Living and Coping with Cancer

Specific Challenges and Adaptation

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Abstract

Wasteson, E. 2007. Living and Coping with Cancer. Specific Challenges and Adaptation. Acta Universitatis Upsaliensis. *Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Social Sciences* 28. 59 pp. Uppsala. ISBN 978-91-554-6849-1.

The overall aims of this thesis were to prospectively investigate how specific challenges among patients with commonly occurring cancers are related to adaptation and well-being, to predict later well-being using a range of psychosocial aspects and to compare two ways of measuring coping with cancer. This was studied at diagnosis in patients with gastrointestinal cancers and their spouses and at termination of cancer treatment and during follow-up in a heterogeneous group of cancers. At *diagnosis,* higher levels of psychological distress were accompanied both by more coping attempts and less perceived control over the stressful events. Somatic aspects and Everyday concerns were frequent stressful events. The most frequently used coping strategies were emotion-focused. The Daily Coping Assessment (DCA) rendered a varied picture of ways of handling the stressful events (Study I). When studying coping as a process, the DCA has advantages compared to the commonly used measure MAC, since DCA better separates coping from both the stressful event and outcome. A comparison of the DCA and the MAC rendered differences regarding the usage of coping strategies (Study II). Patients with higher levels of anxiety/depression also had higher discrepancies between attainment and importance for most life values compared to patients with less anxiety/depression. For the patients, but not for the spouses, the discrepancies for several life values along with anxiety and depression decreased over time (Study III). Anxiety/depression at *termination of treatment* are strong predictors for anxiety/depression and QoL at follow-up. However, other variables like psychiatric history, the bother an event caused, the coping strategy Acceptance, the stressful event Thoughts/affects and emotional and instrumental aspects of social support contributed to the prediction (Study IV). Thus, it is concluded that detailed information regarding specific and frequent situations among cancer patients is possible to reveal and necessary for a better understanding of what influences well-being.

Keywords: stressful events, appraisal, coping, life values, social support, psychiatric history, anxiety, depression, well-being, quality of life, cancer, spouses

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To Andreas, Karolina & Edward

Give us grace to accept with serenity the things
that cannot be changed,
courage to change the things,
which should be changed,
and the wisdom to distinguish the one from the other.

List of Papers

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals.

I.   Wasteson, E., Nordin, K., Hoffman, K., Glimelius, B., Sjödén, P-O. (2002) Daily assessments of coping in patients with gastrointestinal cancer. *Psychooncology*, 11(1): 1-11

II.   Wasteson, E., Nordin, K., Glimelius, B., Sjödén, P-O. (2006) Comparisons of a questionnaire commonly used for measuring coping with a daily-basis prospective coping measure. *J Psychosom Res*, 61(6): 813-820

III.   Nordin, K., Wasteson, E., Hoffman, K., Glimelius, B., Sjödén, P-O. (2001) Discrepancies between attainment and importance of life values and anxiety and depression in gastrointestinal cancer patients and their spouses. *Psychooncology*, 10(6): 479-489

IV.   Wasteson, E., Glimelius, B., Nordin, K. Termination of cancer treatment. Stressful events, adaptation and prediction of well-being at follow-up. (manuscript)

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Contents

Introduction

A range of psychosocial aspects is certainly of importance for a person's adaptation to a severe disease like cancer. In order to make an assessment of the interplay between these aspects and the adaptation meaningful, it is necessary to assume that "cancer" contains multiple situations with very specific challenges and not only a single challenge or situation. More specific and clinically relevant information will hopefully then emerge about how patients adapt to specific and typical stressful events commonly occurring among cancer patients and how different psychosocial aspects influence this adaptation. Information regarding the possibilities to predict later well-being is also of great relevance. This thesis has included several diagnoses considered relevant for the aims, namely, gastrointestinal (GI)-, breast-, and ovarian cancer and malignant lymphomas. To study relevant aspects of adaptation, two situations, viz, "primary diagnosis" and "terminating cancer treatment" are chosen since they are as potentially stressful for the patients.

For the purpose of understanding potentially relevant aspects of adaptation when the patient is confronted with a specific challenge during a disease a model by Moos and Schaefer (Holahan, Moos, & Schaefer, 1996) is used as a framework of the coping process (See Figure 1). The model presumes that both persistent personal factors and more changeable situation specific factors form the coping efforts. The environmental system (Panel 1) constitutes ongoing life stressors and social resources. This is conceptualized by the social support in the thesis. The personal system (Panel 2) is composed by an individual's sociodemographic characteristics and personal factors and is measured by psychiatric history. Both the stable and situational factors influence the significant changes in life (Panel 3) which are represented in the thesis by the stressful events occurring during the two specific situations of the cancers. These significant life changes in combination with environmental and personal factors influence well-being and health (Panel 5). This constitutes the "outcome" panel and is in this thesis measured by anxiety, depression, i.e. emotional well-being, and quality of life. According to the model the impact on well-being is further mediated by additional factors (Panel 4) and measured by appraisal, coping and changes in life values. The paths in the model are bidirectional which indicate that reciprocal feedback can occur at every stage.

Figure 1. Model based on the general conceptual framework of the coping process developed by Moos and Schaefer (Holahan, Moos, & Schaefer, 1996). In the present thesis, the Panels are conceptualized by the concepts marked in bold.

Stress and disease

Within a variety of areas of research, science takes a starting-point in the fact that a somatic disease is associated with distress for the individual. Within philosophy the concept of "Homelessness" has been used to characterize the state when an individual has become ill (Heidegger & Matz, 1993; Svenaeus, 2003). This form of "Homelessness" in the disease affects the individuals' thoughts and movement pattern. The term refers to a state of understanding rather than a state of psychiatric condition. Within the domain of psychology, an individual's disease is an important life event that must be taken into account when assessing risk for stress and stress- related diseases (Holmes & Rahe, 1967). Chronic diseases and their treatments pose a number of threats both to those afflicted and their spouses, cancer being no exception. According to Baum and Posluszny (2001), different aspects (e.g. emotional and social) of the patients' life are potentially affected by the cancer and its treatment, both of which are considered as stressful. The potential stress of having cancer may put the spouse in a stressful situation as well and, according to some studies, spouses experience more psychological distress than the patients themselves (Kornblith, Herr, Ofman, Scher, & Holland, 1994; Vickery, Latchford, Hewison, Bellew, & Feber, 2003). Irrespective of the particular cancer-related stressor, the patients' perception, i.e. appraisal, of

the stressor is of decisive importance for the ensuing reactions. Although high levels of emotional distress related to a life-threatening disease can be expected, other research gives a somewhat different picture. For instance, none or only slight differences between cancer patients and population-based controls regarding psychological distress have been observed (van't Spijker, Trijsburg, & Duivenvoorden, 1997). Several factors may contribute favorably to well-being during stress. Research concerning factors mediating the adjustment process, i.e. coping and appraisal (Richard S. Lazarus, 1999; Richard S. Lazarus & Folkman, 1984; Arthur A. Stone & Neale, 1984), social support (Akechi et al., 2004; Ganz et al., 2003; Parker, Baile, de Moor, & Cohen, 2003), response shift (Sprangers & Schwartz, 1999) and a change in life values (Lampic, Thurfjell, Bergh, Carlsson, & Sjoden, 2002; H. Montgomery, Persson, & Ryden, 1996), strive to describe and explain the relation between stress and adaptation.

The coping process

Stressful events

Much research has investigated the relations between stress and health, focusing on the role of coping as a moderator, with many important findings (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992; Heim et al., 1987). A particular interest has concerned the handling of stressful events. Several studies of coping with cancer have, however, employed very vague conceptualizations of the stressor "cancer" in terms of what specific events the individual attempts to deal with. Thus, cancer has been treated as a unitary stressor (Inoue, Saeki, Mantani, Okamura, & Yamawaki, 2003; Link, Robbins, Mancuso, & Charlson, 2004) with no concerns for its various components. Such research has shed little light on how people manage the multitude of specific stressors that a diagnosis of cancer can infer. A specification of the demand is needed for an understanding of the process (R. S. Lazarus, 1993; Arthur A. Stone & Neale, 1984).

Appraisal and coping

According to Lazarus and Folkman (1984), coping is defined as "constantly changing cognitive and behavioural efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resources of a person" (p.141). Coping is a process that is changeable over time and related to the type of situation in which it occurs (Richard S. Lazarus & Folkman, 1984), Folkman and Lazarus make some important distinctions for the understanding of the phenomenon of coping (Folkman & Lazarus, 1980, 1985). Firstly, their theory of stress and coping consists of three processes, primary

appraisal, secondary appraisal and coping. Primary appraisal involves the perception of something as a threat. Secondary appraisal involves the process of bringing to mind a potential response to the threat. Coping is the process of executing that response. Moreover, a distinction is made between two functions of coping: problem-focused and emotion-focused coping. Problem-focused coping aims at modifying the source of the stress whereas emotion-focused coping aims at reducing or managing the emotional stress that is associated with the situation. The coping processes leads to an outcome of the event. This could be a favourable resolution, an unfavourable or no resolution at all. Throughout the process, emotion is generated (Folkman, 1997; Richard S. Lazarus & Folkman, 1984). Folkman and Greer (Folkman, 1997; Folkman & Greer, 2000) have proposed a modification of the coping model from 1984 ((Richard S. Lazarus & Folkman, 1984) in which they among other things discuss the term meaning-based coping. Meaning-based coping involves the patient's ways of abandoning untenable goals, make sense of what is happening and appraise benefit when possible (Folkman & Greer, 2000). Also, since coping is changeable, repeated assessments may be necessary. Further, for the purpose of understanding the coping process, Lazarus recommends that coping should be measured separately from its outcome (Richard S. Lazarus, 1999).

Measures of coping

Assessment of coping within a specified framework related to the cancer, e.g. the period shortly following diagnosis or receiving a particular therapy, has not provided a sufficiently distinct conceptualization (Ahlberg, Ekman, Wallgren, & Gaston-Johansson, 2004; Stanton, Danoff-Burg, & Huggins, 2002). Rather, patients have been asked to complete the coping assessments without reference to any particular stressor. This procedure makes the interpretation of the results very difficult. Sherliker and Steptoe (2000) examined the relations between assessment of coping on a daily basis and assessment with a checklist, however without any identification of the stressors. Interpretation of the results was thus still difficult. In one study (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992) specific cancer-related events such as fear and uncertainty about the future, limitations of physical ability and acute pain were delineated, but only at a single point in time. According to Stone and Neale (1993) most coping studies have used retrospective single point assessments rather than prospective investigations on a daily basis. Moreover, the frequent use of coping checklists with long recall time between event and assessment has further posed problems for the interpretation of results. Coyne and Gottlieb (1996) stated that the longer the time between an incident and its evaluation, the greater the probability that different response biases will distort data. Stone and co-workers (2004) found, for example, that coping reported retrospectively may not be the actual coping used at the

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time. Taken together, these data support research studies with short recall time, daily assessments and with focus to defined stressors of great clinical importance or identified by the patients themselves.

Life values

An additional way to handle a stressful event as, e.g. cancer, may be to reconsider different aspects of life. Changes in patients' health status may then result in changes in their internal standards and values, and in the conceptualisation of quality of life. This is often termed response shift (Sprangers & Schwartz, 1999). As the attainment of various life values may be changed as a result of the disease, individuals would perceive the same life values as less important. Compared to e.g. coping, patients' satisfaction with life, viewed in terms of the discrepancy between the perceived attainment and subjective importance of various life values, has been less studied. It has been suggested that a discrepancy between importance and attainment of life values is of importance for life satisfaction. A larger discrepancy would relate to less satisfaction with life (Henry Montgomery & Johansson, 1986; H. Montgomery, Persson, & Ryden, 1996). A number of studies demonstrate changes in the perception of life values among cancer patients (Belec, 1992; Frank-Stromborg & Wright, 1984; Halldorsdottir & Hamrin, 1996). Patients felt that the experience of cancer had changed them. However, these studies employ a retrospective design and are open to a variety of biases.

Social support

Social support is a factor which may influence the "outcome" of the coping process. Social support has proved important for well-being (Akechi et al., 2004; Ganz et al., 2003) and more specifically has personal support been positively associated with good QoL (Manning-Walsh, 2005). Moreover, among patients with a variety of cancer diagnoses, those with more social support recorded better QoL in the mental health domain and less anxiety and depression (Parker, Baile, de Moor, & Cohen, 2003). Social support was also predictive of QoL among long-term breast cancer survivors in a review by Mols and co-workers (2005). Thus, social support can be supposed to be a buffer between the stressful events and well-being. Lack of social support also means poorer overall and cancer specific survival in a large study on breast cancer patients (Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006).

Historically, social support has been measured in many different ways. According to a review by House and Kahn (1985), the results indicated a large variation regarding how "social support" has been conceptualized and

measured. Naturally, a consequence may be that results sometimes are diffi-cult to compare and interpret. However, in the review by House and Kahn (1985) they conclude that there has been some concordance regarding the usage of three aspects of social support: structural and functional aspects and quantity of social support. In addition, the source of the support has also been of importance for assessment. The functional aspects concern emo-tional involvement, instrumental help, information and appreciation. Few studies have made a distinction among the different kinds of social support and their impact on QoL of cancer patients. However, Sultan and co-workers (2004) evaluated different types of social support in relation to health related quality of life among colorectal cancer patients. They found that the avail-ability of emotional support as well as instrumental support was related to better mental health. A review by Helgeson revealed that patients assessed emotional support as being the most helpful support (Helgeson & Cohen, 1996). Thus, the functional aspects of social support i.e. emotional and in-strumental help seems to be of importance for the well-being of the individ-ual.

A cancer threatens not only the patients but also indirectly their spouses. Factors correlating with depressed mood among the spouses are their low levels of daily emotional support, low scores on mastery and appraisal of care giving tasks as negative (Haley, LaMonde, Han, Burton, & Schonwet-ter, 2003; Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2001). When compared with cancer patients, their spouses experience more psycho-logical distress (Harrison, Maguire, & Pitceathly, 1995; Kornblith, Herr, Ofman, Scher, & Holland, 1994). Although the literature suggests that the partner experiences more distress than the patient, the partner believes that the patient is the most distressed. This was shown in a thorough review among partners of prostate cancer patients (Couper et al., 2006). Much re-search (Baider & Kaplan De-Nour, 2000) has concerned how cancer can affect relationships, particularly the spousal one. According to Oberst and James (1985), spouses often report disruption in their lives, and a concomi-tant need to maintain a cheerful demeanour (Oberst & James, 1985). As the disease advances and treatment becomes palliative, the spouses often be-come more distressed and more likely to develop psychiatric morbidity (Pitceathly & Maguire, 2003).

Psychiatric history

A factor contributing potentially negatively to well-being is the patient's psychiatric history. In the work by Morasso (2001) psychiatric history pre-dicted mood disorders among cancer patients at follow-up. In another study with 117 cancer patients results give by hand that previous psychiatric his-tory was correlated with psychiatric morbidity (Akechi et al., 2004). In an-

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other study, previous psychological treatment predicted depression and anxiety, in the period one month before diagnosis to four months after diagnosis (Burgess et al., 2005). In a study by Stommel and co-workers (2002), patients with a capability of resilience after cancer diagnosis had no prior history of depressive symptoms or functional limitations(Stommel, Given, & Given, 2002). Moreover, patients reporting pessimistic thoughts, sleep disturbances and feelings of sadness before treatment were at higher risk of depression after treatment has terminated (Capuron, Ravaud, Miller, & Dantzer, 2004).

Anxiety and depression

For the total cancer group, anxiety and depression are frequent psychological reactions. The reported prevalence rates range from about 5 to 50% (Aass, Fossa, Dahl, & Moe, 1997; C. Montgomery, Pocock, Titley, & Lloyd, 2003; Nordin & Glimelius, 1997; Pascoe, Edelman, & Kidman, 2000; Sharpe et al., 2004). In comparison with population-based controls, there seems, however, to be no or only slight differences regarding psychological distress (Osborne, Elsworth, Sprangers, Oort, & Hopper, 2004; van't Spijker, Trijsburg, & Duivenvoorden, 1997). Depression is related to reduced quality of life (Iconomou, Mega, Koutras, Iconomou, & Kalofonos, 2004; Tsunoda et al., 2005) and is also a strong predictor to reduced quality of life later on (Skarstein, Aass, Fossa, Skovlund, & Dahl, 2000). Depressive symptomatology due to the disease and its effects has also been associated with a shorter survival prospects (Brown, Levy, Rosberger, & Edgar, 2003).

Quality of life

Within cancer treatment there has been a movement from a major focus on the patient's quantity of life with assessment of biological markers of therapeutic outcome towards including also the patient's QoL, i.e. evaluating the impact of the disease and its treatment on other aspects of the patient's life (Aaronson et al., 1993). Further, due to prolonged survival after diagnosis and treatment consideration has moved to survivor's QoL and disease related distress (Vachon, 2006). However, QoL is a concept with a broad range of definitions and there is no established consensus concerning the term. Different aspects of the concept have been and still are in focus. For instance ten definitions of quality of life were reviewed in a work by King and co-workers (1997). QoL is a multidimensional concept and involves the impact of the disease and its treatment on at least physical, psychological and social functioning of the patient (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2004; Cella & Tulsky, 1990; Kaasa, 1992; King et al., 1997; Sprangers,

2002). When studying QoL in cancer patients the European Organisation for Research and treatment of cancer, Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30) is an often used instrument. A review including 31 randomized controlled trials found that half of the studies used the EORTC QLQ-C30 (Efficace, Bottomley, Vanvoorden, & Blazeby, 2004).

Cancer

Patients diagnosed with gastrointestinal (GI)-, breast- and ovarian cancer and malignant lymphoma are studied in the thesis.

Gastrointestinal (GI) cancers

In Sweden GI cancers are common to the extent of about 8 000 persons who are diagnosed yearly with a primary malignant tumour of the colon, rectum, stomach, pancreas, liver or biliary passages (National Board of Health and Welfare, 2005). Prognosis varies greatly between these diagnoses. Colorectal cancer has an approximate 5-year survival rate higher than 50%, gastric cancer 20%, biliary cancers 9 % and pancreas and liver less than 5% (Talback, Stenbeck, Rosen, Barlow, & Glimelius, 2003). As a group, these patients have a worse prognosis than patients with most other tumour diagnoses. Cancer with it's various aspects (e.g. pain, side-effects of treatment, uncertain prognosis), has a major impact on the individuals' life and well-being and may be considered as potentially stressful. Although being one of the most common forms of cancer, the impact of GI cancers on patients' well-being has not extensively been studied. Arndt and co-workers (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2004) observed slightly worse physical and global health functioning among colorectal cancer patients compared to the general population. In the same study, more severe limitations were found among the patients for the emotional and social functioning scales (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2004). In one Swedish study, patients with colorectal and gastric cancer reported poorer well-being regarding energy, sleep and mobility six weeks after surgery compared to before surgery (Forsberg, Bjorvell, & Cedermark, 1996). Another Swedish study observed low levels of anxiety and depression among newly diagnosed patients with GI cancers (Nordin & Glimelius, 1997).

The early symptoms of GI cancer are often subtle and sometimes difficult to detect. When the symptoms occur, the disease has often been there for a long time. The most common symptoms within the group are blood in the defecation, changes in defecation habits, stomach pain, nausea, fatigue, weight loss and emaciation(Henriksson, Friberg, & Ringborg, 1998).

Curative treatment for GI cancer patients is in general surgical. The chances for surgery vary considerably between the diagnoses. Among pa-

tients with pancreas cancer in Sweden, e.g. only between five to 15 % are eligible for curative operation.

The surgical treatment may sometimes be completed with preoperative (chemo) radiotherapy or postoperative adjuvant chemotherapy. When the patients have no chance of being cured, palliative treatment may be offered. Palliative treatments aim at improving the patient's total life situation through e.g. alleviating symptoms or delaying their occurrence and/or prolonging the life (Gunnars, Nygren, & Glimelius, 2001). Much progress has been made in the palliative treatments of particularly colorectal cancer prolonging median survival to about 2 years (from about 6 months without any treatment). Besides chemotherapy, several "targeted" drugs are used (Nygren, Sorbye, Osterlund, & Pfeiffer, 2005). In a few patients, a decrease in the size of distant metastases can render previously non-resectable disease resectable. A non-curable patient has, due to this advance in treatment efficacy, become potentially curable.

Potentially cured/non-cured

Among the patients participating in the studies I and III the distinction is made between those who are potentially cured and those who are non-curable. Potentially cured means that all macroscopically known tumours were radically extirpated, i.e. patients have a chance of being cured, although highly variable. Non-cured patients have either an inextirpable primary, locally recurrent disease and/or metastatic disease, i.e. they have presently no chance of being cured. As briefly discussed above, the most recent development, not present during the time period of studies I and III, shows that some "non-curable" patients may respond so well to chemotherapy that the residual disease may be resected, and a chance of cure is present.

Breast cancer

About 30% of the female cancers is formed by breast cancer and is thereby the most common cancer among women (National Board of Health and Welfare, 2005). The survival has increased during the past four decades and the approximate 5-year survival rate is now 84%. These figures are partly explained by earlier diagnosis since mammography screening is now introduced by all county councils in Sweden. Further, the high survival rate is due to new treatments, e.g. cytostatic drugs, better radiation therapy methods, anti-estrogens like tamoxifen and other hormone therapies, and a antibody, trastuzumab (Herceptin®) (Bush, 2007; Hogle, 2007; Moore & Cobleigh, 2007; Talback, Stenbeck, Rosen, Barlow, & Glimelius, 2003).

Many breast cancer patients get their diagnosis after mammography screening. The most common symptom is a lump somewhere in the breast. Other symptoms, however indicating advanced disease, are inversion of the skin and change in the outline of the breast. In Sweden, the diagnostics refer

to what is known as "triple diagnostics".   This is due to the three involved components of diagnostics: clinical examination, mammography and cytology (Henriksson, Friberg, & Ringborg, 1998).

Primary therapy is in general surgery, whenever possible a breast conserving procedure. Most patients get some form of adjuvant therapy, radiation, hormonal, cytostatics or more recently an antibody depending upon risk profile.

Malignant lymphoma

In addition to the above diagnoses, malignant lymphoma is also one of the ten most frequent cancer sites with an incidence rate of approximately 3.5 % among both men and female cancers (National Board of Health and Welfare, 2005). The risk of malignant lymphoma has increased substantially during the past several decades, although it has recently levelled off (Ekstrom-Smedby, 2006). Approximately 2000 new cases are diagnosed each year in Sweden.

Malignant lymphoma constitutes a great number, at least 30, different diseases. They are grouped in different ways according to appearance in the microscope, other characteristics and clinical pattern. One group is Hodgkin Lymphoma (HL), present in both young and elderly patients. The rest constitutes one group, the non-Hodgkin Lymphomas (NHL). About 90% are NHL. NHL is further sub-grouped in different ways, where one group has an aggressive course (high-grade NHL) and another has a more indolent course (low-grade NHL).

Both HL and NHL are very sensitive to chemotherapy and radiation therapy, and cure can be expected in many patients, however, depending upon subtype. Most patients with HL and high-grade NHL receive intensive chemotherapy during several months up to about a half year, sometimes with radiation (Diehl, Stein, Hummel, Zollinger, & Connors, 2003). In addition, some receive an antibody, rituximab (Mabtera®). The cure rate in high-grade NHL is 30-50%, in HL 80-90%. Long term consequences from disease and treatment can then become a great concern. These concerns, including psychosocial problems, have been extensively studied (Abrahamsen et al., 1999; Loge, Abrahamsen, Ekeberg, & Kaasa, 2000; Loge, Abrahamsen, Ekeberg, & Kaasa, 1999).

Ovarian cancer

Ovarian cancer constitutes approximately 3.5 % of all Swedish female cancers (National Board of Health and Welfare, 2005). There has been a gradual increase in survival rates during the past four decades. The 5-year survival rate is dependant on stage of disease and varies between 80-90% for patients with early stages to 25% for patients in advanced stages. This is

mainly due to improvements within surgery, radiation and chemotherapy (Colombo et al., 2006; Talback, Stenbeck, Rosen, Barlow, & Glimelius, 2003). Symptoms are often vague and the disease can be difficult to diagnose early why most are in advanced stage at diagnosis. The patients often show symptoms of e.g. nausea, distension, diffuse stomach pain and later in the process an extensive abdomen (Colombo et al., 2006; Henriksson, Friberg, & Ringborg, 1998). Thus, the symptoms may often initially be referred to other diseases.

The primary therapy is often surgical removal of the primary tumour and, if spread to the abdomen, as much tumour as possible growing on the peritoneum. Ovarian cancer is sensitive to chemotherapy. After surgery, whether radical or not, most patients are treated with intensive chemotherapy for several months or more depending upon response. A fraction of the patients can be considered cured, since they can survive for very long without any recurrence.

Common QoL concerns that are affected by the disease and its treatment are e.g. changes in physical and role functioning, psychological distress, sexual dysfunction and, for younger women loss of childbearing potential (Sun, Ramirez, & Bodurka, 2007).

Aims

General and specific aims

The overall aims of this thesis were to prospectively investigate how specific challenges occurring among patients with commonly occurring cancers are related to adaptation and well-being, to predict later well-being using a range of psychosocial aspects and to compare two ways of measuring coping with cancer. More specific aims were:

- to prospectively explore the interplay between stressful events, appraisal, coping and well-being on a daily basis in newly diagnosed patients with GI cancer (Study I)
- to investigate the relations between two different measures of coping with cancer, i.e. a checklist and a daily basis prospective coping measure, and to relate these to various stressful events and to well-being (Study II)
- to prospectively explore the relations between degree of attainment and importance of life values on the one hand, and anxiety and depression on the other, among newly diagnosed and their spouses (Study III)
- to prospectively investigate the relations between stressful events, appraisal, coping, social support, psychiatric history on the one hand and emotional well-being and quality of life among cancer patients terminating treatment on the other hand, and to investigate to what extent it is possible to predict emotional well-being and quality of life at follow-up on the basis of the same measures at baseline (Study IV).

Methods

Subjects

Patients diagnosed with GI, breast and ovarian cancers and malignant lymphomas constitute the studied group. These are common diagnoses and thus frequent at the clinic. The routine care for these patients makes them suitable for exploring psychosocial aspects in relation to the specific challenges in relation to "diagnosis" and "termination of treatment". In addition, GI cancers are of special interest since this group is one of the most common cancer diagnoses but nevertheless not extensively studied in these aspects.

Study I-III

A consecutive series of newly diagnosed patients with GI cancers attending the Departments of Oncology or Surgery at the University Hospital in Uppsala were included. Those patients were excluded who did not speak Swedish, had a very poor performance (Karnofsky Performance Status ≤ 40, i.e. were bedridden most of the day with a very poor survival), hard of hearing or were senile or confused. The patients in these three studies are all from one large study cohort of patients. The different sample sizes in the separate studies depend on at what point in the patient recruitment process, data were analyzed.

Study I-II

Out of 151 eligible patients with GI cancers, 95 (63%) participated and among these, 62 were potentially cured, and 33 were non-cured. Data on age, gender, and diagnosis were compiled from the medical records and are described further in the paper.

Study III

Out of 132 eligible patients, 85 (67%) participated, 52 potentially cured and 33 with an advanced non-curable disease. Twenty-six spouses (96%) of patients with an advanced disease participated. Patients with an advanced non-curable disease were asked for permission to contact their spouses. Further details regarding the sample are described in the paper.

Study IV

Out of 67 eligible patients, 60 (90%) participated in the study. These were patients with colorectal- (n=6), breast- (n=37), and ovarian (n=10) cancer and malignant lymphoma (n=7) who received their last treatment of intensive chemotherapy with curative intent. Some patients received radiotherapy in addition to chemotherapy. Patients attended the Department of Oncology at the University Hospital in Uppsala. Patients were excluded if they did not speak Swedish, had a very poor psychological performance to fill in questionnaires, were included in another study at the time, were younger than 20 years or were senile /confused. Further details regarding the sample are described in the paper.

Measures

Daily assessment of coping

The Daily Coping Assessment (DCA) (Porter & Stone, 1996; Arthur A. Stone & Neale, 1984) was developed specifically for the daily recording of coping with everyday stressful events. Questions regarding the most stressful event of the day are completed once a day during seven consecutive days. The DCA contains four sections. The first is a question to which the patients respond by describing the most stressful event (illness-related or not) in their own words. The second section is used as a measure of appraisal and assesses the distress occasioned by the stressful event. Scores range from 1 ("Not at all bothersome") to 7 ("Extremely bothersome"). The third section also measures appraisal and includes two questions concerning reactions to the stressful event: (1) "How much control did you have over its occurrence" ("No control"; "Some"; "Quite a lot"), and (2) "Was it an expected stressful event or situation" ("Completely unexpected"; "Somewhat unexpected"; "Somewhat anticipated"; "Completely anticipated"). The fourth section includes eight categories of strategies for handling the stressful event. The strategies have been based on empirically derived themes of Lazarus and Folkman (1984) and are "Distraction" (Thought of something else), "Situation Redefinition" (Looked at the problem in a different way), "Direct Action" (Did something about it), "Catharsis" (Expressed emotions), "Acceptance" (Accepted the problem), "Seeking Social Support" (Sought support from others), "Relaxation" (Relaxed), and "Religion" (Sought spiritual support), and the patients report whether or not they employ each of them to handle the recorded stressor that day. The DCA was translated (EW) with permission by original authors (Study I, II, IV, see Table 1).

Coping

The Mental Adjustment to Cancer (MAC) scale (Watson et al., 1988) describes reactions to having cancer and is an often used measure of coping strategies in cancer patients (C. Montgomery, Pocock, Titley, & Lloyd, 2003; Nosarti, Roberts, Crayford, McKenzie, & David, 2002; Osborne et al., 2004). This "checklist" is a self-rating questionnaire, originally developed for the assessment of mental adjustment to cancer. MAC assessment is typically made on one occasion in order to assess the extent to which patients adopt certain responses in their adjustment to, e.g., the diagnosis and treatment of cancer. In this scale, there is no specification of the stressor other than the ways of adaptation to a general and definite aspect of the "illness". Two separate analyses were conducted, one in accordance with the original version and the other as an alternative analysis proposed by Nordin and co-workers (1999). The original version (40 items) consists of the following five subscales: "Fighting Spirit" (16 items), "Helplessness/Hopelessness" (6 items), "Anxious Preoccupation" (9 items), "Fatalism" (8 items) and "Avoidance" (1 item). The 28-item Swedish reanalysis (Nordin, Berglund, Terje, & Glimelius, 1999) consists of the following four subscales: "Hopeless" (12 items), "Positive" (10 items), "Anxious" (3 items) and "Avoidant" (3 items). A standardization of the individual subscale score was performed, as suggested by Greer and co-workers (1989), in order to categorize patients' most predominant coping style. This was done by subtracting the sample mean from each individual score and dividing by the sample standard deviation, resulting in z-scores. The dominant coping style for each patient was the MAC subscale, which attained the highest z-score. Patients were classified as having "No Predominant Response" (NPR) if all z-scores were below zero (the sample mean) (Study II, see Table 1).

Life values

The life value questionnaire was developed by Montgomery and Johansson (1986). To ensure a good coverage of a wide range of possible life values, they used three different sources to create a list of life values. Firstly, they telephone interviewed a random sample of 75 residents in Sweden about a number of questions about their life values. Secondly, values were collected by penetrating previous research on values and related phenomena and thirdly, values were generated from theoretical considerations. Later, 39 items related more specifically to health and effects of being chronically ill were added to this list of values. A factor analysis resulted in a 10-factor solution including 54 items (H. Montgomery, Persson, & Ryden, 1996). Relevant items were selected for the present study from nine of these original factors on the basis of high factor loadings and their relevance for the present sample. No new items were added and the number of items selected

from each of the original factors was almost equal. The employed version of the questionnaire consists of 34 items, representing nine of the original factors: Harmony, Positive relations, Mobility, Involvement, Communication, Responsibility, Comfort, Religion and Health. A new factor analysis including the 34 items was not performed in the present sample due to the limited number of patients. The Cronbach alphas in the present sample ranged between 0.68 and 0.84. The respondents are asked to first rate the attainment of all values and then perceived importance. All ratings were made on 7-point scales with defined endpoints, "Not at all" and "To a very large extent" (attainment) or "Unimportant" and "Immensely important" (importance). A discrepancy score is calculated and constitutes of the difference between the attainment and importance scores of a life value. (Study III, see Table 1).

Social support

Seven items measuring aspects of social support were derived from the Interview Schedule of Social Interaction (ISSI), a 50-item scale measuring the availability and perceived adequacy of attachment and social integration (Wallin, 1984). The seven items have previously been included in a short version of the instrument which has been investigated according to its validity, reliability and predictive capacity (Unden & Orth-Gomer, 1989). The seven items were drawn from a dimension in the ISSI and measures availability of attachment, i.e. emotional relationships. Chiefly, these items are related to functional aspects of social support, i.e. emotional involvement and instrumental help. The following questions were used: "Do you feel there is a special person giving you real support?", "Do you think there is a special person feeling very close to you?", "Do you know a special person with whom you can share your feelings of happiness? Someone who would feel happy just because you are?", "Do you know someone with whom you can share your inner feelings and entrust yourself to?", "Does someone now and then console or support you by holding you tight?", "Is there anyone in addition to your family, whom you could rely on in case of difficulties? Someone that you easily could get hold of and trust and could get real help from when you have problems", "Is there anyone around who you could easily ask for things? For example persons whom you know well enough to borrow tools or kitchen utensils from". To use some of the total number of items in the original scale is in accordance with the authors' intention. The response format is yes/no where yes is weighted as 1 and no as 2, i.e. a high score indicates in the present study poor social support (Study IV, see Table 1).

Psychiatric history

A study-specific questionnaire was used to investigate psychiatric history, i.e. the occurrence and consequences of psychiatric symptoms. The instrument is based on the diagnostic criteria of DSM-IV (American Psychiatric Association., 1994) and assesses prevalence of Primary symptoms of anxiety and depression and their consequences for the patient. All together, the instrument includes six questions, three concerning present and previous symptoms and consequences of anxious mood and three concerning present and previous symptoms and consequences of depressed mood. Previous symptoms of anxious mood in the patient's life relates to anxiety or fear during a period of at least one month whereas depressed mood relates to sadness or loss of interest in almost all activities for a period of two weeks. Present symptoms relates to those symptoms (anxiety/fear or sadness/loss of interest) occurring at baseline. Patients were scored as having a psychiatric history of depression if they reported depressive symptoms at baseline and had at least one past period of depressive symptoms. The same is valid for psychiatric history of anxiety (Study IV, see Table 1).

Daily assessment of mood

Worry and happiness/sadness were recorded on a numerical rating scale each evening during the same week as patients filled out the DCA. The two questions are: (1) "How bothered have you been by worry today", with endpoints 1 ("Not at all bothered") and 7 ("Very bothered"), and (2) "How happy/sad have you been today", with endpoints 1 ("Very happy") and 7 ("Very sad") (Study I, see Table 1).

Anxiety and depression

The Hospital Anxiety and Depression scale (HADS) (Zigmond & Snaith, 1983) 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). A score of 7 or less is indicative of a "non case", 8-10 a "doubtful case" and 11 or more a "case" (Zigmond & Snaith, 1983). The time window is the last week, in this study the week during which DCA- and VAS-ratings were performed (Study I-IV, see Table 1).

Quality of life

Quality of life during the last week was measured with the EORTC QLQ-C30 (Aaronson et al., 1993). The questionnaire is a 30-item multidimensional scale specifically aimed for cancer patients. The scale consists of a

subscale which assesses global health status/quality of life and five functional subscales assessing physical, role, emotional, cognitive and social functioning. The EORTC QLQ-C30 is also composed of three symptom scales and 6 single symptom items. For the purpose of this study, only the global health status/quality of life scale was used. Response format on the "Global QoL" scale is a seven-point scale ranging from 1 (very poor) to 7 (excellent). The subscale score is transformed into a 0-100 scale on which a higher score is indicative of a better functioning and quality of life or a worse level of symptoms. (Study IV, see Table 1).

Table 1. Instruments used in Studies I-IV

		Studies		
Instruments	**I**	**II**	**III**	**IV**
DCA	x	x		x
Daily assessment of mood	x			
HADS	x	x	x	x
MAC		x		
The life value questionnaire			x	
ISSI				x
Psychiatric history				x
EORTC QLQ-C30				x

Procedure

Summary of Study I-III

These three studies are all part of a prospective longitudinal study with patients with GI cancers and their spouses. The cured patients were interviewed after surgery, as soon as their physical condition permitted, and the non-cured patients were interviewed in connection with, or after the first medical control visit. At the interview, patients were asked to complete two diaries during the following week, one concerned with the daily assessment of stressful events and coping (*DCA*) and one with *daily assessment of mood*. On the last evening of the week, they completed a questionnaire assessing anxiety and depression (*HADS*). They were also instructed to complete questionnaires during the week following inclusion regarding *life values* and coping as measured by a checklist (*MAC*). The spouses completed the questionnaires concerning anxiety and depression and life values the week following inclusion. Respondents returned the questionnaires by mail in a pre-addressed envelope.

Summary of Study IV

Patients received questionnaires to complete before their last cytostatic treatment. The questionnaires were: A diary, i.e. a daily assessment of stressful events and coping (*DCA*) was to be completed during a 7 day period preceding and following the first day of the last treatment. About one week before the last treatment, an administrator phoned the patients to remind them to fill out the DCA. On the last evening of this period they completed the *HADS*. The patients also answered questionnaires regarding *previous psychiatric history* and *social support*. At the visit when the patients received their last treatment, patients returned the questionnaires and filled out the *EORTC QLQ-C30*. The patients who received radiotherapy after terminating chemotherapy, mainly breast cancer patients filled out additional questionnaires (DCA, HADS and EORTC QLQ-C30) in connection with their last radiation fraction (i.e. about 8 weeks after termination of chemotherapy). This measurement point was used as baseline for the patients receiving radiotherapy in addition to chemotherapy. At follow-up after 4 and 16 months all patients again answered the HADS and EORTC QLQ-C30. All questionnaires at follow-ups were sent to the patients by mail and returned in a pre-addressed envelope. The intent was to minimize contact in order to make the situation "Terminating treatment and returning home after hospital stay" as natural as possible.

Data analyses

Study I

The Pearson product moment correlation (*r*) was used to assess correlations between DCA stressful events (Somatic aspects, Psychological aspects, Social aspects, Other consequences of the disease, Contact with the medical services, Everyday concerns, Returning home after hospital stay), DCA coping strategies (Distraction, Situation Redefinition, Direct Action, Catharsis, Acceptance, Seeking Social Support, Relaxation, Religion), frequency of the usage of coping strategies, number of uncontrollable events, HADS anxiety and depression ratings and daily ratings of mood. For comparison of potentially cured and non-cured patients two-tailed (unpaired) *t*-test was used.
Cohen´s kappa was used for analyzing the correspondence between judgments regarding recordings from the DCA (described further below). A p-value of <0.05 was denoted as significant.

Study II

The Pearson product moment correlation (*r*) was used to assess correlations between DCA stressful events (Somatic aspects, Psychological aspects, Social aspects, Other consequences of the disease, Contact with the medical services, Everyday concerns, Returning home after hospital stay), DCA cop-

ing strategies (Distraction, Situation Redefinition, Direct Action, Catharsis, Acceptance, Seeking Social Support, Relaxation, Religion) and MAC subscales (Fighting Spirit, Helplessness/Hopelessness, Anxious Preoccupation, Fatalism, Avoidance, Hopeless, Positive, Anxious, Avoidant). A second-order factor analysis was performed, including the DCA coping strategies, the MAC subscales and the HADS anxiety and depression to test the dependence/independence of factors. A p-value of <0.05 was denoted as significant.

Analysis of type of stressor in study I-II.

The first DCA section consists of a question to which the patients respond by describing in their own words the most stressful event of the day. Content analysis was used to classify these answers (Weber, 1994). For the first 54 patients (30 cured, 24 non-cured), the replies were categorized by the first author, yielding 15 categories. Using these categories, the same statements were independently categorized by the second author. The correspondence between the first and the second authors' judgments was analyzed by Cohen's kappa (Howell, 1997). For 12 of the 15 categories, Kappa values ranged between 0.71 and 1.00. For the remaining three categories, interrater-agreement was very low.

In an effort to attain higher agreement scores and more distinct categorizations, the categories were partly changed on the basis of a discussion between the first and second authors, aiming for the empirically most meaningful and productive categories. Another reason was that some of the categories contained very few recordings. Finally, eight categories remained.

Data from the remaining 41 patients were categorized separately by the first and second authors, using these eight categories. Kappa values ranged from 0.40 to 1.0: "No problem-feeling well" (0.98), "Somatic aspects" (0.87), Psychological aspects" (0.51), "Social aspects" (0.77), "Other consequences of the disease" (0.40), "Contact with the medical services" (0.90), "Everyday concerns" (unrelated to the disease) (0.81), and "Returning home after hospital stay" (1.0).

Study III

Comparisons of two independent group means were performed with unpaired t-tests. In order to determine changes over time and for comparisons of patients and their spouses paired t-test were used. The Pearson product moment correlation was employed for studying the relations between, on the one hand anxiety and depression, and on the other attainment and importance of life values. Spearman rank correlations were computed for ranking attainment and importance of life values. Stepwise regression analyses were performed to determine how much of the variance in anxiety and depression that was explained by attainment, importance and discrepancy of each life value. A p-value of <0.05 was denoted as significant.

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Study IV

The Pearson product moment correlation (*r*) was used for calculating correlations between the variables at baseline (termination of treatment). A p-value of ≤0.05 was denoted as significant. On the basis of statistically significant correlations in the above analyses, independent variables were selected for use in a multiple regression using a stepwise method. Among the versions of statistical regression, the stepwise procedure is considered the safest way to the best prediction equation (Tabachnick & Fidell, 1996). Due to the explorative approach of the study a range of potential independent variables were possible to include in the regression analyses. In order to minimize the amount, only variables correlating statistically significant with the dependant variables were included at baseline. The regression analyses were performed between measures of emotional well-being, coping strategies, stressful events, appraisal, social support and psychiatric history at baseline as independent variables and emotional well-being and quality of life at follow up as dependent variables. For each of the dependent variables, i.e. HADS anxiety and depression, Global QoL at 4 and 16 months, two separate analyses were performed. One includes and the other excludes HADS anxiety and depression at termination of treatment as independent variables. This is due to these variables expected strong capability to predict the scores of the dependent variables and thereby conceal other variables contribution. Significant models which explained <10% (Adjusted $R^2 < .1$) are not reported.

Analysis of type of stressor in study IV

The first section of the DCA asks the patient to describe the most stressful event of the day. In order to classify these answers, content analysis (Weber, 1994) was used. All the statements were divided into three parts. Each part was read and independently categorized by author 1 (EW) and members of the research group (Jeanette Winterling, Annika Lundquist). The categorizers then discussed the categories and agreed on five major categories: Side-effects of treatment, Other physical symptoms, Thoughts/affects, Contacts related to treatment, Setback in everyday life. The members then reread their part of the total amount of statements and then accepted the categories slightly modified. Although the final version of the categories are to a high degree named as mentioned above: Physical side-effects of treatment, Other physical symptoms, Thoughts/affects, Contacts related to treatment, Setback in everyday life, they contain somewhat different aspects. In the first version a statement containing cognitive associations, e.g. related to the hospital were labelled as Side-effects of the treatment but in the final version these are instead included in category Thoughts/affects. All statements were then independently categorized according to the five final categories by E.W. and

A.L. In some cases a discussion was necessary to reach consensus regarding categorization of a statement.

Results

Study I

The aim was to prospectively explore the interplay between stressful events, appraisal, coping and well-being on a daily basis in newly diagnosed patients with GI cancer. The most frequent stressful events in the newly diagnosed patients with GI cancer were Somatic aspects and Everyday concerns. Other stressors reported by the patients were Psychological aspects, Contact with the medical services, Social aspects, Other consequences of the disease and Returning home after hospital stay. Somatic aspects, Social aspects and Other consequences of the disease were rated as most bothersome. The most commonly used coping strategies were Acceptance and Relaxation, strategies that are emotion focused e.g. aiming at handling the emotions following the stressful event rather than eliminating the threat. Positive correlations between the occurrence of stressful events and the use of coping strategies were demonstrated between Somatic aspects and Acceptance/ Direct Action, and between Social aspects and Seeking Social Support. The overall levels of anxiety and depression were low. There were significant positive correlations between the mean number of recordings of coping strategies (irrespective of type) and anxiety and depression. There were also positive correlations between the number of uncontrollable events and anxiety/depression.

Study II

The aim was to investigate the relations between two different measures of coping with cancer, a checklist (MAC) and a daily basis prospective coping measure (DCA), and to relate these to various kinds of stressful events and emotional well-being (HADS anxiety and depression). When using the MAC scales, a more "confronting" or problem-focused coping (Fighting Spirit and Positive) was predominant compared to the DCA for which a more emotion-focused strategy (Acceptance and Relaxation) was most frequent. There were significant positive correlations between the stressful event "Psychological aspects" (DCA) and the coping strategies (MAC) "Anxious Preoccupation" and "Anxious". There was a lack of significant correlations between "Psychological aspects" and coping measured by the DCA. In order to investigate which of the different ways of measuring coping (the two versions of

the MAC scales or the DCA) that best separate coping from outcome, three exploratory second-order factor analyses were performed. The MAC-subscales did not separate from the HADS anxiety and depression. In contrast, the HADS subscales loaded in a separate factor than the DCA. This points out that coping measured by the DCA is more clearly separated from outcome.

Study III

The aim was to prospectively explore the relations between degree of attainment and importance of life values on the one hand, and anxiety and depression on the other. Patients scoring as cases/doubtful cases on HAD anxiety and/or depression also reported higher discrepancies for most life values compared to patients who scored as non-cases. A significant proportion of the variance in anxiety and depression was explained by these discrepancies. For patients, the discrepancies for several life values decreased over time, as did anxiety and depression. This was true both for patients with a non-curable disease as well as for those who were potentially cured. For the spouses of patients with a non-curable disease, there were no reductions either of life value discrepancies or for anxiety/depression. The spouses of patients with a non-curable disease reported more anxiety than the patients close to diagnosis.

Study IV

The aims of the study was to investigate the relations between stressful events, appraisal, coping, social support, psychiatric history on the one hand and emotional well-being and quality of life among cancer patients terminating treatment on the other hand and furthermore to investigate to what extent it is possible to predict emotional well-being and quality of life at follow-up on the basis of the same measures at baseline. Significant positive correlations were demonstrated between the stressful events Other physical symptoms and Thoughts/affects and anxiety. The mean level of the bothersomeness of the stressful events correlated positively significantly with anxiety and depression and negatively with Global QoL. Usage of either of three coping strategies: Direct action, Seeking social support, and Acceptance correlated significantly positively with anxiety or Global QoL. Lack of social support in the following questions: "person close to you" (Q2) and "share inner feelings" (Q4) correlated positively with levels of depression and/or anxiety. For the latter (Q4) there was also a negative correlation with Global QoL. Social support due to "real help-in addition to family" (Q6) correlated negatively with depression. Prevalence of psychiatric history cor-

related positively with depression and anxiety and negatively with Global QoL.

Two separate analyses were performed for each of the dependant variables, i.e. HADS anxiety and depression and Global QoL at 4 and 16 months after treatment termination, one including and the other excluding HADS anxiety and depression at baseline as independent variables. When HADS were not included as independent variables Psychiatric history of depression and Thoughts/affects contributed significantly to predicting *HADS anxiety* at 4 months and Psychiatric history of depression did so alone at 16 months. When HADS were included, no other variable besides HADS anxiety contributed to the model. Regarding *HADS depression* when HADS were not included, Psychiatric history of depression was the only independent variable contributing to the model at 4 months while Psychiatric history of depression together with lack of social support Q2: "person close to you" contributed to the prediction of depression at 16 months. When HADS were included as independent variables, only HADS depression after 4 and 16 months contributed to the model. Bothersomeness together with Acceptance contributed to the prediction of *Global QoL* at 4 months. Bothersomeness did so alone at 16 months. No other variable besides HADS depression contributed to the prediction of Global QoL when HADS were included as independent variables.

Discussion

Challenges and adaptation shortly following diagnosis (Study I-III)

Stressful events

There is previously very little published information about specific stressful event-coping relationships in cancer patients. However, in relation to chronic pain present in patients without a cancer diagnosis, there is documentation of coping strategies such as pain reduction effort, seeking spiritual comfort, distraction, and relaxation (Keefe et al., 1997), and relaxation and direct action to reduce pain (Affleck, Urrows, Tennen, & Higgins, 1992). Overall, the results from the present study are in several aspects difficult to compare with previous studies. This is due to that previously used measures differ from the DCA in at least two important aspects, firstly the use of closed versus open-ended questions regarding potential stress, and secondly, if the entire process from definition of the stressor, its appraisal and the selected coping strategy is studied or not. The present study allowed for patients' own specification of the stressful event whereas earlier studies have employed researcher-generated categories. The findings regarding the most frequent type of stressful events (Somatic aspects and Everyday concerns) reported by the patients are in line with a review by Sprangers and co-workers (1993) concerning QoL in colorectal cancer patients, according to which a sizeable proportion of the patients reported limitations in physical, psychological and social areas. However, other studies suggest a partly different pattern. In a study of a heterogeneous group of cancer patients (13% of the sample had GI cancers), 41% reported that the most stressful event was fear or uncertainty about the future (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992). Uncertainty about the future was rarely reported in the present study, probably due to that the patients were occupied with the many physical concerns that dominated their lives at the time.

Coping

The most frequently used coping strategies (Acceptance and Relaxation) were emotion-focused and these results are in line with the work by Dunkel-Schetter and co-workers (1992) in which distancing techniques tended to be

used most frequently. The results are also in line with a study by Sherliker and Steptoe (2000) with patients with metastatic cancer. Patients used strategies as acceptance, positive interpretation and growth most frequently. Among newly diagnosed cancer patients undergoing adjuvant treatment, distancing was the only QoL coping strategy which enhanced QoL (Lehto, Ojanen, & Kellokumpu-Lehtinen, 2005). The present results partly agree upon the results by Sehlen (2003) in which both distraction and active problem-oriented coping were common. Thus, the present findings agree only partly with earlier findings, also including the same groups of patients. The frequent usage of checklists with no specification of the stressor among the described studies has probably influenced these findings.

Anxiety and depression

The overall levels of anxiety and depression were low. These findings are similar to results from other studies on patients with GI cancer (Nordin & Glimelius, 1998; Norum, 1997). Higher levels of psychological distress were accompanied by reported use of a higher number of coping strategies. This suggests that more anxiety and depression occasioned more intense coping attempts, or that stressful events occasioned both worry and depression and frequent coping attempts. An example of appraisal as a mediating factor in the adjustment process is that there were positive correlations between the number of uncontrollable events and HAD scores. This suggests that a lower level of perceived control over the stressful events was accompanied by more psychological distress. These findings are in accordance with earlier research regarding importance of perceived personal control (Seligman, 1992, 1998).

Comparison of coping measures

When using the MAC scales, a more "confronting" or problem-focused coping was predominant compared to the DCA for which a more emotion-focused strategy was most frequent. This underlines the need of cautiousness when using and interpreting results on coping since the choice of instrument is evident. The demonstrated significant positive correlations between the stressful event "Psychological aspects" (DCA) and the coping strategies (MAC) "Anxious Preoccupation" and "Anxious" indicate relationships in terms of mental adjustment rather than coping. The correlations indicate that this stressful event and the two MAC subscales all describe an emotional state. The lack of significant correlations between "Psychological aspects" and coping measured by the DCA, point out that the DCA coping strategies are more clearly separated from this stressful event. This is important since the original intention of the MAC Scale was to measure mental adjustment rather than coping and the results do not support the use of the MAC Scale

as a coping measure. This is also important according to Lazarus (1993) and Stone and Neale (1984) in the sense that a measure of coping must be separated from the stressful event. In many, also recent studies (Drageset & Lindstrom, 2003; Faller & Schmidt, 2004), the concept of the stressful event is vague, which is inconsistent with the notion of Lazarus (1993). The DCA also seems to better separate coping from outcome than the MAC since the HADS subscales loaded in a separate factor than the DCA. This is in accordance with recommendations by Lazarus who stated that coping must be measured separately from its outcome (Richard S. Lazarus, 1999).

Changes in life values

Patients scoring as cases/doubtful cases on HAD anxiety and/or depression also reported higher discrepancies for most life values compared to patients who scored as non-cases. A significant proportion of the variance in anxiety and depression was explained by these discrepancies. This finding supports the assumption of an association of the balance between attainment and importance of life values with high psychological well being.

Reduction of the discrepancies between attainment and importance may be a way to handle the stressful situation of having a serious disease, as well as using different kinds of coping strategies. For both patients with a non-curable disease and the potentially cured, the discrepancies for several life values decreased over time, as did anxiety and depression. The reasons for these improvements may be multifactorial. Among the potentially cured patients, the immediate stress caused by the diagnosis of a potentially fatal disease, its treatment and side effects, may diminish when health is improved, e.g. when they recover from early postoperative problems and for some, regain of normal activities. Improvement of physical problems due to successful treatments, are likely to contribute among the non-curable patients. For the spouses of patients with a non-curable disease, however, there were no reductions either of life value discrepancies or for anxiety/depression.

The spouses reported more anxiety than the patients close to the diagnosis. This result is in line with previous studies, demonstrating high psychological distress among spouses and family members of cancer patients (Harrison, Haddad, & Maguire, 1995; Kornblith, Herr, Ofman, Scher, & Holland, 1994; Persson, Rasmusson, & Hallberg, 1998). One explanation for the higher levels of psychological distress among spouses may be that they have greater difficulties than the patients in reducing the discrepancy between their attainment and perceived importance of life values. As a patient, you may not be able to perform some of the activities you appreciate and therefore rate them as less important, in order to decrease the discrepancy. The healthy spouses who are able to perform important activities may, however, be prevented from doing so by their obligations as caregiver. Spouses

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may thus not be able to re-evaluate the importance of such activities, leading to a remaining attainment-importance discrepancy. No previous studies have been performed of life values among spouses of seriously ill patients.

Challenges and adaptation at termination of treatment (Study IV)

Stressful events

The most frequent stressful events seem to be in some accordance with those found by Farell and co-workers (2005), i.e. current illness, the future, inability to do things, physical symptoms and treatment. Thus, the complexity of the situation is evident since along with the side-effects of treatment are also e.g. thought/affects. In a study regarding coping among breast cancer patients at the end of treatment, Wengström and co-workers (2001ref) concluded that coping was mainly related to the side-effects of treatment. Thus, these were common concerns which the patients handled by activities directed towards themselves, e.g. resting, reading books (Wengstrom, Haggmark, & Forsberg, 2001).

Appraisal and coping

Regardless of type of stressor, the bother the event caused was related to poorer emotional well-being and QoL. It may be argued that since bothersomeness is an appraisal variable results are in accordance with the coping model but level of control would be a more expected correlate. Previous findings regarding the importance of perceived control indicate that patients are better adjusted when they have higher levels of perceived control (Thompson, Sobolew-Shubin, Galbraith, Schwankovsky, & Cruzen, 1993). When coping strategies as Direct action and Seeking social support are used, the individual has more anxiety. These results may be due to that the individual tries to handle the anxiety through the usage of these coping strategies. Another explanation may be that although the individual uses these coping strategies anxiety is apparent. The positive correlation between the coping strategy Acceptance and Global QoL indicates a better QoL when this coping strategy was in use. This may be explained by that the usage had effect on the QoL. Thus, acceptance of a stressful event seems to be good for the patient's QoL. Susan Folkman proposes a modification of the coping model from 1984 (Richard S. Lazarus & Folkman, 1984) in which she in short discusses the term meaning-based coping (Folkman, 1997; Folkman & Greer, 2000). Meaning-based coping involves the patient's ways of abandoning untenable goals, make sense of what is happening and appraises benefit when possible (Folkman & Greer, 2000). Acceptance of a stressful event

could be a way for the patient to come into terms with the situation and thereby arrive at higher QoL.

Social support

The present results regarding social support are in line with those by Parker and co-workers (2003). They found that patients with more social support recorded better QoL in the mental health domain and less anxiety and depression (Parker, Baile, de Moor, & Cohen, 2003).The present thesis also concludes that support coming from outside the family is frequent among patients with poorer emotional well-being.

Psychiatric history

The results indicated worse emotional well-being and QoL among patients with present and previous psychiatric problems. This is in accordance with the findings of Burgess and co-workers where the patients' anxiety and depression around diagnosis were predicted by their history of psychological treatment (Burgess et al., 2005).

Prediction of well-being at follow-up (Study IV)

The results show that anxiety and depression at baseline have a major impact on the patient's well-being up to more than a year after treatment has terminated. Also Skarstein and co-workers (2000) found correlations between anxiety/depression and aspects of QoL but depression was a stronger predictor for worse QoL (Skarstein, Aass, Fossa, Skovlund, & Dahl, 2000) .

When anxiety and depression were not included a somewhat different picture emerged in the analyses. Thus, by analyzing data in these two ways, other variables beyond the obvious become evident. For anxiety, a predictive relation between thoughts and affects concerning e.g. treatment and family and anxiety was found and between psychiatric history of depression and anxiety. The findings point in the same direction as the results by Burgess (2005) which show that previous psychological treatment predict depression, anxiety, or both around diagnosis.

For depression, social support as in "lack of a person that feels close" seems to be of relevance for emotional well-being. The importance of social support is in accordance with other findings where more support was related to e.g. less anxiety and depression (Parker, Baile, de Moor, & Cohen, 2003). Moreover, the results are in line with other findings showing that depression, social support together with symptom distress accounted for 44% of the total variance for health related QoL (Yan & Sellick, 2004). Therefore, assessing patient's social support may be valuable when identifying patient's risk for

distress. Surprisingly, Psychiatric history of depression is the only contributing variable at 4 months. This is surprising since a variable which contributes to the model later could be hypothesized to have some predictive value even earlier in time.

For QoL, other variables apart from depression seemed to be of importance: the bother an event caused the individual and the coping strategy acceptance. As was hypothesized in connection with the positive correlation between acceptance and QoL at termination of treatment this may be explained by the patient's capability of abandoning untenable goals, make sense of what is happening and appraise benefit when possible, i.e. meaning-based coping (Folkman & Greer, 2000). Acceptance could be a way for the patient to handle the situation and thereby arrive at better QoL. Another, but related way of handling stressful situations was found in study III. It seemed to be positive for the patient to strive for a balance between importance and attainment of life values. Thus, it could be of importance for the individual to re-evaluate and possibly accept the new premises. The value of appraisal and investigation of the patient's coping strategies argues for a concern of the patient's level of bother, coping strategies as well as its emotional well-being during cancer treatment.

Discussion according to the model by Moos and Schaefer

Stressful events

Patients prospectively reported stressful events in their own words. These could be referred to as specific challenges or aspects of "life crises" (Panel 3, Figure 1) occurring either immediately after diagnosis of a GI cancer or at termination of cancer treatment. Most of the challenges were physical and related to the disease or its treatment: Somatic aspects (study I) measured during the time following diagnosis and Physical side-effects of treatment (study IV) measured at termination of the treatment. However, these aspects did not totally overshadow other stressful events that the patients experienced during these periods. Everyday concerns were rather frequent after diagnosis and Thoughts/affects at termination of treatment. It may be concluded that the concerns the patients express are quite different at the two situations, motivating that not just one situation was selected in order to reach more general conclusions. Some physical aspect are present at both situations but patients' thoughts and emotions regarding e.g. the future are more apparent when treatment is about to terminate and everyday life follows. This argues for taking into account also other aspects of the patient's life than the physical ones. The must discuss also other potential concerns and provide support if required. This is especially of importance since Thoughts/affects contributed to the prediction of anxiety 4 months after treatment had terminated.

Appraisal and coping

A lower level of perceived control over the stressful events and more coping attempts were accompanied by higher levels of psychological distress (study I). However, this was not shown in study IV. The most frequently used coping strategies in this thesis are emotion-focused (study II, IV) and thereby results agree only partly with previous findings. On a general level, it could be assumed that the patients find it more prioritized to handle the emotions connected with the concerns rather that the concern itself. To be able to evaluate the adequacy of the coping attempts on an individual level it is evi-

dent to explore if the concern has a potential to change, i.e. if the strategy seems adequate or not. The patient could be helped by e.g. a psychologist in this exploration. The DCA would be a suitable instrument in the work with identifying and modifying inadequate strategies. In study IV the usage of the coping strategy acceptance together with lower levels of bothersomeness of the stressful event seemed to be of advantage for the patient's QoL at follow-up. A further acceptance and possibly a way of re-appraising the situation could then be fruitful for the patient. A way to support the patients in a stressful situation may be for e.g. a psychologist to help the patient identify how bothersome a stressful event is and how to handle it. Improvement of perceived control could possibly also be of importance. In the light of the model by Moos and Schaefer (1993 ref) these are aspects which seem to have a mediating role in the process (Panel 4).

Life values

Results from study III revealed that a reduction of the discrepancies between attainment and importance of life values may be a way to handle the stressful situation of having a serious disease. Finding a balance between attainment and importance of life values could help the patient to achieve improved psychological well- being. This points in the same direction as the results from study IV in which acceptance seemed to be positive for the individual's QoL. As was the case with bothersomeness and acceptance, finding a balance seems to have a decisive influence on well-being (Panel 4).

For the spouses, in contrast to the patient, there were no reductions either of life value discrepancies or for anxiety/depression. This argues for an extended overview of the spouse's situation and needs during the disease of the patient. It is possible that more information about the patient's situation and prognosis or support regarding changing life values could help the spouse to a more realistic approach. In contrast, what other consequences may this give for e.g. providing hope to the patient? Support specially adapted for e.g. spouses who have difficulties leaving home may be a way of reducing the anxiety and depression levels and thereby maintaining their well-being later on.

Social support

Social support was viewed upon as a part of the patient's environmental system (Panel 1). The impact of aspects of social support as on well-being was explored and it was concluded that functional aspects of social support seem to be related to emotional well-being and Global QoL. One aspect, emotional involvement of social support i.e., not having a person that feels

close to the patient also contributed to the prediction of depression 16 months after treatment termination. Aspects of social support may therefore be of importance and could argue for that medical services point out the value of this kind of support and e.g. encourage relatives to engage in the patients and accompany them to appointments. These factors need to be further explored in relation to well-being in similar studies concerning other specified situations. The assessment of additional aspects of social support may also contribute to the understanding of these complex situations.

Psychiatric history

Psychiatric history is an aspect of the personal system (Panel 2) and was proved important for the patient's well-being and QoL. This aspect must therefore be taken into account when identifying patients at risk. An early identification of the patients of risk and necessary actions such as medical and psychological interventions will improve their later emotional well-being and QoL. Moreover, this will enlarge the total amount of patients with a good well-being and QoL. These results favour a prevalent screening procedure regarding psychiatric history.

Anxiety, depression and QoL

Aspects of well-being and health (Panel 5) are depression, anxiety and quality of life. The levels of anxiety and depression were low, especially in study I and these levels are in accordance with those in study IV. These are positive findings since there are other researchers that have found higher levels. However, it is a vital issue to identify those patients who have elevated values. This is due to the results from study IV which indicated that anxiety and depression had a major impact on the patient's well-being up to more than a year after treatment has terminated. These results together with those for psychiatric history favour a prevalent screening procedure regarding psychiatric history besides anxiety and depression. An early screening for anxiety and depression and psychiatric history will help clinicians to quickly identify and refer potential patients at risk to e.g. psychologists for further interventions.

Thus, all the panels described in the model by Moos and Schafer (1993ref) were relevant and contributed to the understanding of the process of coping with specific challenges among patients with cancer.

Methodological discussion

The patients were asked to complete the DCA in connection to diagnosis and termination of treatment. It may be argued that the method of collecting data regarding patients concerns, i.e. stressful events influence the results. Some patients may have preferred another form than the diary and this could have influenced the representativity of the stressful events. The results could possibly have been different if e.g. the patients had expressed their concerns orally to the researchers. The advantage with the diary form is that the patients can express themselves without any interruption or reactions from anyone else. A range of concerns are expressed in the diaries by the patients, also those of a more existential nature such as their thoughts regarding the future. A disadvantage with the DCA is that patients who are unused with expressing themselves in writing may have difficulties and therefore restrict their responses.

The regression analyses are performed both with and without HADS at baseline as independent variables. These analyses therefore reveal complementary results. Information beyond the obvious then appears. Variables such as a psychiatric history, the bother a concern causes, thoughts or affects for e.g. the future or family, acceptance of a concern and aspects of support were of importance for well-being and this would not have been shown with only analyses including the HADS. This is of clinical relevance since the research field according to specific challenges during cancer disease is in need of an improved understanding and foundations for interventions

Due to the explorative attempt of this study, a large amount of variables was included in the regression analyses. This was necessary since so little is known about prediction of well-being later on. Steps were taken to minimize the amount. However, the high amount increases the risk for type one errors.

The participating patients were somewhat few and this may have influenced the results. This is due to the reduced possibility of detecting correlations in a small sample than in a large sample at a statistically significant level. This increases the risk for type two errors.

The use of a model can be a help in describing phenomenon but also entails risks. Aspects of life are seldom easy to objectively categorize. It may be argued that measures selected for the present thesis are more suitable in another panel than the chosen ones. However, the panel in which the concepts are placed into has probably not influenced the results but naturally the discussion regarding them.

Further research

Understanding of the process of coping requires specification of the threat as well as the individual's judgment of the possibilities to handle it. This requires an extensive analysis of the patient's situation in terms of daily stressful events, the perception of these and attempts at control. The extensive use of checklists, which neglects the importance of defining the stressful event and the process of coping, restrains the development within the research area. Therefore, a measure like the DCA, which takes these aspects into account, could be used within the cancer group as in other samples to prove new knowledge.

Analyzing data from the DCA as in study I reveal relationships between the studied variables on a detailed level. These types of analyses are beneficial for clinical practice and could therefore by advantage be performed also in the future. However, in large patient samples they are time consuming.

Due to the explorative approach of study IV, a high number of variables were included for investigating their importance for well-being. However, other variables could be included in a future analysis to investigate their impact on well-being. Possible variables to include would be other aspects of social support such as structural support and the source of the support. Furthermore, the impact of the total amount of stress in the environmental system could be explored.

Several of those already included variables in study IV could be investigated in relation to another potentially stressful situation. Another situation which can occur during the disease and could involve stress is relapse of the disease. To receive pre-operative radiotherapy is another situation which is now explored in a study by the research group.

Conclusions

Study I

The overall levels of anxiety and depression were low. Higher levels of psychological distress were accompanied both by more coping attempts and a lower level of perceived control over the stressful events. Other events than Somatic aspects are stressful during the time following diagnosis such as Everyday concerns. The most frequently used coping strategies Acceptance and Relaxation were emotion-focused. This is partly in accordance with results from study IV in which both emotion-focused and more problem-focused are frequent. Results rendered a varied picture of ways of handling e.g. Somatic aspects. These were handled by as different strategies as Acceptance and Direct Action.

Study II

In order to study coping as a process, the DCA seems to have advantages compared to the more common "checklist" assessments without any identification of the stressors. Coping measured by DCA is better separated from both the stressful event and outcome. A comparison of the daily basis prospective measure (DCA) and the coping "checklist" (MAC) renders differences regarding the usage of coping strategies. E.g. when using the MAC scales, a more "confronting" or problem-focused coping (i.e. Fighting Spirit and Positive) was predominant compared to the DCA for which a more emotion-focused strategy (i.e. Acceptance and Relaxation) was most frequent. Thus, the chosen measure clearly affects which results are revealed. This influences the possibilities to discuss and compare results from different studies.

Study III

The findings support the assumption of an association of the balance between attainment and importance of life values with high psychological well being. Patients with higher levels of anxiety and depression also had higher discrepancies between attainment and importance for most life values com-

pared to patients with low anxiety and depression levels. Moreover, a significant proportion of the variance in anxiety and depression was explained by these discrepancies. For the patients, the discrepancies for several life values along with anxiety and depression decreased over time. For the spouses however, there were no reductions either of life value discrepancies or of anxiety/depression.

Study IV

Anxiety and depression are strong predictors for anxiety/depression and Global QoL at 4 and 16 months after termination of treatment, despite other variables included in the analyses. However, when the levels of anxiety and depression were not included several other variables like psychiatric history, the bother an event caused, the stressful event Thoughts/affects, the coping strategy acceptance and social support as having a person that feels close contributed to the prediction of anxiety, depression and Global QoL. In addition, regardless of type of stressor, the less bother an event caused the better emotional well-being and Global QoL. An acceptance of the stressful event was also associated with better Global QoL.

Sammanfattning på svenska

Denna avhandling visar att detaljerad information om vanliga situationer som cancerpatienter möter är möjlig att erhålla. Fokus för studierna har varit cancerpatienters anpassning och välbefinnande i relation till väl avgränsade besvär som de själva beskrivit. För patienter som nyligen diagnostiserats med mag-, tarm cancer är "fysiska besvär" tillsammans med "vardagliga problem" vanligast. De cancerpatienter som står i begrepp att avsluta sin behandling besväras mest av "bieffekter av behandlingen" men även "tankar/känslor" rörande t ex framtid och familj. Patienternas välbefinnande över tid predicerades av ångest och depression vid behandlingens avslutande men även av aspekter såsom tidigare psykiatriska svårigheter, hur besvärande ett problem var, ett accepterande av problemet som vald copingstrategi, besvär som innebar tankar eller känslor samt vissa aspekter av det sociala stödet. I de två vanliga situationer som studerats, dels direkt efter *diagnos* och dels vid *avslutandet av en längre tids behandling* används oftast så kallade emotions-fokuserade copingstrategier, dvs sätt som inriktar sig mer på att hantera en känsla snarare än själva problemet. Framförallt tre faktorer hänger ihop med att patienterna har mer ångest eller depression: de upplever att de har lite kontroll över problemet, de använder många copingstrategier för att hantera besvären samt att det finns en stor diskrepans mellan vad patienterna tycker är viktigt i livet och vad de i situationen kan uppnå av detta. Dessutom visar avhandlingen att patienterna i motsats till sina närstående mår bättre över tid och att diskrepanserna minskar. Slutligen framkommer att ett mer sällan använt copinginstrument i form av en dagbok har fördelar jämfört med ett annat vanligare förekommande instrument. Det bidrar med ökad förståelse för hur cancerpatienter anpassar sig och mår i relation till specifika besvär under sjukdomsförloppet.

Acknowledgements

Many have encouraged and supported me during this work. In particular I would like to thank:

All patients and spouses for participating in the studies.

Karin Nordin, my supervisor, for your useful feedback on my work and for helping me find the simple solutions on issues pertaining to my studies.

Bengt Glimelius, my co-supervisor, for being an encouraging and constructive discussion partner and for being so even prior to becoming my formal supervisor.

Per-Olow Sjödén, my late supervisor, for his valuable involvement in my work and in the project.

Yvonne Brandberg, for encouragement and for sharing your broad and unique knowledge within the field of psychooncology - as a clinical psychologist and researcher.

All former and present colleagues at the Section of Caring Sciences, Uppsala University, for helpful feedback on my ideas and studies and for providing a stimulating atmosphere, especially Claudia Lampic, Ulrika Pöder, Camilla Fröjd, Elisabet Mattsson, Susanne Lorenz, Marianne Hedström, Frida Antesson, Josefin Westerberg, Ingrid Demmelmaier, Cecilia Arving, Annika Thalén-Lindström, Per Lindberg, Marianne Carlsson, Eva Denison, Anne Söderlund and Pernilla Åsenlöf. Furthermore, Annika Lundquist and Jeanette Winterling for helpful co-operation in the project and Majbritt Sundelin and Rose-Marie Marcusson for administrative help.

The staff at the Section of Oncology, University Hospital in Uppsala, especially Lena Larsson, Inger Hjerström-Öst, Britt-Marie Bräck and Katarina Schoning.

The staff at the Section of Surgery, University Hospital in Uppsala, especially Lars Påhlman, Gerd Andersson and 70B.

Eva and Åke, my parents, for your unlimited belief in me, also in this "project" and for your generosity, humour and open minds.

Martin and Helena, Per and Charlotte, my favourite brothers and sister-in-laws for showing interest in my work but foremost for providing me with your warmth and refreshing sincerity.

Ulf and Birgitta Lindahl, my "Secure base" in Uppsala, for excellent hostelling, care and late talks.

Brita Arver, my aunt, for the reality based view of an oncologist and your helpful sense of humour.

The Section of Psychology, Mid Sweden University, Östersund for a pleasant workplace and inspiring company.

Finally, I would like to express my gratitude to Andreas, for without you this thesis would probably not have been completed, and to Edward and Karolina, for being such wonderful representatives of that other life, outside the PhD-student world.

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Editor: The Dean of the Faculty of Social Sciences