the CES-D scale, a mainly negatively formulated measure of depressive symptoms. The results clearly demonstrated that, both in cancer patients and in references without cancer from the general population, the negatively and the positively formulated items measure two distinct and relatively independent concepts, subsequently called Depressed Affect and Positive Affect. Therefore, subsequent analyses focused on the reliability and validity of these two scales. Both scales were found to have good internal consistency (i.e. Cronbach's $\alpha > .70$). The study also provided strong evidence for the validity of the Depressed Affect scale. First, the content of the items reflected the definition of depression. Secondly, the scale appeared to be strongly correlated with other measures of psychological distress, physical symptoms, and neuroticism and discriminated cancer patients from references.

The validity of the Positive Affect scale, on the other hand, could not be demonstrated. First, the correspondence between the content of the four positively formulated items and the definition of depression was less clear. For example, when someone reports that he or she has rarely or little of the time "felt as good as others", "felt hopeful about the future", "was happy", and "enjoyed life", does this necessarily mean that this person is depressed? Probably not. The scale was also weakly related to other measures of psychological distress and was not able to discriminate cancer patients from references in the initial period after diagnosis. Furthermore, since positive affect has in general been related to extraversion, the weak correlations between the Positive Affect scale and extraversion raised further doubt about the validity of the scale. Finally, Depressed Affect and Positive Affect were about equally strong related to positive outcomes, such as quality of life, life satisfaction, and self-esteem.

All together, the findings indicated that the CES-D measures two distinct concepts questions. This questions the validity of the use of the original total sumscore. The Depressed Affect scale proved to be a reliable and valid measure of

depressive symptoms, both in cancer patients and in the general population, but the validity of the Positive Affect scale could not be determined. Therefore, 16-item version of the CES-D was used throughout the thesis as a more valid measure of depressive symptoms.

Chapter 3 examined the presence and course of depressive symptoms in cancer patients at 3 and 15 months after diagnosis, compared to a reference group of individuals without cancer from the general population. We also examined to what extent sociodemographic and disease characteristics were associated with the presence and course of depressive symptoms. Hereby, two important issues were taken into account. First, sociodemographic factors have also been related to depressive symptoms in the general population. Second, patients' sociodemographic characteristics are likely to be related to their disease characteristics.

Importantly, the results showed that, at three months after diagnosis, cancer patients experienced significantly more depressive symptoms than references, with about a quarter of all cancer patients being possible cases of depression. Despite a small improvement in these symptoms over time, patients continued to report elevated levels of depressive symptoms up till 15 months after diagnosis. Clearly, the findings show that depressive symptoms in cancer patients are associated with the disease and its treatment, rather than merely a reflection of general psychological morbidity. These results provide evidence for the belief that a diagnosis of cancer may be regarded as a life crisis. Adaptation to such a crisis is believed to involve a process in which phases of emotional distress and coming to terms with the disease alternate with phases of denial and repression of intrusive thoughts (Horowitz, 1986). Thus to some extent, depressive symptoms may be viewed as a normal response to the diagnosis of cancer. However, if depressive symptoms become more severe and persistent and impair patients' daily functioning and adherence to cancer treatment, they are not adaptive and frequently require psychological treatment. In this context, it is important to note that the level of depressive symptoms in patients at 15 months after diagnosis was strongly related to the amount of depressive symptoms shortly after diagnosis. This finding demonstrates that early recognition and treatment of patients with heightened levels of depressive symptoms may be fruitful to prevent that these symptoms become long lasting.

The examination of the risk factors showed that especially patients younger than 65 years at the time of diagnosis experienced depressive symptoms in the first year after diagnosis. Of the disease characteristics, only cancer site was associated with higher levels of depressive symptoms. However, this effect of site disappeared when controlling for sociodemographic characteristics such as patients' age and gender. Thus, although it seems to be counter-intuitive, specific disease characteristics seem to be less important than the overall impact of cancer itself. Regarding the *course* of

depressive symptoms in the period between 3 to 15 months after diagnosis, it was found that cancer patients with a lower stage and those with a higher education showed relatively more improvement over time than those with a higher stage and lower education, respectively.

To conclude, a diagnosis of cancer and its treatment may induce depressive symptoms in a significant minority of the patients in the period following diagnosis, especially in those being relatively younger at the time of diagnosis.

Chapter 4 explored the associations of personal and social resources (i.e. self-esteem and social support), measured at three months after diagnosis, with depressive symptoms at 3 and 15 months after diagnosis. First, however, we examined to what extent feelings of positive self-esteem are related to social support (i.e. perceived availability of emotional support, lack of problem-focused emotional support, and negative social interactions). Surprisingly, in contrast to theoretical notions, self-esteem appeared to be rather weakly related to all three types of social support, both in cancer patients and in references. Only the perceived availability of emotional support was moderately related to positive self-esteem.

Next, we examined to what extent self-esteem and social support are independently related to the presence and course of depressive symptoms. We also made comparisons between patients and references in these associations of social support and self-esteem with depressive symptoms. Both resources were independently related to depressive symptoms at three months after diagnosis, indicating that those who lack social support and those who have low feelings of positive self-esteem experience higher levels of depressive symptoms. In general, the associations of social support and self-esteem with depressive symptoms were similar in patients and references. The only exception was problem-focused emotional support, which was more strongly related to depressive symptoms in cancer patients than in references. The longitudinal analyses revealed that only social support but not positive self-esteem was related to the future level of depressive symptoms at 15 months after diagnosis, when controlling for the initial level of depressive symptoms at three months after diagnosis.

Overall, the findings demonstrate that both self-esteem and social support mainly fulfil basic human needs, namely the need to like oneself and to see oneself as competent and the need to belong and to feel attached to others (Maslow, 1970). Only problem-focused emotional support, characterized by reassuring, comforting, problem-solving, and advice, seems to be especially important for cancer patients in the initial period after diagnosis. This shows that the availability of someone with whom patients can talk about the disease and his or her worries and concerns is of great importance for patients' psychological adjustment to cancer.

Second part

In the second part of the book (Chapter 5 and 6), we shifted our attention from patients' short-term adjustment to cancer to their long-term adjustment at eight years after diagnosis. In order to obtain a comprehensive description of their adjustment to the illness, a wide variety of aspects of physical and psychological functioning and personal and social resources were investigated.

The first results were presented in *Chapter 5*. The focus of the study was to examine differences between cancer survivors and references without cancer on a wide variety of outcome measures at three points in time: 3 months, 15 months, and 8 years after diagnosis. We also examined differences between the two groups in the level of changes in these outcomes measures over time. Additional analyses were performed to examine the impact of a recurrence or new primary tumour on survivors' long-term functioning. A key finding of the study was that survivors' levels of psychological functioning and resources at eight years after diagnosis were comparable to those in references from the general population. Thus, cancer and its treatment do not seem to have a long-term effect on psychological functioning, nor does the cancer experience seem to affect the presence of personal and social resources. However, cancer survivors did still experience higher levels of physical symptoms at eight years after diagnosis than references. Survivors who had developed a recurrence or new primary tumour reported also more limitations in their daily and social activities and to some extent more depressive symptoms than references. The data from the qualitative interview showed that many cancer survivors had become more attentive to physical symptoms over time and were still concerned about a recurrence of the cancer.

Longitudinal analyses showed significant improvements in physical and psychological functioning in cancer patients in the first year following diagnosis. In the years thereafter, both survivors and references showed a worsening of physical functioning. The longitudinal data further showed that, at group level, the amount of personal and social resources in survivors and references was stable over time. In contrast, during the interview at eight years after diagnosis, both survivors and references reported positive changes, such as a greater appreciation of themselves and life in general. Furthermore, although the amount of these positive changes in survivors was similar to that in references, many cancer survivors attributed these positive changes to the cancer experience.

Taken together, the findings suggest that long-term cancer survivors still experience elevated levels of physical problems as well as a greater attentiveness to physical symptoms and a fear of recurrence. At the same time, they report good psychological well-being and no loss of their personal and social resources.

In *Chapter 6*, we pursued into greater depth survivors' long-term adjustment to cancer, by examining the role of patients' age at the time of diagnosis in the process of their long-term adjustment. First, we examined, within the group of cancer survivors, age differences in physical and psychological functioning, in a global sense of meaningfulness in life, and in positive consequences of illness. Secondly, we compared the levels of outcomes in cancer survivors with those in similar-aged references.

The findings clearly demonstrated the existence of certain age patterns. Cancer survivors in the age of 65 years or older at the time of diagnosis reported significantly more physical impairment at eight years after diagnosis than younger survivors. However, a similar association of age with physical functioning was found in references. Comparisons of survivors with similar-aged references revealed that the higher levels of physical impairment in older survivors were comparable with those in similar-aged references. Thus, it seems that older cancer survivors experience a level of physical functioning that is normal at their age. Survivors younger than 65 years, on the other hand, did report significantly more physical impairment than similar-aged references. Furthermore, although survivors' age was not significantly related to the level of depressive symptoms at eight years after diagnosis, comparisons with similar-aged references revealed that younger survivors reported more depressive symptoms than references of their age.

A diagnosis of cancer does not seem to affect survivors' global sense of meaningfulness in life, as indicated by similar levels of a sense of meaning in life in cancer survivors and similar-aged references. Interestingly though, younger survivors did report a greater search for meaning in the cancer experience than older survivors, in terms of causal attributions (about the cause of the cancer and the question "Why me?") and finding benefits in the cancer experience. For instance, younger cancer survivors reported that they felt more mature, more aware of own strengths, were less concerned about the approval of others, lived more intense, and had a greater appreciation of the self, life in general, and relationships with others.

On the whole, it can be concluded that the long-term impact of cancer and its treatment on physical and psychological functioning is most apparent in younger cancer patients. Among older cancer survivors, the impact of cancer and its treatment seems to be marginal. Their functioning is more affected by ageing processes in general.

Conclusions

In the following two paragraphs, we will return back to the two main research questions and draw some overall conclusions about the short- and long-term

consequences of cancer and its treatment and the significance of certain factors as predictors of (mal) adjustment.

The impact of cancer on patients' physical and psychological functioning and on their personal and social resources

The vast evidence from the present study is that the majority of the cancer patients adapt remarkably well, after the initial adjustment in the first year after diagnosis. Thus even under conditions of extreme stress and uncertainty, people seem to have a great capacity to adapt to life crises and transitions. Still, certain problems, such as physical symptoms and a greater attentiveness to physical symptoms and fear of cancer recurrence, may endure till years after cancer and its treatment. In the context of less medical surveillance and persistent physical problems, it is not surprising that cancer survivors feel uncertain about their body. Despite these long-term physical and psychological sequelae, cancer survivors also report positive outcomes as a result of their cancer experience. They feel more self-confident and have a greater appreciation of their relationships with others and life in general. In their "struggle for existence", cancer patients attempt to adapt to the new situation as good as they can, by reducing or managing the negative consequences and striving for growth and fulfilment. It has to be emphasized, however, that these overall encouraging concern only patients who have survived cancer for eight years. It should not be overlooked that a substantial number of the patients who were originally included in the study have died.

The impact of cancer and its treatment on patients' physical and psychological functioning is most apparent in the first year following diagnosis. Especially in the first months after diagnosis, patients report physical symptoms and limitations in their activities and experience elevated levels of depressive symptoms. During the year following diagnosis, these problems diminish, but at 15 months after diagnosis, patients still report more physical and psychological problems than references without a history of cancer.

In the years following the first year after diagnosis, a worsening of patients' physical functioning was observed. These changes in physical functioning may partly be the result of ageing in general. In addition, the association of neuroticism (i.e. emotional instability) and a fear of recurrence with physical symptoms suggest that physical symptoms in cancer patients may have both a somatic and psychological component.

The role of patients' sociodemographic and disease characteristics and resources in the process of adjustment

The present study explored a range of disease and sociodemographic characteristics and psychosocial resources as correlates of patients' short- and long-term adjustment

to cancer. These analyses revealed three important factors that were associated with elevated levels of physical and/or psychological problems: (a) a younger age at the time of diagnosis, (b) a lack of social support, and (c) low feelings of positive self-esteem.

Both in the patient and in the reference group, being female was associated with higher levels of depressive symptoms in the first year after diagnosis. This finding suggests that the greater likelihood of depressive symptoms in female cancer patients primarily reflects general vulnerability, rather than an increased risk of depressive symptoms as a result of cancer. A younger age, on the other hand, was only in cancer patients significantly related to higher levels of depressive symptoms. Thus a younger age at the time of diagnosis can be regarded as a predictor of depressive symptoms as a result of cancer. In the long-term, younger patients still reported elevated levels of depressive symptoms, compared to similar-aged references. They also experience relatively elevated levels of physical problems, compared to references of their age.

Besides a younger age, low feelings of social support and self-esteem were related to higher levels of depressive symptoms in the first year after diagnosis, both in patients and in references. Thus as with gender, a lack of these resources seems to primarily reflect general vulnerability. The only exception was problem-focused support, which was clearly more important for patients' psychological functioning in the initial months after diagnosis.

Overall, two different types of risk factors can be distinguished:

(a) factors that are associated with adjustment problems as a result of cancer and its treatment, and (b) factors that primarily reflect an increased vulnerability in the general population. This finding has clinical implications. Whereas some cancer patients may need an intervention that focuses on particular cancer-related issues and concerns, other cancer patients may benefit from general psychological care as well.

Methodological considerations

In the present longitudinal study, a large group of cancer patients and references without a history of cancer from the general population were assessed at four points in time in the eight years following diagnosis. Furthermore, both quantitative and qualitative measures were used to capture the process of long-term adjustment to cancer. This elegant methodological design had important advantages over previous research. First, the use of the age- and gender-matched reference group enabled us to draw more firm conclusions about the true effect of cancer upon outcomes and the factors associated with these outcomes in patients. Secondly, through the use of a

longitudinal design with fixed assessment points in time, we were able to examine the process of adjustment to cancer, thus recognizing that the physical and psychosocial sequelae that patients face may vary over the course of the illness. The multiple points of assessment also enabled us to examine predictors of future (mal) adjustment. Finally, the qualitative data at eight years after diagnosis supplemented the quantitative data in a valuable way and provided more insight in the specific concerns of long-term cancer survivors.

The carrying out of the current study gave rise to some methodological thoughts about the study design and methods being used. In the section below, we will discuss these issues, including the sample characteristics, the use of a reference group, the longitudinal design, and the combination of quantitative and qualitative data. In some cases, the discussion will centre on the present study, whereas in other, more general methodological concerns will be discussed.

Sample characteristics

One of the inclusion criteria of the present study was that patients had to have a life expectancy of at least 12 months. As a result, the majority of the patients were diagnosed with an early stage of disease. An important advantage of including mainly patients with a relatively good prognosis is that a large group of cancer patients could be followed up from diagnosis till eight years thereafter. Obviously, long-term adjustment can only be studied in cancer patients who have a good prognosis. Nevertheless, it can be reasoned that the results of the present study regarding patients' short-term adjustment concern only patients with a good prognosis and not patients with a worse prognosis and those being terminally ill.

During the study, there was a decline in response in cancer patients diagnosed with colorectal or lung cancer, a stage III or IV, a more advanced age, being male, and a lower education. Many of these cancer patients had died. In the reference group, we also found a declining response in those with an advanced age, a lower education, and those without a partner. Some of these references had died, whereas others were too sick or unwilling to participate. These processes of selective drop out may have affected the results presented in the present thesis. That is, it seems that patients with a poorer functioning were more likely to drop out and therefore, one must not exclude the possibility that some of the findings are an underestimation of the effects of cancer upon patients' physical and psychological functioning. The drop out of people is often regarded as a problem in longitudinal studies. However, the position can also be taken that longitudinal studies reveal some of these processes of selection that are often masked in cross-sectional studies or in studies using convenient samples. The availability of the information in longitudinal studies about the sample under study and the characteristics of those who dropped out may thus be more valuable than is often recognized.

The use of a reference group

In the present study, the reference group was matched on age, gender, and region (i.e. city or countryside) with the patient group. At all points in time, we found no significant differences between both groups in their sociodemographic characteristics. This enabled us to make valid comparisons between patients and references regarding outcomes and factors associated with these outcomes. When making such comparisons, we *assume* that the functioning of these references reflects a level of functioning that is “normal” in the general population. However, this does not necessarily have to be the case. Therefore, we compared the levels of physical symptoms and depressive symptoms in references with those in other samples from the general population (Bouma et al., 1995; De Haes et al., 1996; Hann et al., 1999). Both the amount of physical symptoms and the level of depressive symptoms were in line with the levels in other samples from the general population. This finding underpins the representation of the reference group in the present study.

Longitudinal design

In longitudinal studies, it is important to decide at which points in time patients are being assessed. There are various ways of doing this. In this paragraph, we will describe two different approaches that can be distinguished. The first approach argues that assessment points should be *meaningful* and capture the different phases of adaptation or the different stages in the course of the illness. This approach is probably most relevant when the aim of the study is descriptive. The second approach concentrates on the relationship between *predictors* and outcomes. Assessment points need to be chosen in such a way that valid and meaningful conclusions can be drawn about the role of a particular factor as a predictor of a certain outcome. The latter approach is probably most useful when the aim of the study is explanatory.

Meaningful assessment points

The specific physical and psychosocial demands that cancer patients can face at a particular time and that ultimately determine their adjustment to cancer are likely to change over the course of the illness. In order to capture these changes, the present study examined cancer patients at four fixed points in time since diagnosis: at 3 months, 9 months, 15 months, and 8 years after diagnosis. These points in time are believed to capture different phases of *adaptation*: the period of crisis, intermediate adjustment, relatively short-term adjustment, and long-term adjustment, respectively. However, such assumptions about the meaning of the assessment

points may be invalid and thus this approach may lead to a misrepresentation of the adaptational process.

Recently, it has been suggested that, rather than using fixed points in time since diagnosis, it might be more fruitful to examine patients' adjustment in relation to their *stage of illness* (Heim et al., 1997). Such an approach studies adjustment to cancer in terms of different phases in the course of the illness. For instance, in the case of breast cancer, the following stages of illness can be distinguished: (a) initial detection of a problem,

(b) hospitalisation, confirmation of diagnosis, and surgery, (c) post-discharge with no additional therapy, (d) post-discharge with adjuvant chemo- and/or radiotherapy, (e) rehabilitation and adaptation, (f) metastatic disease and cancer recurrence, and (g) terminal illness and dying (Heim et al., 1997; Jacobsen & Holland, 1991). Thus, the stage of illness model proposes a more individual approach of assessing patients over time. Relating assessment to meaningful changes in the course of the illness and its treatment may provide more in-depth knowledge about the process of adjustment. However, it obviously requires complex procedures of data collection, in which the assistance from the medical team is essential. It should also be noted that the model above was developed to characterize the course of breast cancer and its treatment. Other types of cancer may have a different sequence of stages, especially in the short term. This means that for every type of cancer, the different stages of illness have to be determined. Clearly, such an approach is very complex in studies using a heterogeneous sample of cancer patients.

The stage of illness approach is most relevant for patients' short-term adjustment to cancer. In the long term, the impact of the illness and its treatment will be less prominent and other factors such as comorbidity and ageing may play a part in survivors' functioning as well. Therefore, the stage of illness approach will be less useful for the examination of survivors' long-term adjustment. At this point in time, it seems to be most important to distinguish survivors in the phase of rehabilitation and adaptation and those in the phase of metastatic or terminal illness.

Returning back to the design of our study, it can be concluded that the assessment points were meaningful but also arbitrary to some extent. In any case, the design did not use the different phases in the course of the illness as a starting point. Since most changes in the illness stages occur in the first months following diagnosis, it can be argued that our first assessment at three months after diagnosis is too global. Over time, the impact of the illness will diminish. Therefore, the assessments at 15 months and eight years can be taken as a valid representation of the phase of short- and long-term adjustment, respectively.

Predictors and causality

Besides describing the course of functioning over time, longitudinal studies aim to disentangle relationships and to draw conclusions about the causal direction between two or more factors. The problem of examining causality renews the discussion on the time and frequency of assessment. In general, relatively little attention is paid to the question whether the number of assessments and the time between assessments is to such an extent that an effect of a certain predictor on a future measure of outcome can be expected. Issues that need to be considered in this context are for example whether a certain predictor has an immediate effect on an outcome or whether its effect is only visible after some time. Furthermore, certain predictors may have a short-term effect, whereas others may have a long-lasting effect on a particular outcome. It can also be imagined that the direction of the relationship between a predictor and outcome changes over time. For instance, the perceived availability of social support may have a *positive* effect on patients' coping responses in the early phases of the illness, but continued high levels of social support have a *negative* impact, through undermining independent coping and restricting the patients' repertoire of coping strategies. Finally, in the examination of the effect of a predictor on future outcomes, the (in)stability of predictors and outcomes over time has to be taken into account. For instance, if we want to examine the effect of social support on future levels of well-being and social support is not stable over time, we might not find a significant effect, since well-being may be more strongly related to current levels of social support. This holds particularly for predictors with a short-term effect. The aforementioned issues are important to consider in a longitudinal study. All too often, points of assessments are chosen routinely or too global. If the focus of a study is to examine the role of a particular predictor (e.g. social support), it seems to be most important to properly choose the points of assessments, keeping in mind the issues mentioned in this paragraph. If the focus of the study is

to explore which factors are able to predict a particular outcome (e.g. depressive symptoms), it may be less feasible to take these issues into account. But when performing such analyses, we need to be careful in drawing firm conclusions about the role of the predictors under study, since they were examined in a global way.

In the case of long-term adjustment to cancer, it can be questioned whether it is useful to examine the role of certain factors as measured in the initial period after diagnosis as predictors of survivors' long-term functioning. Long-term survivorship is defined as the period starting five years after diagnosis and onwards (Gotay & Muraoka, 1998; Schag et al., 1994). Consequently, there is a long period of time between the time of diagnosis and follow-up assessment. In this period of time, patients may have encountered other stressful life-events and chronic illnesses, and, of course, they have grown older. These factors may have a strong effect upon

survivors' functioning, perhaps even stronger than the factors in the initial period after diagnosis.

So far, we have addressed the importance of the timing and frequency of the assessment points for the examination of the causal direction between a particular predictor and outcome. However, we have not mentioned yet that, in reality, processes are often complex and the concepts under study are likely to influence each other mutually (see the model of Moos and Schaefer). For instance, physical symptoms may induce anxiety and depression and these feelings may subsequently lead to a heightened experience of physical symptoms. Another example is the relationship between resources and outcome. A lack of social support may induce depressive symptoms, which may subsequently influence the amount, perception, and satisfaction with social support. A third example of bilateral relationships is the association between different resources. Persons who lack self-esteem may receive little social support and this lack of support may further deteriorate feelings of personal strength. When conducting a longitudinal study, we need to be aware that, regardless the way in which assessment points were chosen, such a study can only portrait patients' functioning *at a given moment* in time in the on-going feedback loop. In

other words, the results can only provide information about the causal relationship between different factors, *given* the choice of assessment points in time and the assumptions made by the researcher. This again emphasizes the importance of choosing meaningful assessment points.

Combined approach of quantitative and qualitative measures

In the present study, a self-report questionnaire, a semi-structured interview, and a more qualitative interview were used to collect the data.

In general, *quantitative* research methods (e.g. self-report questionnaires) provide systematic measures of specified variables for all persons and has the advantage that within-and between-subjects comparisons can be made. An important limitation of this approach is that one cannot discover new or unexpected variables, that is, factors beyond those that were defined by the researcher in advance. *Qualitative* research methods (e.g. an open unstructured interview) may elicit more in-depth information about a relatively new topic and may lead to a better understanding of the experience from the person's perspective. Important limitations of the latter approach are that sample sizes are often small and that one cannot obtain comparable data for all persons under study, thus persons cannot be compared.

For the present thesis, we developed an interview that can be regarded as a combination of a quantitative and qualitative approach. The interview encompassed a set of topics and interviewers were free to decide in which order to discuss these topics and to (re) formulate the questions. Respondents were

encouraged to talk openly at their own pace. Both cancer survivors and references were interviewed, with the exclusion of particular cancer-related topics in the latter group. The interviews lasted on average for about one hour in the reference group up till two hours in the survivor group. After the interview, the interviewer coded the stories of the respondents on one or more response categories. The advantage of such a type of interview is that, in a large sample of cancer survivors and references, information could be collected that could not have been measured with existing questionnaires (e.g. changes in the appreciation of life and the role of the cancer experience herein). Furthermore, as a result of the coding system, the data could be analysed using statistical tests. As can be read in Chapter 5 and 6, the data appeared to be very fruitful in pointing out the issues at stake and the extent to which they occurred. For instance, the interviews clearly demonstrated the perception of positive changes, both in cancer survivors and in references, and the extent to which survivors attributed these changes to the cancer experience. The interviews also showed that particular illness-related issues, such as a search for positive meaning, attentiveness to physical symptoms, and a fear of recurrence were more noticeable in younger than in older cancer survivors.

When interpreting the interview data, one has to be aware that bias may have occurred, among others, as a result of cognitive processes. Festinger's theory of *cognitive dissonance* (Festinger, 1957) may be relevant to understand these processes. The theory holds that dissonance, being psychologically uncomfortable, motivates people to reduce this dissonance, by denying or minimizing the negative consequences or by looking for positive consequences. This theory may explain why cancer survivors search for and create positive meaning in the cancer experience. The search for meaning is believed to help patients to cope with the stressful aspects of the situation and to restore their emotional balance and resources (Taylor, 1983; Folkman & Moskowitz, 2000). Taylor's theory of *positive illusions* (Taylor & Armor, 1996) may also be useful to understand cognitive processes. The theory states that normal human perception is marked by mild positive biases (e.g. self-aggrandizement, unrealistic optimism, and exaggerated perceptions of control). This may explain why a substantial number of both survivors and references in the present study reported positive changes in their functioning.

To conclude, the quantitative longitudinal data and the more qualitative data were both important sources of information and supplemented each other in a valuable way. The quantitative data enabled us to describe the process of long-term adjustment and the late impact of cancer upon survivors' general functioning. The qualitative data shed more light on cancer-specific aspects of long-term adjustment.

Theoretical reflections and future research

Negative and positive outcomes

An important finding of the present study is that survivors may experience positive consequences of the cancer experience, relatively independent of whether they experience negative consequences as a result of cancer. Traditionally, stress-coping models have focused predominantly on negative affect and other adverse outcomes such as feelings of loneliness, uncertainty, pessimism, and hopelessness. Positive affect and positive outcomes such as hope, optimism, happiness, and meaning in life have received much less attention.


Recently, there is a greater interest in the adaptational function of positive outcomes in the face of adversity (such as a diagnosis of cancer). The model of Moos and Schaefer is a good example of a conceptual framework that takes into account that, in the aftermath of a crisis, people may emerge from a life crisis with enhanced personal and social resources and new coping skills (Schaefer & Moos, 1998). In her theory of *cognitive adaptation*, Taylor (1983) maintains that when individuals have experienced a threatening event and the negative consequences are difficult to deny, they search for positive meaning in the experience (e.g. by reappraisal of life) and try to regain mastery and self-esteem. Such positive perceptions are believed to enhance the person's coping and adjustment to the event (Taylor & Armor, 1996). Similarly, Folkman (1997) suggests that, in the context of significant and enduring stress, distress may motivate people to search for and create positive meaning (e.g. by positive reappraisal and goal-directed coping). Attributing (positive) meaning to certain areas in one's life may help people to cope with the negative consequences of an event and enhance their well-being (Folkman, 1997; Folkman & Moskowitz, 2000). It remains unclear to what extent these processes are conscious or unconscious (Vaillant, 2000). Probably, people use both unintentional and intentional strategies to process threatening information and to reconstruct their lives.

When looking more closely at these theoretical notions, it becomes clear that there exists a lack of clarity regarding the *time frame* (i.e. process) and the *status* (i.e. coping or outcome) of positive consequences. Since it is not clear when coping characterized by positive reappraisal and goal-directedness is most likely to occur (i.e. during the early, middle, or later stages of the crisis or once the crisis is resolved), it may be difficult to distinguish between coping characterized by positive reinterpretation and positive outcomes in general. Nevertheless, these models recognize the strength of human intrinsic motivation and possibilities to cope with life crises. Therefore, they describe the complex processes of adjustment to adversity in a more accurate and complete way. They are the starting point from which the process of positive consequences of illness and its determinants can be studied.

More research is needed to sophisticate the definition and assessment of positive consequences of illness (Cohen et al., 1998). First, regarding the definition, it is possible and necessary to distinguish perceived positive changes or benefits of the illness as an outcome from those of coping strategy or style? In addition, to what extent is perceiving benefits a meaningful outcome in itself, apart from adjustment outcomes? Secondly, what type of changes should be considered as personal growth? Perceived benefits of illness may to some extent be an individual process, that encompasses shifts in values or beliefs that a particular person subjectively experiences as favourable. Thirdly, is the perception of positive consequences a one-dimensional concept (and thus can we add all positive consequences into one overall sumscore) or do we need to distinguish multiple dimensions? Finally, what is the time frame for the assessment of perceiving benefits of illness and which factors are associated with the report of positive consequences of illness?

The notion that positive consequences may occur in the course of the illness and are presumed to be related to better adjustment has implications for designing psychosocial interventions. Rather than focusing solely on alleviating negative sequelae, psychosocial interventions need to incorporate explicitly elements intended to reinforce patient's own positive and adaptive strengths. For instance, by fostering feelings of hopefulness, encouraging a more positive (re) appraisal of the stressful situation and otherwise ordinary event, and helping patients to find new goals and remain engaged with life, such interventions may help patients to cope with the cancer experience.

Risk factors and screening

To the extent that a substantial number of cancer patients suffers from psychological distress as a result of the diagnosis of cancer, early identification and treatment is essential to help these patients to adapt more effectively to the diagnosis of cancer. Treatment of psychological distress may improve medical outcomes, reduce health care costs, and increase patients' overall quality of life. However, the majority of the cancer patients do not experience severe psychological distress and thus probably do not need an intervention. Therefore, it is essential to select cancer patients who are most likely to benefit from  the form of intervention. Clinically strong and cost-effective outcomes are most likely to result from interventions targeted at those patients suffering from or at high risk of significant psychological distress. The question is: how?

One possibility is to offer a psychological intervention to cancer patients who request psychological treatment themselves. However, many cancer patients are unable or unwilling to share their problems with their clinician and thus do not ask for help. Another possibility is that members of the health care team detect and refer cancer patients with adjustment problems to a mental health practitioner. In practice,

clinicians and nurses may not see it as their task to probe into the psychological problems of patients and in the constraints of a busy clinical schedule, they may have little time available to explore the psychological concerns of every patient. Thus, it is probably not sufficient to direct psychological interventions only at those patients who request such support or those who are referred by the health care team.

From a research perspective, it seems logical to target interventions at risk groups. It has been found that certain factors are associated with an increased risk of psychological morbidity: patients' medical (e.g. advanced disease and physical burden) and sociodemographic (e.g. younger age) characteristics, a lack of personal and social resources (e.g. low self-esteem, lack of control, insufficient social support, and poor coping styles), a psychiatric history, and the presence of concurrent life stressors and chronic illnesses. Targeting interventions at risk groups means that, ideally, cancer patients can be offered an intervention *before* they develop severe psychological distress. However, this approach has several drawbacks. First, there is obviously not one predominant factor, but rather a series of factors that may contribute to elevated levels of psychological distress. This makes it difficult to identify particular risk groups. Furthermore, the presence of a certain risk factor in a cancer patient indicates at the most an increased risk of problems, often not even a huge risk but a somewhat elevated risk at *group* level. No firm judgements can be made at an individual level. Furthermore, people that do not belong to any of the risk groups may also experience severe problems that require professional help. Thirdly, offering an intervention to every patient that meets one or more risk factors may be patronizing. For instance, when having a lower education turns out to be a risk factor, does this mean that *all* lower educated cancer patients should be offered a psychological intervention? Obviously, the answer to this question seems no.

A more effective use of the theoretical knowledge about risk factors in clinical practice may be to incorporate the information in individual screening. If clinicians and nurses are aware of the prevalence of psychological distress and the type of cancer patient likely to experience distress, they may detect problems earlier and treat or refer more appropriately. Information about the risk factors may also be incorporated in screening instruments. Most screening instruments focus on existing psychological distress or poor quality of life (Hall et al., 1999; Hopwood et al., 1991). However, careful screening on the presence of multiple risk factors associated with developing psychological problems may increase the effectiveness of these instruments. For instance, an item such as "Do you have someone to talk about your experience with cancer?" may give an indication about the availability of someone with whom the patient can talk about his or her concerns, fears, worries regarding the illness and its consequences. Again, it should not be the case that *all* patients who meet one or more risk factors are routinely offered an intervention. A

clinical judgement from a clinician or specialized nurse is still needed to decide, in consultation with the patient, whether referral for psychosocial care is desirable. Nonetheless, in a busy clinical setting, screening may prove to be a rapid method to gain an impression of patient's strengths and burden and to help health care providers to identify patients who may experience difficulties in their adjustment to the cancer and its treatment. The information from the screening instrument may subsequently be used to *tailor* the amount and type of psychosocial care at the needs and concerns of the patient. The majority of the cancer patients will not report excessive psychological morbidity and will thus benefit mostly from the interactions with the medical team and good information about the cancer, its treatment, the process of physical recovery, the chance and symptoms of recurrence, and life style issues (Ferrell et al., 1998b; Gray et al., 1998; Helgeson et al., 2001; Henderson, 1997). Some cancer patients, however, may need and benefit from specialized psychosocial treatment, with one or more sessions in an individual or group setting.

Information about the risk factors can also identify issues that merit further attention during psychological interventions. For instance, the findings of Chapter 4 concerning the association of social support and self-esteem with depressive symptoms suggest that it may be useful to stimulate patients to focus on the positive aspects of themselves and opportunities in their lives and to teach them communication skills and encourage them to actively seek support. At first sight, the fact that fixed sociodemographic factors such as a younger age are associated with maladjustment seems to be of little practical relevance. However, since age is believed to strongly affect well-being through its effect on patients' appraisal of the cancer, it might be fruitful to discuss the meaning of the cancer for the patient (e.g. sense of deprivation, loss, and threat) during interventions.

In sum, psychological treatment should be available for all cancer patients, but as the costs of medical services are under increased scrutiny, psychological interventions need to demonstrate their necessity and feasibility. Early screening may provide a method of efficiently evaluating a large number of patients and identifying those patients at high risk of or those currently experience severe psychological burden. Future research is needed to identify brief, simple, and accurate screening tools and to investigate the feasibility of these methods to detect patients at risk of or suffering from adjustment problems to cancer. Which factors should be assessed during screening? Do we need to screen all cancer patients? When should screening take place? Should patients be screening only once or multiple times in the course of illness? The ultimate criterion is that interventions are effective. Therefore, more research is needed to examine the effectiveness of interventions targeted at those at risk of or suffering significant distress and to identify *which* form (e.g. group or individual) and components (e.g. psycho-education, relaxation, emotional support, training in coping skills and cognitive

restructuring) of treatment are most effective for *whom* and *when*. All together, this research may lead to more effective screening tools and eventually to standard guidelines for screening and psychosocial intervention and a better integration of medical health care and psychosocial services.

