General discussion

How do patients adapt to cancer? The number of studies aimed at answering this question has grown rapidly over the past twenty years. Consequently, much more is known today about patients’ psychological functioning during the course of cancer and about the strategies they use in order to deal with this disease than was known twenty years ago. However, as was mentioned in the Introduction to this thesis, not all questions have been answered and new questions have been raised. The main purpose of this thesis was, therefore, to address several of these unanswered questions (see Introduction) by investigating the process of adaptation in cancer patients treated with external radiotherapy. We have paid attention to both negative and positive outcomes of cancer and its treatment. To show some individual differences in the ways patients cope with cancer and treatment with radiotherapy, the present thesis included personal accounts from two patients: Anne was diagnosed with breast cancer, and Henry who was diagnosed with prostate cancer. Their stories were found throughout the thesis and served as illustrations.

Main findings

A number of conclusions can be drawn from exploring the four research aims. First, in our overview of 45 studies, it was shown that patients have been found to experience feelings of anxiety, depressive symptoms, and general psychological distress intermittently throughout the different phases of radiotherapy. However, the findings of our studies suggest that feelings of anxiety are experienced especially prior to the start of radiotherapy. Depressive symptoms seem to arise at a later point in time. Second, the examination of cognitive factors in relation to psychological distress revealed that the vast majority of patients does make effective adjustments. Especially optimism and control appear to be very important in the process of
adaptation. Third, it was found that high levels of positive consequences were not associated with low levels of psychological distress. Several variables were found to be related to positive consequences. These include the experience of a substantial degree of threat, an information-oriented style, a higher need for specific illness-related information, and a higher frequency of social comparisons. Finally, our intervention study provided evidence that giving patients additional information after they have completed treatment contributes to their adaptation process. These four major issues will be discussed in further detail below.

The psychological functioning of cancer patients prior to, during, and after treatment with radiotherapy

Despite our efforts to provide a better insight into psychological functioning at different phases of treatment with radiotherapy, firm conclusions are difficult to draw. This may be due to some methodological limitations of previous studies that have focused on psychological functioning among patients receiving radiotherapy. Obviously, studies with a longitudinal design including pre-, during, and post-radiotherapy assessments are best to examine the dynamics of psychological functioning over time. These studies should also take into account patients’ premorbid psychological functioning. A number of patients diagnosed with cancer have suffered pre-existing psychological problems, such as panic disorders, clinical depression, or generalized anxiety disorders. These conditions can have a significant influence on the patients’ psychological functioning during the illness. Therefore, it is important that patients’ premorbid psychological functioning will be assessed and managed as carefully as possible (Bottomley, 1998). Finally, studies should include questionnaires that are designed specifically to measure treatment-related psychological functioning, such as radiotherapy-related anxiety. In spite of the limitations of previous studies, four general conclusions can be drawn.

First, cross-sectional studies during the course of and after treatment with radiotherapy revealed higher levels of depressive symptoms than studies assessing depressive symptoms prior to the start of radiotherapy. This is in line with Taylor and Aspinwall (1990), who suggested that depressive symptoms may be a delayed reaction to the cancer event. We assume that the higher levels of depressive symptoms during and after treatment can be explained by the fact that it may take some time before patients understand the full significance of their condition. During the acute phase of treatment, indicated as the period shortly after diagnosis and at the beginning of treatment(s), patients may have little time to reflect on the implications of the illness. The focus at this point may be merely on the treatment and its possible consequences. Once the acute phase of illness is coming to an end, patients have more time to think things over and the meaning of the illness may begin to sink in. They may realize that cancer is associated with many losses in different life domains, resulting in depressive symptoms.
Second, in contrast to depressive symptoms, feelings of anxiety seem to be prominent in the period around the first treatment with radiotherapy. It can be imagined that this period is characterized by great uncertainty about what is going to happen; one does not know what to expect. As fear of the unknown or feelings of anxiety owing to the unfamiliarity of the treatment is less to be expected when patients are several weeks into the process of daily treatment with radiotherapy, it seems likely that feelings of anxiety diminish during the course of treatment. In line with these assumptions, both the longitudinal study and the majority of the cross-sectional studies revealed a decrease in feelings of anxiety during the course of treatment (Munro et al., 1996).

Third, our overview showed that palliative treatment and not curative treatment was associated with lower levels of psychological functioning. However, no evidence was found that a more advanced stage of disease was associated with a lower psychological functioning. This finding is rather surprising, since palliative treatment is strongly positively associated with the later stages of disease. Possibly, patients who are treated for palliative reasons are better aware that they are in a poor condition than, at least, the larger part of patients who are diagnosed with a more advanced stage of disease. In addition, for a number of these higher Stage (i.e., III or IV) patients, there exists, in general, a longer life-expectancy than for patients who receive palliative treatment. The latter group will definitely not be cured of cancer and all these patients are facing imminent death. In line with the studies that were assessed in the present overview, previous studies did not reveal elevated levels of psychological problems in patients with an advanced stage of disease compared to those with an earlier stage of disease, either (Ell et al., 1989; Hoskins, 1997; Maunsell et al., 1992).

Finally, the results of studies comparing radiotherapy to other cancer treatments revealed few differences in psychological functioning among different treatment modalities. Given that about 45% of patients with malignancy require radiotherapy, our finding that the effect of radiotherapy on psychological functioning is not superimposed on that of other cancer treatments is an important one. Radiotherapy has many side effects for many patients, which can continue till long after completion of treatment, but radiotherapy is not painful and the non-invasive nature of this treatment can make it easier for patients to adapt. Furthermore, the treatment itself may offer a kind of security that there is actually something being done to fight the cancer (Pelusi, 1997). As Henry put it (see Box 5 Chapter 3), “I think radiotherapy was not all that bad. And, it took only a couple of minutes and then we went home to come back the next day. And this lasted for seven weeks, till treatment was completed.” In addition, the interviews with Henry and Anne (see also Box 4 Chapter 2) showed that both regained their strength after treatment with radiotherapy. Their major fear when radiotherapy was completed was fear of
recurrence of the disease, a fear which is not directly treatment-related but regards the cancer situation in general.

It can be concluded that patients who are undergoing radiotherapy are able to adapt to this intensive treatment without developing major psychological disorders, and thus do not need individual psychological treatment (Litwin et al., 1995; Rathmell et al., 1991; Taphoorn et al., 1994). Nevertheless, we must be aware that the start of radiotherapy is characterized by feelings of anxiety and that depressive symptoms can arise at a later stage. I suggest that patients receiving curative radiotherapy may pre-eminently benefit from self-management interventions. Chapter 6 describes the effects of such informational interventions on psychological distress.

The role of cognitive factors (i.e., optimism, control, and self-esteem) and their relationship with psychological distress among cancer patients treated with radiotherapy and healthy references

In the Introduction, the following question was posed: “How can patients, despite having a life threatening disease, be able to report a level of psychological functioning that is similar to that of healthy references?” It was argued that cognitive factors such as optimism and perceptions of control could be of great importance. Taylor’s theory of cognitive adaptation was used to examine this idea in further detail (Taylor, 1983). The purpose of Chapter 3 was to gain insight into whether and how patients psychologically adapt to cancer and radiotherapy.

Concerning the question of whether patients psychologically adapt to cancer successfully, Chapter 3 showed evidence that, on average, they do. More specifically, it was found that cancer patients did not differ in feelings of anxiety and depressive symptoms compared to healthy references. Given that (1) psychological adaptation can be measured by focusing on the degree to which patients experience feelings of anxiety and depressive symptoms, and that (2) healthy references will experience a normal level of psychological functioning, I conclude that patients do psychologically adapt to stressful events such as cancer. To the question of how patients adapt, it can be argued that cognitive factors or strategies (as we labeled them in Chapter 3) seem to be important in maintaining a level of psychological functioning that is similar to that of healthy references. Both optimism and control played a significant role in this adaptation process. Since we controlled for the level of feelings of anxiety and depressive symptoms at the baseline, we can emphasize a causal influence of these cognitive factors on psychological functioning, making the results even more interesting.

Interestingly, levels of optimism, control, and self-esteem were at least as high as the levels of these cognitive factors among healthy references. This seems to be in contrast with common sense reasoning. It is obvious that levels of control are
threatened by the illness experience, that future plans are at stake, and that psychosocial problems as a result of cancer-related treatment emerge.

Our explanation for the findings in Chapter 3 is based on the theory of cognitive adaptation. Taylor stated that the high levels of optimism, control, and self-esteem, that a number of individuals show in response to a threatening event, rest fundamentally upon the ability to form and maintain a set of illusions (i.e., ideas that are not necessarily true). These illusions contribute to psychological well-being (Taylor & Brown, 1988; Taylor & Armor, 1996). One could argue that it is best to see things as they are, and that to succeed in learning about the environment and to maintain a stable psychologically well-being, you need to achieve maximal accuracy. But in line with Taylor (1983), Baumeister (1991) proposed that accuracy is not always the best way to make oneself feel good. People tend to overrate their abilities and to maintain an optimistic attitude. They exaggerate the frequency of successes and the quality of their circumstances in their own minds and they distort their perceptions of the world so as to furnish a view of their lives that is more attractive than a coldly objective view may warrant. As Baumeister (page 222, 1991) stated, “The happiest and healthiest people may be those who show systematic distortions and illusions in their perceptions of reality”. In conclusion, positive illusions may produce confidence that can help people to produce and to regulate positive emotional states. Based on the above, we believe that positive illusions can be an important mechanism responsible for our findings in Chapter 3.

However, there are at least two alternative mechanisms that may explain our findings. One explanation poses that patients are able to compensate a loss of control, optimism, or self-esteem. For instance, the loss of control in the health domain can be compensated by a stronger focus on other things on which control can be exerted. This assumption was not studied empirically, but our qualitative interviews among patients diagnosed with different tumors showed support for this argument. One patient reported that because of his illness he was not able in control of his work anymore. He was often very tired and not able to finish his work on time. However, at the same time, he reported that he was still capable to exert control on the side effects of treatments by taking his medication to prevent nausea and by taking a nap when he was tired. This made him feel good. In An’s story (see Box 5, Chapter 3), it can be noticed that her perceived control was lost in several life domains. She tried to compensate this loss by improving her knowledge on cancer. She read everything she could find on the subject. These illustrations are in line with several investigations that revealed that, when individuals have sustained a traumatic health event, they come to believe that they have control over at least some aspects of that event (Reed et al., 1993; Taylor et al., 1984; Taylor et al., 1991). One could apply the mechanism of “compensating” also to self-esteem. For instance, patients who receive a mastectomy because of breast cancer may experience this as a threat to their self-esteem. They may try to maintain or compensate this loss in self-esteem.
by believing that the illness makes them a stronger person mentally. Thus, they may enhance self-image in other life areas or they may reduce the importance attached to the threatened dimension.

A second alternative mechanism concerns social comparison theory (Taylor & Armor, 1996). In social comparison theory, information about another person or other people is considered in relation to the self (Wood et al., 1985). People may compare themselves with others for many different reasons, such as to learn about treatment, to evaluate how well they are coping, to learn from others who are coping well, or to feel better about their own situation. Thus, social comparison processes include the desire for self-evaluation, self-enhancement, and self-improvement (Festinger, 1954; Hakmiller, 1966; Wills, 1981; Wood, 1989). A number of studies have examined the direction in which people under stress make social comparisons (Buunk et al., 1990; Hakmiller, 1966; Molleman et al., 1986; Van der Zee et al., 1998b; Wood & Van der Zee, 1997). That is, do people compare themselves with others who are doing better or with those who are doing worse? Considerable evidence exists that people prefer to compare themselves with others who are worse off (downward evaluations) in order to bolster self-esteem, to regulate emotions, and to feel better (Taylor & Lobel, 1989; Wills, 1981). However, there is also evidence that people under threat prefer to get information about and contact with more fortunate others (upward contacts). Following Taylor and Lobel (1989), upward contacts (people who are doing better) provide information that may assist one’s problem-solving efforts. In addition, their examples give hope and inspiration.

Returning to the present study, I suggest that the process of social comparison may help patients to maintain their levels of optimism, perceptions of control, and self-esteem. For example, a patient who receives a lumpectomy (removal of the lump itself) is able to restore or maintain her self-esteem because she compares her situation with that of another woman who has received a mastectomy (removal of the entire breast). Seeing that other patients have been cured of cancer can give patients hope that they will also survive this disease. Yet, how this process works is very complicated. Taylor and Lobel (1989) made clear that various motives, and hence preferences, for different types of social comparison can coexist within the same individuals. This was perfectly shown in the stories of Anne and Henry (see Box 9 and Box 10 in Chapter 5). Anne preferred to make more social comparisons than Henry. When Anne had heard that an old friend of her had survived cancer, this information encouraged her and gave her hope. Rather surprisingly, actual contact with a less fortunate woman in the hospital also made her feel better in comparison. If the other woman had also been a breast cancer patient, she would probably have felt differently, since the information would then have been much more threatening.

Finally, it must be mentioned that social comparison strategies can be linked up with illusions. For instance, when no person is around to fill the role of the “worse off” person, the patient can imagine a worse off other (Taylor, 1983). This indicates
that illusions play a role because there’s no “real” person in the patients’ environment that suits the patients’ purpose. It also suggests that social comparison is heavily cognitively based.

**The relationship between illness severity, psychological factors, and cognitive factors, on the one hand, and future positive consequences, on the other hand, among patients treated with radiotherapy**

Only in recent years have systematic attempts been made to investigate and understand the positive consequences of having (had) cancer (Calhoun & Tedeschi, 1999). It has clearly been shown that patients feel that they have developed new coping skills and closer relationships with family and friends after having (had) cancer. Perhaps one of the most reported manifestations of positive consequences has been an increase in one’s appreciation of life and for the “smaller things in life”. This is not surprising, since patients may feel that they can not take life for granted anymore and that they have to live each day to the fullest (see also Box 8 Chapter 4) (Taylor et al., 1984; Tedeschi & Calhoun, 1995).

When considering these findings, it can be argued that the experience of positive consequences is an event-related positive outcome, demonstrating that there have been some real positive changes in the patient’s life due to the cancer experience. However, do positive consequences not merely reflect attempts to positively reinterpret the cancer experience rather than an actual positive outcome of the illness? The findings in Chapter 4 revealed that a certain degree of initial threat is related to the experience of positive consequences, and, in Chapter 5, it was shown that patients with an information-oriented style were more inclined to report future positive consequences. This may indicate that the experience of positive consequences can be triggered by the need to find some meaning in the cancer experience. Indeed, there are scientists who suggest that the recognition of positive consequences results from the coping process (Brooks & Matson, 1982; Folkman et al., 2000a; Park et al., 1996; Schussler, 1992; Taylor, 1983).

Taylor and her colleagues assumed that being diagnosed with a serious illness forces one to reject the assumption that one is invulnerable to such illnesses, but it also sets in motion the re-evaluation of priorities in life, in which one reappraises the event as an opportunity to experience positive consequences (Taylor, 1983). Similarly, Folkman (2000a) considered the finding of positive consequences as a coping process, indicated by growth-related coping, benefit finding, and positive reappraisal. She stated, “Many of these processes involve cognitive reframing whereby the person wrests positive value from the situation by reappraising the situation as having provided benefit, such as wisdom or faith, improved relationships with others, a sense of greater strength or competence, or increased self-esteem or self-worth”. Interestingly, both Taylor (1988, 1989) and Folkman (1997) argued that finding positive consequences helps the patient develop and
sustain a sense of psychological well-being. For instance, Folkman (1997) revealed that a ten-item positive reappraisal scale (e.g., “Changed or grew as a person in a good way; I rediscovered what is important in life”) was significantly associated with positive affect.

In sum, both Taylor (1983) and Folkman (1997, 2000a, 2000b) posed that experiencing positive consequences following negative events is a cognitive coping strategy, which is set in motion to counterbalance the negative aspects of cancer. Nonetheless, whether positive consequences reflect coping or outcome, or even both, is still an issue of debate. Perhaps positive reinterpretation coping and positive consequences are only highly correlated. For instance, making attempts to learn something and to grow from the experience enhances the likelihood that one also reports having done so. Distinguishing coping from outcome is thus very complicated, also because it is hard to verify when the coping process ends (if it ever ends). Considering the experience of positive consequences as a “real” positive outcome can possibly be made somewhat more acceptable when some real changes can be observed among individuals. In the section “future research”, I will provide some suggestions about how this can be examined. Furthermore, Taylor and Folkman indicated that the recognition of positive consequences is significant for psychological well-being. However, few studies have included data on the relation between positive consequences and psychological well-being or distress, and they have produced conflicting findings (Curbow et al., 1993; Klauer et al., 1997; Lehman et al., 1993; Taylor, 1983; Vickberg et al., 2001). The present thesis (see Chapter 5) also revealed no evidence that positive consequences are cross-sectionally related to low levels of distress. At the current stage of research, there seems to be no clear explanation for the inconsistency of these findings. A possible explanation may be that there are subgroups of patients who go through different processes following their experiences. Perhaps some people are able to benefit from their experiences in terms of better adjustment or lower psychological distress. There may be others whose positive beliefs turn out to be defensive coping styles which can lead to negative effects. Such individual differences may be the result of personal characteristics, such as an information-seeking coping style (monitoring), which was shown in Chapter 5 to be associated with positive consequences but not with reporting psychological distress.

The effects of an informational intervention on psychological distress which was provided after patients completed treatment with radiotherapy

“When radiation therapy was finished, I felt a sense of relief but also some growing sense of fear again. There was a feeling of “What now?” and “What to do?” For so many months, my life had revolved around the doctors’ appointments, tests, things like that. But, how was I going to get along without doing anything?” These words
were spoken by Anne (see Box 11) after she completed treatment with radiotherapy. It shows that providing information in the post-treatment period could be useful in preventing patients from experiencing negative affect. To examine this, we developed a self-management booklet for patients who have been treated with radiotherapy. However, one might ask whether patients truly need such an informational intervention. The individual story of Anne leads us to believe that they do. Yet, some questions must be taken into account. That is, how did the patients in the present study experience treatment with radiotherapy, and how great was their need for information after treatment?

Because these questions were not answered in the relevant chapter, I will consider them here. The findings are based on our quantitative data. Next, I will discuss some qualitative results of our telephone interviews, which were held among patients who had received a booklet. These interviews served two aims: (1) to find out whether the patients had read the booklet or whether they intended to read it, and (2) to assess the patients’ first impressions of the booklet. The findings provide some interesting insights regarding individual patients’ responses to the information booklet.

The quantitative results showed that 35% of the patients reported that the treatment was rather severe (N=209). In contrast, 37% did not experience the treatment as difficult. However, different side effects of treatment were commonly reported by the patients. Fatigue was the most common side effect mentioned. After treatment, the need for information was high. The majority of patients still wanted information about (1) the physical and psychological changes they could expect to experience after completing radiotherapy, (2) how they could best ask their physicians questions, (3) agencies they could call when they need help, and (4) how they could cope with painful emotions. These findings confirmed our assumption that providing information after treatment would be a valuable thing to do.

The results of the telephone interview revealed that eighty-four patients (82%) reported that the booklet appealed to them very much and that reading it had been very interesting. Besides that, they found it useful and easy to read. The booklet also gave patients the feeling that they had not been forgotten, that questions that were still relevant were now being answered, and that after reading the booklet they knew better which agencies to call for help. Finally, the short accounts in which other patients talked about their feelings and their ways of coping with problems, were perceived as very valuable. The booklet provided the patient with some recognition that they were not alone with their illness and that the responses they felt to the illness are normal. To read how other patients had coped with the disease also inspired them. Some other interesting remarks included, “Everyone should get one”; “Other patients could also really benefit from it”; “It doesn’t work for me, but I can imagine it would for other people”; “I wished I had received the booklet a lot sooner”. On the other hand, thirteen patients found the booklet not very interesting.
Some reasons included, (1) wanting to leave behind all things related to the cancer experience; (2) having already received too much information; (3) feeling good and having no need for further information.

Regarding the kind of information patients liked to receive, it was noticed that the part on coping with problems that may arise after treatment and the social comparison information (i.e., the short accounts of other patients in the margin of each page) had been read most often. The section that was read the least concerned financial constraints. We also noticed that patients required information that was closely related to their own situations. For example, some breast cancer patients revealed that more specific information about the consequences of axillary’s dissection, such as arm swelling, was lacking. Similarly, several patients with prostate cancer pointed out that they would prefer to receive specifically information about their own tumor site.

Although these results are qualitative in nature, they provide us with valuable information that can be helpful for adapting the booklet or developing new intervention programs. Information that was shown to be important can be extended, whereas information that seemed useless or less interesting for a number of patients can be restricted to only a small part of future intervention programs. This could lead to an optimal intervention program whereby the information is optimally targeted to the needs of many patients.

The findings of Chapter 6 revealed that it were mainly patients low in control and high in uncertainty who benefited from additional information. One could argue that it may not be valid to recommend information uncritically to all patients. However, the results of the present study do not seem to indicate that the information they were given may have detrimental effects on patients. In fact, the telephone interviews suggested the opposite. The majority of patients who had received the booklet were glad to have it. Therefore, I do not suggest that only patients low in perceptions of control or high in feelings of illness uncertainty should receive an information booklet. The conclusion I do want to draw is that higher risk patients show the greatest benefit from receiving the information booklet. Since we are the first to have studied this empirically after treatment, I believe this is a valuable finding.

To conclude, our intervention study is of particular importance both at a practical level and at a theoretical level; at a practical level because of its relevance to patients who underwent cancer treatment; at a theoretical level because it showed that the strong relationship between cognitive factors and psychological distress, as was shown earlier in the present thesis, can be influenced by an information booklet.
Methodological issues and limitations

I will not repeat the methodological issues and limitations of the five studies that were extensively discussed in the appropriate chapters. However, I would like to add several methodological considerations.

The first issue concerns the tumor site. In Chapters 3, 5, and 6, we included a heterogeneous group of cancer patients. Including one tumor site may only have led to different findings. On the other hand, in Chapter 4, we included only women with breast cancer, which limits the possibility to generalize our findings to other tumor sites. Although I believe that medical factors, such as the presence of severe physical impairment, may have a strong effect on patients’ psychological functioning, I do not believe that the psychological processes that were under study in the present thesis vary according to tumor site. In addition, the subjective appraisal of the stressfulness of the situation can be considered a more important focus than tumor site (Dunkel-Schetter et al., 1992).

Second, it is evident that the time of assessment may influence the outcome variable under study. Since the effects of the information booklet on psychological distress were assessed three months after the booklet was provided, it remains unknown whether the same results would also have been found at an earlier or at a later assessment point. However, our assessment point was not chosen at random. We felt that patients would need a certain length of time to read the booklet, to learn how to cope with all kinds of problems, and to choose and put their new skills into practice. Furthermore, some problems may arise at a later point in time and a three-month assessment point would give the patients time to show possible benefits of the intervention. In Chapters 3, 4, and 5 we assessed relationships between illness severity, psychological and cognitive factors measured one week prior to or two weeks after radiotherapy, and psychological distress and positive consequences measured at three months after radiotherapy. It is, however, not clear whether we chose a good point in time when we decided the three-month assessment of psychological distress and positive consequences.

The final limitation concerns the fact that we were not able to control for psychological distress at the baseline in our intervention study. This inability was due to another intervention that influenced psychological distress at the baseline. This means that we had no pre-intervention assessment, which limits the possibility of examining the impact of the intervention on change in levels of distress.
Future research

Positive consequences
Because empirical work on correlates of positive consequences is still in its infancy, it is hard to integrate our findings into a broader framework at this point. Therefore, future research into positive consequences will be of great importance. Several implications for future research have been discussed in Chapter 4. These include (1) the incorporation of patients with a poor prognosis in studies investigating positive consequences, (2) the assessment of the duration of threat in relation to the experience of positive consequences, and (3) the inclusion of multiple assessments of positive consequences. Some other implications for future research are outlined in this section. Below, I will first describe a problem that I ran into when examining the topic of positive consequences.

While mapping previous research into positive consequences, I was confronted with the fact that a great variety of names have been used to label the construct of positive consequences. I reasoned that this interferes with the accumulation of research findings because findings about a construct under one label may never be integrated with findings about the same construct under different labels. A number of these labels included positive psychological changes, perceived benefits, positive contribution, meaning making, psychological adjustment, and personal growth. Especially the latter term, defined as the positive change that the individual experiences as a result of the struggle with a traumatic event, has often been used to indicate positive consequences. Although this definition is similar to ours, I preferred to use the label positive consequences in the present thesis. Personal growth is a narrow concept, whereas positive consequences reflect a broader concept that includes a number of different domains.

As shown in Chapter 5, we did not find a relationship between positive consequences and psychological distress. However, it may be possible that certain domains of positive consequences are related to psychological distress. It can be imagined that individuals experience positive consequences in some areas and negative changes in others. Moreover, different domains of positive consequences may be differentially related to psychological well-being and distress. For instance, one study among college students found that personal positive consequences had a stronger influence on positive adjustment (as measured by positive affect, global satisfaction, and self-esteem) than social positive consequences (Goodhart, 1985). Another issue that may be interesting for future research is whether certain domains of positive consequences occur sooner or later in the process.

Can positive consequences be observed as real changes among patients? In other words, do positive consequences involve more than just the subjective perceptions of individuals reporting that, due to their illness, things changed for the better? Since little information exists that positive consequences are associated with observable
changes in how the person acts, future research could focus on this issue. One way of clarifying the validity of any positive consequences is to obtain validating information from other people in the social network of the patient. So far, there is little evidence that the positive consequences reported by patients themselves are related to reports from other people (Park et al., 1996; Wuthnow, 1991). Another strategy is to utilize a prospective design, in which personality variables and other possible domains that may be relevant to the experience of positive consequences are assessed before and after the stressful event. Individuals who show positive changes in personality, such as becoming more extravert, or who show changes in life orientation, such as showing more compassion to other people, might be considered to have experienced some real positive (outcomes) consequences (Lehman et al., 1993).

Informational intervention research
An important aspect of the booklet was the short accounts of fellow patients as presented in the margin of each page. Based on the qualitative results, I recommend that future research include this social comparison information. Receiving information from fellow patients is unique, since only fellow patients can understand what having cancer feels like. Besides, information from fellow patients is probably much more powerful and is likely to have a more enduring effect. But what kind of social comparison information should we offer to patients? Should this, for instance, be information provided by fellow patients who have been excellent copers or should it be information provided by patients who have been doing worse?

Previous studies have indicated that people who are facing a health threat prefer upward comparison information on the coping dimension (Bennenbroek et al., in press; Van der Zee et al., 1998b). In addition, a recent study among the same patient group as examined in Chapters 4, 5, and 6 of the present thesis revealed some interesting findings on this topic. The study compared audiotaped social comparison information on different dimensions, namely, procedures, emotions, and coping. Considering the effects of the different audiotapes on mood, it was shown that patients who had received the emotion tape (i.e., emotional reactions of fellow patients to treatment with radiotherapy) reported a relatively higher level of negative mood than patients who had received the procedural (i.e., descriptions of fellow patients of the nature of various aspects of the treatment) and the coping tapes (coping reactions of fellow patients to the treatment). Interestingly, most accounts in our booklet contained information in an upward direction, but they also contained much information about the emotions and coping strategies of these patients. However, none of the patients in our study had indicated (in the telephone interview) that reading about the emotions of other patients had bothered them or had upset them.
For future research, it would be interesting to examine in further detail the effects of different *dimensions* of written social comparison information on psychological functioning. This could be done by questioning patients about which kind of social comparison information (i.e., direction and dimension) in the booklet they liked best, or which information was of greatest value to them. However, it remains difficult to filter out the different dimensions in patients’ personal accounts. When using personal cancer stories, one will inevitably be confronted with all kinds of emotions, coping strategies, and factual information from the same individual. One has also to keep in mind that some patients do not like to receive information about other patients. For instance, Henry reported (see Box 10 Chapter 5) that he didn’t like talking with other patients. The likelihood that different phases of treatment and stages of disease dictate different concerns and make different threats salient argues strongly for a perspective that considers these variables in the design and implementation of interventions. Completion of treatment has seldom been a particular focus of intervention research. I suggest that future studies should also focus on the post-treatment period. In order to understand whether there are long-term outcomes and at what time patients may obtain optimal benefit from post-treatment interventions, one should assess the outcomes of these interventions during different assessment points. The assumption is that, by appropriately targeting interventions along stage of disease and phase of care, the chances of achieving meaningful changes in disease course and quality of life should be enhanced.

An important suggestion for future intervention research among cancer patients includes a more intensive collaboration with psychologists, psychotherapists, and clinicians. Important here, is the integration of knowledge from the practical field with knowledge from the scientific field and the other way around. This could enhance the psychosocial effects of informational intervention studies among cancer patients. This assumption is based on my personal experiences with scientists, psychologists, and clinicians. I will explain this assumption in further detail below.

It is mainly the group of patients with the most severe psychological problems that will visit a psychologist or psychotherapist. Patients may experience a wide variety of problems that can relate to different domains, including the psychological, physical, and social domains. Because the psychologist is confronted with these personal and devastating stories, it is not surprising that the majority of psychologists I have spoken to in past years have talked mainly about individual cases. Also at scientific congresses, I saw that the need of psychologists to talk about individual patients overshadows the results of a scientifically based presentation. In sum, the majority of psychologists mainly work and think from an individual perspective.

2 In the following, I will mention only psychologists but I also want to refer to psychotherapists or other social workers who work with cancer patients.
perspective (the patient they see in practice) and from the perspective of their own experiences with their patients.

On the other hand, there is the scientist who frequently examines large groups of patients in order to generalize findings. While exploring very specific research questions among a selective group of people, namely, those with cancer, it is remarkable to note that a number of scientists have not even once spoken with a cancer patient. When the results of intervention studies appear, it is indicated whether the intervention was effective or not, however, possible explanations of these results are sometimes hard to find. Furthermore, the number of practical implications is low. There may be different reasons for this. One reason is that the scientist him- or herself is responsible for the fact that the intervention is not put into practice. Other reasons might be communication problems between the scientist and the clinician, the lack of time (either on the part of the scientist, the clinician, or both) to put the intervention into practice, or the fact that the clinician does not like the intervention very much.

When a scientist is planning an intervention study on, for example, social support, it could be useful for him or her to integrate the knowledge of psychologists and clinicians. Based on many years of experience, psychologists and clinicians know much about the profiles of “problem patients”. They may, for instance, have seen that a number of patients reported that their social networks declined because they were afraid to talk about their problems. Since intervention programs are especially important for patients who are at a high risk of psychological problems (the ones that are often seen by a psychologist), the scientist can make use of this information in the development of interventions. This may lead to a more effective intervention. Finally, new research questions are often based on the previous literature. However, it may be interesting to handle more questions from psychologists and clinicians who work in the practical field, and who probably have other interesting questions.

Although I clearly pointed out the importance of collaboration with psychologists and clinicians, I also propose that using a combination of knowledge from clinicians and psychologists and theory-driven models is the most effective way to achieve optimal benefit for cancer patients. A lack of theory-driven models in intervention research impedes comparison between competing interventions and an adequate understanding of underlying processes that may contribute to interesting outcomes. Unfortunately, there have been only a handful of studies that described an underlying theory-based model for the provided intervention (Antoni & Carver, 2001; Johnson, 1996).
Practical implications

What do the results of the present thesis mean for patients with cancer? This question will be answered in the present section. A section about practical implications seems to be a fixed part of most theses on adaptation to chronic illness. Journals often want scientists to devote some attention to practical implications. This obliges scientists to write a section in which the theoretical knowledge is translated into practice. Of course, it is important to build a bridge between science and practice. However, I would like to make several remarks.

First, making practical implications is not easy. For instance, further research into the topic of positive consequences is required before valuable practical implications can be made. Nevertheless, as can be seen in the various chapters, we were obliged to make some considerations regarding practical implications. Second, it is hard for scientists to give advice about how research findings should be integrated into practice when most scientists do not know about the difficulties that are associated with the psychosocial care of cancer patients. In addition, they are often unaware of the many logistic problems that may arise when putting research findings into practice. Taking into account the fact that much research is focused on exploring different theoretical frameworks, it is even more surprising that many scientists take the risk of making these implications. Finally, when I was reading some practical implications that have been made by scientists, I noticed that scientists frequently make the same suggestions, especially in research into cancer populations. Often, the focus is on screening patients at an early stage in order to prevent them from getting a clinical depression. However, if this suggestion had been taken seriously in the past, there would definitely be a screening device by now that would be used on all patients who have just been diagnosed with cancer.

I decided to make only one additional practical implication, from which I truly believe that patients can derive some benefit. Because as many as half of all patients with cancer may want some form of intervention to help reduce their anxiety, but also because radiotherapy is a very structured treatment, self-management interventions may be an effective tool in decreasing psychological problems (Bottomley, 1998). In the present thesis, we assessed the effects of an extensive information booklet provided after completion of treatment. Considering the effects of our booklet on psychological distress, I suggest that this booklet should be incorporated in practice for several reasons. Our booklet is easy to use and a cost-effective intervention. It may be effective because it can meet the needs of a great proportion of patients and because receiving a booklet may place patients at a lower risk of negative outcomes. A peer support group with complete strangers may be a more threatening situation for some patients, although I would certainly not ignore the benefits these support groups can provide. As a result of personal interviews with many patients, I have reasons to believe that patients want information that best
suits their own situation. One could start by providing information that presents possible ways of coping with problems that have been mentioned by other patients who were diagnosed with the same type of cancer and who received the same treatments. This could be done by developing several self-management information booklets which may overlap on general sections that are important for all patients.

**Closing remark**

The present thesis explored a number of research questions that were related to the process of adaptation among cancer patients treated with radiotherapy. Although an important aim was to highlight the positive side of cancer, I do not want to underestimate or obscure what cancer involves and the problems it brings with it. From an individual point of view (i.e., the personal accounts of Anne and Henry) as well as at group level, the present thesis reported that patients may experience different psychological problems. Some patients will continue to have these problems till long after treatment has been completed. On the other hand, it was shown that people are adaptive. Even in circumstances in which one could easily imagine giving up, such as the cancer situation, patients fight for their lives. By means of cognitive strategies, patients appear to be able to maintain their well being. Many patients even reported that cancer changed their lives in positive ways, indicating that they experienced positive consequences of the illness. Not everyone experiences high levels of positive consequences. It seems especially that those patients who (1) have experienced an initial and substantial degree of threat, (2) are in greater need of different kinds of information (including social comparison information), (3) experience higher levels of illness uncertainty, and (4) have a greater need to compare themselves with others seem to report higher levels of positive consequences at a later point in time. These findings give us reason to believe that people may search for positive consequences in order to counteract the negative effects of cancer on their psychological well-being. Rather surprisingly, and in contrast to some previous literature, there seems to be no evidence that patients who report high levels of positive consequences also report low levels of psychological distress. Future research should focus on these issues. For patients who are at a higher risk of developing psychological distress, those low in control and high in illness-uncertainty, an information booklet in the form of a self-management package proved to be an effective intervention. My suggestion is to incorporate this booklet in practice. Future research should also work more closely with the practical field, so that optimal interventions can be developed and more patients can be helped in an effective way. A final point that scientists involved in cancer research should keep in mind is that “Having had cancer is not an end-point in patient’s cancer journey, it’s a life changing experience, making life less ordinary.”