Hope and Despair

Philosophy of life, expectations and optimism in cancer patients and their spouses

JEANETTE WINTERLING
Dissertation presented at Uppsala University to be publicly examined in Sal IX, Universitetskajen, Övre Slottsgatan 2, Uppsala, Friday, March 23, 2007 at 13:00 for the degree of Doctor of Philosophy (Faculty of Medicine). The examination will be conducted in English.

Abstract

The general aim was to explore philosophy of life, expectations and optimism in patients and spouses in two different cancer situations, and to determine whether these aspects had relevance for psychological distress and quality of life. The first situation was being newly diagnosed with advanced cancer. Data on philosophy of life, optimism and psychological distress were gathered on one occasion (I). In addition, changes in life were described using a qualitative approach in a sub-sample (II). The second situation was having completed curative cancer treatment. Data on expectations for the recovery period, optimism, psychological distress and quality of life were gathered on three occasions (III). Moreover, expectations and how these turned out were described using a qualitative approach in a sub-sample (IV). The results show that being diagnosed with an advanced cancer influenced aspects of patients’ and spouses’ philosophy of life, including that existential questions were common and were related to higher psychological distress (I). All experienced substantial mental changes in life, often also physical, practical and sometimes positive changes. Patients more often seemed to accept their situation and prepared themselves for death, whereas spouses had more difficulties in handling the situation (II). Patients who had completed curative treatment generally had higher expectations for the recovery period than did their spouses, and patients expectations were fulfilled to a lesser degree, however, this generally had little importance for psychological distress or quality of life (III). Patients’ expectation for their recovery period was generally that they would get well. For those whose recovery period had been tough, expectations were often unfulfilled, but they were often satisfied with their current life anyway owing to positive changes (IV). Being optimistic was the most beneficial for decreased psychological distress in both samples, as well as for better quality of life in the recovery group (I, III).

Keywords: philosophy of life, expectations, optimism, advanced cancer, curative cancer, recovery, spouses

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To Nancy

‘Having cancer is like going on a roller coaster between hope and despair’

* A cancer patient
List of original papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals:


IV Winterling, J., Sidenvall, B., Glimelius, B., Nordin, K., Expectations for the recovery period after cancer treatment – a qualitative study. Submitted

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Introduction

Different cancer situations

Being stricken by cancer may principally lead to three different situations. Either the cancer leads to death too early in life, it becomes a chronic disease that the patient can live with for a long time, or the cancer can be defeated and the patient is cured and survives. This thesis will focus on two of the situations, the first and the third.

The first situation, the advanced situation, is often the case when a person is diagnosed with advanced gastrointestinal (GI) cancer. Such a diagnosis means that the tumour is impossible to remove surgically, whether it is local or has spread to other organs, and is therefore incurable. GI cancers, chiefly colorectal, gastric, pancreatic and biliary cancers, are common and constitute about 20% of all cancers in Sweden (The National Board of Health and Welfare, 2004). These patients receive palliative care, which can be divided into an early and a late phase (SOU, 2001). In the early phase, tumour-specific treatments may be part of the palliative care. These treatments, such as radiation and chemotherapy, may improve both the quantity and quality of life for a proportion of the patients, but survival is generally short for most of them (Janunger et al., 2001; Permert et al., 2001; Ragnhammar et al., 2001). In the late phase, tumour-specific treatment is usually not appropriate. At that point, the goal is to achieve the best possible quality of life, but not to prolong life.

The third situation, the recovering situation, is often the case when curative cancer treatment has been completed. This occurs when a person has been diagnosed as being in the early stages of, e.g., colon, breast and ovarian cancer or a malignant lymphoma and has been treated for cure. The treatment includes either surgery, often combined with chemo- and/or radiotherapy to decrease the risk of recurrence, or chemotherapy and radiotherapy for malignant lymphoma. Women with breast cancer are also often treated with antiestrogens or other hormonal treatments for several years (Bergh et al., 2001).
noses are all among the ten most frequent cancer sites is Sweden, and breast cancer is the most common cancer among women (The National Board of Health and Welfare, 2004). The prognosis is good with a five-year survival of 56-58% for colon cancer, 86% for breast cancer, 44% for ovarian cancer and 54% for malignant lymphoma (The National Board of Health and Welfare, 2005).

Getting advanced cancer
Research on perceptions of the life situation for patients with advanced cancer is mostly focused on the very last months in life, when many are in hospice or receiving home-based care. The studies often include patients with a variety of diagnoses who sometimes have a long history of cancer, with recurrent and metastatic disease prior to the study (Axelsson and Sjödén, 1998; Davies et al., 1990; Hinton, 1999; Swensen et al., 1993). However, less is known about the period close to the diagnosis of advanced cancer, especially among patients with no prior history of cancer. Then patients, and their spouses, have a very short time period, some only a few days or weeks to adjust psychologically to dramatic changes in life and to an approaching death. The task can be particularly difficult in GI cancer patients, for whom the clinical course can be rapid and accompanied by many physical symptoms. Psychological adjustment to getting advanced cancer is crucial both for the patients’ and for their partners’ psychological well-being (Folkman and Geer, 2000). In this difficult situation, patients report that their most important concerns are existential, e.g., having hope, knowing that life has meaning and that their life has been productive. Spiritual concerns are also important, e.g., finding strength in beliefs and comfort in faith (Greisinger et al., 1997). This is also true for spouses (Murray et al., 2004). Regardless of whether patients and spouses have religious beliefs, they have a need for love, meaning, purpose and sometimes transcendence (Murray et al., 2004).

Recovering after curative cancer
When the recovering situation begins, i.e. when curative cancer treatment is completed, the disease is supposed to be defeated and the patient and his/her spouse must return to a “normal” life. At this point, the close connection to the hospital is often reduced and health care personnel no longer provide much support to the patients. The patients have to manage the recovering period on their own, often without any
assistance with regard to how to get started. Consequently, approximately one-third of women with breast cancer report that completion of treatment is upsetting due to loss of their safety net (Ward et al., 1992). Patients do not always seem to be aware of the long-lasting changes and problems that can occur as a result of getting cancer and going through intensive treatment. Breast cancer patients are reported not to expect that they will have chemotherapy-related problems six months after ending treatment (Beisecker et al., 1997). All patients are not able to return to a normal life after their curative cancer treatment. It is reported that only a minority of patients who have undergone bone marrow transplant some years earlier return to normal as they had expected (Andrykowski et al., 1995). There is little known about what expectations patients’ have for their recovery period after curative cancer treatment and the degree to which these expectations are realized.

Spouses’ situation

For most spouses, the cancer diagnosis provokes a traumatic crisis no matter the stage of the cancer (Persson et al., 1998). A family must strive to maintain stability through all that happens in connection with a cancer diagnosis. Often other family members must fill the lost role of the sick member if the family is to continue performing their routine functions. Also, they have to cope with the demands and losses that are a part of getting cancer and meet the increased emotional needs of all family members (Lederberg, 1996). Important variables for adjustment are spouses’ emotional and cognitive response, and the support from the rest of the family (Morse and Fife, 1998). The relationship between the patient and the spouse is often important for their distress, irrespective of the situation in the course of the cancer (Hodgkinson et al., 2006b; Morse and Fife, 1998; Persson et al., 1998). Spouses of patients who are experiencing an advanced disease are more vulnerable to increased distress and problems of adjustment than are spouses of patients in a stage of survival (Morse and Fife, 1998).

For spouses in the advanced situation, the advanced cancer of their partner is an emotionally intense and exhausting experience (Strang et al., 2002). Many spouses are plagued by worries about the patient’s comfort, emotional responses to the disease and the patient’s coming death (Kristjanson and Ashcroft, 1994) as well as with practical problems, such as more household responsibilities (Swensen et al., 1993;
Many relatives become caregivers which means that they become the person with primary responsibility for providing care for their dying relative, and many experience a high level of care burden (Davies et al., 1990; Hull, 1990; Kristjanson and Ashcroft, 1994; Meyers and Gray, 2001; Wennman-Larsen and Tishelman, 2002). They have to prepare for the patient’s death, and they have to focus on day-by-day living (Davies et al., 1990), attempting to make life as normal as possible (Strang et al., 2002).

In the recovering situation, patient’s often become more dependent on their spouse than during the cancer treatment, because, as mentioned above, the close connection to the hospital is reduced, but also the extended family and friends tend to decrease their support (Lederberg, 1996). This often puts extra strain on the spouse (Oberst and Scott, 1988). Further, the spouses also live with the fear of cancer recurrence and are reported to regard the illness more negatively than do patients (Northouse et al., 1999). Therefore, spouses themselves need support many years after the patients’ cancer diagnosis (Hodgkinson et al., 2006b). However, spouses as well as patients also report positive changes as a result of the illness (Northouse et al., 1999).

The theory of stress and coping

No matter which cancer situation is at hand, the circumstances are filled with stressful events that the patients and their spouses need to cope with to adjust. One theoretical model that explains how people with a serious disease can experience psychological well-being is the theory of stress and coping (Folkman and Geer, 2000; Lazarus and Folkman, 1984). The model includes identification of the stressful event, appraisal of the stressful event, coping with the situation and the outcome of the process, as demonstrated in Figure 1. The stressful event, in both the situations included here, is chiefly the diagnosis and all that this situation entails. For patients with an advanced GI cancer, the most stressful aspect is considered to be that they know they will die of their disease, within a short time period. For patients who have completed their treatment without any detectable tumour manifestation, what is stressful may vary, but it is common that returning to normal life afterwards is considered to be stressful (Wasteson et al., 2002). This is also true for their spouses.
When a person is exposed to a stressful event, he/she evaluates the meaning of the event through a cognitive appraisal process that includes a primary and a secondary appraisal. In the primary appraisal, the individual evaluates the significance of a stressful event for him/herself. The primary appraisal derives from the person’s personality and its dispositional variables. This is influenced by the person's beliefs, values and commitments (Folkman and Geer, 2000). Beliefs include a person's spiritual, existential and religious beliefs, which can also be expressed as a person's philosophy of life. Beliefs are also assumed to include dispositional optimism (Scheier and Carver, 1985). Both philosophy of life and optimism are investigated in this thesis and further described below.

The secondary appraisal addresses the question “What can I do?” Here, the individual evaluates the demands of the situation, on the one hand, and his or her resources, options and ability to implement the needed coping strategies, on the other (Folkman, 1984). The secondary appraisal includes evaluating whether the situation can be controlled or changed by the person him-/herself. This refers to situational (as opposed to dispositional) efficacy beliefs (Folkman and Geer, 2000). Expectations are beliefs about future states (Olson et al., 1996), and expectations for a specific situation may influence the secondary appraisal. Expectations for future states in a specific situation are investigated in the present thesis and further described below.

The primary and secondary appraisal results in the stressful event being looked upon as irrelevant, positive or stressful. If it is stressful, it can be valued as giving harm/loss, threat or challenge. It can also be a

![Figure 1. Theoretical model of stress and coping](image-url)
The combination of the three (Folkman and Geer, 2000). The appraisal process determines the intensity of the emotional response that accompanies these appraisals.

The appraisal influences subsequent coping. Coping refers to the thoughts and behaviours a person uses to regulate distress, the problem causing the stress and maintaining positive well-being. There are three main coping types: emotion-focused, problem-focused and meaning-based coping. Coping influences the outcome of the situation (Folkman and Geer, 2000).

Many studies have investigated coping types in cancer patients and their importance for well-being. Therefore the focus here is not on further investigating coping types, but rather on exploring three aspects: philosophy of life, expectations and optimism that may be of importance in the appraisal process.

Possible aspects of importance

Philosophy of life
Having personal faith in a divine power can give hope and security, and thereby reduce suffering in association with disease and death. A positive association between religion and health had been reported in 75% of more than 200 published articles in the field (Kallenberg and Larsson, 2000). Another review dealing with patients with a terminal illness concluded that those with an enhanced sense of psychospiritual well-being are able to cope more effectively with their illness and find meaning in the experience (Lin and Bauer-Wu, 2003). Moreover, meaningfulness and a strong religious faith are associated with good quality of life (Axelsson and Sjödén, 1998; Swensen et al., 1993), happiness and a better life satisfaction (Yates et al., 1981).

In Sweden, most empirical studies of the philosophy of life are built on Jeffner’s (Jeffner, 1988) definition of the concept. It is something that all human beings have, but for some individuals, it is unconscious and not formulated. However, it is relatively constant over time. Although two individuals may have an externally similar situation and the same values concerning what is good or bad, right or wrong, they may perceive their situation in different ways. One person may be quite satisfied with life, while the other is characterized by
hopelessness. By studying different philosophies of life, Jeffner (Jeffner, 1988) suggested that three components are central. These are:

- Perceptions of the human being and the world, i.e. about the nature of the human being, what differentiates us from animals, the origin of the universe and what happens after death.
- Fundamental values, e.g., what basic principles we should follow and what is good or bad.
- A keynote of life, e.g., how a person perceives herself as a human being, a basic feeling of trust or distrust/hope or despair.

These three components cannot always be isolated from each other, because there are several connections between them. The first component often functioning as a support for the remaining two components. The third component includes three factors: to what extent a person is prepared to accept his or her own life, attitudes towards the present situation and views of the future. The philosophy of life represents the theoretical and valuable assumptions that determine a person’s overall picture of the human being and the world, that form fundamental values and that give an expression of a keynote (Jeffner, 1988).

Expectations
There are two types of expectations: situation-specific expectations and dispositional expectations across a broad range of situations. The first type can include any type of expectation about the future. Expecting something means viewing it as probable or likely, perhaps the occurrence of something you hope for, await or foresee (American Heritage Dictionary, 1982). Whether expectations in a specific situation are important for a person’s well-being has not been clarified. For example, in studies focused on expectations for the success of a specific medical treatment and future health after the treatment, such a relation is sometimes reported (Cohen et al., 2001; Engel et al., 2004; Koller et al., 2000; Leedham et al., 1995; Sears et al., 2004) and sometimes not reported (Lee et al., 2003; Mahomed et al., 2002). The studies indicate that high or positive expectations as opposed to low or no expectations are related to well-being. Moreover, some of the mentioned studies have also investigated other kinds of expectations, e.g., symptom control, limitation of daily living or complications. They indicated that some expectations, but not others, and not always the same kind of expectations, are associated with good quality of life (Koller et al., 2000; Mahomed et al., 2002).
The few studies that focus on realization of expectations in a specific situation mostly point in the same direction, namely that when expectations for a medical treatment are met, this is associated with better well-being (Koller et al., 2000; Rose et al., 1995). Patients who have completed curative cancer treatment and their spouses, may have expectations for their future in several domains, e.g. socio-economic situation, physical and psychological health as well as sexuality and thoughts about their lifestyle. These domains are commonly mentioned in the quality of life research as domains in which patients experience long-term changes due to their cancer and its treatment (Beisecker et al., 1997; Dow et al., 1996; Persson et al., 1997; Wettergren et al., 2003). Such expectations, which can occur after completion of cancer treatment, are refereed to here as “recovery-related expectations”. These expectations may influence the overall rehabilitation process. Today there are no prospective studies focusing on the importance of these expectations for the recovery period after cancer. However, one study focused on patients’ expectations for physical recovery after stroke and reported that if expectations were not realized, this had no relation to the patients’ depression (only measured outcome) two and four months after discharge from hospital (Hobson et al., 2001).

Optimism
The second type of expectations, dispositional expectations, is the tendency to believe that one will generally experience good versus bad outcomes in life, often expressed in terms of optimism or pessimism. A person may hold favourable expectancies for a number of reasons e.g. personality, because the person is lucky or because he feels favoured by others. The result in any case should be an optimistic outlook – expectancies that good things will happen (Scheier and Carver, 1985). Dispositional optimism is relatively stable across time and context, and forms the basis of an important characteristic of personality (Scheier and Carver, 1992). Being optimistic is beneficial (Scheier and Carver, 1985; Scheier and Carver, 1992). Optimists, compared to pessimists, manage difficult and stressful events with less subjective distress and less adverse impact on their physical well-being. A number of studies in the field of cancer have demonstrated an association between patients’ optimism and various indicators of cancer therapy outcome (Bjoreck et al., 1999; Carver et al., 1993; Carver et al., 1994; Cohen et al., 2001; Lauver and Tak, 1995). However, at the onset of
the present thesis, only one study had focused on optimism in patients who have an advanced cancer (Miller et al., 1996), another study on optimism in patients who had completed their curative cancer treatment (Curbow et al., 1993) and none had focused on their spouses.

Outcome

If a stressful event is successfully coped with, the outcome is a favourable resolution, which generally leads to positive emotions. On the other hand, if the stressful event is not successfully coped with, the outcome is unfavourable or has no resolution and leads to distress. This means that outcomes can be measured in terms of psychological distress and global quality of life.

Psychological distress

Psychological distress can be labelled in many ways, e.g. psychological or emotional well-being, psychological adjustment, subjective stress, mental health or emotional health. Most common, and subsequently used through the present thesis, is that psychological distress is experienced in terms of depression and anxiety.

For patients with advanced cancer, the prevalence of depression and anxiety usually varies between 25% and 30% (Nordin and Glimelius, 1998; Nordin et al., 2001), but may be as high as 70% (Kaasa et al., 1993). Patients’ psychological distress is reported to decrease over time (Hopwood et al., 1991; Nordin et al., 2001), but during the last six months of life distress increases significantly (McCarthy et al., 2000) or remains stable (Nordin and Glimelius, 1998).

The prevalence figures for depression and anxiety in spouses of patients with advanced cancer are 50-60% (Nordin et al., 2001; Siegel et al., 1996), and spouses generally report higher levels of distress than the patients do (Axelsson and Sjödén, 1998; Nordin and Glimelius, 1998; Nordin et al., 2001). Their levels of distress seem stable during the months closest to a diagnosis of advanced cancer (Nordin et al., 2001), but closer to death, distress levels tend to increase (Hinton, 1999).

For patients who have survived cancer, the prevalence of psychological distress is commonly reported to be approximately 30%, but varies greatly from 5% to 50% (Deimling et al., 2002; Hodgkinson et
al., 2006a; Kornblith and Ligibel, 2003; Ramsey et al., 2002). Psychological distress is often high at treatment completion (Dow et al., 1996; Hamilton, 1999; Kornblith and Ligibel, 2003; Ward et al., 1992), but diminishes with time (King et al., 2000). Also, patients who report having high levels of distress at treatment completion often seem to continue to experience high levels long after treatment (Hodgkinson et al., 2006a).

Spouses of survivors generally show levels of emotional distress as high as or higher than those of patients (Lederberg, 1996; Matthews, 2003). Even though most spouses adjust to their new lives after cancer treatment of their loved ones, in some individuals levels of distress can be high long after treatment (Persson et al., 1998; Walker, 1997).

Quality of life
Quality of life refers to a multidimensional concept comprising perceptions of negative as well as positive aspects of at least four dimensions: physical, emotional, social and cognitive function (Aaronson et al., 1993). Quality of life is a subjective evaluation, and the patients themselves are the best judges of their own quality of life.

Patients with advanced GI cancer are generally highly functional until the last months of their life. Despite the poor prognosis, they often express more positive feelings about their quality of life in the earlier phases of the disease than could be expected (Spiroch et al., 2000). As the disease progresses, however, patients develop many symptoms, e.g., pain, nausea and vomiting, anorexia, constipation, intestinal obstruction, and their functional capacity to perform personal and household tasks and recreational activities declines, which worsens their quality of life in the later stages of the disease (McCarthy et al., 2000).

Spouses in the advanced cancer situation also report physical changes (Howell, 1986; Meyers and Gray, 2001), but it is also reported that they deny their own health problems because they put their own health needs “on hold” (Davies et al., 1990).

Among cancer survivors, the negative impact of the curative treatment is reported not to last long after treatment completion. Within a few years, patients’ quality of life is often at the same level found in the general population (Greimel et al., 2002; Hodgkinson et al., 2006a; Kessler, 2002; Michelson, 2002; Ramsey et al., 2002). However, many other studies report that survivors’ quality of life is
reduced for a very long period of time after treatment (Beisecker et al., 1997; Bertero, 2002; Dow et al., 1996; Persson et al., 1997), including physical, social, psychological, existential, economical, sexual and work problems. Survivors’ quality of life is related to the patients’ diagnosis, stage of disease and type of treatment. It is also common that about 70% of survivors report positive changes, such as having a changed life purpose, increased hopefulness and satisfaction with life (Curbow et al., 1993; Dow et al., 1996; Hodgkinson et al., 2006a).
Aims

The general aim of this thesis was to explore philosophy of life, expectations and optimism among patients and their spouses in two different cancer situations, and to determine whether these aspects had relevance for psychological distress and quality of life.

Specific aims were:

- To explore philosophy of life among patients with a newly diagnosed advanced cancer and their spouses (Study I).
- To explore whether philosophy of life had relevance for psychological distress among patients with a newly diagnosed advanced cancer and their spouses (Study I).
- To describe perceptions of changes in life among patients with a newly diagnosed advanced cancer and their spouses (Study II).
- To explore recovery-related expectations and their fulfilment, among patients in a recovering phase after curative cancer treatment and their spouses (Study III).
- To explore whether recovery-related expectations, and their fulfilment, had importance for psychological distress and quality of life among patients in a recovering phase after curative cancer treatment and their spouses (Study III).
- To describe patients’ expectations for their recovery period after curative cancer treatment and whether these expectations were realized slightly more than one year later (Study IV).
- To explore optimism among patients both in an advanced and a recovering situation of cancer, and their spouses (Study II-III).
- To explore whether optimism had importance for psychological distress and quality of life among patients in an advanced and a recovering cancer situation and their spouses (Study II-III).
Methods

Design
This thesis consists of four empirical studies based on data from two distinctively different samples (see Figure 2). The advanced group consisted of a consecutive sample of cancer patients newly diagnosed with advanced cancer and their spouses. The recovering group consisted of a consecutive sample of cancer patients in a recovering situation and their spouses, who were followed from completion of curative cancer treatment (baseline) to a point in time 16 months later (follow-up 2).

Study I had a cross-sectional design. The aim was to explore philosophy of life and optimism, and its relevance for psychological distress in the advanced group using correlational and comparative statistical methods. Study II also had a cross-sectional design and used a qualitative approach to describe changes in life in interview data from the 14 first couples included in the advanced group.

Study III had a prospective longitudinal design. The aim was to explore patients’, and their spouses’, recovery-related expectations at the completion of treatment, and optimism, and its importance for psychological distress and quality of life at two follow-ups in the recovering group, using correlational and comparative statistical methods. Study IV had a cross-sectional design and used a qualitative approach to explore how patients described their expectations for the recovery period retrospectively and how things actually turned out in a purposeful sample from the recovering group.
Figure 2. Description and sample in each study included in this thesis

Subjects

Studies I-II

Consecutive patients who had recently been diagnosed with advanced GI cancer and who visited the Department of Oncology, University Hospital, Uppsala, Sweden from January 2001 and to June 2002 were included. Patients were excluded if they did not speak Swedish, were already in the terminal stage of their disease, i.e. with a life-expectancy of only a few weeks (Karnofsky performance status, KPS < 50 (Karnofsky and Burchenal, 1949)), or were senile or confused. Of 69 eligible patients, 42 (61%) agreed to participate. Thirty of the eligible patients had a spouse living with them, and these spouses were also asked to participate. Of the 30 eligible spouses, 26 (87%) participated.

Interview data from the first 14 couples included in Study I, where the patient had a diagnosis of advanced cancer without any prior cancer history, were selected for Study II. Of the 23 eligible patients, 61% participated; six patients had declined participation in Study I.

The median survival time of patients in Study I was 7 months (range 1-22) and in Study II the median was 3 months (range 1-11) (when the analyses were conducted, six patients in Study I and three patients in Study II were still alive). Further characteristics of the participants in Study I-II are presented in Table 1.
Table 1. Participant characteristics in Study I-IV. Participants in Study II is a sample from Study I and participants in Study IV is a sample from Study III

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</tr>
<tr>
<td>Chemo &amp; radiation</td>
<td>6</td>
<td>2</td>
<td>26</td>
<td>42</td>
<td></td>
<td></td>
<td>6</td>
<td>38</td>
</tr>
<tr>
<td>Only chemo</td>
<td>24</td>
<td>6</td>
<td>36</td>
<td>58</td>
<td></td>
<td></td>
<td>10</td>
<td>62</td>
</tr>
<tr>
<td>Only radiation</td>
<td>2</td>
<td></td>
<td>36</td>
<td>58</td>
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<td>9</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

\*In Study III and IV patients only had colon cancer, and none rectal cancer.
Studies III-IV

Consecutive patients with colon, breast and ovarian cancer and malignant lymphoma, who were about to end their curative treatment at the Department of Oncology, University Hospital, Uppsala, Sweden from January 2003 and to February 2004, were included. All patients were being treated with chemotherapy, and some in addition with radiotherapy. Patients were excluded if they did not speak Swedish, were in a too poor psychological condition to fill in questionnaires, were younger than 20 years, were included in any other study at the same time, or were senile or confused. Also, patients were excluded if they experienced a relapse during they study period. Of 67 eligible patients, 62 (92%) agreed to participate at baseline, 53 at follow-up 1 and 46 at follow-up 2. Fifty of the patients had a spouse and 42 (84%) of these agreed to participate at baseline, 35 at follow-up 1 and 29 at follow-up 2. The attrition from baseline to follow-up was totally 20 patients and 13 spouses, whom 15 patients were excluded due to relapse of the cancer, and thereby also their spouses (seven persons) were excluded.

To capture a variety of perceptions of the recovery period (Study IV), a purposeful sample was taken from the patients included in Study III. The sample was based on the participants’ gender, diagnosis, and their recovery-related expectations, collected using Recovery-Related Expectations (RRE) questionnaire (see data collection). First, all men (n=7) were chosen (all with colon cancer or malignant lymphoma), then all women (n=7) with colon cancer or malignant lymphoma were selected. Thereafter, these seven women were matched with seven women diagnosed with breast or ovarian cancer, who were similar in age and had comparable RRE scores at baseline. When the interview was conducted, two of the chosen participants were excluded due to recurrence, and three did not wish to participate. The characteristics of the participants in Study III - IV are presented in Table 1.

Data collection

Data collection in the present thesis is based on personal interviews and questionnaire responses. An overview of data collection methods used in Study I-IV is given in Table 2.
Table 2. Overview of data collection methods used in Study I-IV

<table>
<thead>
<tr>
<th>Personal interviews about</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Philosophy of life &amp; changes in life</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>The recovering period</td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Questionnaires</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recovery-Related Expectations (RRE)</td>
</tr>
<tr>
<td>Optimism (LOT)</td>
</tr>
<tr>
<td>Psychological distress (HADS)</td>
</tr>
<tr>
<td>Quality of life (EORTC QLQ-C30)</td>
</tr>
<tr>
<td>Demographic data</td>
</tr>
</tbody>
</table>

**Personal interviews**

*Interviews about philosophy of life and changes in life:* The interviews followed a semi-structured interview guide (see Appendix A), but informants were also encouraged to freely develop their thoughts on each question. The questions were based on Jeffner’s theory of philosophy of life (Jeffner, 1988). Some specific questions were taken from Jeffner’s study and others were developed together with Katarina Westerlund, PhD, in an empirical study of views on life at the Department of Theology, Uppsala University. The interview time varied between 25 and 70 minutes; the interviews were tape-recorded and later transcribed verbatim.

*Interviews about the recovering period:* The interviews were based on two questions: When you had completed your cancer treatment, how did you think the first year after treatment would be? Now, slightly more than a year after completion of cancer treatment, how do you think the first year actually turned out? The informants were encouraged to freely develop their thoughts. After the interview, supportive notes were taken to generate ideas for the analysis (Patton, 1990). The interview time varied between 25 and 55 minutes; interviews were tape-recorded and later transcribed verbatim.

**Questionnaires**

*Recovery-related expectations:* A study-specific questionnaire was developed for measuring Recovery-Related Expectations (RRE) in Study III (see Appendix B). The first part, RRE1 (filled out at baseline), concerns what expectations a person has for the future within domains that can be problematic for people who have completed curative treatment or have a partner who has done so. The second part,
RRE2 (filled out at follow-ups), asks whether the same domains have changed since completion of treatment. The questionnaire includes 20 items based on problems commonly reported by cancer survivors (Beisecker et al., 1997; Dow et al., 1996; Persson et al., 1997; Wettergren et al., 2003). All items, except five, were selected from an instrument developed by Persson et al. (1997). Items 7, 12, 15, 18 and 19 were inspired by several other instruments (Persson et al., 1997; Van Harten et al., 1998; Wettergren et al., 2003) and modified by the first author. Items 1-12 are answered on a scale from 1 (very much for the worse) to 7 (very much for the better). Items 13-16, 18-20 are answered on a scale from 1 (increase very much) to 7 (decrease very much). Item 17 is answered on a scale from 1 (decrease very much) to 7 (increase very much). A higher value always indicates that the domain is expected ‘to become better’ or has ‘changed for the better’. Item 4 was excluded in RRE2 due to an administrative failure.

Optimism: The Life Orientation Test (LOT) was used to measure the personality disposition of optimism (Scheier and Carver, 1985). Of the 12 items, four are positively worded, four negatively worded (reverse scoring), and four are fillers (not scored). The response choices range from 0 (I disagree a lot) to 4 (I agree a lot), which yields a continuous distribution of sum scores from 0 to 32, with higher scores representing greater optimism. Items are, e.g., ‘In uncertain times, I usually expect the best’ and ‘I hardly ever expect things to go my way’. LOT has high reliability and validity (Scheier and Carver, 1985).

Psychological distress: The Hospital Anxiety and Depression Scale (HADS) concerns the assessment of anxiety and depression in individuals with somatic illness (Zigmond and Snaith, 1983). The time window employed was ‘during the past week’. The response choices range from 0 (no problem) to 3 (great problems). HADS consists of two subscales, one for depression (seven items) and one for anxiety (seven items). Subscale scores range from 0 (no distress) to 21 (maximum distress). The HADS has sufficient reliability and validity for detecting anxiety and depression in somatically ill patients (Morrer et al., 1991).

Quality of life: The EORTC QLQ-C30 (version 3) is a 30-item cancer-specific questionnaire on quality of life that is widely used (Aaronson et al., 1993). The instrument measures global health status, five functional scales and various symptoms. In Study III, only the global health scale (two items) was used. The respondent indicates his/her answers on a seven-point scale, from 1 (very bad) to 7 (excel-
lent). The scale was transformed to a 0-100 scale according to the EORTC scoring manual. The EORTC QLQ-C30 has high reliability and validity (Aaronson et al., 1993).

Demographic data: The demographic questionnaire included questions about age, gender, having a spouse, children, education, other illnesses and treatment regime.

Procedures

Studies I-II
The patients and their spouses, if they had one, were asked to participate during their first visit to the Department of Oncology (all patients had been diagnosed at the Department of Surgery prior to referral). The main purpose of the visit was to discuss palliative chemotherapy or radiotherapy. They were then given oral and written information about the study. If the spouse did not attend the first visit, the patient was asked to permit the researcher to contact the spouse. When contact was granted, the spouses were informed about the study. All individuals who agreed to participate were interviewed separately in their home or at the hospital about their ‘philosophy of life and changes in life’ and were thereafter asked to complete the questionnaires, LOT and HADS. Data collection was performed within 1 to 4 months (median 2 months) after diagnosis of the advanced disease.

Studies III-IV
The patients were asked to participate during their second to last chemotherapy cycle, which they received at the daycare unit at the Department of Oncology. They were then given oral and written information about the study. Patients who were willing to participate were asked whether they had a spouse and whether the researcher was permitted to contact the spouse. When contact was granted, the spouses were informed about the study. Data were gathered on three occasions. At baseline, directly after completing either chemotherapy or radiation, the participants received the demographic questionnaire, RRE1, HADS and EORTC-QLQ C-30. At follow-up 1, four months later, the participants received RRE2, HADS and EORTC-QLQ C-30. At follow-up 2, 16 months later, the participants received RRE2, LOT, HADS and EORTC-QLQ C-30. The participants obtained their ques-
tionnaires at baseline from the health care personnel at the daycare clinic, except when the last treatment was radiotherapy, in which case the questionnaires were sent by mail. At follow-up, all questionnaires were sent by mail. The spouses filled out the same questionnaires, but from their point of view.

The patients from Study III who were chosen to be included in Study IV received in addition to the mailed follow-up 2 questionnaires an information letter about the study. One week later, the first author (JW) phoned them to obtain their informed consent. Patients who agreed to participate were interviewed in their home or at the university by the same author. The median time of the interview was 16 months (range 13-18 months) after completed treatment.

**Analyses of interviews**

The present interview data were analysed using two different methods, as the goal of the analysis was different. In Study I, content analysis was used to quantify the content in qualitative data. In Study II and IV, the interviews were analysed using a phenomenographic method to capture qualitative descriptions of the participants’ perceptions of a phenomenon.

**Content analysis**

Content analysis is a research technique for making replicable and valid inferences from data to their context (Krippendorff, 1980). It means that data are reduced into more manageable categories. Answers to open-ended questions are suitable for this technique. The basic assumption is that data can always be looked at from numerous perspectives and that people have different perspectives, therefore, the meanings of data are always relative to the researcher (Krippendorff, 1980). A quantitative content analysis (Weber, 1990) was used to quantify the content of the qualitative data.

*Interviews about philosophy of life and changes in life*: The interviews were analysed to find the possible response categories of each question that focused on philosophy of life: these are marked with a in Appendix A. The analyses were performed in the following steps:

1. The first 14 patient transcripts were read and reread by the author until a set of response categories had been developed for each interview question. All questions, except three, were constructed so
that the answers would be ‘yes’, ’no’ or ’uncertain/partly/ little’. The other three questions had five to six response categories.

2. Then the same procedure was carried out for the transcripts of the first 14 spouses. No differences were found between patients’ and spouses’ response categories: consequently, the participants were treated as one group.

3. A response categorization system for all questions was developed.

4. All 67 transcripts were categorized according to the response categorization system.

5. A research nurse, not belonging to the research group, independently categorized 20% of the 67 transcripts using the categorization system. The median interrater reliability (Polit and Hungler, 1999) was 0.79, ranging between 0.57 and 1.00.

Phenomenography

Phenomenography is a qualitative method developed by Marton and co-workers in the domain of pedagogic research in Sweden, in the early 1970s (Marton, 1981). The word phenomenon is derived from Greek and means ‘what happens’. Phenomenography is concerned with what is perceived rather than with the objective truth (Marton, 1981). The focus of phenomenography studying the limited number of qualitatively different ways in which people conceive of, understand, perceive, think about, experience or remember a phenomenon (Wenestam, 2000b). Central questions involve ‘what’ and ‘how’, i.e. what phenomena the informants describe and how they describe these phenomena (Marton and Booth, 2000). Phenomenography is constantly developing, as described in Ming Fai (2003). Traditionally, phenomenography aims at describing the second-order perspective, i.e. how things are conceived of by persons, and not at describing the first-order perspective, i.e. how things really are (Marton, 1981). Lately, the importance of separating these two perspectives has been toned down. The aim is to distinguish separate central categories, based on different perceptions of the same phenomenon by a number of persons, such that each category has a rich description. The aim is also to preserve the content of each statement concerning the focal phenomenon (Dahlgren and Fallsberg, 1991). For each phenomenon, there are limited ways of perceiving it, and saturation is reached when no further variations emerge (Marton and Booth, 2000). The two phenomenographic analyses in this thesis followed the seven steps of Dahlgren and Fallsberg (1991):
1. Familiarization, get acquainted with the interviews
2. Condensation, select the most significant statements
3. Comparison, significant statements are compared to find similarities and differences
4. Grouping, similar statements are grouped together in a category
5. Articulating, describe the essence of each category
6. Labelling, denote the found categories
7. Contrasting, the obtained categories are again compared to find similarities and differences.

The analyses consist of a constant interplay between the steps.

*Interviews about philosophy of life and changes in life*: The interviews selected for Study II were analysed by the author using a focus on what changes in life the individuals described in the whole interview. The patients’ interviews were analysed first and then the spouses’, but the categories were found to be the same. However, it became clear that the number of persons expressing the different categories differed between patients and their spouses. Therefore, we counted the number of persons expressing the different categories, which is not common in a phenomenographic approach.

*Interviews about the recovery period*: The interviews were analysed by the author using a focus on what and how patients described their expectations and what had happened to their expectations. Most phenomenographic analyses are based on statements, and one person can be included in several categories, but in the present analysis a person could only be included in one category in each theme.

**Statistical analyses**

The Statsoft, Inc. (1999) STATISTICA for Windows was used for all statistical analyses. Substitution of missing values on the questionnaire scales, i.e. LOT, HADS and EORTC QLQ-C30 was made if the patient had completed at least half of the items in a subscale.

**Study I**

Relations between interview questions on philosophy of life and HADS were calculated using two-tailed t-tests for interview questions with two response categories and using ANOVA two-way analyses for interview questions with three categorical answers.
The interview questions ‘being able to influence their life’ and ‘being satisfied with what one had accomplished in life’ had three response categories, but as one response category had very few participants, these questions were recategorized into two response categories. The interview question about ‘being able to influence their life’ was recategorized, so that ‘yes’ (n=3) and ‘partly’ (n=57) became the response category ‘yes/partly’, as they had in common that they believed they could influence their lives; the others were totally negative. The interview question about ‘being satisfied with what one had accomplished in life’ were recategorised so that ‘partly’ (n=21) and ‘no’ (n=2) became the response category ‘partly/no’, because they had in common that they were not totally satisfied. Relations between LOT and HADS were calculated using the Pearson product moment correlation (r). P-values of <0.05 were considered statistically significant.

Study III
The answers to each of the 20 items on the RRE1 scale were divided into three categories: worse (RRE scores 1-2), similar (RRE scores 3-5) and better (RRE scores 6-7). The 20 fulfilled recovery-related expectations were calculated by subtracting baseline expectations (RRE1) from what actually happened at follow-up (RRE2). The difference was divided into a dichotomous variable (RREΔ), where a positive score, including zero, indicates fulfilment of the expectation and a negative one represents non-fulfilment. Most of the items in the instruments are at an ordinal level, and therefore non-parametric statistical methods were used. Correlations were calculated using the Spearman rank-order correlation coefficient (RRE1 vs. HADS and EORTC-QLQ C30, LOT vs. HADS and EORTC-QLQ C30). Differences between groups were tested using the Mann-Whitney U test (RREΔ vs. HADS and EORTC-QLQ C30), the Kruskal-Wallis ANOVA (patients vs. spouses on RRE1) and the Chi² (patients vs. spouses on RREΔ). The statistical significance level was set to p<0.01 to lower the risk of mass significance.

Ethical considerations
Ethical approval was obtained for both main studies included in the present thesis, from the local research ethics committee at the Faculty
of Medicine, Uppsala University. The special ethical question at issue here is whether the advanced group may be harmed when asked deeply personal questions, about their philosophy of life and life situation, in an exposed and vulnerable situation. First, in order to gain knowledge of the situation of patients with advanced cancers, it is necessary to approach the primary source, i.e. the patients and their spouses. Second, research has shown that most patients who are terminally ill appreciate the opportunity to share their experience, even if it is burdensome (Barnett, 2001). Third, because the questions posed in the interview can be emotionally upsetting it is important that the researchers are experienced in handling emotional reactions in a professional way. Both interviewers were educated in this matter and could if necessary refer the respondent to further professional help. In this type of research, informed consent is especially important. Even if participants agreed to participate, they were informed that they did not have to answer every question if they did not wish to.
Results

Philosophy of life in the advanced group

There was no difference between patients’ and their spouses’ philosophy of life, consequently they are presented as one group (Study I). Almost half of the participants ‘believed in a divine power’ and 18% in a ‘life after this’. Seventy-two percent had ‘wondered about why’ the disease had occurred and 18% thought that they had ‘found a meaning’ in getting cancer. For about half of the participants, the diagnosis of advanced GI cancer had ‘changed their most important values in life’ a little or a great deal, and ‘being healthy’ was most frequently mentioned as most important in life. About half of the participants felt ‘favoured by nature’ in life despite the diagnosis of advanced cancer, but many in the other half expressed that the illness had made them feel ‘less favoured’ in life in different ways. Sixty-six percent were ‘satisfied with what they had accomplished’ in life, the rest were partly or not at all satisfied. About half of the participants felt ‘uncertainty and anxiety about the future’, 19% ‘did not even think about the future’ and only 14% ‘had hopes about the future’. The majority thought they ‘could influence their life’ to a certain extent. Thirty percent thought that they ‘could live a good life’ at the time of the interview, 43% that they only ‘partly could live a good life’ and 27% ‘did not at all feel that they could live a good life’.

The relevance of philosophy of life

The dimensions of a person’s expressed philosophy of life that had relevance for psychological distress when investigated in the advanced group are presented in Table 3 (Study I).
Table 3. Statistically significant differences between participants’ philosophy of life and their anxiety (Anx) and depression (Dep). Patients and spouses together, n=68 (Study I), p<0.05.

<table>
<thead>
<tr>
<th>Philosophy of life</th>
<th>N (%)</th>
<th>Anx mean</th>
<th>Test</th>
<th>Dep mean</th>
<th>Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wonder about why</td>
<td>Yes</td>
<td>48 (72)</td>
<td>8.9</td>
<td>t=2.49</td>
<td>7.6</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>18 (28)</td>
<td>5.7</td>
<td></td>
<td>5.1</td>
</tr>
<tr>
<td>Can live a good life today</td>
<td>Yes</td>
<td>20 (30)</td>
<td>5.8</td>
<td>F=3.08</td>
<td>4.9</td>
</tr>
<tr>
<td></td>
<td>Partly</td>
<td>29 (43)</td>
<td>9.2</td>
<td></td>
<td>7.3</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>18 (27)</td>
<td>8.4</td>
<td></td>
<td>8.0</td>
</tr>
<tr>
<td>Satisfied with what has accomplished in life</td>
<td>Yes</td>
<td>44 (66)</td>
<td>7.2</td>
<td>t=-2.11</td>
<td>ns</td>
</tr>
<tr>
<td></td>
<td>Partly /No</td>
<td>23 (34)</td>
<td>9.7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

t=t-test, F=ANOVA

Changes in life in the advanced group

In the qualitatively analysed interviews, the patients and their spouses expressed similar categories of changes in life (Study II). However, they often focused on different parts of the changes and used different ways of handling the situation. All participants described the changes in life as substantial even though some did not seem to be aware of the actual poor prognosis. The changes could consist of one or several of parts presented in Box 1, Figure 3. The changes always consisted of a ‘mental change’, which could include ‘uncertainty’, ‘despair’ and the question ‘why’. Spouses more commonly experienced despair than did patients. The changes in life also included ‘physical changes’, which were more commonly experienced by patients, and ‘practical changes’, which were more commonly experienced by spouses. A few also described a positive change that was similar to finding a meaning in getting cancer.

Patients and their spouses also described several ways of handling these changes in life, presented in Box 2, Figure 3. The most common way of handling the situation for the patients was that they ‘could not complain’ and to ‘make the best of it’. The spouses reported more frequently that they used ‘hope’ and also to ‘make the best of it’. In summary, more patients than spouses seemed to accept the new situation, as fewer patients complained and instead prepared for death, whereas more spouses felt despair, used hope and avoidance, and were preoccupied with practical matters.
Figure 3. The categories of patients’ (in the advanced group) and their spouses’ changes in life and their ways of handling the changes (Study II)

<table>
<thead>
<tr>
<th>Changes in life</th>
<th>Ways of handling the changes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental</td>
<td>Can’t complain</td>
</tr>
<tr>
<td>- uncertainty</td>
<td>Make the best of it</td>
</tr>
<tr>
<td>- despair</td>
<td>Hope</td>
</tr>
<tr>
<td>- why</td>
<td>Reconciliation</td>
</tr>
<tr>
<td>Physical</td>
<td>Preparations for death</td>
</tr>
<tr>
<td>Practical</td>
<td>Seeking support</td>
</tr>
<tr>
<td>Positive</td>
<td>Avoidance</td>
</tr>
</tbody>
</table>

Expectations and their fulfilment in the recovery group

According to the RRE questionnaire, patients generally had higher recovery-related expectations than did spouses (Study III), even though the differences were statistically significant only for the items leisure time, working circumstances, fatigue, physical condition, weight, appetite, power of concentration and view of the self. It was most common for patients to expect that physical condition (74%), fatigue (74%), leisure time (64%), working circumstances (62%) and social activities (61%) would improve in the coming four months. Among spouses it was most common to expect that family life (44%), social activities (37%), physical condition (34%), what is important in life (34%) and depression (33%) would improve in the same period of time.

Many of the patients’ and spouses’ expectations were not realized four or 16 months later. Figure 4 demonstrates the percentage of patients’ and spouses’ expectations for each of the items on the REE, that were fulfilled at follow-up 2. Data from follow-up 1 are not shown, as the degree of fulfilled/unfulfilled expectations did not change significantly between follow-up 1 and 2, with one exception. Patients’ expectations for depression were met to a higher degree at follow-up 2 (67%) than at follow-up 1 (58%)($\chi^2=8.15$, $p<0.01$).
Figure 4. Fulfilled recovery-related expectations in patients and spouses in the recovering group at follow-up 2
Figure 4 also demonstrates that spouses’ expectations tended to be fulfilled to a higher degree than were those of patients, although the differences were only statistically significant for physical condition, sleep, power of concentration and interest in sex at both follow-up 1 and 2.

The importance of expectations

The recovery-related expectations at baseline generally had few associations with patients’ and spouses’ psychological distress or quality of life at follow-up (Study III). Among patients, only one significantly positive correlation was found between expectations and outcome, i.e. the higher the expectations for physical condition, the higher the levels of depression at follow-up 1 (r=0.36, p<0.01). However, among spouses, several significantly positive correlations were found between expectations and psychological distress at baseline, i.e. the higher the expectations for appetite (r=0.42), power of concentration (r=0.49) and view of the self (r=0.41), the higher the levels of anxiety. Also, the higher the expectations on the same items, appetite (r=0.52), power of concentration (r=0.44) and view of the self (r=0.40), the higher the levels of depression. A negative correlation was found between expectations and quality of life at baseline, i.e. the higher the expectations for appetite (r=0.48) and power of concentration (r=0.39), the poorer the quality of life. Further, one positive correlation was found between spouses’ expectations and psychological distress at follow-up 2, i.e. the higher the expectations for appetite, the higher the levels of anxiety (r=0.47) and depression (r=0.58). A positive correlation was also found between expectations and quality of life at follow-up 2, i.e. the higher the expectations for interest in sex, the better the quality of life at follow-up 2 (r=0.47).

The differences between fulfilled and unfulfilled recovery-related expectations at the two follow-ups that were of statistically significant importance for psychological distress or quality of life at the same follow-up are presented in Table 4.
Table 4. Statistically significant differences between whether patients’ and spouses’ recovery-related expectations were fulfilled or not, and their anxiety (Anx), depression (Dep) or quality of life (QoL) at follow-up 1 and 2 (Study III), p<0.01.

<table>
<thead>
<tr>
<th>Expectations were fulfilled</th>
<th>N (%)</th>
<th>Anx md</th>
<th>Test</th>
<th>Dep md</th>
<th>Test</th>
<th>QoL md</th>
<th>Test</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patients at follow-up 1</strong></td>
<td></td>
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<td></td>
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<tr>
<td><strong>Family life</strong></td>
<td></td>
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</tr>
<tr>
<td>Yes</td>
<td>23 (44)</td>
<td></td>
<td></td>
<td>83.3</td>
<td>Z=2.44</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>29 (56)</td>
<td></td>
<td></td>
<td>66.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Social activities</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>22 (43)</td>
<td></td>
<td></td>
<td>83.3</td>
<td>Z=2.92</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>30 (57)</td>
<td></td>
<td></td>
<td>66.7</td>
<td></td>
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<td></td>
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<tr>
<td><strong>Leisure time</strong></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>18 (34)</td>
<td>2.0</td>
<td>Z=3.35</td>
<td>83.3</td>
<td>Z=2.89</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>34 (66)</td>
<td>6.5</td>
<td></td>
<td>66.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Thoughts about disease</strong></td>
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<tr>
<td><strong>Power of concentration</strong></td>
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<tr>
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<td>2.0</td>
<td>Z=2.79</td>
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<td>Z=2.97</td>
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<tr>
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<td>Z=2.57</td>
<td></td>
<td></td>
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<td>3.5</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Z=Mann-Whitney U

The recovery period

When patients were interviewed (Study IV) slightly more than one year after completion of their curative treatment, they described their expectations for the recovery period retrospectively in three different ways (Figure 5). Either they ‘took getting well for granted’ or they ‘hoped to get well’ in time. The third way was to actively make ‘specific plans’ for the period, for how to return to work, how to regain their physical condition, etc. The recovery period itself was perceived to turn out either as ‘smooth’, when life had gone on with no consid-
erable troubles, or as ‘tough’, when it had been a troublesome time with many worries and problems (Figure 5). Patients’ expectations for their recovery period were actually realized in four different ways (Figure 5). If it had turned out ‘as expected’ or even ‘better than expected’, expectations were fulfilled, and patients were satisfied both with the recovery period and with their current life. If the recovery period had turned out ‘different from expected’, expectations were unfulfilled, but mostly due to positive changes in life and they were also satisfied with both the period and their current life. If the period turned out ‘worse than expected’, expectations were unfulfilled, patients were not satisfied with the period and they still felt unwell.

There were connections between participants’ expectations for the recovery period, how the recovery period turned out and whether expectations were realized (Figure 5). Those who ‘took getting well for granted’ all experienced the recovery period as ‘smooth’ and their expectations had turned out ‘as expected’. Moreover, if the recovery period was perceived as ‘smooth’, patients’ expectations were always realized, whereas if the period was ‘tough’, expectations were frequently reported to have been unfulfilled.

<table>
<thead>
<tr>
<th>Expectations for the recovery period</th>
<th>How things turned out</th>
</tr>
</thead>
<tbody>
<tr>
<td>Took getting well for granted</td>
<td>Better than expected</td>
</tr>
<tr>
<td>Hoped to get well</td>
<td>As expected</td>
</tr>
<tr>
<td>Specific plans for getting well</td>
<td>Different from expected</td>
</tr>
<tr>
<td></td>
<td>Worse than expected</td>
</tr>
</tbody>
</table>

Figure 5. The patients’ description of their expectations for the recovery period and how things turned out (Study IV). The lines represent how patients moved through the time period.
Optimism in the two groups

In the present thesis, an additional analysis was performed to compare patients’ and spouses’ levels of optimism in the two samples studied (Study I, III). This indicated that spouses of patients in the advanced group had both significantly lower levels of optimism than patients in the advanced group (mean 17.2 vs. 20.5, t= 3.0, df=65, p=0.003) and significantly lower levels of optimism than spouses of patients in the recovering group (mean 17.2 vs. 20.9, t= 3.0, df=53, p=0.004). No other differences were found.

The importance of optimism

There was a negative correlation between optimism and psychological distress among patients in the advanced group and their spouses, i.e. the higher the levels of optimism, the lower the levels of anxiety (r = -0.45, p<0.01) and depression (r = -0.50, p<0.01)(Study I). There was also a negative correlation between optimism and psychological distress among patients in the recovering group as well as in their spouses, i.e. the higher the levels of optimism, the lower the levels of anxiety and depression. Furthermore, there was a positive correlation between optimism and quality of life, i.e. the higher the levels of optimism, the better the quality of life (Table 5) (Study III).

Table 5. Correlation between patients’ (n=44-46) and spouses’ (n=29) optimism (measured at follow-up 2), and their psychological distress and global health throughout the recovering study (Study III)

<table>
<thead>
<tr>
<th>Psychological distress</th>
<th>Optimism</th>
<th>Patients r</th>
<th>Spouses r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>Baseline</td>
<td>-0.54*</td>
<td>-0.62*</td>
</tr>
<tr>
<td></td>
<td>Follow-up 1</td>
<td>-0.60*</td>
<td>-0.37</td>
</tr>
<tr>
<td></td>
<td>Follow-up 2</td>
<td>-0.64*</td>
<td>-0.68*</td>
</tr>
<tr>
<td>Depression</td>
<td>Baseline</td>
<td>-0.49*</td>
<td>-0.77*</td>
</tr>
<tr>
<td></td>
<td>Follow-up 1</td>
<td>-0.51*</td>
<td>-0.72*</td>
</tr>
<tr>
<td></td>
<td>Follow-up 2</td>
<td>-0.64*</td>
<td>-0.69*</td>
</tr>
<tr>
<td>Quality of life</td>
<td>Baseline</td>
<td>0.33</td>
<td>0.54*</td>
</tr>
<tr>
<td>Global health</td>
<td>Follow-up 1</td>
<td>0.37</td>
<td>0.19</td>
</tr>
<tr>
<td></td>
<td>Follow-up 2</td>
<td>0.39*</td>
<td>0.55*</td>
</tr>
</tbody>
</table>

*p<0.01, r= Spearman rank-order correlation coefficient
Discussion

Mental changes in the advanced group
A person’s philosophy of life is considered to be relatively constant over time (Jeffner, 1988). However, in an extremely threatening situation, such as being diagnosed with an advanced GI cancer or being a spouse of someone with such a diagnosis, some aspects of the philosophy of life seemed to be influenced. The aspects that remained constant were similar to what is expressed in the general population (Jeffner, 1988).

In the present thesis, the most commonly influenced aspects of the philosophy of life were that patients’ and spouses’ current life values and meanings in life were called into question. The existential question of ‘why this had happened’ was often raised, and it was related to higher levels of psychological distress. This has not been reported elsewhere. The finding indicates that having existential questions plays a major role in psychological health.

Persons who have existential questions may be considered to have a more complex personality, while those who do not have such questions can be considered to be less complex, which was shown to be beneficial for well-being. A less complex personality may indicate that events are not appraised as being as threatening as they would be by a person with more complex personality. Alternatively this finding could indicate that people with a less complex personality are not, or do not want to be, realistic and therefore do not realize the severity of the situation.

Patients and their spouses were striving to find answers to their existential questions. This often included changing what was most important in life, finding a meaning in getting advanced cancer, and/or finding new life meanings in their everyday life. Finding meaning has been reported to be accompanied by lower levels of psychological distress (Axelsson and Sjödén, 1998; Stetz, 1989; Strang and Strang, 2001), but this was not confirmed in the 18% of the patients and spouses in the present thesis who found a meaning in getting cancer. However, the 30% who could live a good life despite the illness had
lower levels of psychological distress, which may indicate that they found meaning in their day-to-day life. This may also imply that finding a meaning in getting the cancer is not a necessary precondition of finding meaning in life in general. The patients and their spouses participating in the present thesis often expressed that they were content to have been given an opportunity to talk about their situation and their existential thoughts; this was also reported in patients with brain tumour (Strang et al., 2001). The present thesis findings indicate that existential questions constitute a major theme during the early palliative phase; this theme has repeatedly been reported in the later palliative phase (Bolmsjo, 2000; Greisinger et al., 1997; Griffiths et al., 2002; Murray et al., 2004).

Many of the patients’ and their spouses’ attitudes towards the present situation were influenced by the recent diagnosis of advanced cancer. Some participants perceptions concerning whether they had been favoured in life were influenced by the disease, as only 50% felt favoured in life, which is less than in a normal population, where results show that 77% feel favoured (Jeffner, 1988). Also, the participants’ view of their future was influenced. In a normal Swedish population in the 1980s (Jeffner, 1988), the majority looked upon their future with confidence, but the participants studied here mainly looked upon their future with anxiety and uncertainty. The fact that less than one-fourth of the participants expressed that they had a feeling of hope for the future may be expected. All patients had recently (1-4 months earlier) been diagnosed with incurable cancer, and been informed that active treatment of their cancer would have, at best, only temporary delaying effects.

Hope is important for a meaningful life and a dignified death in a advanced situation (Benzein et al., 2001), and it contributes to positive psycho-spiritual well-being (Lin and Bauer-Wu, 2003). However, the hopes for the future that participants had before the diagnosis are often no longer possible. Now they have to find new hopes, such as living as normally as possible and experiencing confirmative relationships, which are common in patients in the later stages of the advanced situation (Benzein et al., 2001).

The religious beliefs, i.e. beliefs in a divine power or what happens after death, found in the present thesis are similar to those of the general population (Jeffner, 1988; Kallenberg and Larsson, 2000). However, in other Western countries, religious beliefs are more common than they are in Sweden (Reis, 1994). Such beliefs are often shown to be associated with better well-being in cancer patients.
(Swensen et al., 1993; Yates et al., 1981), but in a recent review they are also shown to be of no relevance or even harmful to well-being (Thune-Boyle et al., 2006). In the present thesis, religious beliefs had no relevance for psychological distress. Moreover, participants did not report that such beliefs had been influenced by the diagnosis.

Patients in the advanced group and their spouses expressed that they experienced similar mental changes in the qualitatively analysed interviews, i.e. their philosophy of life had become unstable. However, patients and their spouses focused on different things in their life situation and handled them differently. Patients seemed to accept their situation to a greater extent than their spouses did. Patients expressed less despair and had lower levels of psychological distress, which has also been seen in other studies (Axelsson and Sjödén, 1998; Carlson et al., 2000; Nordin et al., 2001; Siegel et al., 1996). This is probably because patients can resolve concerns by setting goals themselves (Harrisson et al., 1995), thereby striving to achieve as small discrepancies as possible between the perceived attainment and the importance of life values, as part of their adjustment to a serious disease (Nordin et al., 2001). Spouses often feel they are helpless observers, who can do little to influence the situation (Harrisson et al., 1995), and they need more help in finding a sense of meaning and dealing with unproductability than the patients themselves do (Soothill et al., 2002). In addition, spouses have larger discrepancies between the perceived attainment and the importance of life values, which is related to higher psychological distress (Nordin et al., 2001).

Expectations in the recovering group

Many patients who had completed their curative cancer treatment, and some of their spouses, had high expectations for their recovery period in most of the items in the RRE questionnaire, and their expectations were not always realized four or 16 months later. This suggests that their lives often did not return to normal as they had expected. These findings have also been reported elsewhere (Andrykowski et al., 1995; Hobson et al., 2001; Holzner et al., 2001). The qualitative interview confirmed that many patients expected that they would get well quite soon after treatment completion, and these expectations were often not realized. The reason why patients, and some spouses, had such unrealistic expectations may depend on the fact that they had received little information about what they could expect from the recovery period
and how they should cope with it, or that they had forgotten about any information they may have received. Alternatively, unrealistic expectations may depend on the fact that, as Andrykowski et al. (1995) have discussed, people are generally overly optimistic and underestimate the likelihood that negative events will happen or are likely to respond to stressful situations with unrealistic optimism. Additionally, being optimistic, as measured using LOT, had a positive effect on a person’s levels of psychological distress.

The few recovery-related expectations in the RRE that correlated with psychological distress and/or quality of life did not show any general pattern. High expectations could theoretically be associated with both better and poorer well-being. Other longitudinal studies have shown contradictory results. Some report an association between high expectations for a medical treatment and a better well-being (Cohen et al., 2001; Engel et al., 2004; Koller et al., 2000; Leedham et al., 1995; Sears et al., 2004), whereas others do not (Lee et al., 2003; Mahomed et al., 2002).

In general, few of the fulfilled/unfulfilled recovery-related expectations in the RRE were of importance for participants’ psychological distress and/or quality of life. If expectations were unfulfilled, this was associated with more psychological distress and/or poorer quality of life in participants, which supports results from other studies (Andrykowski et al., 1995; Holzner et al., 2001; Koller et al., 2000; Rose et al., 1995). In a study by Hobson et al. (2001), no such relation was found. Even though the 20 measured expectations on the RRE were fulfilled to the same extent at the four- and 16-month follow-ups, different items of fulfilled expectations had importance for the participants’ psychological distress and/or quality of life at the two points in time. Additionally, it can be concluded that even though over 70% reported that expectations for physical condition and fatigue had not been realized at either follow-up, this had no relevance for psychological distress and/or quality of life. This may indicate that participants had accepted their physical changes and adjusted to the situation. They might therefore also have adjusted to other changes, so that their original expectations became less important. Expectations are reported to change in the face of new information and changing circumstances (Phillips et al., 2001; Staniszewska and Ahmed, 1999), and patients change their perception of what is important in life to keep their psychological well-being at a high level (Nordin et al., 2001).
This reasoning is confirmed by the qualitative interviews, in which the majority of patients had a feeling of satisfaction with their current life, regardless of whether expectations had been met slightly more than one year after treatment. They seemed to have adjusted successfully, as has also been reported in other studies (Walker et al., 1996; Wallwork and Richardson, 1994). In the present thesis, the patients who perceived that their way back had been tough and that their expectations were not met seemed to compensate negative changes in life with positive changes. Such positive changes are commonly reported among cancer survivors (Curbow et al., 1993; Dow et al., 1996; Hallörsdóttir and Hamrin, 1996; Westman et al., 2006) and their spouses (Northouse et al., 1999). Furthermore, according to the theory of Folkman and Geer (2000), positive changes constitute coping processes that help develop and sustain a sense of psychological well-being, despite unfavourable circumstances, and are believed to result in a feeling of life satisfaction that is greater than for people in general (Kessler, 2002).

It is interesting to observe that, in the recovering group as well, it seemed beneficial for well-being to be a person with a less complex personality, as discussed earlier with regard to the advanced group. Those patients who took for granted that they would get well in the qualitative interview could be considered to have a less complex personality. They all experienced a smooth recovery period and described that things had turned out as expected. The patients who may be considered to have a more complex personality, i.e. those who hoped to get well or had specific plans for getting well, often had a tough recovery period during which expectations were not fulfilled.

Optimism in both groups

The present findings show that optimism is of importance for psychological distress among patients and spouses in both the advanced and the recovering group. This is consistent with results from other studies that have focused on patients in advanced stages of cancer (Miller et al., 1996) or who have survived cancer (Carver et al., 2006; Curbow et al., 1993; Deimling et al., 2006). In another study, optimism in spouses of lung cancer patients had no main effect on depressive symptoms, although, pessimism did. In the spouses of patients with advanced cancer, the effect of optimism on depression was the strongest (Pinquart and Duberstein, 2005). This implies that optimistic indi-
individuals handle stressful situations easier than pessimistic individuals do.

Optimism, as measured by LOT, is thought to be a stable personality characteristic (Scheier and Carver, 1992). Optimism has been reported not to change over time, neither in patients in curative (Carver et al., 1994) nor advanced stages (Miller et al., 1996). It is also reported to be stable even when disease-free patients receive bad news (Schou et al., 2005). However, the trans-situational stability may be questioned, as the increased stress associated with women’s roles as wife and employee is reported to be linked to decreased optimism (Atienza et al., 2003). Only one study is found that reports comparisons of LOT scores among cancer patients in different stages across several studies (Miller et al., 1996). However, because the study by Miller et al (1996) did not consider the fact that different versions of the LOT were being compared, the results are not valid. In the present thesis, the additional comparison of LOT values in the two samples indicated that patients in the two groups and spouses of patients in the recovering group had similar LOT scores, and these were similar to those found in a normal Swedish population (n=2500) (Scott and Melin, 1998). However, spouses of patients in the advanced group had significantly lower levels of optimism than did patients in the advanced group and spouses of patients in the recovering group. This may be because they are caregivers, just as caregivers to patients with dementia, who are reported to have lower levels of optimism than a control-group of non-caregivers (Robinson-Whelen et al., 1997). Further, optimism is a strong predictor of caregivers’ reactions to the burden of caring for a cancer patient (Kurtz et al., 1995). This indicates that even though optimism is stable across time in one life situation, it is not always stable across different life situations. This suggests that the situation of spouses of patients with advanced cancer is particularly difficult, as already discussed above.

Methodological considerations

Design and research perspectives

One strength of this thesis is that both qualitative and quantitative approaches were combined, which gives a more comprehensive picture of the aspects studied. Study I and II were cross-sectional, as the aim
was to explore philosophy of life, optimism and changes in life when patients had been newly diagnosed. It is possible that these aspects change over time, but longitudinal studies are quite rare in this context (Hinton, 1999) due to the difficulties to inherent in following these patients during such a physically and psychologically demanding period. Study III was prospective, designed to enable conclusions to be drawn about the importance of expectations, and their fulfilment, for well-being. Study IV was planned after Study III and therefore become a cross-sectional study with a retrospective design, which is a methodological problem as memory is probably selective. However, Study IV gave a more comprehensive picture of expectations and their realization, thus making it easier to understand the results of Study III.

Sample
The subjects in both samples were chosen consecutively from one Department at one hospital. This makes the setting homogeneous, i.e. participants received similar care. It is a strength that participants are in the same situation when data are collected. However, because only a few participants could be included each month, the inclusion time had to be restricted, which limits the sample size. Another limitation in the sample from the advanced group was the selection of those who had the best performance, which was done because those who were too ill and had a shorter survival time could not be considered for inclusion. Further, some patients never visited the Department of Oncology after the diagnosis at the Department of Surgery, and were therefore never considered for inclusion. In this context, a participation rate of 61% among patients is rather good. In the sample from the recovery group, the greatest limitation was that some participants were excluded due to relapse of their cancer. It was not possible to include recurrent patients, because a recurrence greatly influences their lives. Thus, the attrition rate was rather large, 26% for patients and 31% for spouses from baseline to follow-up 2. The result was that patients who completed the study all had a rather good prognosis. The attrition was not biased, however, in terms of individuals’ different recovery-related expectations, quality of life or psychological distress.

The two qualitative studies (Study II, IV) both used a sample from a larger sample. In Study II, the bias was the same as in the larger sample, that patients with shorter survival and poorer performance were not included. In Study IV, the purposeful sample was intended to capture persons who were as different as possible with regards to gen-
der, diagnosis and expectations measured using the RRE questionnaire in Study III. The bias was that five women were lost because of late relapse of cancer or unwillingness to participate, and therefore the purposeful sample was not as good as planned. In both qualitative studies, the sample included those with higher levels of well-being. Those who did not participate would probably have strengthened certain categories, but not generated new ones.

Data collection and analysis

Talking about one’s philosophy of life is very personal and not easily measured, which is why an interview was chosen to allow patients to develop their thoughts freely. This was a good choice, as a few participants thought that some questions were difficult to understand, did not have a language for expressing their philosophy of life or seemed not to have been thinking about these aspects of life at all. Also, in a few cases, it was difficult to create an optimal atmosphere because the respondent became sad or upset. To increase the construct validity the interviews were conducted by two persons, who both had knowledge of dealing with people in a crisis. The answers to the interview questions were analysed using content analysis, so that it would be possible to do statistical analyses to explore whether the answers had relevance for psychological distress. To increase the reliability of the categories, 20% of the interviews were analysed by two independent researchers. The median interrater reliability was 0.79. It would probably have been better if all interviews had been analysed, because the response patterns became more coherent as more interviews were analysed. However, it can be argued that different raters use different perspectives and that diverging results may reflect the complexity of the data, rather than inconsistencies, as life is often complex and contradictory (Strang, 2000).

Measuring expectations is considered difficult (Staniszewska, 1999), and using the RRE questionnaire constitute one attempt to make such measurements. The questionnaire RRE was created on the basis of knowledge presented in the literature, and includes items measuring problems that patients often experience during their recovery period. When patients in the open interviews retrospectively described their expectations for the recovery period, these were mostly expressed as one general expectation about getting well, and not as possible problems that may arise. A similar pattern was also seen when expectations for a hospital stay were measured in patients with
cardiac problems (Staniszewska, 1999). This indicates that a standard-
ized scale may cause expectations in people that they originally may
not have (Staniszewska, 1999) or that are of rather limited importance
at the time. However, in the open interview, some patients also ex-
pressed having expectations that were measured using the RRE. Peo-
ple’s expectations are not easy to predict, and it would have been bet-
ter if the open interview had been conducted at baseline, as a pilot
study for generating questionnaire items. Then more general items,
such as success of treatment and overall well-being would have been
included in the RRE.

The fact that, in present thesis, optimism was the most clearly im-
portant aspect for psychological distress may be because if was the
only aspect measured using a standardized questionnaire.

Optimism was only measured at follow-up 2 in Study III, as the
use of LOT was not planned originally. If LOT had been used at base-
line, the results may theoretically have been different, but optimism is
considered to be stable across time (Scheier and Carver, 1992) in a
similar life situation and therefore this is not likely to have influenced
the results.

The two qualitative studies presented here were carried out using a
phenomenographic approach. Study II was conducted on data col-
lected for Study I, and therefore the data consisted of interviews that
followed an interview guide with many questions, and not one or two
main questions about the phenomenon studied, as is suggested when
conducting a phenomenographic study. Further, analysing Study II
using a phenomenographic approach can be questioned, as it did not
follow the basic assumption that the outcome should represent a de-
scription of variations in a phenomenon (Dahlgren and Fallsberg,
1991; Wenestam, 2000a). The focus should be on differences in the
sample, rather than on similarities, which were focused on here. How-
ever, differences became apparent when numbers of individuals ex-
pressing each category were presented. Another limitation is that the
analysis was made without a co-researcher. Study IV followed the
main goals of phenomenography, and coherence of categories was
evaluated by a co-researcher.

Mass-significance was not considered to be a problem in Study I
because so few statistical analyses were performed. On the other hand,
many statistical analyses were done in Study III, which is why the
level of significance was increased to p<0.01.
Conclusions and further directions

This thesis uses both qualitative and quantitative methods to describe cancer patients’ and their spouses’ situation in an advanced and a recovering situation, and to study aspects that may be important for psychological distress in the two different groups.

Patients recently diagnosed with advanced cancer and their spouses experienced substantial changes in life. These changes were mainly mental. Aspects of their philosophy of life were being influenced because their current life values and meaning in life were being questioned. The presence of these existential questions was related to worse psychological distress. Also, participants’ attitudes towards the present situation and their views on their future became influenced by the diagnosis. They were often plagued by despair and uncertainty. Changes in life could also include physical and practical changes. Moreover, changes could also be positive, which meant that participants had found a meaning in getting cancer, which was not related to lower levels of psychological distress as other studies have implied. However, one-third of patients, and their spouses, expressed that they could live a good life despite the illness, and these individuals had lower levels of psychological distress. Patients in this group more often seemed to accept their situation and prepare for death, whereas spouses had more difficulties handling the situation and had higher levels of psychological distress.

Patients mainly expected that they would get well in the recovering situation after their curative treatment. They expected that their physical condition would improve, that they would return to work, that leisure time, social life and family life would improve. Some had plans for how this would happen, while others had no such plans. Both four and 16 months later, many of their expectations had not been fulfilled, especially expectations for physical condition and interest in sex. According to the questionnaire and qualitative interviews, however, whether or not expectations had been met was of little importance for patients’ general well-being. This seemed to be because, irrespective of their expectations for the period, those whose recovery
period had gone smoothly, always experienced that their expectations were fulfilled and that they were satisfied with their current life. Further, those whose period had been tough often experienced positive changes, e.g. found new meanings in life, that seemed to compensate for their unfulfilled expectations, causing them to feel as satisfied with their current life as were those whose expectations were met. Only a small proportion of the patients, whose recovery period had been tough and whose expectations were not met, still felt unwell slightly more than one year after curative treatment. Spouses of patients in the recovery group generally had lower expectations for the future than patients did. Furthermore, spouses’ expectations were fulfilled to a greater degree than were patients’ expectations when measured with the questionnaire.

Optimism, as a personal characteristic, was the aspect that was most clearly beneficial for patients’ and spouses’ psychological distress, both in the advanced and the recovering situation. Spouses of patients in the advanced group had the lowest values of optimism, compared with the patients in both groups and spouses in the recovering group. Spouses’ levels were also lower than those found in the general public.

Clinical implications
Some suggestions for clinical practice are based on findings in the present thesis.
In the early stage of the palliative phase, health care personnel should create an atmosphere in which patients’ whole situation can be penetrated. It should include mental, physical and social changes in life. The common existential questions should also be addressed. The main focus should be on helping patient find new hopes and meanings in their lives, as well as on making the best of things regardless of what happens, so that patients feel that they can live a good life despite the illness. If patients wish, they should be referred to more professional help, such as the hospital chaplain, social worker or a nurse specialized in psychosocial oncology. If patients are not prepared to discuss these issues, this must of course be respected.
Spouses of cancer patients in the early stages of the palliative phase have even greater psychological needs than do patients, and these should be assessed by health care personnel, so that both mental
and practical support can be offered. If spouses are more comfortable in the situation, they are likely to be better able to support the patients.

When patients are about to proceed to a recovering situation after curative cancer treatment, their expectations and plans for the recovering period should be addressed by the doctor or a nurse. This should include information about how tough the period can be and that it can take a long time, as well as information about whom they should turn to if they need help. At the next appointment, the patient’s status and how the recovery is progressing should be evaluated. If the period is perceived as tough, the patient should be offered professional help, individually or in a group. This can include physical training to get back into physical condition, psychological support to find a new balance in life and to learn how to cope with the new situation, or possibilities to get answers to medical questions. All of this can be included in a group support programme.

In all stages of a cancer, health care personnel should strengthen optimistic attitudes by encouraging positive expectations regarding the patient’s, or the spouse’s, own ability to cope with their situation, as well as hopes for the future. Further, health care personnel should be aware that pessimistic persons need more help than do optimistic persons in dealing with a cancer situation.

Suggestions for further research

Future research should focus on interventions aimed at helping patients and spouses handle their existential questions in an effective way, so as to decrease psychological distress. Furthermore, research on the early stages of palliative care should focus on spouses’ specific needs, using intervention studies to discover how their psychological burden can be reduced.

In future studies, if expectations are to be explored using a questionnaire, items must be developed on the basis of qualitative interviews or focus groups with persons currently in the situation under study. The validity and reliability of such questionnaire must be well established. If the questionnaire RRE is to be used, it requires further development. Some new items should be included and others removed. Further, the response alternatives should be changed so that both positive and negative expectations are not measured for each item. One suggestion is to make each item a statement about the re-
covery period, with which the patient must agree or disagree, e.g. “I will return to work within four months”.

The relation between expectations for the recovery period and whether these are met, and patients’ well-being seems to be complex. Thus, other aspects, e.g., positive changes in life, optimism, earlier psychological problems, post-traumatic stress, social support, need to be included in future studies.

The notion that optimism is stable over time in a specific life situation has considerable support in the research. However, how stable optimism is across different life situations needs to be explored further. Comparisons of levels of optimism, measured by the same versions of LOT, among patients and spouses in different life situations are called for. Also necessary are studies in which persons in one life situation is followed over time to another life situation, such as in a cancer-screening situation, where some will suddenly receive the disease.

While optimism is beneficial in a cancer situation, future intervention studies need to focus on whether and how an individual’s levels of optimism can be influenced in a positive direction.
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Summary in Swedish

Det övergripande syftet med avhandlingen var för det första att hos patienter som nyligen diagnostiserats med en avancerad cancer och deras anhöriga att undersöka livsåskådning, förändringar i livet och optimism. För det andra att hos patienter som skall återhämta sig efter en avslutad botande behandling av cancer och deras anhöriga undersöka förväntningar på framtiden och optimism. För det tredje, om livsåskådning, förväntningar och optimism hade betydelse för psykologiskt välbefinnande och livskvalitet.

Data samlades in från två olika sampel. Det första bestod av 42 patienter som nyligen diagnostiserats med avancerad mag- och tarmcancer och 26 av deras anhöriga. Data om deras livsåskådning, optimism och psykologiska välbefinnande samlades in vid ett tillfälle (Studie I). Utöver detta användes en kvalitativ metod för att beskriva förändringar i livet hos de 14 första intervjuade paren (Studie II). Det andra samplet bestod av 62 patienter som hade avslutat sin kurativa cancerbehandling och 42 av deras anhöriga (Studie III). Data om deras förväntningar på sin återhämtningsperiod, optimism, psykologiskt välbefinnande och livskvalitet samlades in prospektivt vid tre tillfällen under drygt ett år. Även här användes en kvalitativ metod för att hos 16 patienter retrospektivt beskriva vilka förväntningar de hade haft på sin återhämtningsperiod och hur det var drygt ett år senare (Studie IV).

högre förväntningar på sin återhämtningsperiod än vad deras anhöriga hade. Patienternas förväntningar hade mer sällan än de anhörigas infriats fyra och 16 månader senare. Det var få av deras förväntningar på perioden, och även få av deras infriade förväntningar som hade betydelse för deras psykologiska välbefinnande eller livskvalitet (Studie III). En del patienter beskrev att de hade gjort specifika planer för hur de skulle bli bra under sin återhämtningsperiod, andra tog det för givet eller hoppades på att de så småningom skulle bli bra igen. Om patienterna tyckte att återhämtningsperioden hade gått lätt blev deras förväntningar alltid infriade, medan om de tyckte att perioden hade varit tuff så var det vanligare att deras förväntningar inte hade infriats. Oavsett vad som hänt med deras förväntningar så var de flesta nöjda med sin livssituation drygt ett år efter avslutad behandling, några mådde dock fortfarande dåligt (Studie IV). Att vara optimistisk som person hade betydelse för ett bättre psykologiskt välbefinnande för deltagarna i de båda sampel som studerades, samt för bättre livskvalitet i återhämtningsgruppen (Studie II, III).

Sammantaget så visar denna avhandling att den viktigaste aspekten för ett bättre psykologiskt välmående i de grupper som studerats var att vara en optimistisk person. Det var också tydligt att en avancerad cancer främst framkallade negativa mentala förändringar, så att existentiella frågor blev vanliga vilket hörde samman med ett sämre psykologiskt välbefinnande. Vidare hade främst patienterna förväntningar på sin återhämtningsperiod som inte infriades, men detta hade lita betydelse för deras psykologiska välbefinnande eller livskvalitet, dock var positiva mentala förändringar betydelsefulla om perioden hade varit tuff. Denna avhandling påvisar att sjukvårdspersonal både bör fånga upp och hantera livsåskådningsfrågor bland patienter och anhöriga som nyligen hamnat i den palliativa fasen av en cancersjukdom, samt ge extra stöd till patienter som upplever återhämtningsperioden som tuff.
References


Michelson, H., 2002. Long term health related quality of life among women with high-risk breast cancer receiving adjuvant high-dose chemotherapy: a comparison with the normal population, Department of Oncology-Pathology, Karolinska Institute, Stockholm.


Appendices

Appendix A

The interview guide to the patient about philosophy of life and changes in life

1. What do you think a good life is?
   Do you think that you can live a good life today? a

2. In what way could it get better and what would make it worse?
   Do you feel you have close relationships to other persons?
   What is important in a close relationship?

3. Do you think you can influence your life? a
   What can you influence and what can you not influence?

4. Are you satisfied with what you have accomplished in life? a
   What do you think shaped your life so it turned out like it did?

5. Do you think you are more or less favoured by nature? a

6. What do you think is most important in life? a
   Has what is most important in life changed since the diagnosis? a

7. What do you thing about your future? a

8. Do you wonder about why you got cancer? a
   Can you find a meaning in what has happened? a

9. Do you believe in a divine power? a
   Do you have any experiences of this power?

10. Do you believe in a life after this? a

11. Where do you get your strength from when life is hard?

12. When life is hopeful, how do you express your joy?

The questions marked with a were included in Study II.
Appendix B

The RRE1 for patients. Developed by Winterling, J 2004.

How do you believe that the following domains will change in the four months after you have completed your cancer treatment?

<table>
<thead>
<tr>
<th></th>
<th>Change a lot for the better</th>
<th>Change for the better</th>
<th>Not change</th>
<th>Change for the worse</th>
<th>Change a lot for the worse</th>
</tr>
</thead>
</table>

**Socio-economic situation**
1. Family life
2. Social activities
3. Leisure time
4. Working circumstances
5. Finance

**Physical health**
6. Fatigue
7. Physical condition
8. Weight
9. Appetite
10. Sleep
11. Power of concentration
12. The view of my self

**Psychological health**
13. Depression
14. Anxiety
15. Thoughts about the disease
16. Thoughts about death

**Sexuality**
17. Interest in sex

**Thoughts about lifestyle**
18. Thoughts about future health
19. Thoughts about how to take care of oneself
20. Thoughts about what is important in life
A doctoral dissertation from the Faculty of Medicine, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine. (Prior to January, 2005, the series was published under the title “Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine”.)