Stress and Coping in Parents of Children with Cancer

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Abstract

The general aim of this thesis was to investigate disease-related stress and ways of coping in parents whose children were in active treatment for cancer, or had completed successful cancer treatment. Specifically, the research included examinations of: disease-related stress at various points in time after the child's diagnosis; strain and traumatic stress during and after the child's treatment; the relation of certain demographic and disease-related variables to parental stress; the use of various coping strategies, and the co-variation of coping strategies and level of emotional distress; and the relationships between perceived social support, support-seeking coping, and emotional distress.

The four sub-studies of the thesis involved cross-sectional samples including 265, 413, 395, and 184 parents, respectively. Parents were recruited at Astrid Lindgren Children's Hospital, Stockholm, and at Linköping University Hospital. Both mothers and fathers were invited. The time elapsed since disclosure of the child's diagnosis varied from one week to fourteen years. All four studies were based on quantitative data, collected through self-report inventories. Fourteen various aspects of disease-related stress, and seven types of coping strategies were examined.

Findings indicate that high levels of disease-related distress are particularly frequent among parents during the first period after the diagnosis. However, most aspects of disease-related strain were reported by parents later in time as well. Indeed, years after the diagnosis parents were more anxious than parents of healthy children. Furthermore, although particularly the treatment phase appeared to involve events that affect parents' experience of control, as well as elicit traumatic stress reactions, most of the assessed aspects of stress seemed to occur among parents of children off treatment as well.

Positive perceptions of social support, and a coping style that included problem-focusing appeared to make parents less affected by strain. In contrast, the reliance on a coping style including a passive reaction pattern was associated with higher levels of anxiety and depression. An avoidant coping style was also associated with more distress. However, immediately after a child's cancer diagnosis, the distress seemed to be high regardless of whether parents relied on avoidant coping or not.

Findings indicate that parents with lower education and non-Swedish origin may be less resilient to traumatic stress after end of treatment, than parents with higher education levels and a native Swedish background. In contrast, a good prognosis did not seem to make parents less vulnerable to distress than a worse prognosis or a relapse in the child. Moreover, cancer in a child appeared to affect mothers and fathers similarly.

In conclusion, the data suggest that several aspects of disease-relate strain are relevant in various patterns to parents during the child's treatment as well as when treatment is completed, and that such strain can appear at any point in time after a child's cancer diagnosis. Factors other than the passing of time and the termination of treatment account for the majority of variation in parental stress.

Keywords: Childhood cancer; parents; disease-related stress; coping; social support; traumatic stress

ABBREVIATIONS

ALL	acute lymphoblastic leukaemia
AML:	acute myelogenous leukaemia
CNS tumour:	central nervous system tumour
DSM-IV:	Diagnostic and Statistical Manual of Mental Disorders, 4th ed.
IES-R:	Impact of Event Scale - Revised
LCH:	Langerhans cell histiocytosis
PTS:	posttraumatic stress
PTSD:	posttraumatic stress disorder
UCL:	Utrecht Coping List

We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time
(T S Eliot, from *Four Quartets*, 1943)

The present thesis is based on the following studies, which will be referred to by their Roman numerals I – IV:

I.   Boman, K., Lindahl, A., & Björk, O. (2003). Disease-related distress in parents of children with cancer at varying stages after diagnosis. *Acta Oncologica, 42*(2), 137-146.

II.   Lindahl Norberg, A., & Boman, K K. Parental traumatic stress during and after paediatric cancer treatment. *submitted for publication.*

III.   Lindahl Norberg, A., Lindblad, F., & Boman, K K. (2005). Coping strategies in parents of children with cancer. *Social Science and Medicine,* 60(5), 965-975.

IV.   Lindahl Norberg, A., Lindblad, F., & Boman, K K. Support-seeking, perceived support and anxiety in mothers and fathers after children's cancer treatment. *submitted for publication.*

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Introduction

Despite advances in the cancer treatment a cure is still by no means certain. For parents, the diagnosis of cancer in one of their children is a psychological and existential challenge. As one parent explained: "Sometimes I think that I still live in some state of shock! … I feel now that life is so unfair.". However, a parent's ability to manage his or her psychological distress during cancer treatment of a child is vital not only for the consolation of the parent himself or herself, but it may also influence the child's well-being (Vance, Morse, Jenney, & Eiser, 2001) and long-term psychological adjustment (Kupst, Natta, Richardson, Schulman, Lavigne, & Das, 1995; Noojin, Causey, Gros, Bertolone, & Carter, 1999; Sawyer, Streiner, Antoniou, Toogood, & Rice, 1998).

In Sweden approximately 300 children and adolescents are diagnosed with cancer each year (NOPHO, 1999). The incidence is relatively stable. Although childhood cancer fortunately is a fairly rare group of diseases, in Sweden it is the second leading cause of death in children younger than 16 years of age. When a child is diagnosed with cancer a process starts, which interferes with the family's daily life for a long period of time.

Survival rates in childhood cancer vary largely between different cancer types, from retinoblastoma with a 97% survival in the Nordic countries 12 years after the diagnosis (NOPHO, 1999), to the brain tumour pons glioma, for which no cure is established. A relapse of the disease implies that the prognosis is worsened. Various conditions, as for example the location and the spreading, and the genetic disposition may affect the survival perspective. However, in the end, for the individual family the probability of survival always turns out to be 100% or 0: to survive or not to survive.

The general objective of the present research was to investigate indications of strain and ways of coping in a sample of Swedish parents with children diagnosed as having a malignant disease.

Strain and stress – definitions

The present research is based on some theoretical models and concepts commonly used in psychological research to describe the various aspects of the stress process. To facilitate the comprehension of the study results, these models and concepts are briefly summarized and defined in the following section.

The stress process

Everyone knows what stress is, but the actual meaning of the concept is generally somewhat vague. However, as Lazarus (1966) noted, *stress* is neither a stimulus, a response, nor an intervening variable, but rather a collective term for an area of study. Indeed, stress research has tended to separate into two distinct areas, namely physiological and transactional (Singer & Davidson, 1986). The physiological tradition focuses the reactive organism, whereas the transactional model emphasizes cognitive and emotional processes that influences the stress reaction. According to the transactional model, the theoretical concept of psychological stress refers to a process in which the core elements are *stressors*, *appraisal*, *strain*, *stress reactions*, and *coping*.

A *stressor* is defined as any stimulus that is perceived as harmful, threatening, or challenging. Cognitive *appraisal* refers to the evaluation of the stressor, and one's own resources to handle it. An event appraised as a stressor produces *strain* (i.e. pressure, demand). The manifestations of strain – *stress reactions* – can be observed in the domains of physiological processes, emotions, behaviour, and cognition. Certain strategies are used to handle the strain. The concept of *coping* is used in various meanings, although, as Monat and Lazarus (1991) observed, there seems to be growing agreement among professionals that coping refers to an individual's efforts to master demands that are perceived as taxing or exceeding his or her resources. Stressor, resources, and outcome of coping efforts

are repeatedly reappraised during the stress process. The psychological outcome of the stress process is generally referred to as adaptation or adjustment.

Stressors

According to the transactional model of stress, the significance of a stressor is "in the eye of the beholder", i.e. dependent on individual appraisal. Nevertheless, research on *major life events* has established a record of events, which usually are perceived, at least by people in Western cultures, as initiating considerable adjustment (Holmes & Rahe, 1967). The events rated as requiring the most adjustment typically refer to loss of a close family member through separation or death.

Stress reactions

The physiological stress response involves an immediate stimulation of muscles and organs, and a subsequent neuroendocrine ("fight-or-flight") response (Everly & Lating, 2002). The endocrine activation associated with responses to prolonged strain seems to be somewhat different from the "fight-or-flight" response (Herbert, 1997). Emotional consequences of stress are anxiety and depression, including feelings of uncertainty, loss of control, loneliness, and hopelessness. Behavioural aspects are restlessness, agitation, and withdrawal. Cognitive manifestations includes memory deficits, difficulties concentrating, and intrusive thoughts or flashbacks as well as avoidance of reminders. Common psychosomatic consequences of stress are musculo-sceletal pain, and headache. The increased arousal associated with stress may also lead to sleep disturbances. Research aiming to explore the presence of stressors typically assess one ore more of these various types of responses.

Traumatic stress

When the psychological impact of an event is exceptionally intense the terms *crisis* or *trauma* are used. A traumatic stressor usually includes actual or threatened death or serious injury, or threat to physical integrity. For simple explication Figley (1985) uses the term *catastrophe*, defined as "an extraordinary event or series of events which is sudden, overwhelming, and often dangerous, either to one's self or significant other(s)" (p. xvii). Crises and traumas challenge a person's existential outlook. The purpose of the subsequent emotional and cognitive reactions are a reconstruction of this shattered view of life. General theoretic models for *crisis reactions* often comprise a series of separate phases. According to some models the phases linearly follow each other, and according to others they are recurrently alternating during the crisis process. One well-known crisis model, described by for example Cullberg (1975), includes the phases shock (feeling numb or detached), reaction (chaotic feelings when reality of the trauma is pushing through), adjustment process (beginning to accept the reality of the trauma), and adaptation (accept the new conditions for life).

Consistent with a cognitive information processing model, the response to a traumatic event are alternating intrusive thoughts about the event, and avoidance of reminders. For example, Joseph (2000) suggests that the intrusive and avoidant processes can be understood as mediators between the experience of trauma and subsequent adjustment. A theoretical model that also relates to Piaget's (1971) concepts of accommodation and assimilation, components of the process of integrating any information that is incongruent with a person's idea of the world. In this case avoidance and involuntary as well as deliberate rumination are functional for positive adaptation following a trauma (Linley & Joseph, 2004). However, sometimes the traumatic experience is overwhelming, and an integration not achieved, although the process of intrusions and avoidance goes on. This phenomenon is labelled *posttraumatic stress* (PTS). Three categories of emotional and behavioural reactions are typically associated with PTS: (1) intrusive thoughts or flashbacks of the traumatic event, (2) avoidance of reminders of the event, and (3) increased arousal. Indeed, these three categories of symptoms are included in the criteria of the psychiatric syndrome *posttraumatic stress disorder* (PTSD), as outlined in the 4th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV;

(American Psychiatric Association, 1994). To be regarded as *post*-traumatic, the reactions must relate to an event at least four weeks back in time. Some researchers suggest that traumatic stress responses may be qualitatively different from other stress responses (Stuber, Kazak, Meeske, & Barakat, 1998), while others claim stress responses to be on a continuum, with trauma as the most extreme strain (Ruscio, Ruscio, & Keane, 2002).

Chronic stress

Stressors do not have to be traumatic to have high psychological impact. Even low-intensity stressors may create a severe effect, if they are long-lasting or recurrent. Each exposure to such a stressor may constitute a minimum of threat, but if the strain persists the effect may accumulate over time, and lead to exhaustion (Singer & Davidson, 1986). Chronic stress is most often associated with excessive demand, although it can arise from other persistent conditions such as threat, uncertainty, or restriction of choice (Wheaton, 1997). Such stressors often develop slowly, with no distinct starting point, and typically have longer time course than traumatic life events. However, singly each stressor need not persist for long, as cumulative effects have been suggested to occur across different stressors (Singer & Davidson, 1986). Depression seems to be the predominant emotional response to chronic stress, and has been found to be associated with the experience of entrapment (Gilbert, Gilbert, & Irons, 2004). There is a growing agreement that exposure to chronic stress may lead to negative health consequences (Herbert, 1997; Strike & Steptoe, 2004). The mediating role of certain neuroendocrine processes between chronic stress and psychological and physical consequences has been the subject of several recent studies (e.g. (Blackburn-Munro, 2004; Tafet & Bernardini, 2003).

Coping

Coping efforts include several behavioural and cognitive strategies. These fall into two categories: strategies aiming at eliminating the stressor, and those focusing on the reduction of the stress responses. The first category is typically referred to as problem-focused or primary control strategies, while the latter are called emotion-focused or secondary control strategies. These categories can be divided further into sub-categories. Pearlin Lieberman, Menaghan and Mullan (1981) have, for example, discussed the distinction between the modification of the meaning of problems, and the management of emotional and somatic stress symptoms in emotion-focused strategies. A particular coping strategy is not "good" or "bad" in general. A strategy may be beneficial on one occasion, but ineffective or even harmful in another context (Lazarus, 1999). Adaptive coping produces a reduction of the stress reactions. However, a reduction in stress reactions is not necessarily caused by adaptive coping.

Coping is studied either in the form of situation-specific strategies, employed in the encounter with a certain stressor, or as a persons coping style, i.e. the "tool box" of various strategies that an individual uses in various contexts. Accordingly, when situation-specific strategies are in the focus of research, the question is "Which strategies are used in this situation?". Alternatively, the study of coping style is guided by the question "Is this strategy ever used by this individual?". Indeed, while some researchers emphasize the relative stability of a personal profile of preferred coping strategies (Moos & Holahan, 2003), others underscore the fact that people adjust their choice of strategies to the situational demands (Lazarus, 1999).

Social support

A positive relationship between social support and well-being is often reported in the literature. In this respect, social support is sometimes labelled a coping resource, and has been found to affect the use of various different coping strategies (Daniels, 1999; Dukes-Holland & Holahan, 2003). Furthermore, social support purportedly affects well-being by improving self-efficacy (Major, Cozzarelli, Sciacchitano, Cooper, Testa, & Mueller, 1990), and influences appraisal of the stressor (Daniels, 1999).

As suggested by Hobfoll and Vaux (1993), three aspects of the social support construct can be distinguished: network resources, behaviours, and subjective appraisal of support. Network re-

sources are the actual number of persons, available for supportive interaction. The behavioural aspect refers to seeking support and accepting offered support. The subjective view, a belief that others are willing to provide assistance if needed, is usually signified by the term perceived social support (Pierce, Sarason, & Sarason, 1996). On examination, the frequency of social behaviours, and the number of people available for social interaction may reflect the amount of support obtained, however subjectively perceived support appears to be the factor most strongly associated with well-being (Hobfoll & Vaux, 1993).

Medical aspects of childhood cancer

Early research on the psychosocial aspects of paediatric oncology focused on the consequences for parents preparing for the death of their child (e.g. (Binger, Ablin, Feuerstein, Kushner, Zoger, & Mikkelsen, 1969; Bozeman, Orbach, & Sutherland, 1955). The advances in medical care have led to a 6-year survival rate of more than 80% in average for children with cancer today (NOPHO, 2004). As a consequence, parents are presently encouraged to prepare themselves for a long period of uncertainty associated with the possibility of a cure. During this period intensive medical treatment takes place, bringing forth a range of short and long-term side effects. In the following section, medical aspects of childhood cancer are introduced, in order to clarify the tangible conditions of being a parent of a child with cancer.

Types of cancer

Cancer is a term covering various types of malignant diseases, which have in common a malfunction of the DNA. An extremely rapid cell growth, or a disturbance of the cell's encoded life span results in too many cells living too long. Cancer diseases are classified on the basis of the type of cells involved. The main cancer diagnoses include several subtypes, often differing in resistance to treatment, which guides the intensity, mode, and duration of treatment. The main types of childhood cancer are: leukaemias, lymphomas, tumours in the central nervous system (CNS tumours), sympathetic nervous system tumours, retinoblastoma, hepatic tumours, bone tumours, soft-tissue sarcomas, germ-cell tumours, and carcinoma.

In *leukaemia* the bone marrow produces large numbers of abnormal white blood cells. The production of normal blood cells is reduced, resulting in symptoms such as fatigue, anemia and bruising, and bleeding can take longer than normal to stop. Acute lymphoblastic leukaemia (ALL) is the most common form of childhood cancer in Sweden. The survival of ALL has risen to about 80% during the past decades. Acute myelogenous leukaemia (AML) which affects a smaller group of patients is more difficult to cure.

Lymphoma includes a variety of cancers of the lymphatic system. The two main types of lymphoma are Hodgkin's lymphoma (or Hodgkin's disease) and Non-Hodgkin's Lymphoma.

Most of the *CNS tumours* originate in the brain, although a small number originate in the spinal column. This group of tumours comprise disparate types of malignancies as regards symptoms, treatment and survival probability.

Neuroblastoma is a tumour of the sympathetic nervous system, often occurring in the adrenal glands of the abdomen. It is difficult to diagnose at an early stage, and many neuroblastoma tumours have already spread by the time they are detected. Often neuroblastoma is first discovered when parents feel a mass somewhere in the child's body, representing a spread disease.

Soft tissue sarcomas include several different types of tumours that originate in muscles, sinews, or tissue which surrounds a muscle. The most common type in this group is Rhabdomyosarcoma, which appears usually in the head or neck, including the muscles around the eye, in the back of the throat, or in the cheek.

Other types of solid tumours include *Wilms' tumour* which arises in the kidney, *Hepatic tumours* in the liver, and *Retinoblastoma* in the cells of the light sensitive lining of the eye. *Osteogenic sarcoma* and *Ewing's sarcoma* are the most common types of bone tumours. *Germ-cell tumours* develop from cells producing eggs or sperm, and are mainly sited in the ovaries or testes.

Finally, *Langerhans cell histiocytosis* (LCH) is a disease which although not classified as cancer behaves like a cancer in its more serious forms, requires treatment with chemotherapy, and is therefore usually treated by cancer specialists.

Cancer treatment

Chemotherapy, radiotherapy and surgery are the core treatment modes of cancer in children. Progress in the medical sciences and technology has resulted in a remarkable improvement of survival rates. The powerful treatment needed to conquer the cancer cells is balanced against unwanted short and long-term side effects. Procedures for administering treatment have been developed with the intention of causing as little worry and pain as possible. The specific treatment depends upon the type and subtype of cancer, its location and the age of the child. Various treatment modes are often combined.

The majority of children with cancer are treated with *chemotherapy*, i.e. a treatment of drugs which kills cancer cells or stops them from multiplying. There are numerous different types of chemotherapeutic drugs and often two or more are used in a course of treatment, each with a different way of working. Intravenous injection is the usual method of administration although sometimes drugs are administered orally by way of tablets or liquids. Chemotherapeutic drugs are powerful and often harm normal cells causing unwanted side-effects throughout their administration. Common, temporary side effects of chemotherapy include anaemia, reduced resistance to infection, bleeding problems due to difficulties of the blood to clot, mouth ulcers, diarrhoea or constipation, nausea and vomiting, and fatigue. Body image changes are also common: hair loss, excessive gain or loss of weight, and skin changes like acne, rashes, or changes in pigmentation. Moreover, some types of chemotherapy agents involve a long term risk which can lead to hearing loss, reduced fertility, damage to kidneys or liver, and weakened heart muscle.

Alternatively, *Radiotherapy* works by destroying cancer cells with high-energy rays. However, this technique can also produce unwanted side effects. In particular, the normal healthy tissue surrounding the tumour is sometimes damaged and irradiated tissue may fail to develop normally causing particular problems in growing children. The severity of negative effects is age dependent: the younger the child, the more sensitive to radiotherapy. These effects are most critical when radiotherapy has been given to the brain, which may disturb intellectual development. Radiation to the brain can also affect the production of hormones, causing disruption of growth, puberty and fertility.

Many children with cancer need surgery at some point in their treatment, for example, to insert a central catheter, reduce a tumour, or to take a small sample of the tumour for diagnosis. If possible, solid tumours are removed surgically. For some children with, for example, retinoblastoma or bone tumours, it is sometimes necessary to remove all or a portion of a body part. The ambition is to remove as small a part as possible and yet still remove the entire tumour. Owing to advances in treatment amputation is less frequently necessary.

Indeed, in rare cases radiation or chemotherapeutic drugs may cause another form of cancer many years after completed treatment, a so called 'second cancer'. However, a second cancer may also develop in rare cases of genetic defects.

Tests and supportive treatment

In addition to direct treatments aimed at taking control of the cancer, contact with the hospital normally involves several other medical procedures. Tests are conducted to diagnose the exact type of cancer, and subsequently to monitor the effects of treatment. Blood tests are conducted regularly, especially during chemotherapy. To detect malignant cells samples of bone marrow or cerebrospinal fluid are taken. Bone marrow aspirations are conducted by placing a fine needle into the bone in the hip. Spinal fluid is extracted through a needle inserted between two vertebral bones in the spine. In addition, imaging techniques, including x-ray and magnetic resonance imaging scan, are used to find the exact location of the tumour and determine whether it has spread to other parts of the body.

By way of assistance, supportive medical care has developed to manage or prevent pain and discomfort associated with the disease and its treatment. Nausea and vomiting can be reduced with drugs. Anaesthetics in the form of creams rather than injections can lessen the pain and unpleasantness of some tests and treatments. Anti-anxiety medications and sedatives are sometimes given to ease the anticipatory anxiety and pain experienced with procedures such as bone marrow aspirations and spinal taps.

Due to nausea and mouth ulcers the child may be unable to eat and drink enough to maintain weight or grow. In such cases, feedings may be given directly into the stomach through a tube, threaded via a nostril and down the back of the throat. Moreover, normal infections can be life threatening, especially if the child's immune system is suppressed by chemotherapy. Therefore, infections may be treated with intravenous antibiotic therapy at the hospital. More developed types of antibiotics play an important role. Various types of blood transfusions may be given when blood counts are low. Indeed, for many patients' low blood counts or episodes of infection interfere with the scheduling of treatment. Low blood cell counts may demand red blood cell or platelet transfusion. Finally, some treatments threaten fertility, in which case teenage boys and their parents are made aware of the option of sperm banking, where sperm can be stored for possible use in later years.

Once successful treatment is completed, there is a regular schedule of follow up, involving clinical examinations to screen for disease recurrence. After the first few years the focus of follow up changes to monitor disturbances in growth and development and other possible later side effects of treatment.

The section outlining the medical aspects of childhood cancer has been compiled using a number of sources, including (Björk, Gustafsson, Henter, Kogner, Pal, Söderhäll, & Wahlqvist, 1998; Henter & Björk, 1999; Pizzo & Poplack, 2002).

Being a parent of a child with cancer – previous research

Cancer in a child alters the life situation of the family and implies stressors of varying duration, predictability, and impact. In addition to concerns about the child's prospects of being cured from cancer, the strain relate to demands and changes in everyday life. These demands include, for example, accepting the intensity of one's own reactions, and dealing with the reactions of others (Patistea, Makrodimitri, & Panteli, 2000), witnessing the child in pain (Ljungman, Gordh, Sorensen, & Kreuger, 1999), concerns about the child's future (Cayse, 1994; Leventhal-Belfer, Bakker, & Russo, 1993), the quality of care (Enskär, Carlsson, Golsater, Hamrin, & Kreuger, 1997; Lozowski, Chesler, & Chesney, 1993), aspects of the cancer treatment itself (Best, Streisand, Catania, & Kazak, 2001; McGrath & Pitcher, 2002; Stuber et al., 1998), negative employment and financial consequences (Patistea et al., 2000; Sloper, 1996), and supporting siblings of the ill child (Barrera, Fleming, & Khan, 2004).

The objective of psychological research concerning parents of children with cancer is often to explore whether the situation brings about negative psychological consequences, and if so, when,

and how, and which factors predict such outcome. Sometimes the actual stressors are surveyed. However, more often their effect, i.e. parents' psychological responses, is studied. In those studies a particular stressor is seldom identified, as the intention usually is to capture reactions to all stressful experiences associated with any aspect of the child's disease.

Parental psychological reactions

Researchers have focused on several different categories of parental psychological responses to childhood cancer. Emotional distress, i.e. anxiety and depression, appears to be the most common measure of parental reactions. In addition, anxiety and depression are often found in childhood cancer parents, and are sometimes elevated compared to normal levels (Allen, Newman, & Souhami, 1997; Santacroce, 2002; Stuber, 1996).

Broader measures of mental well-being, including instruments such as the General Health Questionnaire (GHQ) and the Symptom Checklist (SCL-90), point towards an increased risk of psychiatric symptomatology among childhood cancer parents (Dockerty, Williams, McGee, & Skegg, 2000; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1999; Sloper, 2000). Psychiatric symptoms as well as emotional distress seem to be more prominent during the first years after diagnosis. This also applies to psychosomatic symptoms (Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000). Neuroendocrine measures, although rare in the study of childhood cancer parents, have indicated effects which are usually associated with chronic stress (Glover & Poland, 2002; Miller, Cohen, & Ritchey, 2002).

In addition researchers have focused on emotional reactions, which are more directly situation-specific than anxiety, depression, and psychiatric symptoms. These reactions include, but need not be limited to, feelings of uncertainty, helplessness and loneliness, as well as disease-related worry, concerning the child's future health, and recurrence of the disease (Grootenhuis & Last, 1997; Leventhal-Belfer et al., 1993; Van Dongen-Melman, Pruyn, De Groot, Koot, Hahlen, & Verhulst, 1995a).

In this respect, the posttraumatic stress framework has been used to describe the reactions of childhood cancer parents. Studies screening for the diagnosis of PTSD most often address parents of children for whom treatment is completed. The frequency of mothers meeting the criteria for current PTSD has been reported to be 6.2% (Manne, Duhamel, Gallelli, Sorgen, & Redd, 1998), 20% (Goldenberg Libov, Nevid, Pelcovitz, & Carmony, 2002), 25% (Brown, Madan-Swain, & Lambert, 2003; Pelcovitz, Goldenberg, Kaplan, Weinblatt, Mandel, Meyers, & Vinciguerra, 1996), and 43% (Glover & Poland, 2002). Far less is known about fathers but a recent study, which examined stress reactions in both mothers and fathers, one to ten years after a child's cancer treatment, reports that 19% of the families contained at least one parent suffering a current PTSD (Kazak, Alderfer, Rourke, Simms, Streisand, & Grossman, 2004).

Other studies have focused, not on the clinical diagnosis of PTSD, but on examination of posttraumatic stress symptomatology as expressed by intrusions and avoidance, and in some studies arousal as well. Frequently a composite measure of symptoms is presented. Between 10 to 40% of parents report moderate to severe PTS symptoms several years after the end of treatment (Barakat, Kazak, Meadows, Casey, Meeske, & Stuber, 1997; Kazak et al., 2004; Kazak, Barakat L P, Meeske K, Christakis D, Meadows A T, Casey R, Penati B, & Stuber, 1997; Stuber, Christakis, Houskamp, & Kazak, 1996).

Impact of time

Based on crisis theory the time-course of parental reactions has been interpreted by way of a linear model with discrete stages. According to one such model, reactions proceed through five stages: anxiety and disorganization, denial, grief (anger, guilt and sadness), focusing attention, and finally acceptance of the illness as a part of the family's daily life (Die-Trill & Stuber, 1998). After the shock of learning about the diagnosis, producing a "limbo" of worry, uncertainty, vulnerability, and help-

lessness, a new understanding of everyday life emerges where uncertainty about the child's survival is a present reality (Clarke-Steffen, 1993).

Other researchers emphasize the impact of excessive demands and stressful experiences during treatment which interrupt the crisis processing. For each family turbulent phases, including medical complications and other threats to the child's health are interspersed with relatively calm periods (Lederberg, 1998). The equilibrium of the family is repeatedly disturbed each time a new phase of the treatment is entered (Cincotta, 1993). This applies also to the completion of treatment, when parents often experience isolation as the concern of medical staff, and attention from relatives and friends wanes.

The time-course of parental distress and adjustment has been examined by way of repeated assessments of stress variables. During the first months after the disclosure of the cancer diagnosis parents report elevated levels of general psychiatric symptoms and emotional distress, as compared to a community sample (Dahlquist, Czyzewski, Copeland, Jones, Taub, & Vaughan, 1993; Hoekstra-Weebers et al., 1999; Sawyer et al., 2000; Sloper, 2000). On the whole, such psychiatric problems decline and within a few years are comparable to the levels of control parents (Dahlquist et al., 1993; Sawyer et al., 2000). However, continuously elevated distress has indeed been reported 12 and 18 months after diagnosis (Hoekstra-Weebers et al., 1999; Sloper, 2000).

Cross-sectional designs have also been used to examine parental stress in relation to time. Such a design involve parents at different points in time after the initial diagnosis. Although each parent is assessed on one occasion only, tentative conclusions regarding the influence of time are usually drawn. Using this technique studies report that levels of psychiatric symptomatology can not be predicted by considering only elapsed time since the diagnosis, at least among parents assessed within the first years after the child's diagnosis (Dockerty et al., 2000; Mu, Ma, Hwang, & Chao, 2002). Neither has a linear relationship between time, and anxiety and depression been found in two cross-sectional samples with a length of time since diagnosis being up to more than a decade, (Frank, Brown, Blount, & Bunke, 2001; Grootenhuis & Last, 1997). Generic distress symptoms, such as anxiety and depression are not elevated compared to normative data in cross-sectional samples covering several years (Frank et al., 2001; Grootenhuis & Last, 1997). Disease-related distress, as for example symptoms of PTS, helplessness, uncertainty, and low control are reported to occur among parents even many years after completed treatment, and can not be predicted by time in cross-sectional studies (Barakat et al., 1997; Grootenhuis & Last, 1997; Kazak et al., 1997; Leventhal-Belfer et al., 1993; Van Dongen-Melman et al., 1995a).

Parental coping

In the childhood cancer literature, the term coping is used interchangeably to mean either "the ways people try to handle stress" (i.e. certain strategies) or "how they get along" (i.e. adjustment, adaptation). Studies of 'coping' using only the former connotation are referred to here. These studies have focused on situation-specific coping in relation to stressors associated with the child's disease (see e.g., (Dahlquist, Czyzewski, & Jones, 1996; Grootenhuis & Last, 1997; Hardy, Armstrong, Routh, Albrecht, & Davis, 1994; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2000; Sloper, 2000; Wittrock, Larson, & Sandgren, 1994). Parents are asked which strategies they use "in coping with your child's disease" or "dealing with day-to-day problems and stresses caused by your child's illness".

Occasionally certain coping strategies have been presupposed to be adaptive and others inappropriate. In other studies, the efficacy of coping strategies has been investigated more objectively. Coping efficacy has been studied for example by way of ratings of 'parental adjustment' or 'coping adequacy' made by the medical staff (Kupst et al., 1995), or by the researchers themselves (Eapen & Revesz, 2003; Overholser & Fritz, 1990), or parents' own ratings of the effectiveness of their coping strategies (Cayse, 1994; Noojin et al., 1999). In addition, 'level of distress' has been used as a criterion of coping efficacy. In this respect, a causal relationship is assumed between the use of a particular coping strategy and parent's level of distress. As such outcome criteria researchers have studied anxi-

ety and depression (Grootenhuis & Last, 1997; Wittrock et al., 1994), psychiatric symptoms (Hoekstra-Weebers et al., 2000), psychosomatic symptoms (Sloper, 2000), and marital adjustment (Dahlquist et al., 1996).

Coping strategies are categorised in different ways, and occasionally viewed dichotomously, such as *emotion-focused* versus *problem-focused* strategies (LaMontagne, Wells, Hepworth, Johnson, & Manes, 1999), or *avoidance* versus *approach* coping (Noojin et al., 1999). Similar to the latter are the *repression–sensitization* (Dahlquist et al., 1996) and the *engagement–disengagement* categorisations (Hardy et al., 1994; Trask, Paterson, Trask, Bares, Birt, & Maan, 2003; Wittrock et al., 1994).

In addition to the dichotomisation, coping may also be monitored by way of a number of specific strategy clusters. For instance, Hardy and her co-workers (1994) have studied the eight separate subtypes of *engagement* and *disengagement* coping: *problem avoidance, wishful thinking, social withdrawal*, and *self-criticism* ('disengagement coping'), and *problem solving, cognitive restructuring, social support,* and *express emotions* ('engagement coping'). Alternatively, a Dutch research group have used a taxonomy, according to which emotion-focused as well as problem-focused strategies include the four types of *predictive, vicarious, illusory*, and *interpretative* control strategies (Grootenhuis & Last, 1997; Grootenhuis, Last, de Graaf-Nijkerk, & van der Wel, 1996). Another set of strategies includes seven strategy clusters: *active problem focusing, palliative reaction pattern, avoidance behaviour, passive reaction pattern, expression of emotions*, and *comforting cognition*, and *social-support seeking* (Hoekstra-Weebers et al., 2000). Finally, Sloper (2000), has identified five strategy types: *problem solving, self directed*, *support seeking, wishful thinking*, and *distancing*.

Coping behaviours within the composite category of 'engagement coping' appear unrelated to distress among parents of children with cancer (Trask et al., 2003; Wittrock et al., 1994), while a more frequent use of such strategies are associated with less distress in parents, caring for a normally healthy child with the flu (Wittrock et al., 1994). By way of contrast, disengagement coping is associated with higher levels of distress among childhood cancer parents (Trask et al., 2003; Wittrock et al., 1994), as well as among parents of normally healthy children with the flu (Wittrock et al., 1994). Coping by wishful thinking seems to occur more frequently among childhood cancer parents than among parents of healthy children (Hardy et al., 1994). However, the efficacy of this coping strategy is unclear. In one study wishful thinking was found to be associated with more distress (Grootenhuis & Last, 1997) but this relationship has not been confirmed by others (Sloper, 2000). Likewise, in consideration of situation-specific problem solving, Sloper (2000) found this strategy to be associated with less distress among mothers, but in a study by Hoekstra-Weebers and colleagues (2000) no relationship was found between problem-focused strategies and distress.

Social support

In previous research involving parents of children with cancer, three different aspects of social support have been studied; namely, social behaviours, network resources, and subjectively perceived support. Social behaviours are typically studied as 'social-support seeking coping' (Goldbeck, 2001; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998; Hoekstra-Weebers et al., 1999). Network resources have been studied by way of a quantification of network size (Barakat et al., 1997; Dockerty et al., 2000; Kazak et al., 1997; Pelcovitz et al., 1996), as well as a quantification of social interactions, including those perceived as desired and those perceived as unwelcome (Hoekstra-Weebers et al., 1999; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001). Others have assessed the subjective perception of support (Frank et al., 2001; Manne, Duhamel, & Redd, 2000; Speechley & Noh, 1992), or individuals' satisfaction with the support they receive (Dockerty et al., 2000; Pelcovitz et al., 1996; Sloper, 2000). A number of studies have addressed more than one of these aspects of social support. However, relations between different aspects of social support have usually not been the subject of analyses.

Some gender differences in social behaviours and network resources have been identified. Mothers as compared to fathers have been found to report more frequent use of 'support-seeking

coping' (Goldbeck, 2001; Hoekstra-Weebers et al., 1998) and larger social networks (Dockerty et al., 2000; Hoekstra-Weebers et al., 2001), but satisfaction with support is generally reported as equal for both sexes (Dockerty et al., 2000; Frank et al., 2001).

Regarding the association between distress and social support, analyses of gender differences have revealed divergent results. In mothers but not fathers, support network size (Barakat et al., 1997; Kazak et al., 1997), and support-seeking behaviours (Hoekstra-Weebers et al., 1999) have been related to less distress. Indeed, a more frequent use of support seeking in fathers at the time of the child's diagnosis has actually been associated with more distress one year later (Hoekstra-Weebers et al., 1999). Although, in a different study perceived support was related to less distress among fathers but not among mothers (Frank et al., 2001). Other studies report similar associations between social support and distress among mothers and fathers, as regards satisfaction with support (Dockerty et al., 2000; Sloper, 2000; Speechley & Noh, 1992), and network size (Dockerty et al., 2000).

Situation-specific and demographic factors

Notably, some parents evidence particularly high levels of psychological distress when exposed to their child's cancer illness and treatment, whereas other parents although distressed cope better. To facilitate an understanding of differences between parents researchers have not only focused on the parents themselves but also other situational factors, i.e. objective disease-related variables, and demographic factors have been investigated for their potential influence on distress.

One situational factor that can be supposed to be of particular importance is whether the child had suffered a relapse of the disease. Grootenhuis and Last (1997) found that a relapse of the disease was associated with parental distress, in particular feelings of uncertainty and helplessness. However, no differences in levels of anxiety (Mu et al., 2002) and psychiatric symptoms (Sloper, 2000) have been found in parents of a child with a relapse as compared to parents of a non-relapsed child. Indeed, Yeh (2002) found that levels of emotional distress were even lower in parents of a child in treatment for a relapse than in parents of a child newly diagnosed as having cancer

The intensity of treatment the child receives (Barakat et al., 1997), or whether the child had been given cranial radiation therapy (Kazak, Stuber, Barakat, Meeske, Guthrie, & Meadows, 1998) has not been found to systematically affect levels of parental PTS. Neither has the child's medical sequelae after completed treatment, as estimated by the oncologist, been found to predict PTS symptoms in the parents (Kazak et al., 1998). Likewise, estimated chances of survival and responses to treatment have not been found to predict levels of psychiatric symptoms (Hoekstra-Weebers et al., 1999, 2001), neither is illness severity, as rated by the physician, found to predict PTS (Pelcovitz et al., 1996). Anxiety and depression was in a study by Dahlquist and colleagues (1996) equal among parents with a child whose health status had improved, and in those with a child whose health status had not improved twenty months after diagnosis. Notably, although objective situational factors appear to have little systematic impact on distress, subjective perceptions of disease-related threat certainly do appear to reflect parental stress. PTS symptoms have been related to parents' subjectively perceived treatment intensity and perceived life threat to the child, immediately posed by the disease (Goldenberg Libov et al., 2002; Kazak et al., 1998), as well as to past perceived disease-related life threat (Barakat et al., 1997; Kazak et al., 1998).

In a sample of Dutch childhood cancer patients ranging from 8 to 18 years of age mothers of younger children reported more depressive symptoms (Grootenhuis & Last, 1997). However, in other groups of patients, comprising newly-born children to adolescents, the age of the child has not predicted general psychiatric symptomatology, PTS, or other disease-related reactions in parents (Barakat et al., 1997; Hoekstra-Weebers et al., 1999; Kazak et al., 1998). Gilbar (2002) studying disease-related distress in parents of adult cancer patients, concludes that the threat of losing a child is a tragedy for parents regardless of the age of the child.

Parent's age and the number of children in the family has not been found to predict parent distress (Hoekstra-Weebers et al., 1999). Likewise, parent's educational level has equally not been

found to predict distress, when analysed in two studies from the Netherlands (Hoekstra-Weebers et al., 1999) and the US (Barakat et al., 1997). However, in a Taiwanese study, the fathers who expressed the most anxiety were those with the highest educational level (Mu et al., 2002). Further, periods of unemployment and sick leave have been found to amplify the risk of distress (Dockerty et al., 2000; von Essen, Sjoden, & Mattsson, 2004). Although, Goldenberg, Libov and colleagues (2002) have found that higher family income is associated with higher levels of PTS symptoms in mothers of childhood cancer patients.

Parental gender

The sex of the parent is assumed to predict levels of distress, or, to be exact, mothers are supposed to report higher levels of distress than fathers – an assumption subsequently borne out in studies. Indeed, 2-3 months after diagnosis the mean level of state anxiety has been found to be significantly higher among mothers than fathers (Allen et al., 1997; Dahlquist et al., 1996). However, in studies including a follow-up assessment, mothers and fathers expressed the same amounts of anxiety and psychiatric symptoms about one year later (Dahlquist et al., 1996; Hoekstra-Weebers et al., 1998; Sloper, 2000).

In regard to general psychiatric symptoms, mothers have reported higher (Sloper, 2000) as well as equivalent levels to those of fathers (Hoekstra-Weebers et al., 1998). In a prospective study covering a 4-year period from the first months after diagnosis, Sawyer and co-workers (2000) failed to find any statistically significant differences between mothers and fathers regarding general psychiatric symptoms.

Dispositional anxiety, and symptoms of depression have been reported equally by mothers and fathers, shortly after diagnosis (Allen et al., 1997; Dahlquist et al., 1996), as well as twenty months later (Dahlquist et al., 1996). Moreover, in a cross-sectional group of parents up to thirteen years after diagnosis dispositional anxiety and symptoms of depression have been reported equally by mothers and fathers (Frank et al., 2001). Yet in another study, restricted to parents after the end of treatment, mothers retrospectively reported a higher incidence of PTSD than fathers during the entire period since diagnosis, although current rates of PTS symptoms and clinical PTSD showed no gender differences (Kazak et al., 2004).

In a Dutch study, an interaction of effects suggests that additional stressors in combination with less resources affect mothers more than fathers, although the mean scores of mothers and fathers were equal regarding ten various aspects of disease-related distress assessed (Van Dongen-Melman et al., 1995a). In a Swedish study, applying a broad measure of quality of life, mothers reported their mental well-being to be poorer than fathers, while no gender differences were found for physical and social well-being (von Essen et al., 2004). More specifically, mothers reported significantly more suffering than fathers to 3 of 30 studied symptom categories.

Focusing on gender differences Yeh (2002) found mothers scored higher than fathers on general psychiatric symptoms, although fathers reported more disease-related distress. Characteristically, Yeh (2000) discussed thoroughly mothers' higher levels of general psychiatric symptoms but largely ignored fathers' excessive disease-related distress.

In summary, mothers tend to report more distress than fathers, but statistically significant differences are found only occasionally. The assumption that mothers are more affected by cancer in their child may account for why many studies focus solely on mothers (Baskin, Forehand, & Saylor, 1985; Brown et al., 2003; Glover & Poland, 2002; Greenberg, Kazak, & Meadows, 1989; Manne et al., 1998; Manne et al., 2000; Nelson, Miles, & Belyea, 1997; Noojin et al., 1999; Pelcovitz et al., 1996; Sahler, Varni, Fairclough, Butler, Noll, Dolgin, Phipps, Copeland, Katz, & Mulhern, 2002; Williams, Williams, Graff, Hanson, Stanton, Hafeman, Liebergen, Leuenberg, Setter, Ridder, Curry, Barnard, & Sanders, 2002; Yeh, 2001; Young, Dixon-Woods, Findlay, & Heney, 2002). Studies exclusively addressing fathers are rare (Cayse, 1994; Chesler & Parry, 2001; McGrath & Chesler, 2004; Mu et al., 2002).

The empirical investigations

The general aim of the present research was to examine stress and coping in Swedish parents, whose children were in active treatment for cancer, or had completed successful cancer treatment.
This broad objective involved the exploration of

- the occurrence of various psychological symptoms and signs of strain
- psychological reactions at various points in time after the child's diagnosis
- psychological reactions during and after the child's treatment
- the co-variation of psychological reactions and demographic and situational variables
- the use of various coping strategies
- the co-variation of psychological reactions and various coping strategies
- the co-variation of psychological reactions and social support

To reach this general aim, four studies were conducted, with the specific objectives formulated as below.

Study I

The objective of the first study was to investigate the occurrence of eleven different aspects of disease-related distress. This study also included an examination of systematic variations in these stress symptoms in relation to time elapsed since the disclosure of the child's diagnosis, and in relation to the statistical prognosis, the age of the child at diagnosis, and whether the child was in active treatment or had completed treatment.

Study II

The main aim of the second study was to investigate traumatic stress in parents of children in active cancer treatment, compared with parents after the end of treatment. A further aim was to examine the influence of five background factors, of which two were disease-related (whether the child had suffered a relapse, and the time elapsed since diagnosis), and three were demographic (parent's educational level, ethnicity, and gender).

Study III

In the third study parents of children with cancer and parents of healthy children were compared, regarding the use of certain coping strategies. A second aim was to examine any associations between coping strategies and level of anxiety and depression among parents of children with cancer. Furthermore, subgroups of parents were compared, with respect to the two study aims: parents at different time intervals from the child's cancer diagnosis, and parents of children with various types of cancer.

Study IV

The fourth study included two foci: an examination of the relationships between support seeking coping, perceived social support, and anxiety, and an estimation of the mediating effect of perceived social support on the relationship between social support seeking coping and anxiety. In order to particularly describe differences and similarities in mothers and fathers regarding the above outlined associations, mothers and fathers were analysed separately.

Method

Respondents and procedures

The four studies comprised a total of 507 parents of children previously or presently treated for malignant diseases; i.e. the children were in curative treatment or had completed successful treatment. Parents were recruited at two Swedish paediatric oncology units, at Astrid Lindgren Children's Hospital, Stockholm, and at Linköping University Hospital, Linköping. Two inclusion criteria were applied: sufficient knowledge of the Swedish language to comprehend the questionnaires, and a prognosis of the child including the hope of cure. These criteria were applied through not approaching parents who required an interpreter in the communication with medical staff, or parents of children for whom curative treatment was resigned.

The data were collected as part of the entirety of records of a larger study, investigating the psychosocial situation of parents of children with cancer. The data collection of this larger study had begun in 1999, and was still ongoing at the points in time when the four studies were carried out. Consequently, at the time of each study a certain number of respondents had been included in the survey. In addition, some parts of the larger investigation did not include the instruments assessing traumatic stress and coping, and therefore the numbers of parents included in the four studies varies. In addition, the study groups of the studies II and IV were limited to certain subgroups: in study II, parents of children who had been diagnosed more than 6 years and 2 months prior to assessment were excluded. The reason for this was to make the studied groups of parents during and after the child's treatment comparable with regards to the time elapsed since diagnosis. In study IV, only data from parents of children off treatment were included. Response rate was 77% in Study I, and 73% in Studies II, III, and IV. The number of parents of children with cancer in the various studies were: Study I n=265; Study II n=413; Study III n=395; Study IV n=184.

In study III, 184 parents of healthy children were analysed for reference purposes. Two hundred mothers were randomly selected from the population of mothers of children 0-16 years of age, in the catchment area of Astrid Lindgren Children's Hospital. In a letter of invitation, both parents were asked to participate. Out of all returned questionnaires, 205 contained sufficient information for data analyses. Twenty-one of these were excluded from the analyses in this study, since at least one child in the family suffered from chronic and/or severe disease. The remaining 184 parents constituted the final control group, of which 106 were mothers, 77 were fathers, and one parent had not stated his or her gender in the questionnaire. The characteristics of the study group are presented in Table 1.

The parents were assessed on one single occasion, at which point different lengths of time had elapsed since the diagnosis of their child. At Astrid Lindgren Children's Hospital, part of the parents was consecutively invited as their children attended the inpatient unit. Another part was recruited among those who were in a later treatment stage, or in off-treatment follow-up. These were selected by inviting all parents visiting the follow-up clinic during two randomly selected months. Overall response rate for parents invited at Astrid Lindgren Children's Hospital was 73%. At Linköping University Hospital, data were collected by inviting all parents, which at the time of invitation had an ongoing contact with the clinic, either for treatment of their child, or for post-treatment follow-up. Response rate for parents at Linköping University Hospital was 78%.

Parents in the study group were invited to participate in the study when visiting the hospital, or by phone or mail. Reference parents were invited by mail. They were all provided written information about the project. Parents filled out the questionnaires at home, and returned them by mail in a self-addressed, pre-paid return envelope. They were instructed to complete the questionnaires independently, without consulting the other parent. The studies were approved by the Ethics Committee at Karolinska Institutet.

Table 1. Characteristics of the study groups.

	Substudy groups [a]			
	Study I, % (n)	Study II, % (n)	Study III, % (n)	Study IV, % (n)
Mothers	55.3 (146)	55.7 (230)	56.7 (224)	56.0 (103)
Fathers	44.7 (118)	44.3 (183)	43.3 (171)	44.0 (81)
Parent's education:				
Elementary school only	11.7 (31)	14.1 (58)	12.7 (50)	14.1 (26)
College/high school	42.4 (112)	46.7 (193)	43.3 (171)	48.9 (90)
Education at a university level	43.6 (115)	39.0 (161)	44.0 (174)	37.0 (68)
Missing data	2.3 (6)	0.2 (1)	–	–
Parent born in Sweden	83.0 (219)	81.6 (337)	84.6 (334)	86.4 (159)
Parent not born in Sweden	15.9 (42)	18.4 (76)	15.4 (61)	13.6 (25)
Missing data	1.1 (3)	–	–	–
Child in treatment	61.0 (161)	42.4 (175)	44.3 (175)	0
Child off treatment	39.0 (103)	57.6 (238)	55.2 (218)	100 (184)
Missing data	–	–	0.2 (1)	–
Child's type of cancer:				
Leukaemia	44.7 (118)	41.6 (172)	44.1 (174)	42.9 (79)
Lymphoma	7.2 (19)	7.0 (29)	8.1 (32)	7.6 (14)
CNS tumour	10.6 (28)	17.9 (74)	14.9 (59)	15.8 (29)
Neuroblastoma	8.3 (22)	6.3 (26)	6.3 (25)	6.0 (11)
Renal tumour	7.6 (20)	6.1 (25)	6.6 (26)	6.0 (11)
Bone tumour	6.4 (17)	6.1 (25)	5.6 (22)	4.9 (9)
Soft tissue sarcoma	4.6 (12)	3.9 (16)	3.5 (14)	3.3 (6)
Germ-cell tumour	4.9 (13)	5.3 (22)	4.6 (18)	9.8 (18)
Other/unspecified	1.1 (3)	1.7 (7)	2.3 (9)	2.2 (4)
LCH	4.6 (12)	4.1 (17)	4.1 (16)	1.6 (3)

	Study I, min/max (mean)	Study II, min/max (mean)	Study III, min/max (mean)	Study IV, min/max (mean)
Time elapsed since diagnosis, months	0.8/172.9 (33.6)	1.0/73.8 (19.1)	0.25/158.5 (22.3)	12.8/113.5 (47.9)
Age of the child at diagnosis, years	0/21 (6)	0/21 (7)	0/21 (7)	0/21 (7)

[a] Several parents were involved in more than one substudy.

Instruments and assessments

All four studies are based on quantitative data, collected through self-report inventories. The variables of main interest and the background variables analysed in each study are presented in Table 2.

Disease-related psychological symptoms

In study I a questionnaire including eleven subscales was used to survey parents' disease-related distress. The instrument, originally formed in the Netherlands, is intended to capture a broad spectrum of the psychosocial strains of parents of children with cancer. It is developed within a conceptual framework of coping with stress, and described as a measure of the impact and perceptions of the specific stressors of this parent population (Van Dongen-Melman et al., 1995a; Van Dongen-Melman, Pruyn, De Groot, Koot, & Verhulst, 1995b).

Seven of the subscales cover illness-specific distress, while four cover generic distress symptoms and contain items without references to the child's disease. The Dutch research group formulated the seven illness-related subscales after in-depth interviews with parents of paediatric cancer patients. These subscales assess uncertainty, loss of control with respect to the parents personal functioning, loss of control with respect to being a parent, loss of control with respect to the sibling(s), disease-related fear, loneliness, and sleep problems. The four generic subscales cover self-esteem, state anxiety, depression, and psychological and physical distress. The three latter were adapted from three commonly used psychological scales: the state anxiety part of the Spielberger State-Trait Anxiety Inventory, the Zung Self-Rating Depression Scale and the Rotterdam Symptom Checklist. These adaptations were done mainly by reducing the number of items in the scales, in order to keep down the total number of items of the inventory, and in order to omit items that were inappropriate for this population. The instrument was designed especially for the study of the situation of parents of children surviving cancer. After the translation to Swedish, a pilot study including interviews with parents confirmed that it is suitable also for parents of children who are still in treatment. In all eleven scales, higher scores reflect higher reported levels of distress. In line with this, although worth mentioning, a higher score on the self-esteem scale denotes a poorer self-esteem.

In Study I all eleven subscales were used. The scales for anxiety and depression were analysed in relation to coping strategies in Study III. In Study IV the measure of loneliness was used, since *perceived support* was operationalized as the absence of feelings of loneliness. In addition, the relation of anxiety to social support was analysed in Study IV.

Coping

The Utrecht Coping List (UCL; (Schreurs, van de Villige, Brosschot, Tellegen, & Graus, 1993) was used to assess coping strategies (Study III). Parents were asked to respond with respect to stressful events in general, and not only in relation to their child's disease. The items are grouped into seven subscales, corresponding to seven separate clusters of coping strategies: *active problem focusing*: act immediately and be goal-oriented, sorting things out (7 items); *palliative reaction pattern*: engage in other activities, try to relax (8 items); *avoidance behaviour*: draw back from problematic situations (8 items); *social-support seeking*: ask for comfort, show one's feelings (6 items); *passive reaction pattern*: isolate from others, escape into fantasies (7 items); *expression of emotions*: express annoyance and anger (3 items); *comforting cognition*: think that worse things happen, or that the situation may not be as bad as it seems (5 items). The seven subscale sum scores constitute the individual result. Higher scores on the subscales in the UCL indicate more frequent use of the specific coping strategies.

Traumatic stress

Symptoms of traumatic stress were assessed using the Impact of Event Scale-Revised (IES-R; (Weiss & Marmar, 1997), which is an elaborated version of the original IES (Horowitz, Wilner, & Alvarez, 1979). IES-R assesses stress responses during the last seven days in relation to a specified event, in the realms of intrusion (8 items), avoidance (8 items) and arousal (6 items). These symptoms are congruent

with the B, C, and D symptom categories of the diagnostic criteria of posttraumatic stress disorder (American Psychiatric Association, 1994). According to the instructions, parents were told to answer the questionnaire with reference to the illness of their child; i.e. they could report symptoms, related to any aspect of the child's disease.

Table 2. Variables analysed in the four studies.

	Variables	Study I	Study II	Study III	Study IV
11 signs of disease-related strain	Uncertainty	X			
	Control – personal functioning	X			
	Control – parenting the ill child	X			
	Control – parenting sibling(s)	X			
	Self-esteem	X			
	Anxiety	X		X	X
	Disease-related worry	X			
	Loneliness/ perceived social support	X			X
	Sleep disturbances	X			
	Depression	X		X	
	Psychological & physical distress	X			
Traumatic stress *(IES-R)*	Intrusion		X		
	Avoidance		X		
	Arousal		X		
Coping strategies (UCL)	Active problem focusing			X	
	Palliative reaction pattern			X	
	Avoidance behaviour			X	
	Social-support seeking			X	X
	Passive reaction pattern			X	
	Expression of negative emotions			X	
	Comforting cognition			X	
Background variables, disease-related	Whether in or off treatment	X	X		
	Time elapsed since diagnosis	X	X	X	
	Prognosis [a]	X			
	Type of cancer [b]			X	
	Whether the child had suffered a relapse		X		
	Age of the child at diagnosis	X			
Background variables, demographic	Parent's sex		X	X	X
	Parent born in Sweden or immigrant		X		
	Parent's educational level [c]		X		

[a] Retrospective statistical data for the Nordic countries concerning the probability of 12-year survival with the given diagnosis.

[b] CNS tumour or acute lymphoblastic leukaemia (ALL).

[c] Elementary school only, college/high school, or education at a university level.

Furthermore, traumatic stress was assessed in relation to experiences in the past as well as recent experiences, and was consequently not restricted to symptoms of posttraumatic stress. Individual results are expressed by sum scores, with higher scores indicating the presence of more symptoms.

Background factors

Data on demographic factors were collected directly from the parents through the questionnaires. Objective disease-related information was obtained from the medical records.

Data management and statistical analyses

A general rule was that respondents who had left more than 25% of the items unanswered on one or more of the instruments assessing the concepts of main interest were excluded from the analyses in the study in question. For respondents with 25% or less of the items unanswered, missing values were replaced by the individual mean score of the instrument. Furthermore, respondents with data missing in a background variable were excluded from the analyses of that particular variable.

Pearson correlation analyses were used to examine the relations between variables, regarded as continuous, i.e. scores of distress and coping, and the background factors time elapsed since diagnosis, prognosis, and the child's age at diagnosis. Throughout all correlation analyses, 2-tailed tests were applied.

For comparisons regarding a background variable of two categories t-tests have been used, and when the background variable had three or more categories ANOVA was used. The analyses of gender differences in studies II and IV included two different series of analyses: (a) the scores of the fathers and mothers from families where only one parent had participated were compared by independent samples t-tests, and (b) paired samples t-tests were used to compare social support and levels of intrusion, avoidance, and arousal in mother and father from the couples where both parents had participated in the study.

Multiple linear regression analyses were done in studies I and IV. In Study I the focus was to examine the relative ability of the background variables, and time since diagnosis in particular, to predict distress. In Study IV, multiple regression analysis was used for an estimation of the coefficients in a path model, describing the mediating effect of perceived social support on the relationship between support-seeking coping strategies and anxiety.

All effects were tested using a significance level of $p < 0.05$, except for Study III. Considering the total number of statistical tests performed in that study, an adjusted alpha level ($p < 0.005$) was applied in the main analyses to fend off the risk of Type I error. In the following Results section, findings of Study III significant at a level between $p < 0.05$ and $p < 0.005$ are related to as 'tendencies'.

Study results

Four studies were conducted to investigate psychological symptoms, coping, and social support in parents of children with cancer. Studies I and II focused on the occurrence of symptoms. Studies III and IV examined further the severity of symptoms, in relation to coping and social support.

Psychological symptoms and signs of strain

Various psychological symptoms in parents were investigated in all four studies. In the studies I and II the occurrence of symptoms were the main focus.

In Study I, between 3 and 47% of the parents were found to show marked expressions of various aspects of the eleven assessed manifestations of disease-related distress. Sleep problems were reported frequently. Indeed, 47% of the parents reported experiencing extensive sleep disturbances. Moreover, 41% of the parents reported low self-esteem. In four of the subscales, which all included explicitly disease-related items, various other stress symptoms were also reported frequently: uncer-

tainty (42%), loss of control regarding personal functioning (40%), loss of control regarding parenting the sick child (42%), and loss of control regarding parenting the sibling(s) (34%). The least reported symptom comprised a composite measure of psychological and physical distress; 3% of the parents reported high levels of psychological and physical distress. Likewise, high levels of disease-related fear, depression, and loneliness were seldom reported, just 10% of the parents reported such symptoms.

Study II focused on three aspects of traumatic stress: intrusion, avoidance, and arousal. Seventy one percent of the parents with a child still in treatment and 59% of the parents with a child off-treatment reported intrusions to be "quite a bit" or "extremely" bothering. Avoidant behaviour characterized 37% of parents with children in treatment, and 28% of parents with children who had completed treatment. Arousal was reported by 54% of parents of children in treatment, and 29% of parents of children in off-treatment. Co-occurring symptoms of intrusion and avoidance were reported by 33% of the parents during treatment and 23% of the parents after treatment, and symptoms within all three categories were reported by 27% (in treatment) and 14% (off treatment) respectively (not presented in the article).

In Study III levels of anxiety and depressive symptoms in parents of children with cancer were consistently higher than those in parents of healthy children (mothers' anxiety t=8.4, p< 0.001 and fathers' anxiety t=7.5, p< 0.001; mothers' depression t=5.4, p< 0.001 and fathers' depression t=4.8, p< 0.001; not presented in the article; Fig. 1).
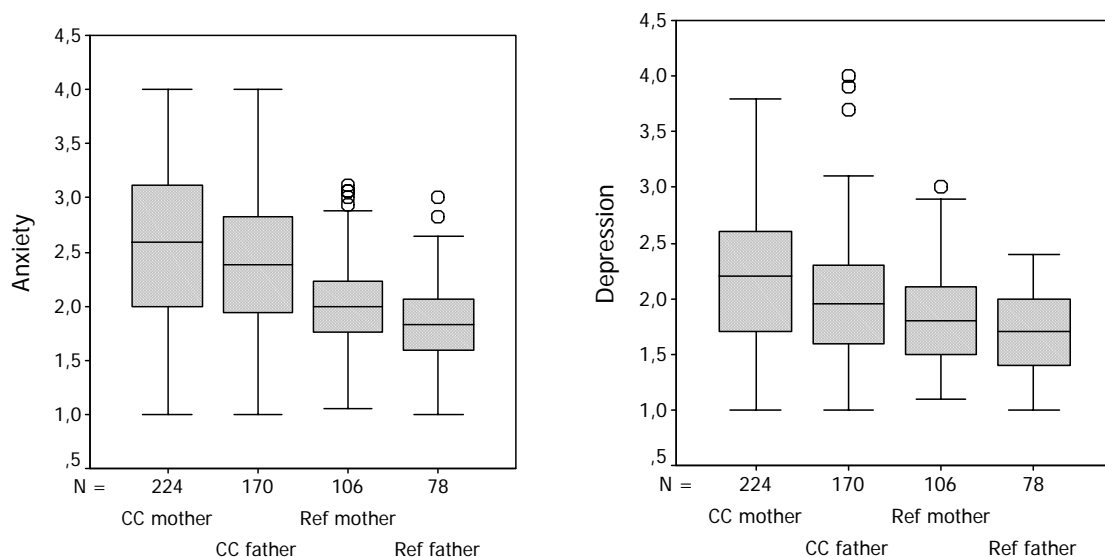

Fig. 1. Anxiety and depression reported by mothers and fathers of children with cancer, and reference mothers and fathers. Boxes represent the interquartile range; the line across each box indicates the median. Whiskers extend to the highest and lowest values, excluding outliers. Circles indicate outliers.

Relation between time and psychological symptoms

The relation of time to parental stress was examined in studies I, II, and III. Zero-order correlations in studies I and II indicate lower levels of certain stress symptoms among parents temporally distant from the child's diagnosis. On the whole, these linear associations were relatively weak; at the most just 14% of the variation in stress symptoms was explained by variation in elapsed time. Associations became even weaker when controlling for the statistical prognosis, the age of the child at diagnosis, and whether treatment was ongoing or completed (study I). In these multivariate analyses, 6 of the 11 aspects of distress were related to time: loss of control -personal functioning, loss of control

-being a parent, self-esteem, sleep disturbances, anxiety, and depression. Concerning arousal (off treatment only) and intrusions, study II revealed linear associations between time and traumatic stress. However, avoidance was not associated with length of time since diagnosis.

In Study III three separate groups of parents were identified in regard to time elapsed since diagnosis. For each group of parents, anxiety and depression levels were compared to those of parents of healthy children (not presented in the article). Parents in their second month after diagnosis, and those 1½ to 2½ years later reported significantly higher levels of anxiety (early group t=12.1, p< 0.001; later group t=4.1, p< 0.001) as well as depression (early group t=7.7, p< 0.001; later group t=2.5, p= 0.015; Fig. 2). For parents five to ten years post-diagnosis the level of anxiety was slightly higher than that of reference parents, although this difference did not reach statistical significance (t=1.7; p= 0.095).
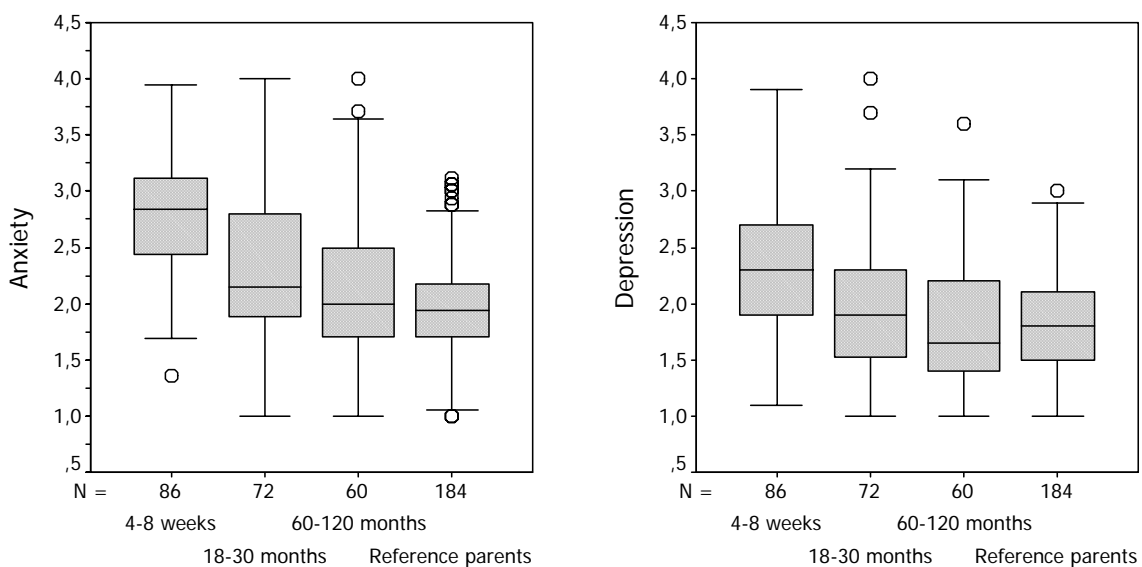

Fig. 2. Anxiety and depression in parents at different points in time after the child's diagnosis, compared to anxiety levels in parents of healthy children (Reference parents). Boxes represent the interquartile range; the line across each box indicates the median. Whiskers extend to the highest and lowest values, excluding outliers. Circles indicate outliers.

Being in or off cancer treatment

Parental stress in relation to treatment situation was analysed in studies I and II. In the main, parental stress symptoms occurred more frequently during active treatment than during off-treatment. However, when the variable 'time' was entered into the multivariate analyses of Study I, an impact of treatment remained only for two of the eleven aspects of stress: loss of control -personal functioning, and loss of control -being a parent, explaining about 10% of the variation.

In study II, the amount of time elapsed since diagnosis was the same for the group of parents with a child in treatment, and for the group of parents with a child in off-treatment. Traumatic stress was more salient among parents during treatment, as they reported significantly more intrusions and arousal (Study II). In addition, avoidance was reported to a greater extent by parents of a child in treatment, although this difference was not statistically significant.

Compared with the reference group, parents of children in treatment as well as parents after completed treatment reported higher levels of anxiety (in treatment t=15.1, p< 0.001; off treatment t=4.8, p< 0.001) and depression (in treatment t=9.8, p< 0.001; off treatment t=2.4, p= 0.016; study III, not presented in the article).

Coping

Study III investigated the use of seven different coping strategy types, and their relation to levels of anxiety and depression. To a similar extent, parents in the study group and reference group used the various strategies. Likewise, the use of coping strategies did not differ between parents of children with various cancer diagnoses (CNS tumours or ALL), or between parents at different time points after their child's cancer diagnosis.

Exploring the associations between single coping strategies and emotional distress, certain strategies showed a similar outcome in all the analyses – among subgroups of parents of children with cancer as well as among reference parents. *Passive reactions* were consistently associated with higher levels of distress. *Comforting cognition* was unrelated to distress. The use of *active problem focusing* was related to less distress in all analyses, although only a weak trend was found among parents of children with CNS tumours. No relationship was found between *social support seeking* and distress, except for a weak tendency of this strategy to predict less distress in the group of parents for whom more than five years had passed since diagnosis.

However, three types of strategies displayed somewhat different patterns depending on the child's type of cancer and time elapsed since diagnosis. *Palliative reaction pattern* correlated positively with distress in the entire group of parents of children with cancer but not in the reference group. *Palliative reactions* were also associated with distress in the CNS-group, and there was a tendency toward such an association in parents more temporally distant from diagnosis. However, *palliative reactions* were not associated with distress in the ALL-group. *Avoidance behaviour* was related to higher levels of distress in most analyses, with the exception of parents temporally close to diagnosis for whom avoidance was unrelated to distress. *Expressing negative emotions* positively correlated with distress in parents of children with cancer but not in parents of healthy children. In certain subgroups of parents, this association was prominent, especially in parents of children with CNS tumours, those temporally close to diagnosis, and parents more than five years from their children's diagnosis.

Social support

The objective of Study IV was to examine the relationship between support-seeking coping, and perceived social support. Moreover, Study IV investigated associations between anxiety, support-seeking coping and perceived social support.

A modest relationship obtained between support seeking coping and perceived support. Support perceived as good was associated clearly with less anxiety, but the frequent use of support seeking only weakly predicted anxiety. Moreover, the mediating effect of perceived support did not strengthen this relationship. However, in regard to relations between support and anxiety the significance of social support is somewhat greater for mothers than for fathers. Nonetheless, both mothers and fathers reported similar patterns of interrelationships between support seeking, perceived support, and emotional distress.

Disease-related background factors

Studies I, II and III examined the impact of certain disease-related factors on parental psychological symptoms. Disease-related factors explained none or only a minor portion of variation in the stress symptoms.

Prognosis. The prognosis of the child's illness, defined as the retrospective 12-year survival probability for the main diagnostic groups, did not explain any variation in any of the 11 variables as assessed in Study I.

Type of cancer. Parents of paediatric CNS tumour patients and those of ALL patients did not differ regarding level of anxiety or depression (Study III). Subsequent analyses revealed no difference regarding parents assessed during active treatment. However, there was a tendency among parents of CNS tumour patients who had completed treatment to report higher levels of depression (t=2.0, p= 0.044; not presented in the article).

Age of the child at diagnosis. There was a tendency among parents of older children to report more uncertainty, loss of control -being a parent, low self-esteem, and anxiety (Study I).

Relapse. Parents of children who were in treatment for a relapse were compared with parents of children in treatment who had never suffered a relapse, and in the same manner parents whose children had completed treatment for a relapse were compared with parents whose children had completed treatment without a relapse (Study II). These comparisons revealed no differences in traumatic stress between parents whose child had suffered a relapse and parents of non-relapsed children.

Demographic factors

The demographic factors examined in studies II, III and IV predicted parental distress under certain conditions.

Educational level. No effects of educational status on reported levels of anxiety or depression were found (Study III). However, when analysed separately parents with children in treatment and parents of children who had completed treatment revealed different patterns in their expressions of traumatic stress (Study II). Among parents of children who had completed treatment, those with a shorter education generally reported more intrusions, avoidance, and arousal, as compared to parents with a higher educational status. However, no systematic associations between educational status and traumatic stress obtained between parents with children in treatment.

Ethnicity. Examination of relations between ethnicity and traumatic stress revealed a similar pattern as those found in analyses of educational level. Parents with a child in treatment revealed no differences regardless of their ethnicity. However, non-indigenous Swedish parents of children who had completed treatment reported more intrusions, avoidance, and arousal as compared to indigenous Swedish parents (Study II).

Gender. On the whole, mothers reported higher levels of anxiety and depression than fathers (Study III). However, in a paired analysis of couples, and in a comparison of unrelated mothers and fathers difference in anxiety failed to reach statistical significance (Study IV). Nonetheless, both mothers and fathers of children with cancer reported higher levels of anxiety and depression than mothers and fathers of healthy children (Fig. 1).

The pairwise analyses in Study II showed that mothers, as compared to fathers, reported a generally higher level of intrusions and arousal, both during treatment and after treatment (Fig 3). Fig. 3 shows a remarkable distribution of markers (representing parent couples).indicating a large variation in the distress reported by the mother and father within each couple. Mothers and fathers of parent couples reporting equal levels of distress are shown along the diagonal from the lower left to the upper right corner. In cases where the father has reported more distress than the mother a marker is shown above the diagonal, while the opposite is true for markers below the diagonal.
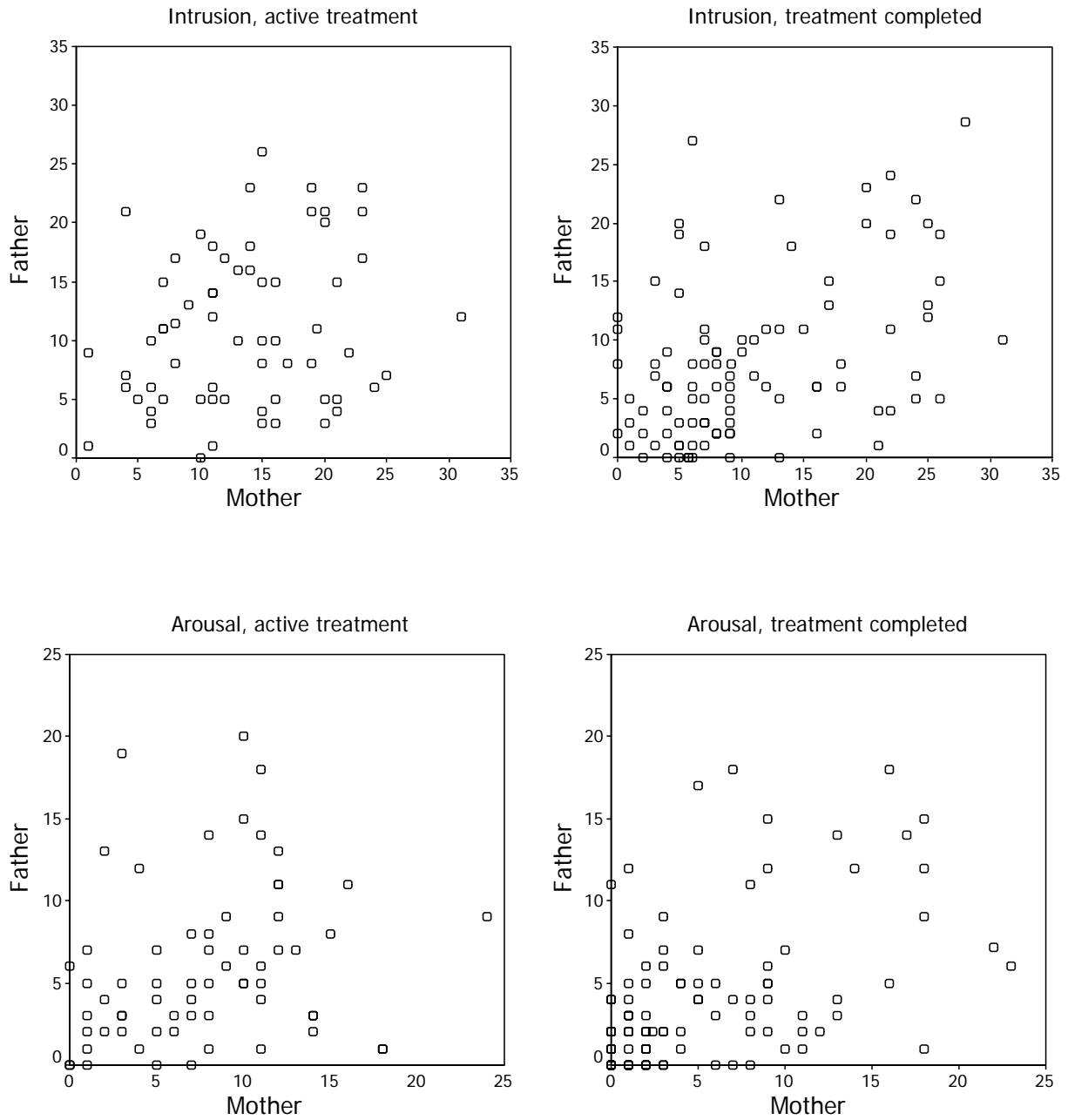
Fig 3. Plots illustrating the association between mother's and father's intrusion and arousal scores within parent couples with children in treatment (n=64), and in couples with children off treatment (n=98). Each marker represents a parent couple.

General discussion

Anxiety, depression, and general distress

Reactions to the diagnostic announcement of the child's illness characteristically include shock, disbelief, anxiety, and sadness (McGrath, 2001; Patistea et al., 2000). Anxiety is thought to be a reaction to perceptions of threat, while depressive symptoms are regarded as an emotional response to experiences associated with loss (Lazarus, 1991). In the present research, these two aspects of emotional distress, and the general measure of psychological and physical distress all occurred more frequently during the first period after the disclosure of the diagnosis. This resonates with previous studies including a longitudinal evaluation in which emotional distress decreased over time (Dahlquist et al., 1996; Hoekstra-Weebers et al., 1999; Sawyer et al., 2000). Yet, symptoms of anxiety and depression are more common among parents of children with cancer, than parents of normal healthy children, even up to 2½ years after diagnosis. This suggests that the emotional distress expressed by parents of children with cancer is not limited to acute stress immediately following the diagnosis.

Traumatic stress

Traumatic stress is a strong indicator of parents' concerns. Anxiety and depression are expressed at normal levels some years after diagnosis, but the incidence of PTS symptomatology has been reported to be between about 10 and 40% several years after the end of treatment (Barakat et al., 1997; Brown et al., 2003; Kazak et al., 1997; Manne et al., 1998; Pelcovitz et al., 1996; Stuber et al., 1996). Traumatic stress emanating from both present and past stressors were considered in the present studies, and this may have contributed to the higher rates of symptoms found in the present studies. However, a stricter rule was adopted in classification of symptom presence, in the present than in previous studies. Specifically, items endorsed as *Moderately* distressing (or less), by respondents in the present study, were not regarded as reflecting the presence of PTS symptoms.

Kazak and co-workers (2004) assume that the risk of emerging late medical effects of treatment, and disease recurrence screened for at the follow-up examinations, imply a continued exposure to potentially traumatic events even after treatment has concluded. However, stressful experiences during active treatment are assumed to have an even greater effect. Indeed, the disclosure of the diagnosis qualifies as a sudden, one-time traumatic event (American Psychiatric Association, 1994). Moreover, in one study it was shown that a "Child's life-threatening illness" had a 100% probability of producing fear, helplessness, or horror among women, and an 89% probability among men, exceeding most other potentially traumatic experiences (Breslau & Kessler, 2001). Further, parents' experiences during the treatment of their child may be perceived as a repeated trauma (Smith, Redd, Peyser, & Vogl, 1999). Parents frequently report medical procedures when asked about the most distressing events during the course of the illness (Stuber et al., 1996). In Study II, parents of children in treatment reported higher levels of traumatic stress than parents of children who had completed their treatment. Consequently, these findings point to the importance of paying attention to traumatic stress during the years of active treatment, and complement previous studies that focus on late symptoms of PTS.

Traumatic stress symptoms were most frequent during active treatment. Nonetheless, parents whose children had completed treatment were also found to be suffering from traumatic stress, providing an indication that measures of traumatic stress not only capture the reactions to the every day strain of the treatment but also the concerns of parents when treatment is completed. After treatment, such symptoms may relate to previous traumatic experiences and to worries about a relapse of the child's disease. Indeed, intrusions and avoidance in parents of cancer survivors have been found to be associated closely with a perception that the child's life is still threatened by the disease (Kazak et al., 1998). On the one hand, this disease-related fear may be viewed as a symptom of a posttrau-

matic stress, similar to intrusive images of the past perceived threat. On the other hand, fear related to the disease may be viewed as indicating the parent's appraisal of present stressors.

Control, self-esteem and parenting

A substantial number of the parents reported low control as regards parenting and their own everyday life. This was particularly salient among parents of children in active treatment. Most parents of children with cancer want to take an active part in the care of their children (Forinder, 2004; Pyke-Grimm, Degner, Small, & Mueller, 1999). They are also encouraged to take part in the decisions about treatment. However, few have any true knowledge about the decisions made concerning the treatment at the time of diagnosis, and a lack of knowledge, often due to insufficient information, continues to hinder parents' consultation in decisions about treatment (Levi, Marsick, Drotar, & Kodish, 2000; Massimo, Wiley, & Casari, 2004). Although parents wish to have control over such judgements, they prefer to have a collaborative or even passive role instead of being the ones who make the final decision about the child's treatment (Pyke-Grimm et al., 1999). When it comes to the day-to-day care, parents may for example claim to judge their child's pain better than professionals, and request more efficient pain treatment (Ljungman et al., 1999), yet parents are still dependent on the medical staff for relief of the child's pain.

A parent's active participation in the often intense treatment scheme can also influence their everyday life by restricting autonomy, decision latitude, and control. Close examination of the present data shows that the most frequently reported item of the subscale *Loss of control regarding the patient* was "(Because of my child's disease and its treatment) it is less easy to take time off for myself". Moreover, this statement was most relevant for parents during active treatment, of whom 80% answered yes. However, as many as 39% of the parents whose children had completed treatment also replied in the affirmative. Low control combined with high demands typically lead to an accentuation of strain, as observed typically in workplace settings (Karasek, Brisson, Kawakami, Houtman, Bongers, & Amick, 1998). In the same way as an enduring work strain may lead to chronic stress reactions (Hepburn, Loughlin, & Barling, 1997), the constant strain placed on parents caring for a child with cancer can entail chronic stress (Miller et al., 2002).

Low self-esteem was frequently reported, and more often by parents temporally close to the initial diagnosis. Compared with parents from the general community and parents of children with diabetes, self-esteem has been found to be lower in parents of children with cancer up to five years after the child's diagnosis (Boman, Viksten, Kogner, & Samuelsson, 2004). These findings may reflect a challenged experience of the parental role, which often accompanies a cancer diagnosis in a child (Dixon-Woods, Young, & Heney, 2002; LaMontagne et al., 1999). This is particularly salient during the early phases of treatment, although the child-rearing habits appear to be altered after treatment end as well. In the scale *Loss of control regarding the patient*, the item "(Because of my child's disease and its treatment) rearing my child goes less smoothly than before" was confirmed by 49% of the parents in treatment, and 34% of the parents with a child off treatment. Moreover, the item "I cannot get a grip on what's going on in my child's mind" was confirmed by 49% of parents with a child in treatment and 40% off treatment. At the same time, behaviour problems among children during cancer treatment are common (Vance & Eiser, 2004). Indeed, parent's lack of control regarding the disease and its treatment, and regarding the child's experiences, as well as an experience of an increased overall parenting burden, are known to affect the parent-child relation (Steele, Long, Reddy, Luhr, & Phipps, 2003).

Cancer has been found to engender a perception of life threat, which accompanies parents for years after successfully completed treatment (Goldenberg Libov et al., 2002; Kazak et al., 1998; Koocher & O'Malley, 1981). In Study I, few parents reported an intense disease-related fear. Yet, of all the parents in this study only 2, 0.8% of the group, stated that they were "Not at all worried" in regard to all the various issues that comprised the scale assessing disease-related fear (Study I). The question referring to *worry about a recurrence of the disease* was by far the most frequently reported. In this case, the answer "Extremely worried" was chosen by 27% of the parents during treatment and

20% of the parents after treatment, while 52% (in treatment) and 33% (off treatment) chose the answer "Quite worried". As described in spontaneous comments made by parents, worry about the child's health is aroused after the experience of a cancer diagnosis through a high vigilance for signs of cancer relapse: "I'm still very sensitive, and react as soon as he gets a fever. Then my worry is stirred up" (father, 9 years after diagnosis).

In summary, the perception of low control, and the potential fatality of the disease may partly explain the altered child-rearing practices that have been reported in the literature (Vance & Eiser, 2004). As noted by Kazak and colleagues (2004), the intrusive thoughts and hyper-vigilance of traumatic stress may contribute to an excessive attention to possible signs of disease recurrence. Hillman (1997) found a tendency among childhood cancer parents to spoil the child and to be over-protective, compared with parents of healthy children. Yet at the same time, childhood cancer parents more often feel angry with their children as compared to other parents of healthy children.

Significance of time, and being in or off cancer treatment

In the present research, certain indicators of stress occurred more frequently shortly after diagnosis than after a longer period from diagnosis. However, findings indicate that the stress process rarely yields a linear relationship between time and amount of stress reactions expressed, when analysed on a group level. Accordingly, if parents' psychological adaptation processes approximate a linear path, as has been suggested by certain 'general crisis models' (Clarke-Steffen, 1993), the time course of events would appear to vary largely between individuals.

Stressful experiences during treatment may repeatedly arouse stress in parents. Furthermore, it would appear that parents may face various aspects of disease-related stress at any time, once they have learned their child's cancer diagnosis. Consequently, our findings can be seen as supporting the assumption that the psychological impact of childhood cancer is not linear over time even in the individual case (Cincotta, 1993; Lederberg, 1998). A comment in one of our questionnaires illustrates how this non-linearity in the adaptation process is expressed: "I would describe my way of being and feeling by saying that life is like roller coaster. How you feel is totally dependent on how the sick child is for the moment." (a mother, 3 years, 6 months after diagnosis).

Although particularly the treatment phase appeared to involve events that affect parents' experience of control, as well as elicit traumatic stress reactions, most of the assessed aspects of stress seemed to occur among parents of children off treatment as well. Indeed, previous studies have reported anxiety, depression, and general psychiatric symptomatology to appear equal in parents of children in and off treatment, when time from diagnosis is the same (Dahlquist et al., 1996; Frank et al., 2001; Sloper, 2000).

In conclusion, the data suggest that time has some influence on parental distress, independently of treatment situation, and being in or off treatment has some influence independently of time. Nonetheless, factors other than the passing of time and the termination of treatment account for the majority of variation in parental stress.

Coping

In the present studies, and in contrast to previous studies, coping strategies were considered a part of general coping – i.e. strategies which are used in various stressful situations, and not only in relation to the child's cancer. In this respect, the general repertoire of coping strategies did not differ between childhood cancer parents and parents of healthy children, or between the various subgroups of childhood cancer parents.

Note the discrepancy in findings regarding dispositional problem-focused coping in the present study, as compared to situation-specific problem-focused coping in previous studies. According to previous studies neither problem-focused strategies (Hoekstra-Weebers et al., 1999) or engagement strategies (Trask et al., 2003; Wittrock et al., 1994) appear to be effective in managing the specific stresses associated with the child's illness. However, in the present studies a dispositional coping

profile including problem-focusing was found to be consistently associated with lower levels of distress. Since a problem-solving mode of coping is likely to be associated with benign appraisals of potential threats, and perception of high self-efficacy (Benight & Bandura, 2004), the *attitude* of being problem-focused may be more important for the well-being in parents of children with cancer, than the actual use of problem-focused strategies.

In the present studies the expression of negative emotions as a characteristic of the coping disposition was related to distress in certain subgroups of childhood cancer parents. In other studies, parents have only occasionally been found to express negative emotions as a means of handling the stress caused by the situation (Berenbaum & Hatcher, 1992), although frustration and anger are expected stress reactions of parents having experienced a threat directed towards their child. Nonetheless, behaviours in congruence with a positive appraisal of the situation are likely encouraged by the medical staff with whom the family comes into contact, and to a greater extent than are expression of negative emotions and fears (Karrfelt, Lindblad, Crafoord, & Berg, 2003). Consequently, if manifestations of irritation and anger are perceived as unacceptable in the paediatric medical setting parents relying on this coping style may be exposed to additional strain.

A frequent use of situation-related avoidance early during treatment does not appear to predict future distress or adjustment among childhood cancer parents (Dahlquist et al., 1996; Hoekstra-Weebers et al., 1999). In line with this, the present studies show that habitual avoidance coping is unrelated to distress, temporally close to diagnosis. This indicates that avoidance is not harmful when coping with the first wave of stressors in childhood cancer. Avoidant coping refers to a deliberate avoidance of getting down to a problem, and an attitude of 'wait and let things pass'. Avoidance as a component of the traumatic stress response, on the other hand, is a cognitive function, avoiding reminders of a stressful event, and avoiding being upset about it. Nevertheless, these two concepts may sometimes serve the same purpose. Repeated confrontations with reminders of the child's illness may, under certain circumstances, serve as exposure to memories of traumatic incidents, and so facilitate parents' ability to work through the experience. At the same time a certain amount of avoidance may also be functional to balance integration of an overwhelming experience (Joseph, 2000; Linley & Joseph, 2004).

The relative lack of associations between certain coping strategies and emotional distress in the present study, as well as in studies of situation-specific coping among childhood cancer parents may, at least partly, be due to the fact that the situation that parents of children with cancer face is not *one single event* to cope with, but a multitude of threats, demands, and challenges. Indeed, in coping with the threat to the child's life, few strategies may have the capacity to actually give relief. Although, in a North-American study praying was the most frequently reported strategy, and this was also rated by parents themselves as most helpful (Cayse, 1994). As a father said in one of our interviews: "It's so fundamental, this thing about your child. The greatest love of all. You want to do so much, but you can't do a thing – just be there."

Social support and loneliness

Over half of the parents in the present study reported feelings of loneliness (Study I). Although, when disease related items are omitted, the extent to which parents of children with cancer report loneliness is equal to that reported by parents in the general population (Boman et al., 2004). Indeed, Grootenhuis and Last (1997) note higher levels of loneliness among mothers more temporally distant from their child's diagnosis. They propose that mothers of children with cancer have the feeling that other people do not understand what they have gone through. Therefore, disease-related aspects of loneliness seem to be the most relevant for parents of children with cancer, and in this respect, the experience of cancer in a child may affect a parent's perception of loneliness and social support. This assumption is reinforced by parents spontaneous comments in the questionnaires of Study 1. For instance one father wrote "During the period of illness it became obvious who are your real friends." (a father, 2 years and 8 months after diagnosis); and one mother wrote "There are a few friends who have been there all the time. I was very disappointed when I found out that the ones I

thought would be there disappeared. But when it comes down to it, you're all alone." (a mother, 3 years and 6 months after diagnosis).

The subscale assessing loneliness was at the same time considered to describe perceived (lack of) social support: parents reporting lower levels of loneliness were assumed to have more positive perceptions of social support. A positive perception of support was associated with lower levels of anxiety. However, the present data suggest that perceptions of social support do not reduce distress by encouraging support-seeking, although support-seeking coping indeed was pursued more frequently among those with a positive perception of social support. Taylor (1991) suggests that social support can be seen as a trait resource, and that people with this resource have the ability to benefit from the potential social support at their disposal. This could explain why the parents of children with cancer perceiving good support were generally less anxious than those parents perceiving poor support, while support-seeking itself was only associated weakly with lower levels of distress. Consequently, seeking social support may not be a guarantee for lower levels of distress, but faith in support availability may possibly be helpful.

Disease-related background factors

Parental stress is not predicted by statistical prognosis of the child's disease, or whether the child suffers a relapse. This resonates with previous research. Generally speaking, previous studies indicate that objectively estimated disease severity is unable to influence systematically parental emotional distress (Barakat et al., 1997; Kazak et al., 1998; Mu et al., 2002; Sloper, 2000; Yeh, 2002). Further, the findings of Grootenhuis and Last (1997) indicate that parents' reactions to relapse in a child are expressed through uncertainty and helplessness, rather than anxiety, depression, or PTS. However, such conclusions are based on group level analyses and, at an individual level, the possibility remains that prognosis and relapse do affect parental stress. By way of group level analyses individual differences cannot be clarified.

On diagnosis of a potentially fatal disease fear of losing the child can become a permanent concern, regardless of what the actual probability of survival is. The presence of disease-related fear can indicate such a concern. Arguably, a process of anticipatory grief starts regularly when parents learn of the cancer diagnosis (Koocher & O'Malley, 1981; Van Dongen-Melman & Sanders-Woudstra, 1986). However, in the present case such questions cannot be fully addressed, as the sample of participants in the present studies included only families of children in curative treatment. In the worse cases, a poor prognosis implies that the child will die, and in this case the psychological reaction of the parents may be quite different.

In the present studies, whether the disease was leukaemia or a CNS tumour was not predictive of parental anxiety or depression during treatment. Yet, subsequent analyses revealed differences after treatment and, in particular, parents of children who had completed treatment for CNS tumours reported more depression as compared to parents of children after treatment for ALL. One plausible account of these differences is that children surviving CNS tumours are often exposed to severe long-term effects due to brain damage (Reimers, Ehrenfels, Mortensen, Schmiegelow, Sonderkaer, Carstensen, Schmiegelow, & Muller, 2003), whereas in ALL, and despite the lengthy treatment, children are normally spared from medical sequelae after treatment end (McGrath & Pitcher, 2002).

Demographic factors

Broadly speaking, parents with lower education levels and non-ingenious backgrounds reported higher levels of traumatic stress after end of treatment, than parents with higher education levels and a native Swedish background. Demographic factors have long been observed for their potential influence on stress, as these conditions may involve material scarcity and psychosocial stressors, adding to the strain of having a child with cancer (Grossi, 1999; Mackenbach & Howden-Chapman, 2003; Sundquist & Johansson, 1997). They may also entail other factors, such as socialization effects,

and lack of power, which may in turn affect stressor appraisal and coping resources. During ongoing treatment, however, neither education nor ethnicity predicted traumatic stress.

Gender

Mothers and fathers of paediatric cancer patients can play an important role in the cure of their child, and so medical staff should take care to understand the different reactions of mothers and fathers. One might expect to find gender differences in behaviours, congruent with stereotypical societal views of female expressiveness and male instrumentality (Chesler & Parry, 2001; La France & Banaji, 1992). Indeed, previous studies reporting gender differences have typically found that mothers report more distress than fathers, regarding for example state anxiety (e.g. (Allen et al., 1997; Dahlquist et al., 1996), although frequently no gender differences are found in other aspects of distress (e.g. (Frank et al., 2001; Hoekstra-Weebers et al., 1998; Kazak et al., 2004).

In the present research, anxiety, depression, intrusion, avoidance, arousal, and the use of coping strategies were analysed for differences between mothers and fathers. Depression was the symptom showing the most prominent group mean difference between mothers and fathers. This statistically significant difference indicates a need to be aware of gender differences in clinical practice. However, and especially when an awareness of gender differences reflects merely commonly held beliefs, potentially harmful assumptions may be made about individuals; such as "mothers are always more affected by a child's cancer than fathers are". As shown in Fig 1, there is a small group of women who report more depression than the majority of men. However, the vast majority of both women and men reported depression within the same range. Indeed, just 17 (7.6%) women reported more depression than the men, and two men actually scored higher in depression than any of the women. Likewise, in study II, it was the mother in each parent couple that most often reported the highest level of intrusion. However, this was only true for 58% of the couples. In 33% of the couples fathers reported most intrusion, and in the remaining 9% the mothers and fathers reported exactly the same amounts of intrusion. Finally, no differences were found between mothers and fathers in their reports of avoidance, anxiety, and the seven coping strategies. Consequently, an awareness of gender differences in clinical practice may be ineffective and even harmful if applied crudely on the basis of common stereotypical assumptions.

In a recent study of fathers of children with cancer, McGrath and Chesler (McGrath & Chesler, 2004) notes that **the gender stereotype for coping style and the way of expressing of emotions, as proposed by** previous research, does not always apply. Furthermore, in their study, as in the present studies, the individual variation of behaviours of men and women **was considerable.** McGrath and Chesler **refer to changing of social norms and pressures that allow men to show emotions more openly, and to a greater extent.**

Change and growth

Along with the psychological burden laid on parents, the cancer experience may also entail the experience of personal growth and positive change. Parents often say that they have come to appreciate the small things in life (Clarke-Steffen, 1993), and several spontaneous comments in the present studies referred to the questionnaire item "I am not yet my old self again" (included in the subscale *Loss of control -personal functioning*), which reveal experiences of personal growth. For example "I can never be 'my old self'! I grow and change 'thanks to' the disease.", and "I want to be this 'wise' me, which I have become from this experience".

However, while many parents confirm positive growth and a greater appreciation of life, this is certainly not true for all. As one father said: "This business about 'coming out of it stronger' is a bit of rubbish." (Chesler & Parry, 2001). Whether the sum total in the end is positive or not appears to be more dependent on the subjective experience of the event, rather than the event itself (Linley & Joseph, 2004).

Methodological considerations

There were several methodological limitations to the present studies. These shortcomings are discussed in the following section. Also included are some suggestions for further research that overcome the problems and clarify the ambiguities of the present studies.

Representativity and generalizability

The number of parents included in this research was larger than is usual for these type of studies. Therefore, it is safe to assume that the findings obtained in the present studies are reasonably representative of the population of parents from which the samples were taken. However, the generalizability of the present findings to parents of children treated at other hospitals may be restricted.

The procedures for inclusion were sufficiently rigorous to ensure an unbiased selection of parents in the study group. This assumption is supported by the fact that the distribution of cancer types was similar to that of the entire population of childhood cancer patients. However, there is one exception to this: the proportion of parents of children with leukaemia is somewhat larger, and the proportion of CNS tumour patients somewhat smaller in the study group than in the total population. This most likely reflects one of the methods of invitation. The parents who where consecutively invited to take part in the present study as their children attended the inpatient unit, may have been unequally selected, because different cancer types require different amounts of time at the ward. In particular, the treatment of CNS tumours is administered primarily on an outpatient basis, while the treatment for leukaemia includes several months of repeated treatment periods at the inpatient unit. Consequently, although every effort was made to ensure an unbiased selection of parents, certain self-selection biases are apparent, because of differences in the way that different types of cancers are treated.

A further question of representativity is the extent to which non-responding is systematically linked to one or more of the studied variables. However, by the very nature of missing values, data on the non-responders' situation is not available. The most common reason for not participating has previously been reported to be lack of time, especially for parents of children in active treatment (Landolt, Boehler, Schwager, Schallberger, & Nuessli, 1998), which may be a factor systematically associated with strain. Therefore, study samples may be biased toward a selection of the least strained parents. Alternatively, non-participation may be taken to indicate that parents felt well, and so do not consider such investigations important. However, this view is not borne out in surveys of the general population. In such surveys, those experiencing poorer mental well-being tend to be overrepresented among the non-responders (Stordal, Bjartveit Kruger, Dahl, Kruger, Mykletun, & Dahl, 2001). Arguably, excess avoidance, as a result of traumatic stress, underlies parents refusal to participate in such studies (Kazak et al., 2004; Manne et al., 2000). This being the case the occurrence of distress is likely underestimated in studies of the parents of children with cancer.

Finally, the generalizability of findings to childhood cancer parents in other countries may be limited. This is because of cultural and tangible differences in medical care as well as in parents' everyday life, which are thought to affect parental strain as well as the conditions for coping.

Background variables – selection and categorisation

The background factors addressed in the present studies were selected for their potential impact on parental distress. The choice of variables was based on previous research as well as clinical experience. However, while some of these factors where found to exert an influence on parental levels of distress, only a minor part of the variation was explained. This suggests that there are other factors influencing the level of distress in childhood cancer parents. Further, the way of estimating and classifying the background factors can be questioned. In the following section some of these problems are discussed.

The individual value for prognosis was based on retrospective statistical data concerning the probability of 12-year survival within the given main type of childhood cancer (NOPHO, 1999).

This is a 'quite square way' of estimating prognosis and may too often be incorrect in individual cases. Consequently, more sensitive and encompassing measures relating to the severity of the disease may usefully be examined in future studies.

Two main types of cancer – CNS tumours, and ALL – were examined for possible influence on coping and emotional distress. However, these two broad diagnoses encompass many different patients with fundamentally differing prognosis, and course of the disease and treatment. This is especially the case for the group of children with CNS tumours, which is heterogeneous from the medical perspective. Nonetheless, differences between these two groups were found in the present study, indicating that there indeed are factors associated with objective medical conditions which systematically influence parents' psychosocial situation. It is also reasonable to assume that the diagnoses themselves may have different connotations for the parents and so provoke different psychological reactions. The differences found in the present study encourages further exploration of the psychological significance of cancer type, and the underlying factors engendering strain.

The treatment situation was examined using two categories; being in treatment, and being off treatment. Consequently, all parents of children in treatment were analysed together, as were all parents of children for whom treatment was completed. A further developed approach could address potential differences in parental strain related to the type of treatment, and to the various phases of treatment.

The situations of parents of children off treatment, and those temporally further from the initial diagnosis, were not studied in regard to possibly distressing long-term medical effects of the disease and its treatment. Parental distress during the period immediately after completion of treatment could also be addressed specifically.

Parent's educational level was selected as an indicator of socio-economic status (SES). Other measures of SES are current occupation and income. Education, occupation, and income are often classified in various ways, and in various numbers of categories. However, which ever method is used to identify the SES of parent can be supposed to express fully the features which affect psychological resistance and well-being.

In regard to cultural background, the group of parents not born in Sweden comprised a very heterogeneous sample. This group is considered to be representative of the total population of non-indigenous Swedish parents, but is nonetheless restricted to those who are relatively fluent in the Swedish language. The findings concerning this disparate sample signify the importance of additional, more thorough examination of the dynamics involved

Assessment validity and reliability

The data used in all four studies were collected as self-reports, which is the most conventional and convenient method of surveying large groups. However, although self-report is an important source of information about subjective experiences, this method of data collection has certain limitations. Different response styles may be systematically prevalent in different groups. Such response styles may involve a reluctance or inability to report distress, as well as a tendency to over-report symptoms. Similarly, self-report measures also implicate a risk of a "contagion" effect, as people who are experiencing distress may judge, for example, their coping abilities more negatively. In addition, studies of self-reported distress and coping may also contain problems of overlapping concepts and possible underlying personality factors which can contribute to covariation in the assessed variables. Consequently, the addition of complementary qualitative data, including interviewing, would add to assessment validity, and partially eliminate the general limitations associated with self-report questionnaires.

To various extent, the psychometric properties of the self-report instruments used in the present studies have been evaluated. Previous studies present evidence suggesting that the original IES has adequate reliability and validity (Joseph, 2000). Psychometric data on the IES-R is sparse, but the content validity of this revised version is satisfying (Joseph, 2000). The IES was developed originally

to measure reactions to current stressors. Nevertheless, the scale is used frequently to assess symptoms of PTS as well (Joseph, 2000).

An evaluation of the validity of the UCL has been thoroughly undertaken (Schreurs et al., 1993). Specifically, construct validity and predictive validity (prediction of self efficacy and negative affect) has been examined by comparing the UCL with a range of other measures including those assessing coping, behaviour patterns, stress reactions, negative emotions, and personality variables. Moreover, factorial validity has been evaluated in several studies (Schreurs et al., 1993). Overall, the validity of the subscales of the UCL are considered to be reasonably good. Regarding the instrument combining eleven subscales for the assessment of parental distress, the process of forming the subscales warrants a certain degree of validity (Van Dongen-Melman et al., 1995b). However, construct validity, factorial validity, and reliability of this instrument requires further evaluation.

Originally, the scale used to assess perceived support was intended to capture feelings of loneliness. Therefore, our measure of perceived support could more accurately be labelled "absence of feelings of loneliness". However, according to Pierce, Sarason, and Sarason (1991), both general and relationship-specific perceptions of available support contribute to loneliness. Moreover, since the construct *perceived social support* is not specific to a particular relationship, or type of support (emotional support, advice, or tangible aid; (Pierce et al., 1996), the scale used here arguably covers this concept better than instruments relating to specific persons in the subject's social environment.

Accuracy of result interpretation

From the findings in this cross-sectional sample, conclusions cannot be drawn about causal directions of the relationships between variables. Moreover, the findings do not allow conclusions about individual change. In this respect, a longitudinal approach would provide a more reliable estimation of the progress of parental stress over time.

Clinical implications

The present findings indicate that many parents experience high levels of disease-related stress, not only at the early stages of onset and treatment, and not only in families where the child's prognosis is poor or where the child has suffered a relapse. However, the perceived threat of a relapse may be taken as a stressor at any time after the disclosure of a cancer diagnosis in a child. Therefore, in clinical practice, the practitioner should maintain an awareness of the fact that parents' perception of disease-related threat may be dependent on stress and emotional reactions. If the parent's perception of threat does not correspond with the view of the medical expertise, this need not be because of a lack of information or knowledge on the part of the parents.

Furthermore, the findings of the present studies show that parents of children in treatment, as well as those whose child has successfully completed treatment, experience situation-specific stress, such as low control, uncertainty, and intrusive thoughts about disease-related events. The previous literature has tended to describe parents' reactions to their child's cancer in terms of psychopathology and maladjustment, and a few parents may experience remaining psychiatric problems, such as posttraumatic stress. However, the stress of parenting a child with cancer may not be primarily expressed through psychopathology. In line with this, Marshall, Spitzer, and Liebowitz (1999), have criticised the notion that individuals whose reactions to a traumatic event stay within the range of the expectable, and individuals that are likely to recover spontaneously should not be in need of clinical interventions. Accordingly, there are at least two different approaches for parental psychosocial support in the paediatric cancer setting: I) to distinguish and provide care for those who demonstrate psychopathology, and II) to offer support to parents, who are not at risk of permanent psychiatric problems, but who may be overburdened during a demanding period.

For a successful integration of traumatic experiences, a certain amount of intrusive rumination, as well as avoidance are beneficial (Linley & Joseph, 2004). At the same time, clinical PTS also includes a process of intrusions and avoidance. Therefore, it is important to examine whether a par-

ent's traumatic stress reactions are primarily caused by recent events, or whether their stress reactions relate to previous experiences during the course of the illness. Parents' struggling to cope with present stressors as well as those showing signs of persistent posttraumatic symptoms may be in need of professional support, although the most suitable ways of meeting their needs may differ.

In coping with the many stressors following a child's cancer diagnosis, some strategies seem to be good enough in the early phases of acute stress, but can prove less adaptive in the long run. However, the only coping style that was consistently associated with higher levels of distress was one including a passive reaction pattern. Consequently, parents showing signs of passive reaction have a particular need of support, and as individuals reliant on a passive coping style may be less assertive, their needs can become overlooked. It is therefore important to pay particular attention to the needs of parents with a passive coping approach.

Mothers and fathers in Sweden increasingly share the practical responsibilities of the family, but mothers still appear to be the ones who spend most time with their child at the hospital. Yet, the findings of the present research support the recommendations of Seagull (2000), regarding the importance of not excluding fathers in paediatric psychology research and practice. Chesler and Parry (2001) emphasize the **utility of making visible any** gendered patterns and structures that may obstruct fathers' opportunities to express and manage the emotions associated with the child's illness.

Finally, it is important to be aware that despite significant differences between groups, the experiences, behaviours and needs of the individual parents met in clinical practice need not necessarily correspond to the patterns of the group.

Conclusions

- High levels of disease-related distress are frequent among parents during the first period after the diagnosis.

- Although anxiety is a symptom commonly occurring during an acute crisis, parents nevertheless report high levels of anxiety years after a child's cancer diagnosis, compared with parents of healthy children.

- Indications of disease-related parental strain can appear at any point in time after a child's cancer diagnosis.

- The disease-related strain, experienced by many parents during active treatment also occurs when treatment is completed.

- When treatment is completed parents with low education and non-indigenous parents may be less resilient to disease-related stress.

- Parents of children with good prognosis are just as vulnerable to distress as parents of children with a worse prognosis, and parents of a child suffering a relapse.

- Cancer in a child may affect mothers and fathers alike.

- Parents with a coping style that includes problem focusing are less affected by strain than those whose coping style does not include problem focusing.

- Parents with a coping style including a passive reaction pattern are more affected by strain than those whose coping style does not include this strategy.

- An avoidant coping style is associated with higher levels of anxiety and depression, although immediately after a child's cancer diagnosis, the distress seems to be high regardless of whether the parents rely on avoidant coping or not.

- The association between parental coping style and level of distress varies according to the amount of time elapsed since diagnosis.

- The association between parental coping style and level of distress varies depending on the child's type of cancer.

- Parents who perceive their social support as good appear less affected by strain.

Future perspectives

Further research into this area may longitudinally address disease-related psychological symptoms in parents, investigate whether high levels of distress persist in individual parents. If this is the case, the nature of such distress could be explored to distinguish persisting symptoms of posttraumatic stress from reactions to chronic stressors.

In the present research, fourteen aspects of parental strain were evaluated. The findings indicated varying patterns of significance for the different signs of strain. However, there may well be several additional parental concerns which are equally or even more relevant. Furthermore, as the situation involves numerous potential sources of stress, it is important to examine whether interactions between various stressors may exaggerate the negative effects.

The experience of a relapse is not predictive of higher levels of anxiety or depression. Consequently, additional investigation might include a broader spectrum of psychological reactions among parents of relapsed children. Any special concerns among parents may also be captured with a qualitative approach.

Certain coping strategies, as part of a coping style, are systematically associated with different levels of emotional distress. Therefore, further examination might clarify whether the aspect of importance is the actual coping behaviour, or something else, as for example various appraisal of coping efficacy associated with different coping styles. Longitudinal investigations may also clarify whether the experience of childhood cancer shape parents' coping style.

Findings indicating additional stress among non-indigenous parents justify supplementary studies, which may also include parents forced to communicate with medical staff through an interpreter.

Gender differences have been studied widely in other research areas. However, psychological research addressing gender issues in parents of children with cancer could strive to understand research questions more complex than the simple descriptive "How much do women and men differ?". One related issue, and one of interest to parents as well as medical professionals, is parents' experiences of the paediatric medical care system in a gender perspective.

Summary in Swedish – Sammanfattning

Syftet med det föreliggande arbetet var att undersöka symptom på psykologisk belastning och strategier för stresshantering hos föräldrar till barn i aktiv cancerbehandling, och föräldrar vilkas barn hade fullföljt en framgångsrik cancerbehandling. Undersökningen som gjordes omfattade bland annat sjukdomsrelaterad belastning i förhållande till den tid som förflutit sedan diagnosen ställdes; belastning och traumatisk stress under respektive efter barnets cancerbehandling; betydelsen av vissa demografiska faktorer och objektiva sjukdomsvariabler; förekomsten av olika strategier för stresshantering, och deras relation till nivå av stress; samband mellan upplevelsen av socialt stöd, att söka stöd som stresshantering, och nivå av ångest.

De fyra delarbeten som ingår i avhandlingen bygger på tvärsnittsstudier. Antalet föräldrar i de olika delarbetena var 265, 413, 395 respektive 184. Föräldrarna hade kontakt med Barncanceravdelningen vid Astrid Lindgrens Barnsjukhus eller Barnmedicinska kliniken vid Universitetssjukhuset i Linköping för barnets pågående cancerbehandling eller uppföljningskontroller efter avslutad behandling. Tidsrymden sedan diagnosen ställdes varierade från en vecka till fjorton år. Både mammor och pappor ingick i studierna. Fjorton olika aspekter av sjukdomsrelaterad stress och sju typer av stresshanteringsstrategier kartlades med självskattningsinstrument.

Särskilt påtaglig stress rapporterades av föräldrar den första tiden efter diagnos. De flesta aspekterna av belastning tycktes dock förekomma även långt senare. Ångest, som vanligtvis förknippas med akut stress och kris, förekom flera år efter diagnosen i högre grad än hos föräldrar till friska barn. I synnerhet behandlingsfasen förefoll att påverka föräldrarnas upplevelse av kontroll och handlingsutrymme, men även innebära upplevelser av traumatisk stress. De flesta belastningssymptom förekom emellertid även efter avslutad behandling; vissa typer i lika hög grad.

Resultaten antyder vidare att en upplevelse av gott socialt stöd och en problemfokuserad inriktning vid stresshantering kan göra föräldrarna mer tåliga mot belastning, medan ett stresshanteringsmönster som bygger på passivitet istället tycktes ha samband med en större känslighet för påfrestningar. Även undvikande strategier hade samband med mer stressymptom. De första månaderna efter diagnosen förefoll dock den emotionella belastningen att genomgående påverka föräldrar, oavsett om de hanterade stressen genom undvikande eller ej. Lägre utbildning och icke-svenskt ursprung verkade kunna skapa förutsättningar som gör föräldrar mer sårbara för stress efter behandlingens slut. Vidare var en bättre prognos för barnets sjukdom inte en faktor som automatiskt bidrog till en lägre stress. Slutligen tycktes mammor såväl som pappor påverkas starkt av att ett barn i familjen drabbas av cancer.

Sammanfattningsvis pekar resultaten mot att cancer hos ett barn medför en mängd olika aspekter av belastning för föräldrarna. Vissa typer av påfrestning verkar förekomma främst den första tiden efter sjukdomsbeskedet och under den aktiva behandlingen, samtidigt som erfarenheten av cancer hos ett barn kan väcka oro, osäkerhet och stress långt efter det att behandlingen avslutats.

Tack till…

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