

Mika Niemelä

STRUCTURED CHILD-
CENTRED INTERVENTIONS
TO SUPPORT FAMILIES WITH
A PARENT SUFFERING FROM
CANCER

FROM PRACTICE-BASED EVIDENCE TOWARDS
EVIDENCE-BASED PRACTICE

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MIKA NIEMELÄ

**STRUCTURED CHILD-CENTRED
INTERVENTIONS TO SUPPORT
FAMILIES WITH A PARENT
SUFFERING FROM CANCER**

From practice-based evidence towards evidence-based
practice

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Abstract

Several studies have highlighted the need for the provision of extra support for parenting and for the children of families with parental cancer, with particular emphasis on the need to protect the psychosocial wellbeing of these children. However despite this, child-centred work still rarely forms part of clinical practice in adult health-care settings.

The aims of the present work were: 1) to calculate a population-based estimate for the number of Finnish children affected by parental cancer, 2) to investigate whether these children had used specialised psychiatric services to a greater extent than their peers, 3) to conduct a systematic review of the scientific literature regarding the current state of structured interventions directly targeted at children with parental cancer, 4) to outline the clinicians' experiences of the use of structured child centred interventions in long-term clinical practice, and 5) to assess whether the "Let's Talk about Children" (LT) and "Family Talk Intervention" (FTI) approaches have any impact on the psychiatric symptom profile of seriously somatically ill parents and their spouses.

It was found that every 15th child (6.6% of the children) had a mother or father who was treated for cancer during the years 1987 to 2008. Cases of parental cancer increased these children's use of specialised psychiatric services significantly by comparison with their peers. A systematic review revealed that the existing number of structured child-centred interventions was small and their methodological content was highly heterogeneous. Clinicians' long-term experiences of the use of structured child-centred interventions in everyday clinical practice highlighted: the flexible choice of interventions, the importance of taking the children's needs into account, inter-team collaboration and the need to regard death as an essential topic when working with families with parental cancer. A significant improvement in the parent's psychological symptoms was observed four months after the completion of the structured intervention.

It can be concluded that children affected by parental cancer comprise a substantial part of the general population. Both the increased use of specialised psychiatric services by the children and the positive effect of interventions on the parents justify the pursuance of research-based child-centred work.

Keywords: children, interventions, prevalence, prevention, promotion, psychiatric treatment in cases of parental cancer, psychological wellbeing

Niemelä, Mika, Strukturoidut lapsikeskeiset interventiot syöpäpotilaiden perheiden tukemisessa : Kohti näyttöön perustuvaa käytäntöä

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Tiivistelmä

Useat viimeaikaiset tutkimukset ovat suosittaneet lisätukea vanhemmuudelle ja lapsille syöpäpotilaiden lasten psykososiaalisen hyvinvoinnin turvaamiseksi. Tästä huolimatta lapsikeskeistä työtä tehdään aikuisterveydenhuollossa vähän.

Tämän tutkimuksen tavoitteena oli: 1) arvioida väestötasolla niiden suomalaisten lasten lukumäärä, joilla on syöpää sairastava vanhempi, ja verrata näiden lasten psykiatrisen erikoissairaanhoidon käyttöä muihin vastaavaan ikäisiin, 2) selvittää systemaattisesti olemassa oleva tutkimustieto lapsikeskeisten strukturoitujen interventioiden käytöstä syöpää sairastavien vanhempien lapsilla, 3) tutkia työntekijöiden pitkäaikaisia kokemuksia strukturoitujen lapsikeskeisten interventioiden käytöstä osana jokapäiväistä kliinistä työtä, 4) selvittää kahden strukturoidun intervention, Lapset puheeksi -keskustelun ja Beardsleen perheintervention, vaikutusta vanhempien psykiatrisiin oireisiin neljä kuukautta intervention jälkeen verrattuna tilanteeseen ennen interventiota.

Tulosten mukaan Suomessa 6,6 %:lla vuonna 1987 syntyneistä lapsista oli vanhempi, jota oli hoidettu syöpän takia seurantajakson 1987–2008 aikana. Syöpää sairastavien vanhempien lasten psykiatrisen erikoissairaanhoidon käyttö oli tilastollisesti merkitsevästi kohonnut verrattuna muihin samanikäisiin. Lasten tukemiseen tarkoitettujen strukturoitujen interventioiden määrä oli vähäinen ja niiden tutkimuksellinen taso oli vaihteleva. Työntekijöiden kokemukset lapsikeskeisten interventioiden toteuttamisesta potilastyössä nostivat esille useita huomioonotettavia asioita: on tärkeää voida valita interventio joustavasti perheen tarpeiden mukaan, yli sektorirajojen ulottuva yhteistyö on keskeistä, lasten yksilöllisten tarpeiden huomioiminen on tärkeää, kuoleman teema nousee usein esille perheiden kanssa työskenneltäessä. Vanhempien psyykkisten oireiden todettiin vähentyneen intervention jälkeen tehdyssä mittauksessa verrattuna ennen interventiota tehtyyn mittaukseen.

Tutkimuksen tulosten perusteella voidaan päätellä, että syöpäpotilaiden lapset muodostavat merkittävän ryhmän väestössä. Syöpäpotilaiden lasten lisääntynyt psykiatrisen erikoissairaanhoidon käyttö jo yksin ja myös interventioiden myönteiset vaikutukset puoltavat lapsikeskeisen työn kehittämistä aikuisterveydenhuoltoon. Kehittämistyön pohjana voidaan käyttää tässä tutkimuksessa käytettyjä strukturoituja lapsikeskeisiä interventiota.

Asiasanat: esiintyvyys, interventio, lapset, preventio, promootio, psykiatrisen hoito, psyykinen hyvinvointi, vanhemman syöpä

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Oulu, August 2012

Mika Niemelä

Abbreviations

95%CI	95% Confidence Interval
CDI	Children's Depression Inventory
COSIP	Children of Somatically Ill Parents project
EC&F	Effective Child & Family programme
EFN	Effective Child & Family network meeting
FTI	Family Talk Intervention (previously PFI = Preventative Family Intervention)
FGP	Finnish general population
FPO	Finnish psychiatric outpatient sample
GSI	General Severity Index
HDR	Hospital Discharge Register
IAS	Illness Attitudes Scale
LT	Let's Talk about Children intervention
OR	Odds Ratio
PACT	"Parenting at a Challenging Time" programme
PASW	Predictive Analytics Software
PTSD	Post-Traumatic Stress Disorder
SAS	Statistical Analysis System
SCL-90	Symptom Checklist 90, for adults and children aged 13 years or more
SES	Socio-Economic Status

List of original publications

This thesis is based on the following original publications, which are referred to in the text by the Roman numerals I-IV.

- I Niemelä M, Paananen R, Hakko H, Merikukka M, Gissler M & Räsänen S (2012) The prevalence of children affected by parental cancer and their use of specialized psychiatric services: The 1987 Finnish Birth Cohort study. *International Journal of Cancer*. In press. Doi: 10.1002/ijc.27466.
- II Niemelä M, Hakko H & Räsänen S (2010) A systematic narrative review of the studies on structured child-centred interventions for families with a parent with cancer. *Psychooncology* 19(5): 451–461.
- III Niemelä M, Väisänen L, Marshall C, Hakko H & Räsänen S (2010) The experiences of mental health professionals using structured family-centred interventions to support children of cancer patients. *Cancer Nursing* 33(6): E18–27.
- IV Niemelä M, Repo J, Wahlberg KE, Hakko H & Räsänen S (2012) Pilot evaluation of the impact of structured child-centered interventions on psychiatric symptom profile of parents with serious somatic illness: struggle for life trial. *Journal of Psychosocial Oncology* 30(3): 316–330.

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1 Introduction

“A parent’s cancer is like a tsunami which rolls over the whole family. If it strikes a thousand families at the same time the entire health care system would be mobilized. But when it strikes one family at a time you are left alone with your children” (quote from a father during a family intervention).

Cancer is a severe life-threatening illness which raises existential questions and causes distress to the individual concerned and to family members (Albaugh 2003). If the patient has young dependent children there are additional special needs concerning both parenthood and the children’s wellbeing (Barkmann *et al.* 2007, Huizinga *et al.* 2010, Visser *et al.* 2004, Visser *et al.* 2006).

A recent population-based estimate from the USA indicates that cancer patients living with young children represent a substantial part of the US population (Weaver *et al.* 2010), and several studies have documented psychological and behavioural symptoms of various types in the children of cancer patients (e.g. Grabiak *et al.* 2007, Osborn 2007, Visser *et al.* 2004), although comparisons with symptoms in children with healthy parents are rare (Su & Ryan-Wenger 2007) and the findings are seldom based on population samples (Barkmann *et al.* 2007). Nevertheless, the majority of studies addressing the psychosocial wellbeing of the children of cancer patients agree that such children need additional psychosocial support. To date, the practices and interventions required for children of cancer patients are rarely incorporated into regular clinical health care programmes (Diareme *et al.* 2007).

Based on the previous literature, it appears that there are only a few systematic clinical settings that provide help for cancer patients with children in their care (Diareme *et al.* 2007). This is an unfortunate situation and occurs despite numerous recommendations by study groups (Schmitt *et al.* 2008a, Schmitt *et al.* 2008b, Visser *et al.* 2004) and published reports identifying an evident need for help among families affected by parental cancer (Huizinga *et al.* 2010, Huizinga *et al.* 2010, Romer *et al.* 2002). Current levels of support for cancer patients with children and its quality are extremely variable, and it seems that the support that is made available to such children depends predominantly on the policies and activities of local healthcare authorities.

There is an evident need in everyday clinical practice for research-based interventions targeting severely ill patients with young children. It is important that participation in such interventions should be a positive experience for the patient, the family members and the health care professionals.

Establishing a research-based clinical practice nevertheless raises a range of important questions, such as: How many children in the general population have a parent suffering from cancer? Do they require specialised psychiatric services more than their peers? What is the current state of child and family-centred interventions? What are the experiences of clinicians who have already introduced structured child and family-centred interventions into their clinical practice? Since parental psychological wellbeing is essential for the wellbeing of the child, it is important to find out what is the impact of the intervention on parents' psychological wellbeing at an early stage in the study.

The investigations included in this doctoral thesis have endeavoured to answer the questions listed above. Population-based estimates for the numbers of children living with cancer patients and the use they make of specialized psychiatric services were investigated using the national Finnish 1987 Birth Cohort database, the current state of research into structured family and child-centred interventions was evaluated using a systematic literature review, and clinicians' experiences of the use of such interventions were screened by means of personal interviews with a sample of experienced psychiatric professionals who also had training and long-term experience in the use of these interventions in regular clinical practice. The preliminary impact of the interventions was examined in a clinical sample of cancer patients with young children at home, providing results capable of serving as a basis for developing research-based child-centred clinical interventions for use in adult health care.

2 Review of the literature

2.1 Prevalence of parents suffering from cancer living with young children

Population-level estimates of the number of cancer patients who have young children are extremely scarce. Rauch and Muriel (2004), using data from the National Cancer Institute, estimated that 24% of cancer patients in the United States had young dependent children, while one third of a sample of patients with breast cancer (usually women of child-bearing age) were estimated to have young children at home. Studies of the rates of children affected by parental cancer in European countries are extremely rare (Bloom & Kessler 1994, Schmitt *et al.* 2007), although Barkmann and his working group (2007) reported that 4.1% of children living in Germany were affected by serious parental physical illness, including cancer.

One recent report based on data from the United States National Health Interview Survey obtained between the years 2000 and 2007, including 13,385 adults with a history of cancer, estimated that the rate of cancer survivors living with young children was 14%, while the figure among recently diagnosed cases is 18%. The authors conclude that there are about 1.58 million cancer patients with 2.85 million children in the USA, and that a significant proportion of the population are struggling with the many problems associated with cancer, including concerns regarding parenting and the wellbeing of their young children (Weaver *et al.* 2010).

2.2 Parental cancer as a risk factor for adverse psychosocial outcomes in children

A risk factor has been defined as an experience, event or characteristic which is associated with the increased probability of a negative outcome than in the general population (Kazdin *et al.* 1997). Once a risk factor is identified as preceding a particular outcome, it is possible to categorise the population into a high-risk and a low-risk group (Kraemer *et al.* 1997). In the present case parental cancer is addressed as a risk factor for adverse psychosocial consequences in children (Figure 1).

An outcome is defined as an event or a personal characteristic that is either to be prevented or to be promoted (Kazdin *et al.* 1997). Once an outcome has been identified it is possible find individuals who are at risk of attaining that particular outcome (Kazdin *et al.* 1997).



Fig. 1. Parental cancer as a risk factor for children's adverse psychosocial consequences.

Hoke (1996) identifies four outcome categories in children affected by parental cancer: 1. *emotional/mood*, 2. *somatic*, 3. *academic*, and 4. *social/interpersonal*, arguing that the outcomes (consequences) of parental cancer for children can be classified into *bonadjustment* and *maladjustment* in each of these four categories. Bonadjustment includes the child experiencing less biopsychosocial problems than in an average population, or the same amount, while biopsychosocial symptoms which appear to be more prevalent than is usually the case in children represent maladjustment.

Gabiak *et al.* (2007) went one step further, suggesting that the adverse outcomes caused in children by parental cancer can be divided into *internalising* and *externalising* forms of behaviour, these being defined, in accordance with Lerner (2002), as follows: 1. "Internalising behaviour is behaviour that is 'directed inwards to the individual and affects his or her mental, cognitive, or emotional functioning, such as depression or anxiety.'" 2. "Externalising behaviour is behaviour that is 'directed towards other people, or more generally, to the social context, i.e. aggression or disruptive behaviour at school or at home.'" According to the systematic review by Osborn (2007) internalising behaviour accounts for the most commonly investigated mental health problems in the young/adolescent children of cancer patients (Figure 2).

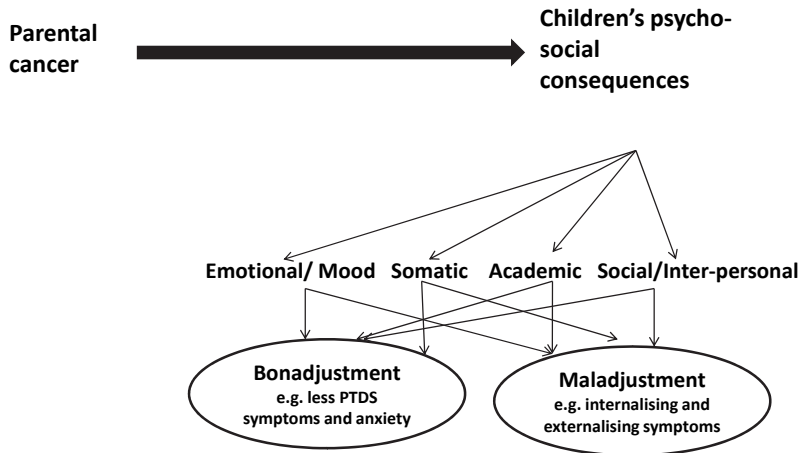


Fig. 2. Parental cancer and psychosocial outcomes in the children.

The findings in existing studies of the adverse outcomes observed in children affected by parental cancer, as shown in Table 1, have been compared with previously gathered normative data, (i.e. data representing an average population) (Armsden & Lewis 1993, Birenbaum *et al.* 1999, Thastum *et al.* 2009, Welch *et al.* 1996), children of parents with other less serious illnesses (Cappelli *et al.* 2005), or children of healthy parents (Hoke 2001).

Previous studies of the risk of an adverse outcome in children have commonly focused on cases involving parental breast cancer, with the number of participants varying from 13 to 352 children and from 13 to 350 parents (Armsden & Lewis 1993, Birenbaum *et al.* 1999, Cappelli *et al.* 2005, Harris & Zakowski 2003, Heiney *et al.* 1997, Howes *et al.* 1994, Sigal *et al.* 2003, Thastum *et al.* 2009, Welch *et al.* 1996), the most commonly investigated outcome categories being internalising and externalising symptoms, followed by forms of coping behaviour, self-esteem, social competence and cancer-related worries. Visser *et al.* (2004) concluded in their review that adolescents, particularly girls, have an elevated risk of internalising symptoms, and this was confirmed by Grabiak *et al.*(2007). A review by Osborn (2007) concluded that adolescents seem to have a slightly increased risk of internalising problems, whereas the situation with regard to younger children's psychological adversities remained unclear.

The findings showed that children of mothers with breast cancer had an elevated risk of lower self-esteem, internalising problems (including stress symptoms and anxiety) and more illness-related worries than did children of healthy mothers (Armsden & Lewis 1993, Birenbaum *et al.* 1999, Cappelli *et al.* 2005). Conversely, children of healthy parents reported more post-traumatic stress, stress response symptoms and anxiety than children affected by parental cancer (Harris & Zakowski 2003, Hoke 2001), while the latter have been reported to have increased levels of internalising problems relative to children with healthy parents (Edwards *et al.* 2008, Heiney *et al.* 1997, Osborn 2007, Romer *et al.* 2002, Thastum *et al.* 2009, Visser *et al.* 2005). Birenbaum *et al.* (1999) also revealed a risk of internalising outcomes in adolescents having a parent with cancer compared with children whose parents do not have cancer. Adolescents were found to be more distressed (Compas *et al.* 1994, Grant & Compas 1995, Huizinga *et al.* 2005b, Nelson & While 2002, Visser *et al.* 2005, Welch *et al.* 1996) and to suffer from more anxiety than their peers with healthy parents (Heiney *et al.* 1997, Lewis & Darby 2003). In general, when both groups were questioned about the impacts of a parent's illness on the children, the adolescents reported a higher incidence of problems than their parents reported them as having.

The evidence for externalising symptoms in children affected by parental cancer is not as strong, although Thastum *et al.* (2009) and Sigal *et al.* (2003) have described elevated levels of externalising symptoms in adolescents and children. When internalising and externalising symptoms occurred together, the level of symptoms were found to be elevated still further (Armsden & Lewis 1993, Birenbaum *et al.* 1999, Hoke 2001).

Table 1. Studies addressing parental cancer as a risk factor for children and/or adolescents, modified from Osborn (2007).

Study	Children (n), Parental cancer cases (n)	Comparison	Outcome categories	Findings in children
Armsden and Lewis (1993)	Children n=13, Mothers with breast cancer n=13	1. 17 children of 17 women with fibrocystic breast disease, 2. 18 children of 18 mothers with diabetes 3. vs. average population data (except for coping effectiveness)	Internalising and externalising symptoms Coping effectiveness Self-esteem	Children's reports: lower self-esteem Mothers' reports: increase in total problems
Birenbaum <i>et al.</i> (1999)	Children n=66, Mothers with breast cancer n=66	Average population	Internalising, externalising and total symptoms, social competence	Mothers' reports: increased level of internalising symptoms Children's reports: increased level of internalising symptoms and total symptoms, better social competence*
Cappelli <i>et al.</i> (2005)	Children n=55, Mothers with breast cancer n= 55	55 adolescents with healthy parents in a children's hospital emergency department without life threatening reasons	Internalising, externalising and total problems, social competence, cancer-related worries	Children's reports: increase in cancer-related worries
Edwards <i>et al.</i> (2008)	Adolescents whose mothers had breast cancer n=56	No comparison group, but clinical cut off points	Stress responses, psychological functioning	Adolescents' reports: 33% of males and 45% of females suffered from high rates of stress, 28% of males and of 32% females reported psychological symptoms.

Study	Children (n), Parental cancer cases (n)	Comparison	Outcome categories	Findings in children
Harris and Zakowski (2003)	Children n=27, Mothers with breast cancer n=22	23 children of 19 healthy parents	Depression, anxiety, post-traumatic stress disorder (PTSD) symptoms. Stress response symptoms	Children's reports: less PTSD symptoms and stress response symptoms*
Heiney <i>et al.</i> (1997)	Children n=33, Mothers with cancer n=22	Average population	Internalising symptoms	Children's reports: increased level of anxiety
Hoke (2001)	Children n=35, Mothers with breast cancer n=28	35 children and their 24 mothers with benign breast biopsies	Internalising, externalising symptoms and social competence	Mothers' reports: decreased level of total symptoms* Children's reports: lower levels of anxiety*
Huizinga <i>et al.</i> (2010)	Adolescents n=49, parents with various cancers n=37, and 37 spouses	Adolescents with parental cancer diagnosed 1–5 years previously 76 sons and 98 daughters	Stress response symptoms (SRS) one year after a cancer diagnosis in three measurements from dg:T1 0.2–4.0, T2 7.6, T3 13.5 months	Adolescents' reports: elevated levels of SRS were found at: T1: 29% T2: 16% T3:14%
Sigal <i>et al.</i> (2003)	42 children of 42 mothers with metastatic breast cancer	Children n=45, Mothers with (non-metastatic) breast cancer n=45	Internalising and externalising problems	Mothers' reports: lower level of externalising symptoms*

Study	Children (n), Parental cancer cases (n)	Comparison	Outcome categories	Findings in children
Thastum <i>et al.</i> (2009)	Children: n=352, parents with various cancers n=350 ill, 250 healthy partners,	National average population	Emotional and behavioural functioning of children and adolescents	Children's reports: An increased level of psychosocial symptoms in latency-aged boys and adolescent girls; parental depression increased internalising symptoms; family dysfunction, increased externalising symptoms Children's reports: increased level of internalising symptoms
Weich <i>et al.</i> (1996)	Children n=89, Mothers with various cancers, n=45	Average population	Internalising problems	Children's reports: increased level of internalising symptoms

*divergent finding= children with parental cancer managing better than the controls

2.3 Factors intervening between parental cancer and children’s psychosocial outcomes

By examining processes intervening between a risk factor (here parental cancer) and outcomes (adverse psychosocial consequences), it is possible to identify the factors which serve as moderators and mediators, i.e. factors explaining how and why (mediator) or when (moderator) the impact occurs (Baron & Kenny 1986, Bennett 2000). Understanding the intervening process through these two relations is important, when the direct impact of a risk factor on the outcome, as shown in the Figure 1, cannot be explained completely (Figure 3).

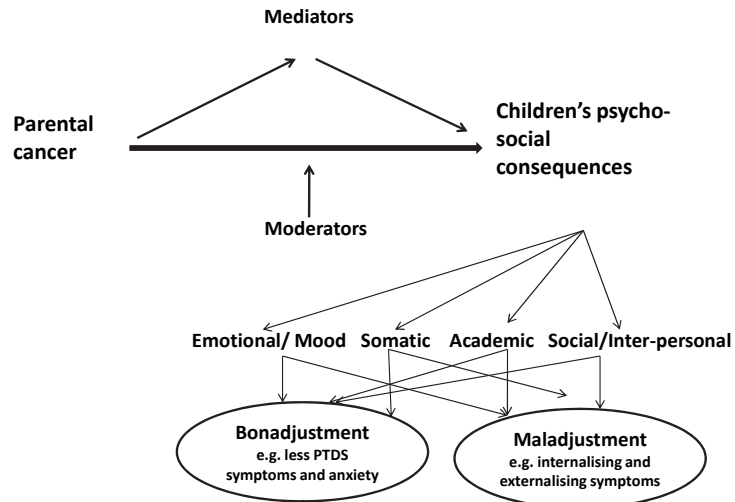


Fig. 3. Mediators and moderators as factors intervening between parental cancer and children’s psychosocial outcomes (adapted and modified from Baron and Kenny 1986).

In their theoretical model developed to explain children’s adjustment to parental cancer, Su and Ryan-Wenger (2007) employed the concepts of moderators and mediators to explaining how a parent’s cancer and the children’s psychosocial outcomes are related. They defined moderators as pre-existent variables (e.g. age and gender of the child) that will influence the intervening process. Thus moderators are quite stable factors that exist regardless of whether or not the parent is ill. Correspondingly, mediators include factors “that exert their influence after the occurrence of parental illness, e.g. the quality of the parent-child

relationship, or the child's coping behaviour". Thus mediators are instable factors that are prone to change (Figure 4).

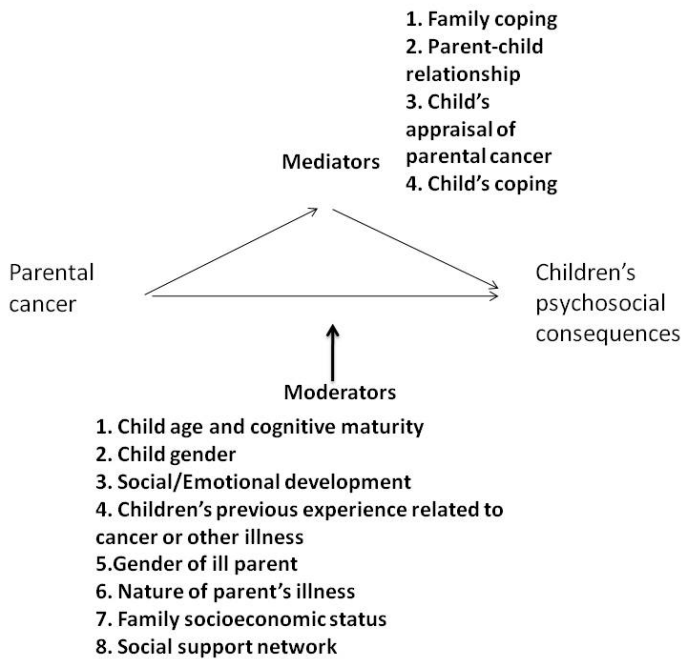


Fig. 4. Moderating and mediating variables adapted and modified from Su and Ryan-Wenger (2007).

2.3.1 Age and gender of the child

Children of different ages will react in contrasting ways to a parent's illness. Small children are unable to understand the concept of illness, but toddlers have been found to notice changes in their parents' behaviour and everyday family life resulting from illness (Rauch *et al.* 2003, Swick & Rauch 2006). Nevertheless, the potential physical limitations caused by the illness, along with the side-effects of treatment or hospitalization, have an evident impact on parenthood and child-parent interaction.

Pre-school children have been observed to understand that cancer is a serious illness and can even cause the death of a parent (Forrest *et al.* 2006), while school-aged children are reported to have very concrete techniques for dealing with parental cancer, e.g. a firm belief that the treatment will always heal the

illness (Rauch *et al.* 2003). Both pre-school and school-aged children have been reported to show emotional, behavioural, social and physical reactions such as sadness, loss of sleep, problems at school, or conflicts with peers and family members (Hymovich 1993). Latency-aged boys have been found to suffer from high rates of stress (Edwards *et al.* 2008) and other internalising problems (Thastum *et al.* 2009, Visser *et al.* 2005).

It has been noted in several studies that adolescents think about the consequences of parental illness in terms of their impact on family members, so that they may react strongly to the various phases in a parent's illness (Rauch & Muriel 2006, Rauch *et al.* 2003). Exaggerated risk-taking behaviour is one reaction that has been associated with a parent's illness (Muriel & Rauch 2003, Rauch & Muriel 2006, Visser *et al.* 2006).

Among the offspring of mothers with breast cancer, adolescent girls in particular have commonly been found to have psychosomatic symptoms such as headaches, stomach ache, dizziness, sleeping problems and loss of appetite (Spira & Kenemore 2000) and also shown to have an increased risk of internalising problems (Compas *et al.* 1994, Grant & Compas 1995, Heiney *et al.* 1997, Huizinga *et al.* 2005b, Huizinga *et al.* 2010, Nelson *et al.* 1994, Thastum *et al.* 2009, Visser *et al.* 2004, Visser *et al.* 2005, Visser *et al.* 2006, Welch *et al.* 1996). Outcomes in children are also thought to be affected by gender, so that adolescent boys have reported that parental illness had a negative effect on their schoolwork and the amount of leisure time available for sports and activities with friends (Gabiak *et al.* 2007). Ill parents reported that their adolescent daughters had more emotional and behavioural problems than their adolescent sons (Visser *et al.* 2004, Visser *et al.* 2005). Davey *et al.* (2005) found that adolescent children of parents with cancer tended to hide their thoughts, fears and feelings in an attempt to protect the parent and avoid causing tension in their relationship.

Huizinga *et al.* (2005b) reported that every fifth son and more than every third daughter suffered from clinically elevated stress response symptoms and other internalising problems when a parent had cancer. In addition when their mother was suffering from breast cancer, 28% of adolescent sons and 32% of daughters reported that they had psychological problems (Edwards *et al.* 2008).

2.3.2 A cancer patient's psychological wellbeing

Despite dramatic improvements in cancer treatment, it is still considered a life-threatening illness (e.g. Hall *et al.* 2000, Kuczynski 2008, Miller *et al.* 2005, Shah *et al.* 2006, Unruh *et al.* 2000, Vrkljan & Miller-Polgar 2001). Cancer patients have been shown to struggle with both existential (LeMay & Wilson 2008) and spiritual questions (Albaugh 2003, Kub *et al.* 2003, Unruh *et al.* 2000). Under these circumstances it is understandable that an ill parent may also suffer from psychological symptoms. Patients who have children are younger, of course, and young age has been reported to be associated with depressive symptoms and/or distress in a patient (Green & Kreuter 1999).

According to a recent study, being a parent of young children increases a cancer patient's psychological symptoms. Cancer patients with young children have reported to have significantly more psychological problems such as panic disorder and decreased peacefulness compared with cancer patients without young children (Nilsson *et al.* 2009).

Osborn (2007) noted that mothers with cancer and depressive symptoms reported increased amounts of internalising and externalising problems among their children, but this finding was not confirmed in the children's own reports. The author suggested that negative reports from the parents could be explained by a negative impact caused by the mothers' depression. Conversely, Hoke (2001) found better social competence in children whose mothers suffered from both cancer and depression.

It is well-documented that psychological symptoms are very common in cancer patients (Lloyd-Williams *et al.* 2004). There is also robust evidence to show that a parent's mental health problems generally have a strong adverse impact on their child's psychological wellbeing (e.g Feder *et al.* 2009, Vidair *et al.* 2011, Weissman & Olfson 2009, Weissman & Talati 2009, Wickramaratne *et al.* 2011). It is evident, therefore, that the psychological wellbeing of parents suffering from cancer has an association with (adverse) psychosocial outcomes in their children (Visser *et al.* 2004). The following three sections will address the psychological symptoms and psychiatric disorders that cancer patients are most likely to have, as documented in the literature.

Psychological adversities of cancer patients

Cancer patients may suffer from psychological adversities and psychiatric disorders as a consequence of cancer. In addition they may also be vulnerable to psychological adversities despite the occurrence of cancer.

Approximately 50% of patients with advanced cancer meet the criteria for a psychiatric disorder, e.g. adjustment disorders, major depression, anxiety and post-traumatic stress, personality disorders, substance abuse and major mental disorders such as schizophrenia and bipolar disorder (Miovic & Block 2007). Patients with cancer are also reported to experience Post-Traumatic Stress Disorder (PTSD) associated with their cancer diagnosis or treatment (Amir & Ramati 2002, Kwekkeboom & Seng 2002, Levine *et al.* 2005). A connection between common trait anxiety and post-traumatic stress symptoms has been found in a sample of patients with rectal cancer (Ristvedt & Trinkaus 2009). Post-traumatic stress symptoms may reduce patients' ability to attend for treatment or control visits (Kwekkeboom & Seng 2002).

Traumatic life events may also lead to positive consequences for the patient, a theory that has gained recognition, particularly in the area of trauma. It is suggested that an individual may experience positive consequences after a traumatic event, e.g. by making positive changes to their lives in terms of priorities, relationships with others, etc. (Steel *et al.* 2008).

Psychological distress and anxiety in a cancer patient

The overall prevalence of distress among cancer patients has been reported to be 35.1%, the highest rate (43.4%) being among patients with lung cancer and lowest (29.6%) in those with gynaecological cancers (Zabora *et al.* 2001). The incidence of high levels of emotional distress among cancer patients in North America has been shown to range from 35% to 45% (Carlson *et al.* 2004). One study with 3,095 participants showed patients with lung, pancreatic, head and neck or brain cancer or Hodgkin's disease to be the most distressed (Carlson *et al.* 2004). Correspondingly, it was found in a recent Finnish study that 28.4% of cancer patients suffered from distress (Luutonen *et al.* 2011).

Marrs (2006) estimated that the prevalence of serious psychological distress among long-term cancer survivors was significantly higher than in a comparison group with no disease (5.6% vs. 3.0%), a half of the recently diagnosed cancer

patients being reported to suffer from anxiety, while the occurrence of chronic anxiety among long-term cancer survivors was approximately 30%. According to a review by Meyerowitz *et al.* (2008), however, the distress caused by cancer will decline over the years as the fear of a recurrence subsides, so that the levels of distress measured after five years were found in age-matched comparisons to be the same as in people who had never had a cancer diagnosis.

Psychological distress and anxiety in cancer patients is strongly associated with the illness and the subsequent treatments. Receiving the cancer diagnosis, undergoing chemotherapy, surgery and radiation therapy, or engaging in discussions over family issues can all trigger anxiety (Marrs 2006). In addition, uncertainty concerning the seriousness of the illness and the time spent waiting for surgical treatment and confirmation of the diagnosis can all increase anxiety in cancer patients (Sukegawa *et al.* 2008). Psychological distress has been associated with pain (Brown *et al.* 2010, Mosher *et al.* 2010, Mystakidou *et al.* 2006), and distress related to the physical symptoms of cancer can also increase anxiety (Chen *et al.* 2010).

According to a meta-analysis, women tend to suffer more psychological distress and anxiety than men (standardized mean difference = 0.31) (Hagedoorn *et al.* 2008), while younger, unmarried and less educated patients have been reported to be more susceptible to serious psychological distress (Hoffman *et al.* 2009). Close relationships are shown to protect cancer patients from anxiety. Indeed, the quality of the patient's close relationships has been found to be a good predictor of the occurrence of anxiety symptoms (Mystakidou *et al.* 2006).

Decreased self-efficacy (Mosher *et al.* 2010) self-esteem (Kobayashi *et al.* 2009) and optimism (Rustoen *et al.* 2010) have also been associated with a cancer patient's psychological distress, and close connections have been found between anxiety and adverse intrusive cognitions (Whitaker *et al.* 2008, Whitaker *et al.* 2009). A significant linear relationship has been demonstrated between the number of intrusive cognitions and the severity of anxiety in cancer patients, so that 48% of the cancer patients studied (67 out of the total of 139) reported frequent, uncontrollable intrusive cognitions (Whitaker *et al.* 2009). Depression and anxiety often occur simultaneously among cancer patients (Brown *et al.* 2010).

Although psychological distress and anxiety are an evident burden for a cancer patient, many do not seek help and do not consult the supportive services available to them (Carlson *et al.* 2004). Anxiety, like depression, has been shown to be under-diagnosed and under-treated in cancer patients (Bottomley 1998), and

it is possible that patients and professionals may see anxiety as a direct consequence of a serious life situation and thus do not perceive these psychological consequences as independent reasons for seeking help.

Depression in cancer patients

Depression is the most prevalent phenomenon mentioned in the literature reporting psychological symptoms and disorders in cancer patients (Lloyd-Williams *et al.* 2004). It has been widely acknowledged since the 1960's that depression is a common adverse consequence of cancer (Massie 2004). In the 1970's 23–49% of adult cancer patients were reported to suffer from clinically elevated depressive symptoms (Plumb & Holland 1977), and more recent findings have suggested that approximately 25% of cancer patients have clinically elevated depressive symptoms (Derogatis *et al.* 1983) and that depression is four times more common in cancer patients than in the general population (Du-Quiton *et al.* 2010).

Recently, 32.1% of cancer patients in Finland were found to have depressive symptoms (Luutonen *et al.* 2011). The prevalence of depression was associated with a younger age (Luutonen *et al.* 2011), but so that the prevalence of depressive symptoms in older patients (mean age 58 years) did not differ from that in healthy controls (Gustavsson-Lilius 2010).

Depression has also been shown to be related to the form and stage of the patient's cancer (Caplette-Gingras & Savard 2008, Laird *et al.* 2009, Love *et al.* 2004, Lydiatt *et al.* 2009), being closely associated with oropharyngeal (22%–57%), pancreatic (33%–50%), breast (1.5%–46%) and lung (11%–44%) cancers (Massie 2004) and with head and neck cancer 15–50 % (Lydiatt *et al.* 2009), for example.

Depression is common at the time of diagnosis, during treatment and in the six-month period following treatment, but may continue for years after diagnosis (Haisfield-Wolfe *et al.* 2009, Montazeri 2008). Depressive symptoms are also said to be associated with the severity of cancer, and the prevalence of depression, for example, has been reported to increase in cases of advanced cancer, to reach 33–37% (Caplette-Gingras & Savard 2008, Laird *et al.* 2009, Love *et al.* 2004).

In clinical practice depression has been reported to be under-diagnosed and under-treated among cancer patients, in spite of strong research-based evidence for an association between cancer and depression (Caplette-Gingras & Savard

2008, Fann *et al.* 2008, Lydiatt *et al.* 2009, Montazeri 2008, Wasteson *et al.* 2009). Research-based tools have been developed to help in the diagnosis of depression in cancer patients (Wasteson *et al.* 2009).

Pain and depression are reported to occur with same prevalence: in 36.5% of cancer patients (Laird *et al.* 2009). Depression has been shown to have an adverse impact on the quality of life as experienced by cancer patients (e.g. Brown *et al.* 2010, Chen *et al.* 2009, Montazeri 2008, Zenger *et al.* 2010), and in addition to pain, depression has been linked with insomnia, anorexia, fatigue and wound or pressure sores in cancer patients (Chen & Chang 2004, Laird *et al.* 2009). Cancer patients with a major depressive disorder reported that their most common concerns were related to interpersonal relations, loss of interest, low mood and cancer recurrence or relapse (Kleiboer *et al.* 2011).

There is also evidence that depression can affect the survival rates of cancer patients. In a study by Mainio *et al.* (2006) patients with a glioma and depression were shown to have shorter survival times (3.3–5.8 years) than glioma patients without depression (10.0–11.7 years). Depressive disorder can also have a substantial negative influence on a cancer patient's prognosis (Archer *et al.* 2008).

2.3.3 Family factors

Family cohesion and structure

It is evident that cancer can have a dramatic impact not only on the patient but on all the people nearby. Cancer has been identified as a “we-disease”, highlighting its interpersonal influence. An association has been clearly demonstrated, for example, between the levels of distress experienced by a patient and his or her spouse, as also between a higher psychological quality of life in a cancer patient and a good spousal relationship (Gustavsson-Lilius 2010).

Family cohesion has been shown to be an intervening factor in the association between parental cancer and a child's psychosocial wellbeing. When investigating the impact of family functioning, five family types have been proposed, depending on the level of family cohesion, i.e. how family members are emotionally attached to each other, high cohesion being associated with good psychological outcomes and low cohesion with poor outcomes (Kissane *et al.* 1994, Kissane *et al.* 1996a).

According to a review by Osborn (2007), there is evidence of an association between family cohesion and a child's psychosocial wellbeing when a parent is suffering from cancer. Moreover, poor family cohesion has been shown to predict internalising and externalising problems in children of a parent with cancer (Edwards *et al.* 2008, Harris & Zakowski 2003, Huizinga *et al.* 2003). On the other hand, Nelson & While (2002) found no evidence of any connection between poor family cohesion and the children's psychosocial wellbeing.

Watson *et al.* (2006) reported that ill-defined (e.g. unclear) family roles generated internalising problems, poor behavioural control and externalising problems among school-aged children of breast cancer patients.

Family communication

Family communication has been found to affect the children's psychosocial wellbeing. Poor communication within the family is associated with internalising and externalising symptoms in the children of parents with cancer (Edwards *et al.* 2008, Gazendam-Donofrio *et al.* 2007, Grant & Compas 1995, Huizinga *et al.* 2005a, Huizinga *et al.* 2005b, Lewis & Darby 2003, Osborn 2007), but open communication with the healthy parent was associated with a lower amount of stress response symptoms in the children, while problematic communication was associated with an increase in stress response symptoms (Huizinga *et al.* 2005b). The association between family communication and the psychological wellbeing of the children of parents with cancer has mostly been established for adolescent-aged children, whereas for younger children the relation has remained unclear (Osborn 2007).

The parents' style of communication appears to be related to a child's ability to cope with significant changes within the family (Thastum *et al.* 2008). Muriel & Rauch (2003) have provided detailed guidelines regarding effective communication with children, stating that children are able to maintain their own lives and cope most effectively when they know that their parents will keep them informed about important events related to the illness. They emphasized, for instance, that it is important as a part of clinical practice to help parents prepare for conversations with their children about the illness.

Muriel and Rauch (2003) stress that it is important for parents and other people involved in the child's care to be mindful of the child's temperament and styles of communicating. One child may communicate openly about a parent's

illness, for example, while a sibling refuses to discuss it. They also emphasised that it is important to use the real names of illnesses when talking to a child and to encourage the child to ask questions and freely express his or her worries. They believe that it is important to give the child time to digest the news and return to the topic later to assess the child's understanding and address any questions or concerns. The child may not always want to talk, and this should be respected. It is important to provide children with information that is appropriate to their age and encourage them to discuss information about the illness that they may have heard from outside the family environment.

Developmental environments outside the family

Like the home, a child's day nursery, school and hobbies are important developmental environments, and experiences within these environments will have an independent influence on the child's development. Illness-related difficulties at home will increase the importance of developmental environments outside the family and can act as important factors which hinder or enhance resilience in the child's life (Solantaus 2002).

In order to enhance children's wellbeing, Rauch *et al.* (2003) note that schools, day-care centres and hobby circles attended by the children should be kept informed about the medical situation regarding the parent with cancer. It would also be beneficial to have a contact person for the child at school to help monitor and understand the ways in which the child reacts to his or her parent's illness, for example. Social connections outside the family can help children to direct their thoughts to things other than their parent's illness. It also gives them the opportunity to share feelings with their peers and obtain support from them (Rauch & Muriel 2006).

2.4 Psychosocial interventions for adult cancer patients and their adult family members

2.4.1 Individual interventions for adult patients

Individual adult-targeted interventions are designed to enhance a patient's ability to cope with cancer and to alleviate illness-related consequences. The interventions are implemented by designated health care professionals, e.g. nurses

(Cruickshank *et al.* 2008) and involve treatments such as cognitive behavioural and problem-solving therapy (Akechi *et al.* 2008). The purpose of such interventions is to alleviate cancer patients' psychological burden and enhance their coping skills.

The outcomes of these interventions compare favourably with those reported for medications (Carr *et al.* 2002, Rodin *et al.* 2007a, Rodin *et al.* 2007b, Williams & Dale 2006). Evidence suggests that individual support, such as psychotherapy, can be very useful for treating depressive states in patients with advanced cancer (Akechi *et al.* 2008). This was identified by Cruickshank *et al.* (2008) in their review, where they discussed ten randomized, controlled trials (RCT) with 780 participants that included individual support interventions.

2.4.2 Interventions for cancer patients and their adult family members

Interventions for adult family members, i.e. partners, have been summarised in various reviews (Akechi *et al.* 2008, Barsevick *et al.* 2002, Carr *et al.* 2002, Cruickshank *et al.* 2008, Osborn 2007, Pitkethly *et al.* 2008, Rodin *et al.* 2007b, Williams & Dale 2006), which together cover a total of 126 studies. These studies analyse the impact of the interventions in terms of alleviating the consequences of the cancer patient's depression and/or anxiety for family members.

According to a recent review, interventions for cancer patients and their adult family members can be categorized into three main types (Northouse *et al.* 2010). The first category includes psycho-educational interventions, designed to provide education and information for the patient and family members such as the spouse. The second group consists of training in certain skills with the purpose of enhancing coping, communication and problem-solving in patients and family members. The third category covers therapeutic counselling, which focuses on enhancing relationships and addressing worries concerning cancer or the provision of care. A meta-analysis has revealed that these interventions significantly alleviated the burden on care providers, increased their ability to cope and improved their self-efficacy and quality of life (Northouse *et al.* 2010).

2.5 Child-centred, non-structured practices for families with parental cancer

Child and family-centred interventions for families with young children represent a small proportion of the psychosocial interventions available for adult cancer patients and their families. They are carried out with families and children and their prime objective is to enhance the children's psychosocial wellbeing.

Johnson (1997) was the first to publish an article summarising the various ways of providing psychosocial support for the children of cancer patients and interventions for siblings of children suffering from cancer. Diareme *et al.* (2007) summarised the practices and interventions used for providing mental health support for the children of parents suffering from chronic somatic illnesses such as cancer. They identified ten interventions which were specifically aimed at supporting children of cancer patients. The review concluded that there were very few interventions focused on children affected by parental cancer, and that those that did exist tended to be targeted at school-aged children.

Since the work of Johnson (1997) various pioneering groups such as Rauch and Muriel with their Parenting at a Challenging Time programme have begun to provide support for children and parents (e.g. Muriel *et al.* 2005, Muriel & Rauch 2003). The following sections summarise the current state of child-centred practices as described in the literature.

2.5.1 European child-centred practices

Child and family-centred practices for this purpose have been scarce in Europe in the past. There was, however, a European Union-funded project called Children of Somatically Ill Parents (COSIP) in 2002 which included eight research centres in different European countries. Besides research, this project instigated the development of practices and interventions for the children of somatically ill parents (e.g. Romer *et al.* 2007, Schmitt *et al.* 2007, Thastum *et al.* 2006).

As part of this project a web-based support service for children was developed in the Netherlands, as evaluated qualitatively and quantitatively by Giesbers *et al.* (2010). Their report included data on three months of web discussions (n=158) with children (n=129) aged over 13, in which the children had the opportunity to express their emotions and share their experiences. Without the COSIP project child-centred interventions would have remained very rare in Europe.

2.5.2 Child-centred practices outside Europe

One of the longest-established and largest clinical interventions has been carried out at the Massachusetts General Hospital in the USA. The Marjorie E. Korff Parenting at a Challenging Time (PACT) programme was initiated during the mid-1990's by Dr Rauch, a child psychiatrist, who started to provide support for parents and children within families affected by cancer (<http://www.mghpact.org/who.history.php>).

The PACT programme includes parent and child consultations conducted by a PACT team consisting of professionals in child psychiatry (Muriel *et al.* 2004, Muriel *et al.* 2005). The team has also trained professionals in cancer care units in providing support for parents concerning the care and wellbeing of their children. The professionals are taught how to encourage parents to enter into open discussions about their children. They stress the importance of maximizing support systems to keep everyday life stable, providing safe, non-parental adult support for the children, keeping the immediate family updated on the situation regarding the illness and providing emotional support for the parents. They also highlight the importance of good communication, particularly in discussing difficult questions and issues about death with the parents. The basic principle is to provide effective support for the parents so that they can support their children (Moore & Rauch 2006, Muriel *et al.* 2004, Muriel & Rauch 2003, Rauch *et al.* 2007, Rauch *et al.* 2002, Swick & Rauch 2006). It is noted in descriptions of the PACT programme that 124 families participated in the guidance programme during a one-year period (Muriel *et al.* 2005, Rauch *et al.* 2003) and that 106 families were referred to the programme for consultations over another 9-month period (Muriel *et al.* 2005).

In another part of the PACT project, a pilot programme entitled "When a Parent Has Cancer: Strengthening the School's Response" (Fasciano *et al.* 2007) was focused on school staff, with the aim of increasing their ability to respond to the challenges posed by children dealing with parental cancer. The content of the programme was based on literature regarding children's coping with parental illness.

For the report on this programme, 244 participants (school personnel) completed questionnaires assessing their own knowledge and anxieties about helping families before and after the programme. The results revealed that the

participants were significantly more knowledgeable and confident about helping families with parental cancer once they had completed the programme.

The key principle in the “Interactive Family Learning” working mode as described by Friesen *et al.* (2002) is that patients should help other family members to understand their experiences concerning their illness and to identify helpful methods of support. The practice is based on the literature related to the consequences that cancer may have for other family members and for the functioning of families. Semi-structured interviews were conducted with eight families, involving a total of 30 participants. The interviews pointed to a process of gathering, interpreting and sharing information and experiences related to the illness among the families concerned.

Dale and Altschuler (1999) described the experiences of families where a parent has “a life-risking or very serious illness”. They reported clinical experiences from consultations conducted with parents suffering from various physical illnesses, most frequently cancer, and with families covering family matters, spousal relationships, parenting and children.

The Decision Support programme (Peshkin *et al.* 2010) was developed for situations where a mother was struggling to tell her children about inheritable breast cancer. The programme provides educational materials and advice for mothers to support them in discussing an inheritable illness with their children. The programme was reported to be based on the previously developed Ottawa Decision Support Framework (O'Connor *et al.* 2002), which had included a study based on standardized interviews with 17 mothers. These interviews provided information about the communication process, highlighting the need for open, honest information. The findings were used to develop and improve the programme.

Moon (2007) identified a need for home care nurses to support the adolescent children of cancer patients, describing how they can help such children and providing a number of recommendations for the professionals involved based on the literature and her previous experiences in clinical practice.

Turner *et al.* (2008) described the development of a self-directed educational manual designed to help professionals in the field of oncology to understand better the emotional impact of parental advanced cancer. It included information about children’s reactions, ways of helping children and of enhancing families’ coping mechanisms. The manual is based on the scientific literature concerning parental cancer and its consequences for the children. It provides information about the emotional aspects of parental illness, communication with the patients,

parenting, age-specific information with respect to the children, interventions to support this target group, how to act in cases of parental death and the resilience of the children.

A year later Turner *et al.* (2009) published an article reporting a day-long communication skills training workshop based on the same manual as was described in their earlier publication. This workshop method was targeted at oncology nurses, to enhance their capacity to provide support for advanced cancer patients who have young children. The workshops included role-playing for training in communication skills. The nurses noted improvements in their communication skills, the training of certain specific skills and a decrease in blocking behaviour.

A brief report entitled “Art, play-therapy programs help children whose parents are dying of cancer” also describes ways to provide help for children with a parent who is dying (Johnston 1993). A therapist describes how to help children in different age groups with their worries and questions concerning their parent’s death.

Walsh-Burke (1992) reported on a programme called “We Can Weekend”. This American Cancer Society initiative is still going on and provides weekend meetings for families with a parent suffering from cancer. Its aim is to enhance communication and coping within these families. No background theory is described. The study was conducted with 14 families participating in one such weekend meeting, and the results revealed that the families who communicated more often and used a wider variety of coping strategies experienced fewer difficulties in coping with cancer.

The Kid’s Connection support groups (Bourne & Tingwald 1990) were targeted at children aged 5–15 years. The groups met after school and provided information about cancer and its treatment and on the possible impacts on the family. No background theory or research was described.

2.6 Summary of the literature reviewed here: what is known and what should be studied

A substantial number of cancer patients have young, dependent children at home. A recent US-based population study estimated that as many as 14–18% of all cancer patients had young children (Weaver *et al.* 2010). Research has shown that the children of cancer patients have an increased risk of developing various

psychosocial problems relative to children with healthy parents (Osborn 2007, Thastum *et al.* 2009, Visser *et al.* 2004, Huizinga *et al.* 2010). The majority of the findings have been based on clinical samples, and there is a lack of population-based studies. Population-based estimates are important as they increase knowledge about the exact numbers of children living in particular family environments. Estimates of the numbers of children affected by parental cancer in European countries are extremely rare, and no national population based studies exist.

Various studies have produced recommendations for the provision of additional psychosocial support for the children of cancer patients in adult health care settings (Grabiak *et al.* 2007, Osborn 2007, Visser *et al.* 2004), but these have not yet resulted in any consensus regarding appropriate clinical practices and interventions. The child-centred practices and interventions reported in literature are extremely heterogeneous in content, so that research into the various interventions available for the support of children of cancer patients has not yet produced any conclusive evidence on how feasible or effective any particular intervention may be when employed as a part of a systematic clinical practice. Reports concerning the long-term use of interventions in systematic clinical practice are also scarce. The interventions are frequently carried out only during a specific project and within limited time periods, and so that the use of such interventions has not continued once the project has ended.

One essential requirement for the development of successful systematic clinical practices for use with the children of cancer patients is scientifically valid research-based information. This information must include a comprehensive review of findings regarding the interventions aimed at helping children of cancer patients. Further assessment of the experiences of the health care professionals involved in implementing such interventions in their clinical work is also required, along with an evaluation of the perceived benefits for the patients and families targeted in the interventions.

3 Aims

The primary aim of this work was to produce new information that will serve as a basis for developing research-based child-centred clinical practices in adult health care.

The detailed goals of the work were:

1. To determine the prevalence of children affected by parental cancer at the national level and to assess whether these children use specialised psychiatric care more frequently than their peers. (I)
2. To review the scientific literature regarding the current state of structured interventions directly targeted at children with a parent suffering from cancer. (II)
3. To describe clinicians' experiences of using structured child and family-centred interventions to address the children's needs, and to assess their perceived benefits and limitations. (III)
4. To assess whether there are changes in the psychiatric symptom profiles of seriously somatically ill and healthy parents at the baseline before intervention and four months after the intervention. (IV)

4 Materials and methods

4.1 A population-based study of the prevalence of children affected by parental cancer and their use of specialised psychiatric services (I)

4.1.1 The 1987 Finnish Birth Cohort

Altogether 60,069 children, including all live births and stillbirths of infants weighing more than 500 grams or having a gestational age of 22 weeks or more born in Finland in 1987 were included in the 1987 Finnish Birth Cohort study (Paananen & Gissler 2011). Since 73 children (0.1%) were untraceable on account of either an incomplete, missing, incorrect or changed identification number, a total of 59,996 children were available for the present follow-up study, comprising 59,669 live births and 327 stillbirths. Only those surviving the perinatal period were actually included in the study (n=59 476), of whom 58,320 (98.1%) were alive and living in Finland at the end of the follow-up (31st December 2008).

4.1.2 Data on psychiatric hospital care

The Finnish Hospital Discharge Register (HDR) includes all in-patient care episodes at all hospitals and all outpatient visits to public hospitals since 1998 (Paananen & Gissler 2011). The quality of the register has been shown to be at least satisfactory for statistical and research purposes (Gissler & Haukka 2004, Keskimäki & Aro 1991). Data on hospitalizations were collected from the HDR and used to identify cohort members who had received specialised psychiatric care. For follow-up purposes the date and cause of each hospital visit were recorded for all cohort members who were treated as in-patients between January 1, 1987 and December 31, 2008 and all those treated as outpatients between January 1, 1998 and December 31, 2008, including dates of admission and discharge, main diagnoses and up to two secondary diagnoses. All diagnoses were reported using ICD-9 between 1987 and 1995, and ICD-10 from 1996 onwards. Information on cohort members' use of specialised psychiatric care services between January 1, 1987 and December 31, 2008 was also recorded. Data on psychiatric hospitalizations of the cohort members' parents was collected from the

HDR and linked to those for their children. All parents with data on specialised psychiatric in-patient care between January 1, 1987 and December 31, 2008 and outpatient care between January 1, 1998 and December 31, 2008, including admission and discharge dates, main diagnosis and up to two secondary diagnoses, were included in the study.

4.1.3 Data on parental cancer

Data on cohort members' parents treated for cancer were collected from the HDR and linked appropriately in order to identify the cohort members affected. For the follow-up, the dates and reasons for all hospital episodes were obtained for all cohort members' biological parents who were treated as in-patients in a hospital between January 1, 1987 and December 31, 2008, including dates of admission and discharge, main diagnosis and up to two secondary diagnoses. All parents with cancer as the main diagnosis for an episode of in-patient hospital treatments between January 1, 1987 and December 31, 2008 were included in the study.

4.1.4 Data on parental socioeconomic status and education

Data on the socioeconomic status (SES) of the cohort members' biological parents were collected from the Finnish Central Population Register on 10 June 2009. SES was determined according to their most recent occupations. Information on educational achievements was obtained from Statistics Finland. SES was classified into the categories of upper level employee, lower level employee, manual worker or 'other', and education into high school or higher, lowest level tertiary, lower secondary or primary. Parental SES and education were used to adjust the odds ratios for parental cancer and children's use of psychiatric services.

All the combining of register data was done using the individuals' unique personal identification numbers.

4.1.5 Statistical methods

Binary logistic regression analysis was used to define the associations between parental cancer or parental cancer and parental use of psychiatric care and children's use of psychiatric care. Parental SES and education were used as

confounding factors to adjust the odds ratios for parental cancer and children's use of psychiatric services. The data analysis was performed using commercially available software (PASW Statistics, version 18).

4.2 Systematic review of the studies on structured child-centred interventions for families with a parent suffering from cancer (II)

4.2.1 Literature search

The review includes papers reporting on structured child-centred interventions in cases of parental cancer that had initially been identified through PubMed, PsycINFO and MEDLINE using the keywords 'intervention', 'preventive', 'program', 'child', 'parental', 'illness', 'cancer' and 'neoplasm' in different combinations. No time limit was set for the review. The titles and abstracts of all the papers identified were examined thoroughly, and if the reviewer was uncertain as to whether a paper met the criteria it was requested in full. The electronic search was supplemented by checking review articles and the reference lists of all the papers obtained. Only those papers that reported results of interventions that provided psychosocial support for children with parental cancer and had in addition used a structured pattern of intervention were included in this review. This meant, for example, that papers reporting the results of child-focused non-structured practices aimed at children with parental cancer were excluded. In addition, papers not published in English and unpublished works (e.g. theses) were excluded. A total of 11 papers met the inclusion criteria.

4.2.2 Narrative analysis

In view of the heterogeneity of the study designs, no statistical synthesis was made, and instead a systematic narrative synthesis approach was adopted (Mays *et al.* 2005, Jones 2004). This approach attempts to formulate a synthesis from diverse accounts in a structured way.

The first phase included a systematic analysis of the papers found through the literature searches, extracting the following data from each one: the type(s) of intervention, characteristics of the paper itself (authors, year and country; title, background theory/research, parental illness, target groups, participants and manner of realization of the intervention), aims of the intervention, study design

(designation, number of participants) and findings (impact of the intervention on the children and parents, health professionals' experiences).

In the second phase the narrative analysis was performed based on the results of the systematic analysis. Following the principles of the narrative approach, the content revealed two main intervention categories: 'structured family interventions' and 'structured peer group interventions'. After identifying these two categories the outcomes (positive, negative or no improvement) were reported under the following three headings: the impact of the intervention on the children, the impact of the intervention on the parents and the health professionals' experiences of the intervention. Special attention was focused on the objectives and outcomes of the preventive interventions, i.e. whether their preventive effect was examined by means of long-term follow-up measurements or by evaluating their impact on the children using controlled assessments.

4.3 Experiences of mental health professionals using structured family-centred interventions to support the children of cancer patients (III)

4.3.1 Participants

There were two inclusion criteria for this study. Firstly, all participants must have been trained via the "Effective Child & Family Programme" (EC&F), which means that all the clinicians had gone through a year-long intervention training programme in accordance with the Finnish version of that programme (Solantaus *et al.* 2009). The training programme included instruction on all three EC&F interventions (Family Talk Intervention, Let's Talk about Children and EC&F network meetings). The training, requiring eleven working days, six days of theory and five days of supervision, included basic instruction on how to recognize the most common problems in the psychosocial wellbeing of children and adolescents having a parent with cancer. After the basic training programme the clinicians had a regular monthly supervision group meeting related to the use of all the interventions. Secondly, all the participants were required to have used the Family Talk Intervention (Beardslee & MacMillan 1993, Beardslee *et al.* 2003) with at least three families.

The participants were seven mental health professionals (2 men, 5 women) working in the general psychiatry ward of the Clinic of Psychiatry at Oulu

University Hospital, Finland. In terms of occupation they comprised four psychiatric nurses, one social worker and two mental health nurses. All of them had extensive experience of providing psycho-social support for cancer patients and their families, covering an average of 23 years since obtaining their professional degrees.

4.3.2 Narrative data collection and analysis

Data collection

All the interviews with the voluntary participants were conducted by the present author. The purpose was to solicit oral narratives of the clinicians' personal experiences of using the three intervention approaches, FTI (previously PFI), LT and EFN meetings). Two questions were prepared in advance: "Is there an intervention process that you have used as part of your work that comes to mind as being particularly meaningful to you?", and if the participant answered "yes", "Could you tell me more about it?" The audio-taped narrative interviews were carried out at times and places chosen by the interviewees. In all cases, the location chosen was the interviewee's workplace. The interviews lasted between 45 and 60 minutes, and all the recordings were transcribed verbatim for subsequent analysis, after which the interviewees were asked to, re-read their transcripts, and correct or edit them as necessary. A flowchart illustrating the overall procedure is presented in Figure 5.

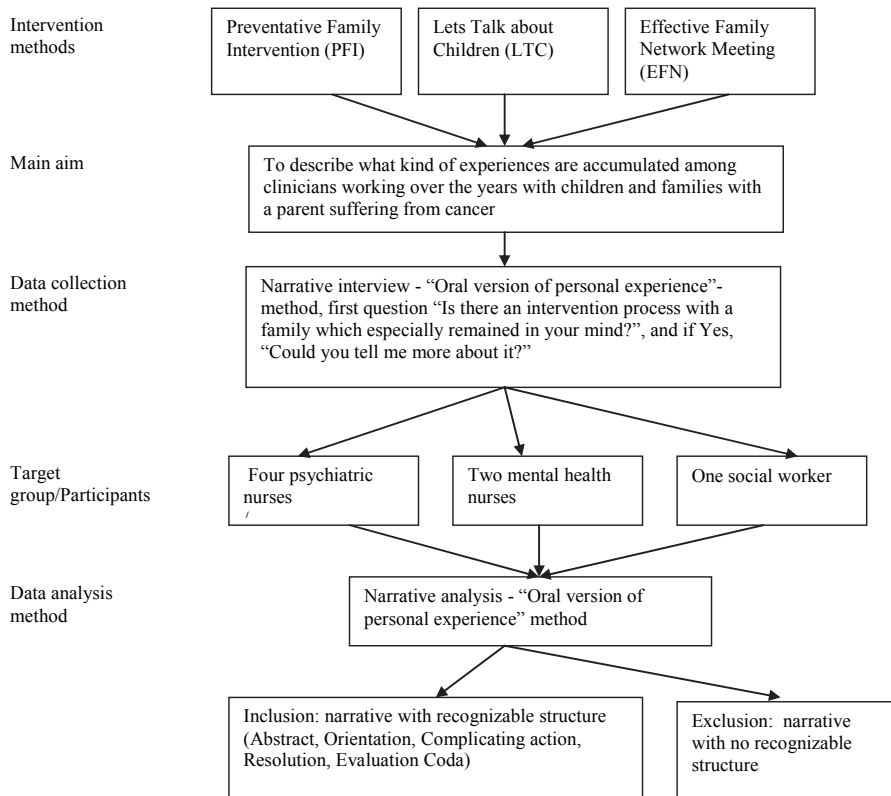


Fig. 5. (Figure 1 from original paper III) Flowchart of the study design.

Narrative analysis

The content of the interviews was subjected to narrative analysis according to the “oral versions of personal experience” method developed by Labov and Waletzky (1967, Labov 2006). The main goal of this narrative analysis is to create a recognizable structure comprising six parts: Abstract, Orientation, Complicating Action, Resolution, Evaluation and Coda. The Abstract recounts the core part of the experience. The Orientation describes the time, place and participants. The major part of the narrative, referred to as the Complicating Action, describes what really happened. The Resolution tells how the story ended. The Evaluation

explains why it was important to record this experience, and finally the Coda sums the case up and shifts the perspective back to the present time. In accordance with the principles of Labov and Waletzky (1967), if the Complicating Action part could not be identified, the whole experience was excluded from further processing. The various parts of the narrative analysis process are set out in Table 2 of paper III.

4.4 “Struggle for Life” trial - pilot phase (IV)

4.4.1 Description of the trial

The research project “Struggle for life: A preventive intervention trial in families with parental serious somatic illness” is a randomized, controlled treatment trial for children in families with a serious parental somatic illness. The objective of the trial is to produce new information on how to support parenthood and the psychosocial wellbeing of parents and children in such families. This information will be used in planning and implementing preventive and promotive child-centred work for adult health services. The project has been approved by the ethical committee of Oulu University Hospital.

It was considered important in the pilot phase of the trial to examine whether the interventions concerned are safe to use with cancer patients. This was carried out by examining the preliminary evidence of effectiveness with respect to the parents’ psychological wellbeing.

4.4.2 Participants

The inclusion criteria for the “Struggle for Life” trial are that the family should include a parent with a serious somatic illness (i.e. one which can be considered life-threatening) who has at least one child aged 8 to 17 years. For example, cancer can be considered such a serious somatic illness due to its intensity, duration, the possibility of death and the strong impact it has on the everyday life of the family. The families at Oulu University Hospital that met the inclusion criteria were randomized into two intervention groups.

The staff treating the sick parents provided verbal and written information about the study and informed the participants of the rights of all family members (the patients, their spouses and the children) to refuse to participate and/or to

withdraw at any point during the study. The parents were further instructed to inform the younger children of their rights to refuse and/or withdraw. Informed written consent based on the rules and regulations of Finnish legislation was obtained from both the parents and the children.

4.4.3 Interventions

The interventions used in the “Struggle for Life” trial are (1) the Let’s Talk about Children intervention (LT) (Solantaus *et al.* 2009, Solantaus *et al.* 2010) and (2) the Family Talk intervention (FTI, previously PFI: Preventive Family Intervention) (Beardslee & MacMillan 1993, Beardslee *et al.* 2003, Hoke 1997). Both interventions were originally developed to support families with parental mood disorder, but the FTI was later applied to families with parental cancer (Hoke 1997).

The LT intervention includes two psycho-educational sessions with parents only, in the first of which the protective factors for the children (at home, with friends and hobbies, at school/day care etc.) are charted, while the second is a counselling meeting focused on how parents can strengthen their children’s protective factors (Table 2).

Table 2. Structure and main content of the Let’s Talk about Children Intervention (e.g.Solantaus *et al.* 2009, Solantaus *et al.* 2010).

Sessions	Participants	Focus of the meetings
1.	Parents	Getting to know the family situation, charting the children’s protective factors
2.	Parents	Discussion on how parents can strengthen their children’s protective factors

The FTI includes six to eight sessions with different combinations of family members. The intervention begins with two sessions involving the parents, for the clinicians to gain an understanding of the parents’ illness experiences and explore their thoughts and questions about their children’s possible worries in this respect. The third session is an individual session with each child, covering the questions raised by the parents, mapping out the child’s protective factors and discussing his or her questions and worries. In the subsequent planning session the parents and clinician plan how to discuss with the children the topics that are important for that particular family, after which a family meeting is held to explore the planned

topics. Finally there is a follow-up session with the parents that includes a review of the intervention and plans for the future (Table 3).

Table 3. Structure and main content of the Family Talk Intervention (e.g. Beardslee & MacMillan 1993, Beardslee *et al.* 2003).

Sessions	Participants	Focus of the meetings
1.	Parents	Information about the intervention, illness history,
2.	Parents	Education, charting children's situation and protective factors
3.	Children individually	Children's thoughts, possible questions and concerns
4.	Parents	Planning the family meeting, what information to share
5.	Whole family	Open discussion, answering of children's questions
6.	Parents (sometimes also children)	Review of the family meeting and intervention, planning the future
7.-8.	Parents (sometimes also children)	Promotion of the process in the family

4.4.4 Instruments

Data on the “Struggle for Life” trial were gathered using several questionnaires and structured research instruments. The demographic questionnaire covered information on the parents’ socio-demographic background (age, marital status, education, work), the composition of the family (intact or of some other type, age and gender of the children living in the family), parents’ own and family history of somatic and mental illnesses and measures relating to the birth of the children (children’s weight, height and APGAR scores at birth, obstetric and birth complications, adverse life events during pregnancy). The children’s risk and protective factors were screened via a questionnaire developed especially for the present purpose and based on the previous literature dealing with this issue (Beardslee & Podorefsky 1988, Gass *et al.* 2007). This elicited information regarding the children’s growth and development before school, factors related to their schooling, friends, hobbies, home activities, relationships between siblings and the family’s and the child’s knowledge about the sick parent’s illness. Information on the psychological wellbeing of the family members was measured using several standardised age-appropriate instruments: Children’s Depression

Inventory for children aged 8–12 years (CDI) (Kovacs 1992), Symptom Checklist 90 for adults and children aged 13 years or more (SCL-90) (Derogatis et al. 1973), Strengths and Difficulties Questionnaire (SDQ) (Goodman 1997), Parent Adolescent Communication Scale (PACS) (Barnes & Olson 1985), Sense of Coherence (SOC) (Antonovsky 1983) and Illness Attitudes Scale (IAS) (Kellner 1987). The intervention feedback questionnaire (Solantaus *et al.* 2009) measures satisfaction with the intervention after its completion.

Table 4. Instruments used in the Struggle for Life study.

Measurement point	Parents	Children	Professionals
1. Before intervention	SCL90, PACS, SDQ, RiSu, SOC, IAS	CDI/SCL-90, PACS, SDQ, RiSu, SOC, IAS	-
2. 4 months after intervention	SCL90, PACS, SDQ, RiSu, SOC, IAS, Feedback questionnaire	CDI/SCL-90, PACS, SDQ, RiSu, SOC, IAS, Feedback questionnaire	Logbook questionnaire FTI
3. 10 months after intervention	SCL90, PACS, SDQ, RiSu, SOC, IAS	CDI/SCL-90, PACS, SDQ, RiSu, SOC, IAS	-
4. 18 months after intervention	SCL90, PACS, SDQ, RiSu, SOC, IAS	CDI/SCL-90, PACS, SDQ, RiSu, SOC, IAS	-

CDI = Children's Depression Inventory for children aged 8–12 years (Kovacs 1992)

IAS= Illness Attitudes Scale (Kellner *et al.* 1987)

PACS = Parent-Adolescent Communication Scale (Olson 1985)

RiSU= Risk and protective factors questionnaire

SCL-90=Symptom Checklist 90 for adults and children aged 13 years or more (Derogatis, Lipman & Covi 1973)

SDQ = Strengths and Difficulties Questionnaire (Goodman 1997)

SOC= Sense of Coherence (Antonovsky 1983)

4.4.5 Pilot phase

The interventions used in this project were applied to a population with severe somatic conditions. According to the previous literature, the study design should be prepared with caution when some participants may have a terminal illness (Grande & Todd 2000). Thus the impacts and perceived benefits of the interventions needed to be considered and elucidated early in the project. This was done by means of a pilot phase.

Participants

The pilot evaluation of the data examining the impact of the interventions on parents' psychological wellbeing was performed at the end of 2010. By that time a total of 19 families had participated in the baseline assessment at Oulu University Hospital and 10 families were engaged in the four-month follow-up assessment. The characteristics of the participants are presented in Figure 1 of paper IV. Nine families failed to return the four-month follow-up questionnaires, including 7 patients (6 mothers, 1 father) and 7 spouses (1 mother, 6 fathers). Two mothers died before the four-month follow-up assessment.

Instruments

A psychiatric self-report inventory, the Symptoms Checklist 90 for adults (SCL-90) (Derogatis *et al.* 1973), was used to assess the psychiatric symptom profile of the sick and healthy parents at baseline and at four months. SCL-90 is used in general to measure the psychological symptom patterns of people in populations of various types, such as non-patients and medical and psychiatric patients (Holi 2003.). The SCL-90 does not measure personality, but has been used as a psychiatric screening instrument, as a measure of symptom severity and as a descriptive measure of psychopathology (Ayalon & Young 2009, Kapidzic-Durakovic *et al.* 2006, Lynn *et al.* 2003, Olivett 2008, Sander & Jux 2006).

The SCL-90 questionnaire includes 90 items (Derogatis *et al.* 1973), each rated on a five-point scale ranging from 0 (none) to 4 (extreme), and takes about 12 to 20 minutes to complete. As in our study, the standard time window is "7 days including today", but evaluation over other time periods is also possible. The SCL-90 measures symptom intensity on nine dimensions: Somatization, Obsessive-Compulsivity, Interpersonal sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, and Psychoticism). The summary score on each dimension is the mean score of all items included in that dimension. The summary mean score of all 90 items is called the Global Severity Index (GSI) and is used to indicate the current level of psychopathology.

The reliability of the SCL-90 has been shown to be good (Schmitz *et al.* 2000), and its use as a psychiatric screening instrument has been validated in a Finnish population (Holi 2003, Holi *et al.* 1998). The internal consistency of the instrument in particular seems to be high, but the validity findings are

controversial (Aben *et al.* 2002, Holi *et al.* 1998, Martinez *et al.* 2005, Munoz *et al.* 2005, Olsen *et al.* 2004, Schmitz *et al.* 2000) .

4.4.6 Statistical methods

Appropriate statistical methods were used to test statistical significances. The statistical significance of the intervention impacts on parents' psychological wellbeing was assessed with Pearson's Chi-square test or Fisher's Exact test in the case of categorical variables and with Student's t-test or the Mann-Whitney U-test for continuous variables. All the statistical tests were two-sided and the limit for statistical significance was set at 0.05. The statistical software used in all the analyses was PASW, version 18, and SAS for Windows, version 9.2.

4.5 Ethical considerations

This doctoral thesis includes four original studies, each having its own samples or participants, so that most of them needed separate approval on ethical grounds.

Approval for the work in paper I was obtained from the Ethical committee of the National Institute for Health and Welfare (§28/2009).

Paper II was a systematic review of the scientific literature and thus did not require approval from any ethical board.

The data for paper III were not collected from individual patients, but were based entirely on clinicians' experiences, so that no approval from an ethical committee was needed. Before its commencement, however, the research was approved by the Management Group of the Department of Psychiatry, Oulu University Hospital, within the Northern Ostrobothnia Hospital District.

Paper IV was based on the Struggle for Life trial, which was approved by the Ethical Committee of Oulu University Hospital on April 16th 2007. The staff treating the cancer patients provided participants with verbal and written information about the research and informed them of the rights of all family members (patients, spouses and children) to refuse to participate and/or to withdraw at any point. The parents were further instructed to inform their younger children of their rights to refuse and/or withdraw. Informed written consent based on the rules and regulations of Finnish legislation was obtained from both the parents and the children.

4.6 Personal involvement

The author of this thesis has made a major contribution to all the original papers and is named as the first author and corresponding author in each of them. He was also involved in the study design and data collection, performed the statistical analyses and interpreted the results in consultation with his co-authors. He wrote the first draft of each manuscript and was responsible for the final version of each paper as submitted.

5 Results

5.1 The prevalence of children affected by parental cancer and their use of specialised psychiatric services: the 1987 Finnish Birth Cohort study (I)

Paper I was based on information from the Finnish Hospital Discharge Register (HDR) over a 21-year period from 1987 to 2008. The aims were to investigate the prevalence of children affected by parental cancer and to determine whether these children had made greater use of specialised psychiatric services than their peers.

5.1.1 Prevalence of children affected

Based on information from the HDR, 3,909 out of the 59,476 children from the 1987 Finnish Birth Cohort (6.6%) had a parent suffering from cancer during the 21-year period from 1987 to 2008 (Table 1, original article I), 2.7% having a father with cancer and 4.0% a mother.

Of all parents with cancer, there were 408 mothers (17.1%) and 245 fathers (15.1%) who had received both cancer treatment and specialised psychiatric care during the same period. 4.5% of the cohort members were under the age of 18 at the time of diagnosis their parent's cancer.

5.1.2 Children's use of psychiatric services

Overall, 361 (15.2%) of the cohort members whose mother had suffered from cancer and 274 (16.9%) whose father had done so were treated in specialised psychiatric care. The likelihood for resorting to specialised psychiatric services was significantly increased in the female cohort members regardless of whether it was their mother (1.20, 1.04 to 1.40, $P=0.015$) or their father (1.25, 1.05 to 1.49, $P=0.014$) who had cancer (paper I, table 4) compared with the rest of the cohort. Similarly, there was an increase in outpatient psychiatric care in the female cohort members (mother with cancer: 1.20, 1.03 to 1.40, $P=0.011$, father with cancer 1.25, 1.04 to 1.50, $P=0.015$; paper I, table 2). Among the male cohort members an increased likelihood of in-patient psychiatric care was found (1.39, 1.06 to 1.82, $P=0.018$), but only when it was the father who had cancer (paper I, table 3).

5.1.3 Parents with cancer and psychiatric disorder in relation to children's use of psychiatric services

Among the female cohort members, the occurrence of a psychiatric disorder in the father in combination with cancer was associated with increases in the children's use of outpatient services (1.58, 1.05 to 2.39, $P=0.029$; paper I, table 2) and all psychiatric services (1.53, 1.02 to 2.29, $P<0.001$; paper I, table 4). No significant association between a parental psychiatric disorder in combination with cancer and the use of specialised psychiatric services of any type was observed in the male cohort members.

5.1.4 A parent's cancer and the spouse's psychiatric disorder in relation to children's use of psychiatric services

An increased likelihood of the use of outpatient (2.58, 1.62 to 4.12, $P<0.001$; paper I, table 2), in-patient (3.62, 2.14 to 6.12, $P<0.001$; paper I, table 3) and all specialised psychiatric services (3.21, 2.10 to 4.92, $P<0.001$; paper I, table 3) was observed among the male cohort members if the father was treated for cancer and the mother for a psychiatric disorder. Conversely, when the mother suffered from cancer and the father was treated for a psychiatric disorder an increase was found in the use of in-patient psychiatric services (2.00, 1.12 to 3.58, $P=0.019$; table 3) and all specialised psychiatric services (1.66, 1.06 to 2.60, $P=0.027$; paper I, table 3) in male cohort members relative to the rest of the male cohort and in the use of outpatient (2.62, 1.79 to 3.84, $P<0.001$; paper I, table 3) and all specialised psychiatric services (2.63, 1.80 to 3.84, $P<0.001$; paper I, table 3) among the female cohort members. Meanwhile, cancer in the father and psychiatric care for the mother increased the likelihood of the use of outpatient services (2.08, 1.35 to 2.84, $P<0.001$; paper I, table 3) and of all specialised psychiatric services (1.88, 1.30 to 2.72, $P<0.001$; paper I, table 3) among the female cohort members.

5.1.5 Parental cancer and children's age in relation to use of psychiatric services

The age of a child at the time of diagnosis of cancer in a parent was associated with increased use of psychiatric services, in that cancer in the father occurring while the child was under school age (less than 7 years old) led to elevated in-

patient care for males (2.31, 1.32 to 4.05, $P=0.003$; paper I, table 3) and outpatient care for females (1.76, 1.17 to 2.66, $P=0.006$; paper I, table 3), whereas the only effect if this occurred at school age (7 to 12 years old) was that the girls showed increased use of specialised psychiatric outpatient care (1.49, 1.03 to 2.15, $P=0.033$; paper I, table 3). Additionally, male cohort members' If, on the other hand, the father's cancer occurred during the child's early adulthood (13 to 17 years old) the boys showed a significantly increased use of psychiatric in-patient services (1.57, 1.01 to 2.44, $P=0.045$; paper I, table 3). Likewise, a girl's use of outpatient psychiatric care was found to be significantly increased if her mother's cancer had occurred during her own adolescence (1.33, 1.01 to 1.75, $P=0.046$, paper I, table 3) or early adulthood (1.34, 1.04 to 1.72, $P=0.023$; paper I, table 3).

5.2 Review of structured child-centred interventions for families having a parent with cancer (II)

The second original paper appended to this thesis provides a systematic review of publications regarding structured interventions targeted at children with a parent suffering from cancer. Eleven such papers met the search criteria, six of which had adopted a family approach and five a peer group approach (Figure 6).

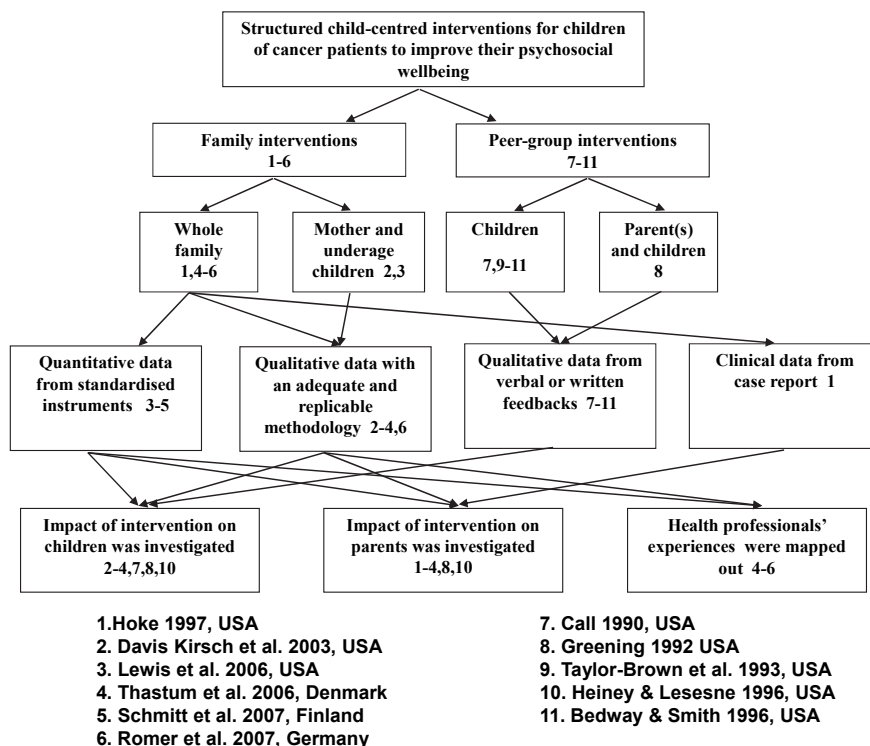


Fig. 6. (Figure 1 from original paper II) A narrative flowchart of 11 structured child-centred intervention studies for families with a parent with cancer.

5.2.1 Structured family interventions

Six structured family interventions were identified by means of the literature searches (paper II, table 1), the background theory or approach being described in five instances as follows: 1. A broad research approach from the field of parental mental health disorder (Hoke 1997), 2. The contextual model of parenthood, coping theory and cognitive theory (Davis Kirsch *et al.* 2003, Lewis *et al.* 2006), 3. Theoretical moves from the individual to the family approach and a move from the patient perspective to the parents' perspective (Schmitt *et al.* 2007), and 4. Developmental psychotraumatology, attachment theory, psychoanalytic family therapy and current developmental views on how children cope with critical events (Romer *et al.* 2007). One paper contained no description of the background

theory (Thastum *et al.* 2006). Two interventions focused on breast cancer (Davis Kirsch *et al.* 2003, Lewis *et al.* 2006) and the others on any parental cancer (Hoke 1997, Romer *et al.* 2007, Schmitt *et al.* 2007, Thastum *et al.* 2006). The target group was most commonly the whole family, and the participants were family members in different combinations (Hoke 1997, Romer *et al.* 2007, Schmitt *et al.* 2007, Thastum *et al.* 2006). In two papers the target group was the mother and child, although only the mothers participated in the intervention (Davis Kirsch *et al.* 2003, Lewis *et al.* 2006). The German COSIP intervention involved 2–3 sessions (Romer *et al.* 2007), while all the others included at least five sessions.

All the family intervention studies were aimed at facilitating communication between the family members, while additional aims included preventing future difficulties (Hoke 1997) and assessing the need for additional help among the children (Schmitt *et al.* 2007). The work carried out within the COSIP project focused on alleviating the challenges caused by parental illness, promoting active coping skills, using surrounding resources, improving children's understanding, promoting hope and reducing guilt, and facilitating the process of loss and grief (Romer *et al.* 2007, Schmitt *et al.* 2007, Thastum *et al.* 2006). Further aims were to enhance self-perceived parenting and the parent's emotional availability for the child, together with flexible handling of the divergent needs of individual family members and the prevention of dysfunctional parentification (Romer *et al.* 2007).

Three types of study design were found. A quantitative design was used in three interventions, involving various types of questionnaire (Lewis *et al.* 2006, Schmitt *et al.* 2007, Thastum *et al.* 2006). Two of the interventions included counselled and non-counselled groups as well as a group of professionals (Schmitt *et al.* 2007, Thastum *et al.* 2006), while one focused on parents' and children's reports (Lewis *et al.* 2006). The qualitative study design involved collecting data from the mothers and fathers (Davis Kirsch *et al.* 2003) or from staff members (Romer *et al.* 2007). Two studies adopted both a quantitative and a qualitative approach (Lewis *et al.* 2006, Thastum *et al.* 2006), while one paper took the form of a case report of a family in which both parents suffered from cancer (Hoke 1997).

5.2.2 Structured peer group interventions

As seen in table 2 of paper II, the literature searches identified five structured peer group intervention studies (Bedway & Smith 1996, Call 1990, Heiney & Lesesne 1996, Taylor-Brown *et al.* 1993). In two of these the background theory was

based on surveys of the literature or of previous programmes focused on the children of cancer patients (Bedway & Smith 1996, Greening 1992), while three made no mention of the research or theory that lay behind the intervention(s) (Call 1990, Heiney & Lesesne 1996, Taylor-Brown *et al.* 1993).

All the peer group interventions reviewed here were directed at families with a parent suffering from cancer (Call 1990, Greening 1992, Taylor-Brown *et al.* 1993), and one also at families with a parent / grandparent with cancer (Heiney & Lesesne 1996). In all of these interventions the target group and participants were children aged between five and 18 years. Only one intervention offered parents the opportunity to participate in parallel sessions (Greening 1992).

Two types of group structure were found in these peer group interventions. The first was a fixed group for the same participants, with the number of sessions varying from 5 to 10 (Call 1990, Heiney & Lesesne 1996, Taylor-Brown *et al.* 1993), and the second consisted of workshops with a changing combination of participants (Bedway & Smith 1996, Greening 1992).

The overall aim of the interventions was to support the children (Bedway & Smith 1996, Call 1990, Greening 1992, Heiney & Lesesne 1996, Taylor-Brown *et al.* 1993) or the parents (Greening 1992), the more specific aims being to give the children the possibility to share their feelings regarding their parent's illness (Bedway & Smith 1996, Call 1990, Greening 1992, Heiney & Lesesne 1996, Taylor-Brown *et al.* 1993, Greening 1992), to enhance understanding and knowledge of the psychosocial aspects of parental cancer, to increase the children's repertoire of coping strategies (Greening 1992, Heiney & Lesesne 1996, Taylor-Brown *et al.* 1993), to improve communication within the family and to reduce isolation (Heiney & Lesesne 1996).

The findings were mainly based on data from feedback interviews or questionnaires (Bedway & Smith 1996, Call 1990, Greening 1992, Heiney & Lesesne 1996, Taylor-Brown *et al.* 1993). The feedback interviews were targeted at children and at the parents whose children were participating in a group (Bedway & Smith 1996, Call 1990, Greening 1992, Taylor-Brown *et al.* 1993), and at counsellors (Call 1990, Greening 1992, Heiney & Lesesne 1996). One study also included an advertisement experiment aimed at discovering how people accessed information about the groups and how many subsequently participated in them (Heiney & Lesesne 1996).

5.2.3 The impact of interventions on children's psychosocial wellbeing

Impact of the structured family interventions

Only two papers made use of quantitative data (structured instruments) when assessing the impacts of the interventions on the children's psychosocial wellbeing (Lewis *et al.* 2006, Thastum *et al.* 2006), and both reported positive changes in children's cancer-related worries and a significant decrease in their depression scores. No significant improvements or changes, however, were shown in children's illness-related pressure, grief or anxiety (Lewis *et al.* 2006) or in adolescents' anxiety and self-concepts (Thastum *et al.* 2006). Parents reported several positive impacts of interventions on their children, the main benefits of the intervention for the children being seen to lie in improvements in their behavioural-emotional functioning and a decrease in anxiety and depression scores (Lewis *et al.* 2006).

Both quantitative family intervention studies focused on the current situation regarding children with a parent suffering from cancer. The follow-up time varied from 10 weeks (Lewis *et al.* 2006) to one year (Thastum *et al.* 2006), and a control group without any counselling was used in one instance (Thastum *et al.* 2006), although no follow-up assessment was conducted for the control group. The lack of any follow-up, nevertheless meant that the actual protective effect of the intervention on the children could not be evaluated in either of these cases.

Three studies had been conducted using qualitative data with a replicable methodology (Davis Kirsch *et al.* 2003, Lewis *et al.* 2006, Thastum *et al.* 2006). The children reported having had important, positive experiences as a result of the intervention(s) and they mentioned being more aware of other family members' reactions and emotions (Thastum *et al.* 2006). Some children felt that the family meetings were boring due to the discussion being adult-centred and the counsellor taking the parents' side in the meetings. Some children wanted more individual time with counsellors (Thastum *et al.* 2006). The fathers' impressions were that the children and mothers managed better with the illness as a result of intervention, but they acknowledged that parental cancer seemed to be hard for the children (Davis Kirsch *et al.* 2003).

Impact of the structured peer group interventions

The feedback in the form of children's verbal or written evaluations proved to be extremely positive, i.e. children were well satisfied with the content of the interventions (Call 1990). The favourite part of the intervention for the children was the tour of the unit where their parent was being treated, and they stated that all their questions were answered (Heiney & Lesesne 1996). In one case the children found the intervention to be a positive way of sharing their feelings with other children with similar experiences (Call 1990). There were two studies in which the impact of the intervention on the children was not documented (Greening 1992, Taylor-Brown *et al.* 1993).

Parents reported numerous positive impacts of peer group interventions on their children (Bedway & Smith 1996, Call 1990, Greening 1992, Heiney & Lesesne 1996), noting that they benefited from the programme since they were better informed about their parent's illness. As in the children's reports, the parents noted that their children enjoyed the intervention, especially the tour of the unit where their parent was being treated (Heiney & Lesesne 1996). In general, the parents acknowledged the benefits of and need for a support system for their children, such as a peer group intervention (Greening 1992). As a result of the interventions both the parents and the counsellors and teachers considered the children to be less angry and less worried, their concentration and grades improved, they shared their feelings more openly and they were calmer (Call 1990).

None of the peer group interventions assessed the effect on the children by means of a follow-up or controlled measurements with structured instruments. The feedback evaluations focused on the content of the intervention and on perceived aspects of the children's own wellbeing. This meant that the protective effect of the peer group interventions on the children could not be examined.

5.2.4 Impact of the interventions on parents' psychosocial wellbeing

Impact of the structured family interventions

The impact of the intervention on the parents' psychosocial wellbeing was examined in two quantitative studies using structured instruments (Lewis *et al.* 2006, Thastum *et al.* 2006), both of which reported positive changes in the

mothers' level of depression, state of anxiety and self-efficacy (Lewis *et al.* 2006, Thastum *et al.* 2006), but no significant improvement was reported in the fathers' depressive symptoms (Thastum *et al.* 2006). A positive association between depression scores and affective responsiveness to the success of the intervention was observed among the mothers, while among the fathers a positive correlation was found between affective responsiveness and satisfaction with participation in the intervention (Thastum *et al.* 2006). No improvement in the bond between mother and child was reported (Lewis *et al.* 2006).

In one case the mothers' and fathers' quantitative data were combined (Thastum *et al.* 2006), whereupon a number of positive findings were reported: improvements in the parents' depression levels, family functioning, communication within the families and affective responsiveness, a positive association between a lower level of depression and affective responsiveness in the families who were satisfied with the intervention, more understanding/awareness of other family members, more closeness/cohesion in the family, normalization and a sense of the legitimacy of one's own feelings.

In the qualitative study by Davis Kirsch *et al.* (2003) the mothers reported an improvement in coping with their own emotions and in interaction with their children, and also in their own self-care and understanding of their children's behaviour. The mothers also noted that they had started to think about the situation and spent more time communicating with their children and doing things together with them. Some mothers, however, felt that the intervention was harsh in the context of a hectic family life and that they did not have the time to commit themselves fully to the intervention. The fathers observed that the mothers and children spent more time together and interacted more with each other as a consequence of the intervention. In addition, the parents found that the intervention provided beneficial support for their parenthood (Thastum *et al.* 2006). Some parents wanted more meetings during and after the intervention, while others felt that the timing was not right relative to the phase of the illness.

One case report focused on the impact of the intervention on the parents (Hoke 1997). The findings, based on clinical data, were that the intervention helped the parents to understand their own responses to the illness and helped them to recognize their children's concerns, thus facilitating improved understanding of their experiences.

Impact of the structured peer group interventions

None of the peer group intervention studies reported the effects of the intervention on the parents. In one case the parents stated that they were worried about their children and would do whatever was necessary for them, but it was noted that the groups were not helpful for the parents themselves (Greening 1992). The parents also reported that the booklets and handouts were helpful in explaining the children's ability to understand and cope with parents' illnesses (Heiney & Lesesne 1996).

5.2.5 Health professionals' experiences of the interventions

Experiences of the structured family interventions

In the report by Thastum *et al.* (2006) the counsellors observed that there was a lack of discussion of emotional attitudes towards the illness within the families and that family members were afraid of showing their emotions because they wanted to protect the children. They interpreted the lack of discussion as causing uncertainty about how the children really felt about the illness and how to deal with their reactions. Additional topics noted by the counsellors were conflicts in the family, a certain emotional distance between family members, marital problems or other problems in personal relationships before the onset of the illness. Counsellors described their role as being to facilitate coping strategies and to focus attention on the needs of family members and the relationship between the parents and their children. Some counsellors noted that they had not succeeded in stressing the needs of the children, as the parents did not change their behaviour during the intervention. The counsellors also found that more help was needed in some cases, while in others the goals of the counselling remained unclear to counsellors themselves.

The experiences of the oncology clinic staff were evaluated in one paper (Schmitt *et al.* 2007). The staff reported having obtained a clearer picture of the family situations of their patients, and they had also learned to seek advice or consultation in the case of psychologically challenging or problematic situations. Their ability to provide psychosocial support for the patients was also reported to have been strengthened.

The results of the German COSIP study (Romer *et al.* 2007) were based on qualitative data extracted from standardised monitoring forms filled in by COSIP team members. The physicians indicated that they required more practical evidence of the value of a new mental health intervention. Some found the intervention ineffective, while others found that it disturbed patients' families "by churning up existential fears". Professionals also noted that families approved of the intervention more if the referral was made by a physician associated with the patient's cancer treatment. The timing of the intervention was also considered crucial: it should not come too soon after the parent's initial diagnosis, for example, or coincide with a period of intensive somatic treatment. Furthermore, previous family conflicts must be taken into account and the intervention should be implemented as a standard procedure.

Experiences of the structured peer group interventions

The effect of a peer group intervention was evaluated by health professionals in only one study (Heiney & Lesesne 1996). The criticisms from staff were that the intervention should have been less structured and educational and that more time was required for the group process.

5.3 Clinicians' experiences of using structured family-centred interventions to support children of cancer patients (III)

The eleven narratives completed by the seven clinicians fell into four thematic categories which had emerged through the data analyses: "Inter-team collaboration", "Focus on the children", "Death" and "Perceived impact of interventions" (Table 5).

5.3.1 Inter-team collaboration

The clinicians highlighted the need for inter-team collaboration and co-operation with other professionals from different health services by describing four narratives:

In the first narrative the importance of working in pairs was revealed when a clinician encountered a family who had experienced family relationship problems prior to the onset of the illness (FTI).

The second narrative (FTI) emphasized inter-team collaboration. Clinicians not originally working in the same team had nevertheless gone through similar intervention training programmes, so that although their clinical experience had been gained among different groups of patients, their co-operation led to successful and fruitful work with the family. Furthermore, they changed the environment for the intervention from a hospital to an outpatient setting, thus encouraging a new point of view regarding the clinician's way of considering the life of the family.

In the third and fourth narratives health problems and worries about the psychological well-being of the family members were emphasized. The clinicians changed their intervention from FTI to EFN and in this way achieve additional help for the family with regards to problems related to the illness. The opportunity to use services available in other fields of health care was found to be essential in helping these family members, given their divergent needs, even though the original intervention as such was not continued.

5.3.2 Focus on the children

The category "Focus on the Children" covered outcomes of three types. First, the clinician's attitude towards his/her working practices altered upon recognising that the children's needs must also be addressed in cases of parental cancer.

Secondly, children in different age ranges express their needs and worries in differing ways. Individual meetings seemed to be especially necessary for children aged ten years or more, enabling the clinician to delve into their thoughts about their sick parent's cancer or the family's overall situation.

Thirdly, feedback in the form of the clinicians' evaluation of the factors which protect children helped the parents to cope better in the challenging situation of cancer in the family. The clinicians described how the parents had explicitly told them during the FTI that their worries about their children's psychosocial wellbeing had changed that they were encouraged regarding their children's future in view of the protective factors that had been put into place. The knowledge that the children would be able to cope in their own lives reduced the parents' emotional burden.

5.3.3 Death

The key issue in two narratives was the sudden death of a parent. Firstly, the clinicians described how, after receiving a referral from the oncology department for an FTI intervention, an appointment was made for the parent with cancer to be seen the following day. The sick parent died that night, however. Even so, the clinicians still met with the widow and together they decided to carry out the LT intervention in order to see how the children were coping.

Secondly, the clinicians described a case where a father died during the FTI intervention. The mother was exhausted and concerned about how she would manage with the children. This led the clinicians to arrange an additional EFN meeting to provide support for the children. In accordance with the mother's wishes, they invited the father's relatives to the meeting in order to talk about the children's needs. While the mother reported that she did not require any professional help, the relatives who attended the EFN meeting were pleased to come and planned to share the child care responsibilities in order to help the mother. The clinicians felt that they really could help and make a difference by supporting the children and the mother in this difficult situation.

5.3.4 Perceived impact of interventions

Two narratives highlighted the theme of changes in the functioning of the family as one outcome of the intervention. In one case the clinician noted that the intervention usually resulted in positive changes in family functioning. In fact, positive results were seen immediately during the FTI intervention, e.g. in that the parents received guidance on dealing with their children's needs and concerns and identified new ways of sharing responsibilities in everyday life. However, one clinician questioned whether the FTI intervention could produce any permanent positive changes, especially with adolescents who were reluctant to participate in it.

Table 5. (Table 2 from original paper III) Results of the narrative analysis performed by the “Oral versions of personal experience” method (Labov & Waletzky, 1967).

Narrative /Structural Component/ Function	Abstract/ Nuclear content of the experience	Orientation/ Time, place and participants	Complicating action/ What really happened	Resolution/How it ended	Evaluation/Why it was important to recount this experience	Coda/ Final words, shifting the perspective back to the present time
Inter-team collaboration						
Narrative 1: It is better to work as a team with another clinician	'You can never know what will come up when you start to work with families'	Time was not specified, oncology unit, family members	'We started to talk about cancer, but the conversation turned to family relationship problems prior to the onset of the parent's illness' (PFI)	'We focused on the cancer, because the family members were reluctant to talk about prior problems'	'Problems prior to the cancer will often arise. ... Working with another clinician gives a higher potential for dealing with these problems.'	'It was an experiment for me to work alone. Two clinicians is a better way of working with a family.'
Narrative 2: Discontinued intervention	'The most important experience was discontinued intervention'	Time and place not specified, family members, staff from adult and child psychiatric services	'Health problems affecting the parents and children arose in the intervention sessions (PFI). Additional meetings with professionals in adult and child psychiatric services' (EFN)	'The intervention did not continue, because it was more beneficial to go on working with professionals in adult and child psychiatry'	'It is possible to help children and families together with surrounding collaborative services.'	'The final family meeting of the intervention has not yet been held even today.'
Narrative 3: Co-operation with child psychiatry services	'Worries arose during the intervention about the psychological wellbeing of the child'	Time was not specified, child psychiatry unit, one nurse from the child psychiatry unit	'The parents expressed their worries about the child (PFI). To relieve these worries an EFN meeting was prepared and held'	'The nurse from the child psychiatry unit arranged additional help for the child.'	'It is important to have a professional from the child psychiatry services to evaluate the need for additional help.'	None

Narrative /Structural Component/ Function	Abstract/ Nuclear content of the experience	Orientation/ Time, place and participants	Complicating action/ What really happened	Resolution/How it ended	Evaluation/Why it was important to recount this experience	Coda/ Final words, shifting the perspective back to the present time
Narrative 4: Working together with a professional from primary health care	'Working together with a clinician who was experienced in carrying out interventions in a primary health care setting, but not with cancer patients'	Summer, patient's home, family members, a clinician from a primary health care setting	'Intervention was asked for a cancer patient being treated as an outpatient in a primary health care setting, making home visits together with the intervention.' (PFI)	'A textbook PFI intervention was conducted'	'It is important to make home visits to see the reality of family life. Working together with another PFI-trained clinician, although not otherwise acquainted, was a positive experience'	None
Focus on the children						
Narrative 5: Helping children	'You cannot treat just the adults if you know there are underage children in the family.'	Spring, hospital, family members	'I met the child of this family in the PFI child session and became worried about her situation.'	Together with the parents we contacted the child psychiatry unit' (EFN)	'It is important to map out the needs of patients' children.'	None
Narrative 6: Children over ten years of age may keep their thoughts secret.	'Children over ten years of age often have unspoken worries'	Time and place not specified, father and son	'In the individual PFI meeting with the son he said that everything was fine, but then he expressed a worry about his father's drinking. We talked about the boy's worries in the family meeting, which was quite a relief for everyone'	'The conversations also covered other issues relating to family matters.'	'It is essential to have individual meetings with children in this age group, otherwise significant thoughts that they have may remain hidden.'	None

Narrative /Structural Component/ Function	Abstract/ Nuclear content of the experience	Orientation/ Time, place and participants	Complicating action/ What really happened	Resolution/How it ended	Evaluation/Why it was important to recount this experience	Coda/ Final words, shifting the perspective back to the present time
Narrative 7: Information on children's protective factors can benefit the parents	'The feedback from clinicians can help parents to calm down about their children's situation.'	Time and place not specified, family members	'We had PFI conversations with the parents about the children's protective factors.'	'The parents described how their attitudes and worries regarding their children's psychosocial well-being had changed.'	'Knowledge about the children's protective factors is important if you are worried about the children. It is hard to plan the family's future.'	None
Death Narrative 8: The patient's death	'We could not start the intervention, because the patient died.'	Time not specified, oncology unit, family members	'The staff of the oncology unit asked for a PFI intervention. We made a reservation for the next day, but before the first session we were informed that the parent had died.'	'LC intervention with the widow was accomplished'	'Death is more common in interventions with parents with cancer than in interventions with depressed parents, for example. You have no control over death.'	'One way or another... the theme of death is present almost every time in interventions with cancer patients'
Narrative 9: A parent's sudden death and worry on the part of the children	'The father died in the middle of the intervention and we had to make a plan for coping with the children'	Spring, family members, relatives	'The father died before the PFI family meeting. The mother was exhausted, and we planned an EFN meeting with the mother and called relatives in to help the mother to take care of the children'	'The relatives shared the responsibilities for the children's everyday living.'	'Despite a parent's death the children can be supported. Death is a common theme in interventions with cancer patients.'	'I feel that in this way I can really help the children'

Narrative /Structural Component/ Function	Abstract/ Nuclear content of the experience	Orientation/ Time, place and participants	Complicating action/ What really happened	Resolution/How it ended	Evaluation/Why it was important to recount this experience	Coda/ Final words, shifting the perspective back to the present time
Perceived impact of interventions						
Narrative 10: Permanency of change	'Can intervention produce permanent positive changes?'	Time and place not specified, family members	'The children were reluctant to participate in the intervention. There were PFI family meetings where no one talked.'	The children's situation remained unclear.	'What would be a beneficial way to work with reluctant children?'	None
Narrative 11: Clear positive change	'The positive change within the family during the intervention was clear.'	Time and place not specified, family members	'The meetings with family members easily followed the exact structure of a PFI meeting.'	The parents found similar guidelines for their parenthood'	'It is very common for there to be positive changes within the families as a result of intervention.'	None

5.4 Changes in parents' psychiatric symptoms between the baseline assessment before the intervention and the situation 4 months after the intervention (IV)

Changes in the parents' psychiatric symptoms between the baseline assessments before the intervention and the follow-up measurements made 4 months after the intervention were measured. A total of 10 out of the 19 families had completed the four-month follow-up. The other nine families were not yet at the four-month measurement point when this aspect of the work was studied.

5.4.1 Changes in parents' profile of psychiatric symptoms during the intervention

As seen in Figure 7, a statistically significant decrease in GSI was found between the baseline and the four-month follow-up assessment among both the patients (mean change -0.35, $t=2.64$, $P=0.039$) and their spouses (-0.19, $t=2.73$, $P=0.029$). Among the dimensions of the SCL-90 (paper IV, table 1), significant decreases were also observed in Anxiety and Hostility among the patients and in Obsessive-Compulsivity, Interpersonal Sensitivity and Paranoid Ideation among the spouses.

5.4.2 Comparison of the results with Finnish community and psychiatric patient samples

The psychiatric symptom profiles of the parents who had completed both the baseline and the 4-month follow-up assessments were compared (data not shown) with that of a Finnish general population (FGP) and a Finnish psychiatric outpatient (FPO) sample (Holi *et al.* 1998).

At the baseline, the patients had significantly higher scores on the GSI, Somatisation, Obsessive-Compulsivity and Depression than the FGP, but did not differ from the FPO, while the spouses had significantly lower mean scores on Somatisation, Obsessive-Compulsivity and Psychoticism than the FGP and in GSI and lower scores than the FPO on all dimensions. No significant differences in GSI or any of the dimensions were observed between the patients and the FGP at the four-month follow-up, while the patients had significantly lower scores than the FPO on the GSI, Interpersonal Sensitivity, Anxiety, Hostility, Paranoid Ideation and Psychoticism. The spouses' scores on the GSI and all the dimensions

except for Depression were significantly lower than those of either the FGP or the FPO (paper IV, table 1).

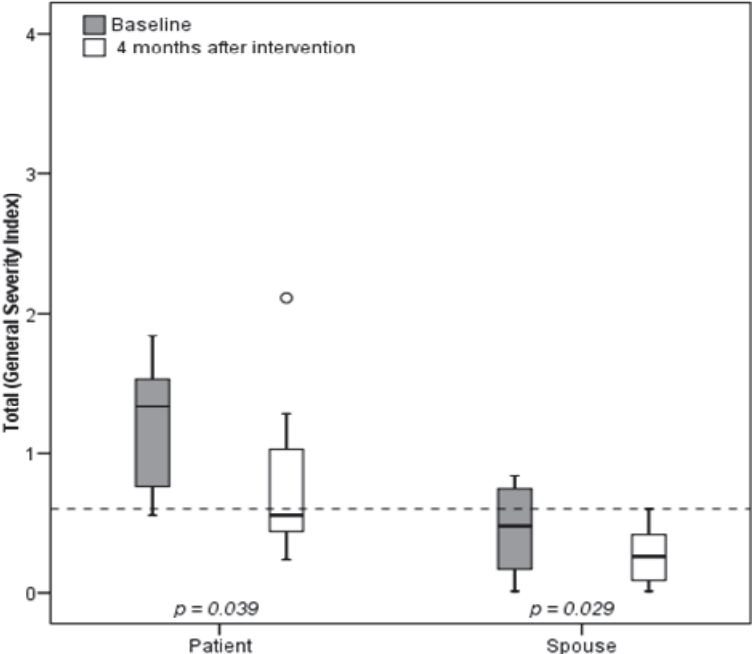


Fig. 7. (Figure 2 from original paper IV) Changes in the psychiatric symptom profile of parents between the baseline assessment before the intervention and that performed four months after the intervention.

6 Discussion

6.1 Significance of the main findings for child-centred practice

The primary focus of this thesis was to produce new information that would serve as a basis for developing child-centred clinical practice in an adult health care context. This was achieved by conducting altogether four original studies which approached the issue from various viewpoints. This thesis thus includes 1) a population-based estimates of the prevalence of children affected by parental cancer and of their use of health care services, 2) a review of the current research literature on this topic, 3) a mapping of clinicians' experiences of child-centred family interventions as gained from clinical practice, and 4) an evaluation of the influence of child-centred family interventions on the psychiatric symptoms of somatically ill parents and their spouses. The significance of these studies for research-based child-centred clinical practice will be discussed in detail in the following sections.

6.1.1 Prevalence of children having a parent with cancer

It was found in paper I that every 15th child (6.6%, 3909/59476) in the 1987 Finnish Birth Cohort had a mother or father who was being treated for cancer during the years 1987 to 2008, i.e. when the child was aged 0 to 21 years. At the population level, this means that a considerable number of children each year will have to face parental cancer, a situation that could last until they reach early adulthood. This estimate, which is the first to be published in Finland, is an extremely important contribution towards developing a child-centred setting in adult health care, as it allows us to evaluate the resources needed for child-centred work among cancer patients in the adult health care services. The children studied here had 2 372 mothers and 1 623 fathers diagnosed with cancer during the follow-up period, so that it can be estimated that each year there will be approximately another 4000 patients who together with their spouses will be facing cancer while still bringing up young children. The follow-up time in this register study was 21 years, so that we are talking about 84 000 patients and almost as many spouses or partners to be provided with support in coping with their children. It is important to remember, however, that cancer is only one of many serious parental illnesses, and the prevalence of children having parents

with other somatic illnesses should also be taken into account. These figures clearly indicate that steps should be taken to increase child-centred practices in the treatment of cancer in Finland.

The finding arrived at in the first paper belonging to this thesis confirms previous results based on survey data which have established that the children affected by parental cancer make up a substantial part of population. The United States National Health Interview Survey (NHIS), for example, when assessing the prevalence and characteristics of cancer survivors (n=13,385) living with young children in the years 2000 to 2007, both in the total sample and among survivors diagnosed within the last 2 years (Weaver *et al.* 2010), reported that 14% of all cancer survivors in the USA have underage children at home. Likewise, the Hamburg Health Survey (part of the COSIP project) (Barkmann *et al.* 2007), when analysing the prevalence of parental physical illnesses, of which cancer was the most common, found a total of 1950 families that had a parent with a physical illness and included children aged 4–18 years. Thus 4.1% of the children were living with a parent suffering from a physical illness.

6.1.2 Children's risk of using specialised psychiatric services

It was considered to be essential to evaluate children's risks of having to make use of specialised psychiatric services in order to justify the need for extra support for child-centred practices. There are various previous studies which have recommended extra support for the children of cancer patients (e.g. Visser *et al.* 2004, Schmitt *et al.* 2007), but none has examined the real use of such services by children at the national level.

The results presented in the first paper show that the children of cancer patients had made elevated use of psychiatric services up to the age of 21 years. Altogether 361 of the cohort members, whose mother suffered from cancer (15.2%) and 274, whose father did so (16.9%), were treated in specialised psychiatric care. Parental cancer especially increased the use of outpatient psychiatric services by girls and in-patient services by boys. The increased use of psychiatric services was associated especially with the child's gender and age and the presence of a psychiatric disorder in one or other of the parents.

One novel finding was that the occurrence of cancer in a girl's father when she was of pre-school or school age was liable to increase her use of psychiatric outpatient services. This marks an important step in investigations in this field, as

the psychological symptoms of small children have previously been reported to have remained unclear (Osborn 2007). Although the first paper did not include any analyses of the children's psychological symptoms, since the register-based data do not include such information, the findings justify the conclusion, also observed in many other studies, that parental cancer is a serious risk factor for psychosocial problems in children (Visser *et al.* 2004, Osborn 2007, Thastum *et al.* 2009, Huizinga *et al.* 2010).

Osborn (2007) has stated previously, based on the results of her review that children affected by parental cancer are not at risk for psychiatric disorders but only for psychological symptoms. The children's increased use of specialised psychiatric services may nevertheless indicate that children's psychosocial problems attributable to parental cancer could be more serious than has previously been thought, or has previously been claimed in the scientific literature. The Finnish health care registers cover all hospital treatment episodes and the majority of specialised outpatient treatment provided in Finland. Since less severe psychological symptoms are treated in primary health care settings, information on which is not included in the national registers, the use of health care services is probably somewhat under-estimated in paper I. In summary, the conclusion that extra support should be provided for the children of cancer patients is warranted.

6.1.3 Structured interventions described in previous research

An up-to-date review of published research on structured child-centred interventions (paper II) was considered to be essential for summarising the existing research-based information for the purposes of the "Struggle for Life" trial and subsequent clinical practice. The logical, and perhaps easiest, way to build up evidence-based clinical practice is to test and develop an intervention which has turned out to be appropriate in certain circumstances.

As reported in paper II, the number of publications dealing with structured child-centred interventions was surprisingly small. Only eleven that were focused on helping the children of cancer patients were found in the literature searches, and only six of these described structured child-centred interventions that had adopted a family approach (Davis Kirsch *et al.* 2003, Hoke 1997, Lewis *et al.* 2006, Romer *et al.* 2007, Schmitt *et al.* 2007, Thastum *et al.* 2006), while the remaining five used a peer group approach (Call 1990, Greening 1992, Taylor-Brown *et al.* 1993, Heiney & Lesesne 1996, Bedway & Smith 1996). By comparison, Meyer and Mark (1995) reviewed 45 randomized controlled studies

describing 62 interventions among cancer patients that enhanced adults' psychosocial wellbeing.

Three more intervention studies were located or published after the completion of paper II: one on the German rehabilitation programme for breast cancer patients and their children "Gemeinsam gesund werden" (John *et al.* 2010) and two on the Norwegian "Family Support Programme" (Bugge *et al.* 2008, Bugge *et al.* 2009). However, neither these nor those included in paper II provided enough advice on how to build up a clinical practice for assisting the children of cancer parents. The German project reported research-based evidence of the benefits of the intervention, but as it was carried out outside a hospital setting, it was not directly relevant to the provision of support for children in such a setting, although it could be useful for cancer associations, for example.

Some studies were excluded from paper II because interventions and practices used in them lacked any recognizable structure. The Parenting at a Challenging Time (PACT) programme described by Rauch and Muriel, for example, has remained valid in systematic clinical practice over the years. The researchers highlighted the importance of taking the children's needs into account by giving recommendations as to what can and should be done in clinical practice (Muriel *et al.* 2005, Muriel & Rauch 2003, Rauch *et al.* 2007, Rauch *et al.* 2002). On the other hand, this knowledge has been important in planning the educational content of the FTI and LT interventions as used in the Struggle for Life trial. PACT is based on consultations with a child psychiatrist, however, and thus it does not meet the needs of an adult health care setting.

6.1.4 Clinicians' long-term experiences

According to the previous literature there are only a few systematic practices which have remained in everyday clinical use for years (Muriel *et al.* 2005, Muriel & Rauch 2003, Rauch *et al.* 2002, Rauch *et al.* 2007). It is evident that the experiences gained in long-term child-centred clinical practice with structured interventions are fundamental from the viewpoint of health care professionals when developing research-based child-centred practices for an adult health care setting.

Systematic child-centred work with families having somatically ill parents has been used in routine clinical practice at Oulu University Hospital since 2003, and for paper III the clinicians were asked to describe their long-term experiences

related to the use of structured child and family-centred interventions in their work among severely ill patients with children.

The viewpoints of these clinicians are highly important, as they have a unique body of practical experience of the kind required under the new Finnish health care legislation to be a part of the whole health care system. The key messages from the clinicians' experiences for child-centred practice are:

Firstly, they stressed that if you have worked with children as a part of the treatment provided for somatically ill adult patients it is no longer sufficient to work only with adults.

Secondly, child-centred work cannot be done alone within adult health care. Effective support for a family and a child with divergent needs requires flexible inter-team collaboration and networking with surrounding children's services. It is clear that there has to be a collaboration agreement between the services intended for adults and for children. To avoid excessively exhausting work, it is essential that staff should be given additional backing if the child needs more intensive psychological support than the intervention can provide, for example. It is essential to be able to move easily from universal services (for all families) to specific ones (for fewer families who need more) whenever needed.

Thirdly, if we acknowledge and address the needs of the children of cancer patients, the parents will also benefit and will be empowered in their parenting role. This finding was confirmed in paper IV, which showed that parents' psychological symptoms decreased after the interventions. It is an enormous relief for a parent struggling with a serious illness to hear that the children in the family are managing in their lives, or even to be able to initiate a discussion on the illness with the children.

Fourthly, although dramatic improvements have been made in the medical treatment of cancer, it is often a life-threatening illness in many peoples' minds. This is a one of the key themes to be discussed in the interventions. Death can be a worrying topic for a child, especially when combined with the reality of a poor prognosis for the parent's illness. When a parent is dying, the clinicians must change their ways of working with the family or modify the content of the intervention. In some instances they have had to continue the intervention with the surviving parent alone, or else they have had to change to another kind of intervention that is more suitable for the new situation. A similar result was found by Rotheram-Borus *et al.* (2006), who reported that flexibility in the choice of intervention produced successful results among HIV-positive patients and their families.

6.1.5 Parents' psychological wellbeing

It is evident that the use of an intervention in clinical practice must be safe for the participants. Thus, it is essential that before final implementation of the intervention its benefits must be assessed by research-based methods. If the intervention as a whole or any part of it appears to cause a negative effect in participants, the clinicians must be ready to change the content or course of the intervention.

Paper IV examines the impact of the LT (Solantaus *et al.* 2010) and FTI (Beardslee 2003) interventions on the psychological wellbeing of parents with cancer and their spouses. Firstly, the previous findings that a cancer diagnosis is associated with psychiatric symptoms in the patient were confirmed (Chen *et al.* 2009; Lloyd-Williams *et al.* 2004, Zabora *et al.* 2001). In fact the patients' psychiatric symptoms before the intervention were at the same level as in Finnish psychiatric outpatients in general and significantly higher than in the Finnish general population community sample (Holi 2003, Holi *et al.* 1998). A positive effect of the interventions was seen after four months, when the patients' psychiatric symptoms were shown to have decreased to the same level as in the general population.

The findings of paper IV clearly demonstrated that providing structured support for parenthood and for the children is one way of enhancing the psychological wellbeing of a patient who is also a parent. The family's children are a parent's immediate concern upon becoming aware of his/her own cancer diagnosis (Muriel & Rauch 2003, Rauch *et al.* 2002), and it is thus an enormous relief to realize that the children are coping well with their everyday life or that they can get support or professional help when needed.

6.2 Implications for interventions in clinical practice

It is possible to pinpoint some implications of the present study for interventions as used in clinical practice. These implications are based on observations made in papers II–IV (Figure 8).

6.2.1 Background theory of the interventions

Determination of the main idea of the intervention is one of the core questions when adopting this approach towards providing support for the children of cancer patients. As seen in the previous literature (see paper II, table 1), the primary ideas among the interventions available are quite heterogeneous.

Increasingly highlighted as the objectives of interventions are prevention and promotion: the prevention of maladjustment and the promotion of adjustment in the children, given the change in their life situation. Professor Frances Marcus Lewis pointed out, for example, that “Ultimately, we should be in the business of prevention: identifying and preventing maladjustment while enhancing the child’s healing and thriving” (Lewis 2007).

Dealing with prevention and promotion requires a background theory which includes promotion of the factors which help the children and the whole family to carry on despite the burden of parental illness. In order to provide this kind of support, a coping theory (Davis Kirsch *et al.* 2003, Lewis *et al.* 2006) and the concept of resilience (e.g. Rutter 1981, 2006) could be valuable.

Active coping and resilience supported by the social environment can be recommended as the primary goals of child-centred interventions, as in the Norwegian intervention described above (Bugge *et al.* 2008, Bugge *et al.* 2009), which is clearly based on a coping theory for children (Allison *et al.* 2003, Libo & Griffith 1996).

Highlighting the need for prevention and promotion does not mean that children who are already in need of treatment, e.g. psychotherapy, should be forgotten. Quite the opposite; a universal preventive and promotive way of working lays emphasis on those children who need more intensive support. Conversely, if the main idea of the intervention is only to alleviate internalizing or externalizing symptoms in the children or family members, the preventive and promotional goals are liable to be missed.

6.2.2 Focus of the interventions

Su & Ryan-Wenger (2007) point out that a knowledge of the process by which a parent’s cancer and the children’s psychosocial outcomes are associated provides an opportunity to focus the interventions on mediators and moderators. They note in their theoretical model that mediators such as family and child coping, the parent-child relationship and a child’s appraisal of parental cancer should be the

main focus of the interventions (Su & Ryan-Wenger 2007). It is easy to agree with this, and the present work did not provide any additional information on these matters. Furthermore, these authors defined parental illness and a social support network as being moderators of a “stable nature”. The present work in combination with papers III and IV provides new viewpoints on these remarks.

At first the nature of a parental illness has much to do with the parent’s psychological wellbeing (see, for example, Luutonen *et al.* 2011). A parent who is suffering from cancer and has young children will experience more psychological symptoms (Nilsson *et al.* 2009). As seen in paper IV, parents’ psychological symptoms decreased after child-centred interventions, in which case the psychological situation of a parent with cancer must be considered as an integral part of the illness and should be one of targets of the intervention.

Secondly, paper III provided an example of how to use the surrounding social environment to support the child upon the death of the parent with cancer (Narrative 9: A parent’s sudden death and worry on the part of the children). This example shows that the social environment might be more flexible than has been proposed by Su and Ryan-Wenger (2007), and that it can and should be one of the targets of an intervention.

In conclusion, more research is needed to identify which factors are essential in mediating and moderating the impact of parental cancer on the children, and it would be beneficial to focus interventions on recognized mediators which have been identified in the proposed theoretical model (Su & Ryan-Wenger 2007). As our understanding of this phenomenon progresses, however, it will be important to recognise a wider range of intervening factors which could also be influenced.

6.2.3 Structure of the interventions

Rauch and Muriel (2003) have recommended that cancer care professionals should prepare the parents to face their children. Some of the structured family approach interventions (e.g. Davis Kirsch *et al.* 2003, Lewis *et al.* 2006) had same idea of preparing parents to talk with their children. This principle is also included in both the LT and FTI interventions as used for cancer patients with children in the “Struggle for Life” trial (papers III and IV). In the preparatory sessions the clinicians and parents plan together what information on the parent’s illness and its consequences for everyday family life it is essential to provide for the children and how to respond to the questions and needs of boys and girls of various ages.

Parental cancer with its related dramatic changes in family life usually appears on the scene rapidly, so that the time available for the children to find the appropriate words to ask about the situation and for the parents to reply is short. The preparatory meeting after the onset of the illness will also help the parents to appreciate the situation from the other family members' point of view. It is therefore essential to provide a situation in which the parents can calmly sit down to think together with health care professionals about what influence the serious illness will have on the future lives of the patient, spouse and children.

Paper II includes two types of structured family approach intervention: 1. less intensive structured interventions, with a small number of sessions, only for the parents (Davis Kirsch *et al.* 2003, Lewis *et al.* 2006), and 2. more intensive structured interventions, with sessions for all the family members. Apart from the German COSIP intervention, which comprised 2–3 sessions (Romer *et al.* 2007), all the other structured family approach interventions have included at least five sessions. The LT (sessions with parents) (Solantaus *et al.* 2010) and FTI (sessions for the whole family) (Beardslee 2003) interventions are in line with these previously described types.

According to papers II and III, it can be suggested that research-based clinical practice should include at least the above two kinds of intervention: 1. a less intensive structured intervention intended to provide systematic information for the parents (or other adults who are close to the children) on how parental cancer may affect the children and prepare them for supporting the children, and 2. a more intensive structured intervention which is targeted at families who need or want more support, in initiating discussions about the children's needs and questions. If these two kinds of intervention are not enough, as the clinicians cited in paper III pointed out, it will be essential to find support from other surrounding services. In this way it should be possible to gather together services which are capable of promoting the children's wellbeing, anticipating their possible current or subsequent problems and providing more intensive help or treatment if and when it is needed.

A structured intervention gives allows professionals to provide homogeneous services for all cancer patients and their children. Its structure may serve as a guideline for professionals engaged in child-centred work who have previously treated mainly adult patients. A clear structure also provides an opportunity for family members to anticipate what is going to happen next. This is important because the illness and the whole family situation can make the future insecure and hard to predict.

6.2.4 Target group

The target group for a structured intervention (paper II) can vary greatly. Some primary and less intensive interventions are intended to provide support only for parents, while other, usually more intensive ones give support to all family members.

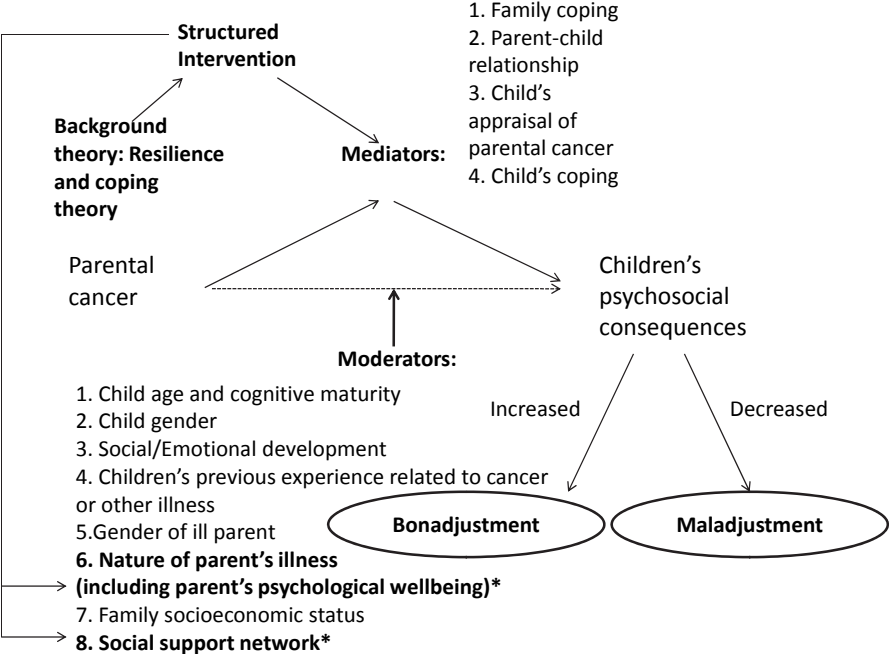
Some of the family approach interventions were targeted only at mothers (Davis Kirsch *et al.* 2003, Lewis *et al.* 2006), although they were quite similar to the LT intervention, which is targeted at both parents. The child-centred interventions which entail a family approach were most commonly targeted at the whole family, and the participants were family members in various combinations (Hoke 1997, Romer *et al.* 2007, Schmitt *et al.* 2007, Thastum *et al.* 2006).

The intervention can provide help for one family at a time (Hoke 1997, Romer *et al.* 2007, Schmitt *et al.* 2007, Thastum *et al.* 2006) or for several families simultaneously (Davis Kirsch *et al.* 2003, Lewis *et al.* 2006). Family approach interventions such as LT and FTI (papers III and IV) are targeted at one family at the time, which makes them easier to apply as a part clinical practice in our health care system, as this is based on an individual and family-centred working tradition. If groups for children from several families at the same time were to be arranged in hospitals this would require changes in organization and resources. On the other hand, working with one family at a time may mean missing the possibility to receive peer support from other families who are in the same situation. One possibility would be for cancer associations to provide support for families, using peer groups for both the children and their parents. In this way families could benefit from both. As shown in paper II, there has been a strong tradition of structured peer group interventions in the USA, particularly groups arranged by cancer associations.

6.2.5 Achievable impacts of the interventions in children

One primarily achievable impact of an intervention is promotion of the children's psychosocial wellbeing, which could result in positive coping, or as Hoke (1996) put it, "bonadjustment", in the children. The impact could be seen as positive or at least "normal" development in the fields of emotional/mood, somatic, academic and social/interpersonal wellbeing (Hoke 1996). Another impact could take the form of prevention: a decrease in the children's risk of developing current or

subsequent psychosocial symptoms and a diminished need for treatment in the health care services. It is evident, however, that the achievable impacts form a topic that demands further research.



* More flexible than previously proposed

Fig. 8. Implications of the interventions for clinical practice.

6.3 Implications for the development of infrastructure for child-centred work

The Finnish national plan which defines the main principles and priorities for the future of mental health and substance abuse work (Moring *et al.* 2011) highlights the development of preventive and promotive services, and the National Institute for Health's Effective Child & Family (EC&F) project (Solantaus *et al.* 2009, Solantaus *et al.* 2010) was similarly set up to develop and implement preventive and promotional child-focused practices (Moring *et al.* 2011). In recent years this EC&F work has provided some experience of the implementation of such practices, and this will also be useful when planning systematic child-centred

interventions in an adult health care setting. The Effective Child & Family implementation procedure includes four levels.

6.3.1 Implementation

Strategy

The first level is a written strategy which states the background to this particular child-centred practice in an adult health care setting, gives guidelines that should be followed and defines actions that are independent of individual willingness to take account of children in everyday work. The strategy should ensure universal promotive and preventive services for all families with parental cancer whether there is anxiety concerning the children or not.

The law is the strongest possible guideline to ensure that concrete actions are taken in a society. Finland, Sweden and Norway all have legislation which demands that the children's wellbeing should be taken into account when a parent is being treated in health care. In Finland, for example, the recent Healthcare Act as well as the Child Welfare Act, in force since 2007, requires that when an adult is being provided with social and health-care services and is as a consequence no longer able to give full attention to his or her child's care and upbringing is deemed to have deteriorated, the need for care and support must be evaluated and safeguarded (<http://www.finlex.fi/en/>, 14.3.2007/417, 10 y). The law alone is not enough, however, unless we have models for providing systematic support for families with a parent who is seriously ill.

Organisation

At the organisational level there is a need for a structure which is integrated into the strategy or legislation in order to fulfil its requirements. In addition, this organisational structure should also act in favour of child-centred systematic practices embedded into everyday clinical routines.

The main task is to create a chain of responsibility from the health care professional who asks whether the patient has children and wants to talk about them to the head of the organisation who ensures that the intended work has been done.

Professional skills

It is important for health care professionals have the appropriate skills to provide preventive and promotive support for the children and families of cancer patients. A training programme in structured child-centred interventions will serve this purpose well. The structured interventions described here (papers III, IV) can easily be implemented by health service professionals in various settings. They are relatively easy to learn through intensive training programmes and they do not require any specific background, e.g. psychotherapy to be performed by trained clinicians. It must be remembered, however, that these interventions are not aimed to replace any other form of support, e.g. family therapy. They are aimed primarily at providing supportive services for all patients with underage children.

The consensus as to what is an appropriate intervention must be based not only on valid research evidence but also on evidence gained from the experiences of professionals in clinical practice. A consensus between the scientific community and professionals in clinical practice can help in determining which intervention methods can be reliably and widely implemented as part of current clinical practice within the health care system, after which a training and implementation programme for the interventions must be created, to be targeted at staff working in oncology.

Informing the patients

People with newly diagnosed cancer should be systematically informed about the possibilities for obtaining the appropriate services to support children and parenting. In this way it should be possible to avoid confusion over why the professionals want to ask about the children of particular parents. The main message for parents is that the intervention is provided for all the cancer patients in the hospital, and the easiest way of communicating this is for the information to be provided by the clinicians responsible for treating the patient's cancer.

6.3.2 Future directions

A parent's life-threatening illness imposes a heavy burden on family life, and the intervention as such also requires an extra effort from the family members. The benefits of the intervention must therefore be clearly demonstrated by research methods before any intervention can be recommended for families, or becomes

widely available in clinical practice. As reported in paper III, the impact of the interventions was evidently unclear for some families, because some of the children were reluctant to attend the meetings, for example. Thus future research should try to match the support more specifically to the type of family, combining intensive interventions with individual meetings with children (FTI), for instance, or conversations with parents about their children (LT intervention).

The use of structured interventions for children with a parent suffering from cancer is a relatively new therapeutic area, but the systematic review of the literature (II) revealed that there is a need for evidence-based high-quality research that employs structured methods for collecting data. This usually means a controlled study design and long-term follow-up, to enable the psychosocial preventive impact of the intervention to be assessed. On the other hand, it is important to remember that the target population includes dying patients and families that find themselves in a very severe life situation, so that the use of straightforward control groups functioning as usual is a complicated issue, because the usual functioning of a family rarely includes child-centred support and it would be unreasonable to expect some of the families with severely ill parents to manage without any outside support for their children. Instead, it would be worth considering comparisons between values recorded in the accumulated patient data and either clinical cut-off points, for example, or measurements obtained using nationally validated research instruments such as SCL-90, which has been validated for the Finnish population.

6.4 Methodological considerations and strengths and weaknesses of the present research

The prevalence of children affected by parental cancer and their use of specialised psychiatric services: the 1987 Finnish Birth Cohort study (I)

The major strength of paper I is that the data are based on a complete census of all infants born in Finland in a single year, 1987 (n=59,476). All the cohort members (except those who moved abroad) were followed up from birth to the end of the year 2008 via various national registers. Data on cohort members' biological mothers and fathers who had been treated for cancer were collected from the Finnish Hospital Discharge Register (HDR) covering the period after from 1987 to 2008 and linked to the appropriate cohort members to identify those having a

seriously ill mother or father. The main limitation is that, since the work was based solely on register data, we were not allowed to identify people in order to check the validity of the information or to collect additional primary data, e.g. case notes. It is the case, however, that the registers in themselves are of high-quality and appropriate for research purposes (Gissler *et al.* 1998), and that the continuation of the follow-up into early adulthood also provides information on the later use of psychiatric services, since it is known that the mental health problems often occur in late adolescence and early adulthood even if their roots may go back to childhood (Fryers 2007).

A systematic narrative review of research into structured child-centred interventions for families with a parent suffering from cancer (II)

The strengths of the systematic review were that the literature searches employed valid databases. The reports concerned were initially identified through PubMed, PsycINFO and MEDLINE, and additional papers were located by systematically going through all the reference lists in the papers found in the search.

In view of the heterogeneity of the study designs no statistical synthesis was performed and the present work was thus based on a systematic narrative synthesis approach (Jones 2004, Mays *et al.* 2005) which attempts to synthesize diverse studies in a structured way. This narrative synthesis is one of the strengths of paper II, because current state of structured child-centred interventions could not have been revealed without it. The evidence of the works included was too weak for them to be estimates in the usual way as part of a systematic review. One limitation is that some papers may have accidentally been excluded, although the aim was to find systematically all possible papers on this topic.

Experiences of mental health professionals using structured family-centred interventions to support children of cancer patients (III)

One strength of the narrative study addressing clinicians' experiences is that the data represent the accumulated long-term experience of mental health professionals. All the participants had had an extensive career working among patients with cancer, and were well qualified in using structured, child-centred interventions, as they had implemented these interventions in the standard practices used for treating cancer patients at Oulu University Hospital.

All the interviews were performed by the present author, which helped to ensure the homogeneity of the research process. The narrative method used here, oral narratives of personal experience, has been used widely in the social sciences (Bamberg 1997, Bruner 1997, Waller 2006), and although it has rarely been used in a health care connection or in qualitative health care research, it is well suited for investigations of the kind represented by paper III, where the purpose was to record clinical experiences that document clinicians' opinions. The nature of the method guarantees that the participants' viewpoints were not single snapshots but derived from real-life events and clinical experience, yielding narratives with a recognizable structure. The interventions described in paper III (FTI, LT intervention, EFN meeting) have been shown to be valid and reliable for child and family-centred work in cases where a parent has a serious illness (Beardslee & MacMillan 1993, Hoke 1997, Solantaus *et al.* 2009, Solantaus *et al.* 2010, Väisänen & Niemelä 2005, Pihkala *et al.* 2012). The limitations of this paper are the small number of individual clinicians (n=7, producing 11 narratives) and the lack of narrative data obtained directly from participating family members.

Pilot evaluation of the impact of structured child-centred interventions on the psychiatric symptom profiles of parents with a serious somatic illness: the "Struggle for Life" trial (IV)

The strength of paper IV lay in its reliance on the valid and widely used SCL-90 instrument for assessing the psychiatric symptom profiles of the parents (Derogatis *et al.* 1973). The psychometric properties of the SCL-90 have been established for the Finnish population (Holi 2003, Holi *et al.* 1998). On the other hand, the SCL-90 was the only instrument used. The sick parents represent a homogeneous group who were all suffering from a serious somatic illness. In Finland all persons are guaranteed equal access to health care services, and no bias attributable to differences in socio-demographic factors, for example, is possible in our results. The present pilot evaluation was conducted in the early phase of the trial, which means that the sample size was rather small and some findings may have remained statistically non-significant (Type II error). On the other hand, the possibility of type I errors cannot be excluded, on account of the multiple statistical comparisons performed in this study. One clear weakness is the lack of a control group.

7 Summary

The results achieved in this thesis can be summarised as follows:

1. Every 15th child, totalling 3909 (6.6%) out of the 1987 birth cohort, had a mother or father treated for cancer during the years 1987 to 2008.
2. At the population level, parental cancer increased the children's use of specialised psychiatric services relative to their peers.
3. The number of structured, child-centred interventions was small and their content heterogeneous. Structured interventions are not yet in common use in systematic clinical practice.
4. Experiences with the use of structured, child and family-centred interventions highlighted the following themes: a flexible choice of interventions, the importance of taking children's needs into account, inter-team collaboration and the importance of considering death when working with families with parental cancer.
5. The LT and FTI interventions reduced the incidence of psychological symptoms in the parents (patients and spouses) to the same level as in the general population. It thus seems to be safe to use these interventions for research purposes and in clinical practice in connection with the treatment of cancer.

8 Conclusions

It can be concluded that at the national level children affected by parental cancer represent a substantial proportion of the population, and since they make more use of specialised psychiatric services than their peers, the provision of psychosocial child-centred preventative and promotional services is justified. On the other hand, there are only a few structured interventions available for implementing these services. The quality of the intervention studies described in the literature rarely meets the needs of research-based clinical practice, but clinicians' long-term experiences show that it is possible to work systematically with families by means of structured child-centred interventions. These interventions seem to improve parents' psychological wellbeing, and from that point of view it seems to be safe to perform these with parents suffering from cancer.

It can be concluded that research-based interventions could possess: a) at least a recognizable structure, including preparatory meetings with parents to help them face their children, b) a background in resilience and coping theory, c) a principal focus on recognised mediators, d) a target group which includes the parents and/or the whole family, and e) a primary focus on promoting children's psychosocial wellbeing and preventing possible difficulties.

It is important, however, to acknowledge that child-centred work in an adult health care setting is a relatively new field, so that it is difficult to declare any intervention, structure or practice superior to another. More research is needed to achieve a consensus over the minimum requirements for a child-centred clinical practice, but despite this shortcoming, the present results imply that parents should be provided with the following information at least: 1) how the changed situation may affect their children, and 2) what they can do to protect their children. This knowledge is available to professionals and it is essential to share it with the parents. A structured intervention provides an opportunity for making the child-centred work more systematic and implementation easier. Nevertheless, if these minimum requirements can be achieved by some other approach, that possibility should not be excluded.

Child-centred, research-based clinical practice needs an infrastructure which includes a) an accepted written strategy, b) actions and clearly defined responsibilities at the organisational level, c) training in professional skills, d) research-based structured interventions, and e) information for patients with underage children concerning the available child-centred services.

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- I Niemelä M, Paananen R, Hakko H, Merikukka M, Gissler M & Räsänen S (2012) The prevalence of children affected by parental cancer and their use of specialized psychiatric services: The 1987 Finnish Birth Cohort study. *International Journal of Cancer*. In press. Doi: 10.1002/ijc.27466.
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