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FAMILIES IN THE SHADOW OF CANCER

by

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Families in the shadow of cancer

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Abstract

The aims of this study were 1) to clarify the factors associated with family functioning in cancer patient's families with dependant children, 2) to examine children's mental health when they are exposed to parental cancer, 3) to explore the subjective experience of having cancer during pregnancy, and finally, 4) to describe the implementation of a child-centred family intervention for cancer patients' families with dependant children in an adult oncology setting.

The study groups were collected between May 1st 2002 and April 30th 2004. They consisted of one European group collected from six different countries (N = 381) and two Finnish clinical groups (N = 85 and N = 2). The first Finnish clinical group of 85 cancer patient families with dependant children included a sub-sample of 54 families with children aged 11-17 years. The second Finnish clinical group consisted of two pregnant cancer patients. Additionally, a control group (N = 59) consisting of a sub-sample of 49 families with children aged 11-17 years was used.

Quantitative methods (FAD, BDI, YSR, SOC, SF-8) and qualitative methods (observation, interviews, diaries, videotapes) were used exclusively and/or in combination.

The results can be summarised as follows: 1) cancer "per se" did not impair family functioning, children's mental health, early interaction between ill mothers and their infant, 2) maternal depression or the ill parent's depression were significantly associated with impairment in family functioning, 3) the individual's good sense of coherence was associated with improvement in family functioning, and 4) a child-centred family intervention, which aims to give space for elaborating on cancer in the family, validates the sense of coherence and children's feelings, and promotes open communication was welcomed. It is important to note that in the European study group, the prevalence of depression was 35 % (BDI \geq 16) among ill mothers, and 28% among healthy mothers, 28% among ill fathers, and 13% among healthy fathers.

Early screening and effective treatment of depression in cancer patients and their partners is of paramount importance for the mental health of children and the well-being of the family. Pregnant cancer patients are in need of psychosocial support.

Keywords: cancer, children of cancer patients, children's mental health, counselling, depression, family functioning, pregnancy, psychosocial support.

Florence Schmitt

Lapsiperhe syövän varjossa

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Tiivistelmä

Tämän tutkimuksen tavoitteena oli: 1) selvittää lapsiperheiden toimintakykyyn ja 11–17-vuotiaiden lasten mielenterveyteen yhteydessä olevia tekijöitä toisen vanhemman sairastuessa syöpään, 2) tutkia raskaana olevien syöpäpotilaiden subjektiivista kokemusta, sekä 3) tutkia lapsikeskeisen perheeseen kohdistuvan psykososiaalisen tuen tarjoamista lapsiperheille, joissa toinen vanhempi sairastaa syöpää.

Tutkimusaineisto kerättiin 1.5.2002–30.4.2004 välisenä aikana. Se koostuu yhdestä kansainvälisestä tutkimusaineistosta kuudesta eri Euroopan maista (N= 381), ja kahdesta kotimaisesta aineistosta. Ensimmäinen suomalainen aineisto koostuu 85 lapsiperheestä; siihen sisältyy 54 perheen osa-aineisto, jossa on vain 11–17-vuotiaita lapsia. Toinen suomalainen aineisto koostuu kahdesta raskaana olevasta syöpäpotilaasta. Suomalaisiin analyyseihin liitettiin kontrolliryhmä, johon kuuluu 59 lapsiperhettä; tähän sisältyy 49 perheen osa-aineisto, jossa on vain 11–17-vuotiaita lapsia.

Analyyseissa käytettiin sekä kvantitatiivisia (FAD, BDI, YSR, SOC, SF-8) että kvalitatiivisia (havainnointi, haastattelu, videointi) menetelmiä erikseen ja/tai yhdessä.

Tutkimuksen tulokset voidaan kiteyttää seuraavasti. 1) Syöpä sinänsä ei aiheuttanut häiriöitä perheen toimintakykyyn, lasten mielenterveyteen eikä raskaana olevien/synnyttäneiden äitien ja heidän vauvansa väliseen varhaiseen vuorovaikutukseen. Sen sijaan äidin masennus tai sairaan vanhemman masennus olivat yhteydessä huonontuneeseen perhe-toimintakykyyn. Perheenjäsenten hyvä koherenssintunne oli yhteydessä parempaan perhe-toimintakykyyn, 2) Lapsikeskeinen perheeseen kohdistuva psykososiaalinen tuki, joka mahdollistaa syövän aiheuttaman stressin käsittelyn ja edistää perheenjäsenten välistä kommunikaatiota sekä tunnustaa lasten tunteiden oikeutuksen, vaikuttaa toimivalta. Kansainvälisessä aineistossa depression esiintyvyys oli 35 % äitisyöpäpotilailta, 28 % isäsyöpäpotilailta sekä 28 % terveillä äideillä ja 13 % terveillä isillä.

Johtopäätöksenä voidaan esittää, että syöpäpotilaiden depression varhainen seulonta ja hoito ovat ensisijainen toimenpide aikuissyöpäpotilaiden lasten mielenterveyden tukemisessa ja koko perheen hyvinvoinnin vaalimisessa. Raskaana olevat syöpäpotilaat tarvitsevat monipuolista tukea.

Avainsanat: lapset, perheen toimintakyky, psykososiaalinen tuki, raskaus, syöpä, syöpäpotilaiden lapset.

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ABBREVIATIONS

ANOVA	Analysis of variance between groups (statistics)
BDI	Beck Depression Inventory
COSIP	Children of Somatically Ill Parents
FAD	Family Assessment Device
FSI	Family Systems Illness
M	Mean (age)
Mn	Median
MCS	Mental component summary of the SF-8
N	Number of...
NS	Non-significant
p	Significance level, p value
PCS	Physical component summary of the SF-8
r	Correlation coefficient
SD	Standard deviation
SES	Socioeconomic status
SF-8	Short Form of Medical Outcomes Health Survey
SOC	Sense of Coherence
YSR	Youth Self Report

LIST OF ORIGINAL PUBLICATIONS

The thesis is based on the following original publications, which are referred to in the text as Studies I-V

- I. Schmitt F., Santalahti P., Saarelainen S., Savonlahti E., Romer G., Piha J. Cancer families with children: factors associated with family functioning. A comparative study in Finland. Published online in Wiley InterScience (www.interscience.wiley.com) *Psycho-Oncology* - DOI: 10.1002/pon.1241/5.7.2007
- II. Schmitt F., Piha J., Helenius H., Baldus C., Kienbacher C., Steck B., Thastum M., Watson M., Romer G. A Multi-national Study of Cancer Patients and their children: Factors associated with Family Functioning (submitted).
- III. Lindqvist B., Schmitt F., Santalahti P., Romer G., Piha J. Factors associated with the mental health of adolescents when a parent has cancer. *Scandinavian Journal of Psychology*, 2007, 48, 345-351 (DOI: 10.1111/j.1467-9450.2007.00573/30.4.2007)
- IV. Schmitt F., Manninen H., Santalahti P., Savonlahti E., Pyrhönen S., Romer G., Piha J. Children of parents with cancer: A collaborative project between a Child Psychiatry Clinic, and an Adult Oncology Clinic. *Clinical Child Psychology and Psychiatry*, 2007 12 (3), 421-436.
- V. Schmitt F., Jyrkkö S., Tamminen T., Piha J. Cancer during pregnancy: two case studies. (submitted)

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1 INTRODUCTION

Cancer is a severe disease deeply affecting the patient's own life, but also his/her family members' lives. Cancer treatment impairs patients' quality of life if surgery is mutilating, when chemotherapy and/or radiotherapy cause side-effects such as nausea, vomiting, allergic reactions, alopecia, loss or gain of weight and exhaustion. When the treatment is over, the patient lives in fear of relapse for years. Cancer casts a shadow over the family. While significant medical advances in the treatment of cancer have been made in recent decades, families and children of cancer patients have been neglected, although psychosocial care is advocated as a routine during the treatment of cancer patients (Brennan and Sheard, 1994).

This study is a part of a European multi-site research project (COSIP - Children of Somatically Ill Parents) involving eight research centres in eight European cities: Athens (Greece), Basel (Switzerland), Bucharest (Romania), Hamburg (Germany), London & Sutton (United Kingdom), Turku (Finland), Vienna (Austria), and Århus (Denmark). Besides conducting research on the issue of children's mental health, the European Union requested the implementation of preventive services for children of somatically ill patients. In Finland, the study was carried out in the Child Psychiatry Clinic, in collaboration with the Department of Oncology and Radiotherapy at Turku University Hospital.

How does cancer affect the functioning of a family with children? What happens if the diagnosis is made in a critical life phase like pregnancy? What happens to the children? What kind of psychosocial services could alleviate family members' anxiety and stress?

To addressing these questions, this dissertation used triangulation of theories, data and methods. It combines analysis of data on a macro-level (a large sample of 381 cancer families from six different countries) and on a micro-level (two cases of cancer during pregnancy). It combines sophisticated statistical analysis and qualitative analysis with more clinically oriented considerations. This dissertation connects two very distinct and different worlds: adult oncology and child psychiatry. In a more and more fragmentary medical world, where the disease and the patient, the body and the mind are split from each other, the present dissertation is an attempt to integrate different theoretical frameworks, data from research and clinical expertise for the benefit of the patients, their spouses and their children.

2 REVIEW OF THE LITERATURE

2.1 Family and Family Functioning

In this study, *family* is defined as a system composed by at least two persons belonging to two generations, one parent and one child, who live together under the same roof, bound together by emotional, biological, social and juridical bonds, with a common history and a future as a group.

The concept of family *functioning* has been developed from a systemic point of view, which considers families as systems. Families are more than the sum of their members, and the family's functioning affects each member's functioning. Family functioning is a complex network of relationships, interaction, norms, rules, communication skills and styles. The family as an entity affects each individual, and any phenomenon affects the individual and the family as a whole (Goldenberg and Goldenberg 2000; Palmer and Glass 2003).

The McMaster Model of Family Functioning (Epstein et al. 1983) has been designed to describe family functioning more concretely in terms of observable behaviours. It was first designed to address the needs of clinicians and integrated the factors found in previous studies to be relevant for the good functioning of families. The model describes *structure* and *functions* (Miller et al. 1994). The McMaster Model of the Family Functioning model presents six factors essential for the fulfilling of the three main tasks of a family, namely; 1) providing food, protection, and everyday life, 2) providing for the development of each family member's tasks, and 3) confronting adversity (Table 1). The McMaster Model of Family Functioning was the basis for a measurement instrument, the Family Assessment Device, which is used in this study and described in the method section.

Table 1. Factors of family functioning in the McMaster Model of Family Functioning (according to Epstein et al. 1983; Miller et al. 1994).

Problem-solving:	Refers to the family's ability to resolve issues which threaten the integrity and functional capacity of the family.
Communication:	Is defined as the exchange of information among family members
Roles:	Refers to the pattern of behaviours aimed to deal with providing nurturance, support, resources, managing the family systems and providing sexual gratification
Affective responsiveness:	Addresses the ability of family members to experience appropriate affect over a range of stimuli
Affective involvement:	Evaluates how family members are interested in and place values on each other's activities and concerns
Behaviour Control:	Assesses the way in which a family expresses and maintains standards of behaviour of its members

2.2 Family resilience and sense of coherence

The family resilience approach means changing from seeing families as damaged to viewing them as challenged. The "problem-free" or "healthy" family concept is called into question and there is a need to understand how families face overwhelming situations (Hawley and DeHaan 1996; Patterson 2002; Walsh 1996, 2003). Elements of resilience include cohesion, flexibility, open communication, problem-solving skills and affirming belief systems (Walsh 1996, 2003). Hawley and DeHaan (1996) described "family resilience as the path a family

follows as it adapts and prospers in the present and over time". Walsh (1996) proposed that shared beliefs and narratives that foster a sense of coherence, competence and confidence are resources for withstanding painful crises and adversity.

A core concept in family resilience is the "sense of coherence" of the family members, which means the capacity to make sense of the crisis situation by developing a narrative, in the light of previous experiences, and to use flexibility and creativity to predict the future and to face adversity. The world is perceived as coherent, fitting together with things making sense, and being predictable because, since very early childhood people are creating ever more complex representations of the physical and social world around them (Brennan 2004, pp 10 -13).

The concept of "sense of coherence" appears in the literature of family resilience as the main relevant feature of the individuals belonging to the family. The development of the "sense of coherence" has been described in various terms: Bowlby (1969) wrote of "internal working models of being with", cognitive theorists used the term "schema" to refer to cognitive structures which "guide the screening, encoding, organizing, storing and retrieving of information (Beck and Clark 1988, p. 24). Brennan (2001) wrote in terms of "mental maps" which he defined as more dynamic and flexible. Memory and "internal maps" allowed us to draw conclusions or assumptions from previous experiences, which are organised in life narratives with the aim of predicting the future (life trajectory) (Brennan, 2001).

Moreover, Rolland (2005) emphasises how important is the family's sense of mastery in facing cancer. Some families develop positive narrative as a resource for facing disease and mastering painful situations. The strength of families has seldom been explored, albeit for instance, Pederson and Valanis (1988) called for research comparing families who cope well with those that were "dysfunctional", while Brennan (2001, 2004), in his adjustment model, advocated the positive role of empathic social support, which includes the family.

In this study involving developing children, the concepts of family resilience and sense of coherence were found to be useful to describe and emphasize positive aspects of family functioning rather than psychopathology.

2.3 The Family Systems Illness Model (FSI)

Clinicians and researchers have struggled to clarify the impact of psychosocial factors on the onset, course, and prognosis of somatic diseases (e.g. Kuper et al. 2002; Strike and Steptoe, 2004). To clarify a comprehensive model of the variables involved in the interplay between somatic disease and family, Rolland presented a psychosocial typology of chronic and life-threatening disease, which he developed for over twenty years. The Family Systems Illness (FSI) model provides a useful framework for mapping involved variables, assessing families and resources, designing psychosocial interventions for families and understanding the situation of a family confronted with severe somatic illness (Rolland, 1984, 1987a, 1987b, 1990, 1994a, 1994b, 1998, 2002, 2005).

The FSI model (Figure 1), takes into consideration the ecological and cultural frame in which the families are operating. The individual's illness is considered in the frame of 1) the family life stage within the family life cycle (e.g. early childrearing vs. family

with adolescents), 2) the history of the family across generations (previous traumatic situations, losses, suicides, illnesses, social breakdown like bankruptcy, unemployment, addictions), 3) the legacies (unspoken tasks over generations, coping systems, resilience, communication skills, pattern of replications, alliances, triangles etc.) and 4) the belief systems (ethnic, religious and cultural beliefs, myths, family pride, taboos, etc.) (Carter and McGoldrick 1999; Rolland 2005).

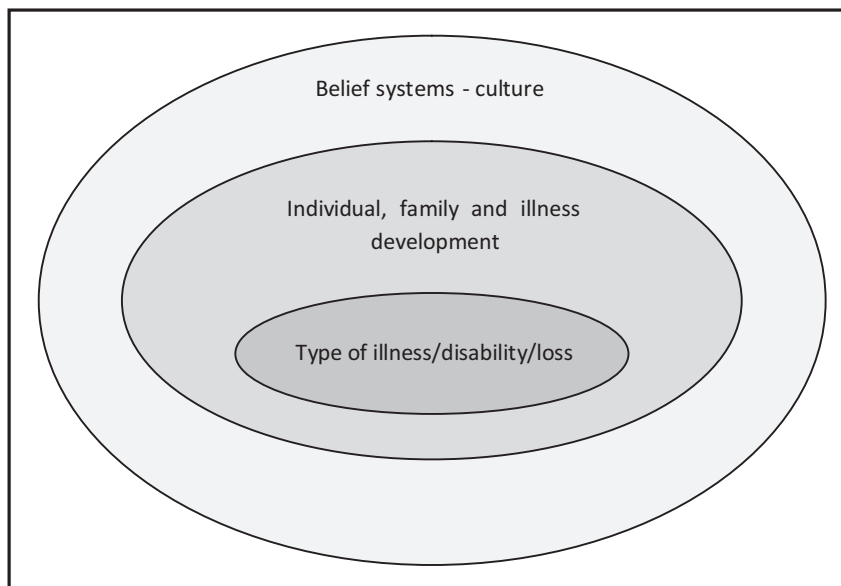


Figure 1. The Family Systems Illness Model (from Rolland JS. *Families, illness and disability: an integrative treatment model*. New-York: Basic Books, 1994a).

The FSI includes three dimensions: 1) the “psychosocial types” of illness, disability or loss, 2) the developmental aspect, (individual and familial level), but also the development of the illness (acute, chronic and terminal phase, and 3) the family system variables (Rolland 2005).

The “psychosocial types” of illness is a distinct concept from medical diagnosis; this typology has been designed to integrate the psychosocial demands for the patients (and his/her family) and the clinical manifestations of the illness. Illnesses can vary in terms of onset, course, and outcome, level of incapacitation and level of uncertainty. Onset can be divided into acute (e.g. a stroke) or gradual (e.g. Alzheimer disease). The course of a disease can be progressive, constant, or relapsing/episodic (Figure 2). The outcomes can be very variable, but especially crucial are family members’ initial expectations, and their previous experiences of losses (Rolland 2004, 2005).

Additionally, each phase of illness imposes its own developmental challenges for the individual and the family (Table 2).

Differences in level of incapacitation and level of uncertainty are essential from a family perspective. Incapacitation can include impairment of cognition (e.g. Alzheimer, brain tumour, stroke), sensation, locomotion, and changes in appearance (e.g. mastectomy) or social stigma (e.g. Aids). The nature, extent, timing and development of incapacitation have different consequences for the family members, especially from the role allocation

perspective. Coping with uncertainty is a challenge for family members, especially with highly unpredictable illnesses (e.g. non-Hodgkin lymphoma) and/or high risks of relapse. The risks for exhaustion and dysfunction are accentuated if the family is rigid and the communication among family members is poor (Rolland, 1984, 1987, 1998, 2005).

The FSI offers a psychosocial map to address the challenges of a family confronted with severe illness. It is a helpful model for the clinician dealing with psychosocial support of somatically ill people and useful for the researcher reviewing the areas of research.

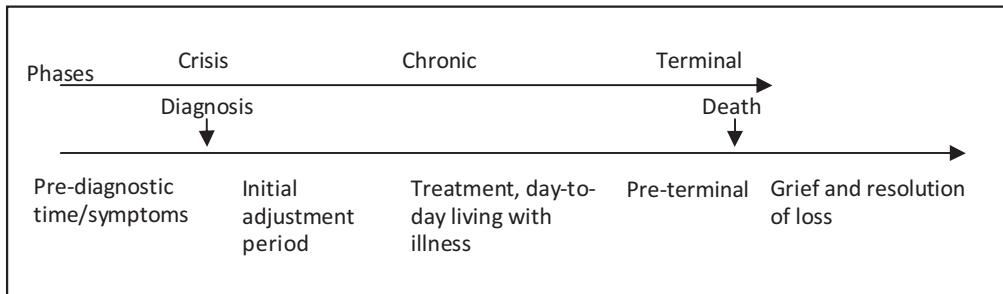


Figure 2. Time line and phases of illness (from Rolland JS. Families, illness and disability: an integrative treatment model. New-York: Basic Books, 1994a).

Table 2. Developmental challenges of illness phases in families (Rolland JS. Families, illness and disability: an integrative treatment model. New-York: Basic Books, 1994 a).

Crisis phase

1. Family members understand themselves in terms of systems
2. Gain psychological understanding of illness
 - a) in practical and emotional terms
 - b) in longitudinal and developmental terms
3. Gain appreciation of development perspective (individual, family, illness life cycles)
4. Crisis reorganisation
5. Creating meaning that promotes family mastery and competence
6. View challenge of illness as a shared one in "we" terms
7. Accept permanence of illness/disability
8. Grieve for loss of family identity before chronic disorder
9. Acknowledge possibilities of further loss while sustaining hope
10. Develop flexibility on ongoing psychosocial demands of illness
11. Learn to live with symptoms
12. Adapt to treatment and healthcare settings
13. Establish functional collaborative relationship with healthcare providers

Chronic phase

1. Maximize autonomy for all family members given constraints of illness
2. Balance connectedness and separateness
3. Minimize relationship skews
4. Mindfulness of possible impact on current and future phases of family and individual life cycles
5. Live with anticipatory loss^(a) and uncertainty
6. Balance open communication (vs. avoidance, denial) and proactive planning with need to live a "normal" life, keeping threatened loss in perspective

Terminal phase

1. Completing process of anticipatory grief and unresolved family issues
2. Support the terminally-ill member
3. Help survivors and dying member to live as fully as possible in the time remaining
4. Begin the family reorganization

(a) for the concept of anticipatory loss, see Rolland JS. Anticipatory loss: a family systems developmental framework. Family Process 1990; 29:229–244.

2.4 The impact of cancer on family functioning

Family functioning is one essential aspect which has been studied in cancer patients' families. It has been seen as deteriorating when a parent has cancer (Kissane et al. 1994, 1996a, b; Lewis and Hammond 1992, 1996a; Lewis et al. 1989, 1993, 1996b; Northouse et al. 1998, 2000; Visser et al. 2004). The research has followed two main lines. The first line of studies has focused on family functioning as the explaining variable, and in the second line of studies, family functioning has been the variable explained by different factors.

Family functioning has been seen as explaining family members' well-being, and explanatory models or typologies have been proposed. Kissane and colleagues (1994, 1996a, b) proposed a five family type classification, which predicted variations in level of psychological distress and depression in family members. Individuals were clustered into five family types: supportive (high cohesion and no reported conflict), ordinary (high cohesion and negligible conflicts, resolvers (high cohesion and some conflicts), sullen (low cohesion and moderate conflict), and hostile (high conflict and low cohesion). For families of patients in palliative care, level of distress was highest in sullen and hostile classes (Kissane et al. 1994), while for bereaved families more depression and distress were reported in sullen families (Kissane et al. 1996b). The study of Edwards and Clarke (2004) corroborated the model proposed by Kissane and colleagues, and showed that good communication within the family was associated with lower level of anxiety. Additionally the family members who acted openly, expressed feelings and had a good problem-solving ability were found to have a lower level of depression.

In studies where family functioning was the variable to be explained, factors such as characteristics of the family members or characteristics of the disease, associated with family functioning have been focused on. Among factors related to the characteristics of adults, parents' age (Murtonen et al. 1998), family structure (Hayden et al. 1998) and families' social network and social support (Romer et al. 2002) were found to be associated with family functioning. Lewis and colleagues (1992, 1993, 1996a) suggested that the impact of individuals' depression on family functioning is mediated through marital adjustment. Moreover, the quality of marital adjustment was affected by the level of depression in women and the experienced illness demands (Lewis et al. 1989, 1993; Lewis and Hammond 1992, 1996a). However, one study suggested that depression had a direct effect on family functioning (Lewis et al. 1993).

The theoretical model proposed by Northouse and colleagues (2000, 2002) includes cognitive appraisal as an important mediating variable having an impact on family functioning. By cognitive appraisal Northouse means the ability of the patient to give a meaning to the life events. However, there was also a direct (not mediated) relationship between the mental health of relatives of patients with relapsing cancer and family functioning (Northouse et al. 2002).

Among factors related to the disease, a high level of illness-related demands (treatment, exhaustion, and side-effects) was found to have a negative effect on family functioning (Lewis et al. 1989, 1993, 1996a). However, a longitudinal study revealed that, over time, the families experienced significantly lower levels of illness-related demands, and marital satisfaction improved (Lewis et al. 1992). In Lowdermilk and Germino (2000), the type of cancer and the changes in life induced by the diagnosis, as well as the timing of illness in the life cycle of women negatively affected family functioning. A summary of previous studies is presented in Tables 3 and 4.

Table 3. Summary of the main studies on couples' and family functioning in cancer patients' families¹

Researcher, year of publication, country	Aims of study	Material and Methods	Main results
Lewis FM, Woods NF, Hough EE, Bensley LS. 1989, USA	1) To test hypothesis about family functioning with the mother's chronic illness from the spouse's perspective. A cross-sectional study within a longitudinal design (3-year)	Families N = 125 (5 measures at 4-month intervals during a 18-month period) Sub-sample of 48 fathers who had at least one child 6-12 years of age 48 ill mothers (M age 37.8, SD 4.8), 48 spouses (M age 39.5, SD 6.3) - DIJ, SES, SDAS, FPRO, FCOPEs, CES-D, FACE II - Path analysis	1) Number of illness demands experienced by the father predicts more depression 2) Marital adjustment was affected by father's depression and type of mother's disease 3) More depressed spouses had lower levels of marital adjustment 4) More frequent illness demands and higher level of marital adjustment were associated with better family coping (frequent feedback, reflection and discussion) which in turn affected the quality of father-child relationship 5) In "introspective" families, fathers reported more exchanges with their children
Lewis FM, Hammond MA. 1992, USA	1) To assess the impact of mother's breast cancer on her family during rehabilitation. 2) To determine the processes used by families to adjust to the illness over time. - longitudinal design	- Ill mothers N = 111 (M age 41.6, SD 5.6) – Spouses (N unspecified, M age 44.8, SD 7.3) – at least one child at home – N and mean age of children unspecified - - DIS, CES-D, SDAS, F-COPES - Three measurement at four-month intervals - Path analysis and multiple regression	1) Over time families' lower level of illness-related demands and better marital adjustment 2) Level of mother's depression remains stable 3) Maternal depression affected quality of marital relationship, which in turn, affected family coping and functioning
Lewis FM, Hammond MA, Wood NT. 1993, USA	1) To test an explanatory model of family functioning with women having breast cancer	- Ill mothers N = 40 (M age 39.3, SD 5.4) - Spouses N = 40 (M age 41.2, SD 6.1) – Children N unspecified, M age 9.3 (SD1.8) - DIJ, DOT, NSSS, SDAS, FPRO, F-COPES, CES-D, FACES II - path analysis and multiple regression analysis	1) More frequently experienced illness demands were associated with higher level of parental depression, which in turn affected the quality of marriage 2) Less well adjusted marriage affected family's coping behaviour 3) Children functioned better when the healthy parent interacted more frequently with them
Kissane DW, Bloch S, Burns WI, Patrick JD, Wallace CS, McKenzie DP. 1994, Australia	1) To develop a typology of families, 2) To identify dysfunctional or "risk" families and 3) To examine the association between family type and individual and social morbidity	Families N = 102, Patients N = 102 (M age 56, SD 9) – Mean survival time from entry into the study until death was 294 days. - Spouses N = 84 (M age 55, SD10) – Children N = 179 (M age 28, SD 8) – One-child families 13%; two children 38%, three children 22%, and four or more 27% - BDI, SAS, FES, FACES-III - Cluster analysis, correlations, ANOVA	1) 34% of families were found "supportive", 21% were found to have resolved conflict effectively → low psychological morbidity. 2) 6% were classified as "hostile" (high conflict) while the "sullen" 9% had moderate conflict, poor cohesion and limited expressiveness → higher level of psychological morbidity, poorer social functioning. 3) 31% were "ordinary" with intermediate level of cohesion, expressiveness and conflict → moderate psychological morbidity effectively
Kissane DW, Bloch S, Dowe DL, Snyder RD, Ong'hena P, McKenzie DP, Wallace CS 1996a, Australia	1) To identify patterns of family functioning in adult families after the death of a parent	Families N = 115; (patients dead), Spouses N = 115 (M age 55.9, SD 9.2) – Children N = 153 (M age 28, SD 7.7) – Mean of children in the family 3.1 (SD 1.6). - BDI, BSI, BPO, FACES-III, SAS, FCOPEs - cluster analysis, MANOVA	1) 36% of the families were supportive, 23% resolved conflicts effectively 2) 30% were "hostile" (high conflict, low cohesions, poor expressiveness) or "sullen" (moderate limitations in the three areas) 3) 26% were "intermediate"; midrange cohesiveness, low control, low achievement orientation

Researcher, year of publication, country	Aims of study	Material and Methods	Main results
Kissane DW, Bloch S., Ongheena P., McKenzie DP, Snyder RD, Dowe DL. 1996b, Australia	1) To describe the intensity of grief, the psychosocial morbidity, and coping in members of families classified in a typology	Families N = 115, (patients dead), Spouses N = 115 (M age 55.9, SD 9) – Children N = 153 (M age 28, SD 7.7) Mean of children in the family 3.1 (SD 1.6) - BDI, BSI, BPQ, FACES-III, SAS, FCOPEs - cluster analysis, MANOVA	1) "Suller" families displayed the most intense grief and the most severe psychosocial morbidity 2) "Supportive and conflict-resolving" families resolved their grief and adjusted better.
Lewis FM, Hammond MA. 1996a, USA	1) To examine the impact of early stage breast cancer on the functioning of families with adolescents	- Ill mothers N = 70 (M age 42.9, SD 5.2) – Spouses N = 70 (M age 47, SD 6.6) – Adolescents N = 70 (M age 16.3, SD 2.1) – (data from studies 1989, 1993) - DII, NSSS, SDAS, RS-ES, F-COPES; CES-D, RS(CPAS), FACES II, - path analysis and multiple regression analysis	1) Parent's experiences of high illness-related demands predict higher level of maternal depressive mood, poorer marital adjustment and lower parenting quality 2) Self-esteem in adolescents was associated with parenting quality (parents being more attentive)
Lewis FM, Zahlis EH, Shands ME, Sinsheimer JA, Hammond MA. 1996b, USA	1) To describe the adjustment of single women to early stage breast cancer in comparison with married women 2) To document the psychosocial functioning of school-aged children	22 single ill mothers and 69 married mothers – median age 42 – two children in the family - FIS-FFS (data from 1989–1993) - rank order correlations - qualitative; interviews.	19 single women were significantly more depressed (36.4% vs 16.8 % for married women) – children age 6–12y, abnormal range on global self-worth (p = 0.03), and social acceptance p = 0.01, more behaviour problems (p < 0.10) and lower adjustment in the quality of relationships with peers (p = 0.11)
Murtonen I, Kuisma M, Paunonen M, Lehti K., Koivula m., White M. 1998, Finland	1) To describe family dynamics of families with cancer	Families N = 96, ill mothers N = 82 (no mean age given) ill fathers N = 14 - Spouses male N = 75 and spouses female N = 21 - Most of the patients and relatives were over 50 (no mean age given) – - FDM, FDQ - t-tests, ANOVA	1) Singlehood did not impair family functioning 2) No differences between cancer patients and relatives on any of the family dynamic dimensions
Northouse LL, Templin T, Mood D, Oberst M. 1998, USA	1) To compare the concurrent stress, resources, appraisal and patterns of adjustment in benign and malignant groups 2) to compare patients' and spouses' responses Longitudinal study – 1 week after diagnosis, 60 days after, one year after.	Couples with cancer N = 58 (women M age 51, SD 10.7 – husbands M age 53, SD 10.9) – couples with benign breast disease N = 73 (women M age 46, SD 9.8 – husbands M age 49, SD 10.6) – - SSS, NLEQ, DAS, Family APGAR, SSQ, MUIS, BHQ, BSI, PAIS - ANCOVA	1) couples facing cancer reported greater decreases in marital and family functioning than other couples 2) couples reporting high distress and number of role problems at diagnosis remain distressed at 60 days and 1 year 3) High correspondence between women and husbands
Northouse LL, Mood D, Templin T, Mellon S, George T. 2000, USA	1) To compare colon cancer patients' and their spouses' appraisal of illness, resources, concurrent stress, and adjustment 2) To examine the influence of gender and role 3) To assess the degree of correlation between patients and spouses 4) To identify factors associated with adjustment to the illness	A sample of 56 patients and their spouses (both M age 61, SD 13) – 34 patients were male and 22 females. - demographics, SSS, Family APGAR, SSSC, SDAS, appraisal was measured by MUIS for uncertainty and hopelessness by BHS - Emotional distress by BSI – Role adjustment problems by PAIS - longitudinal design: one week after diagnosis, 60 days after surgery and one year after surgery	1) Spouse reported more emotional distress and less social support than patients 2) Women reported more distress, role problems, less marital satisfaction regardless of whether they were patients or spouses 3) Both partners reported decreases in family functioning, social support and emotional distress over time. 4) The strongest predictors of patient's role adjustment were hopelessness and spouse's role problems 5) The strongest predictors of spouse's role adjustment were own baseline role problems and marital satisfaction

Researcher, year of publication, country	Aims of study	Material and Methods	Main results
Northouse LL, Templin L, Mood D, 2001, USA	<p>1) To determine which factors predict the woman's and husband's adjustment to breast cancer during the first year following diagnosis</p> <p>2) To compare partners' scores</p> <p>3) The interaction between the coping of the spouses</p>	<p>Couples (N = 131) – Ill women 58 (M age 51, SD 10.7) received a cancer diagnosis; husbands (M age 53, SD 10.9), and 73 (M age 46, SD 9.8) a benign diagnosis; husbands (M age 49, SD 10.9) SSS, SDAS, appraisal was measured by MUIS for uncertainty and hopelessness by BHS – Emotional distress by BSI – Role adjustment problems by PAIS</p> <p>- longitudinal design: one week, 60 days and one year after diagnosis</p> <p>- correlation coefficient and structural equation models (SEMs) and path analysis.</p>	<p>1) The strongest predictors of adjustment for women were severity of illness and hopelessness</p> <p>2) For husbands it was their own baseline of adjustment at week 1</p> <p>3) Husband's and wife's level of adjustment had a significant effect on each other's adjustment</p>
Nothouse LL, Mood D, Kershaw T, Schafenacker A, Mellon S, Wlaker J, Galvin E, Decker V. 2002, USA	<p>1) To assess patients' and family members' quality of life within one month after recurrence, and effect of multiple factors on quality-of-life scores</p>	<p>Cancer patients N = 189 women (M age 54, SD 11.2) – caregivers were 59% husbands, 14% adult daughters, 5% adult sons, 8% sisters, 14% other relatives or friends (M age 52, SD 13.4)</p> <p>- OSQ, LCS-ES, FHI, AIS, ACS, MUIS, BHS, FACT-Scale –</p> <p>- t-tests – goodness of fit tests -</p>	<p>1) Patients reported significant impairment in physical, functional and emotional well-being</p> <p>2) Family members reported significant impairment in emotional well-being</p> <p>3) Self-efficacy, social support, family hardiness had positive effects on quality of life</p> <p>4) Symptom distress, concerns, hopelessness, negative appraisal of illness or care-giving had detrimental effects on quality of life</p>
Edwards B & Clarke V. 2004, Australia	<p>1) To examine levels of depression and anxiety in newly diagnosed adult patients and their adult relatives with, the hypothesis that family functioning, and patients' illness may have an impact on depression and anxiety</p>	<p>Adults patients (N = 48; M age 54.6, SD 10.66) and relatives (N = 99; M age 44.17, SD 15.87) –</p> <p>- the BDI, STAI, SR-KPS, FRI and FAD</p> <p>- Statistical methods (multilevel model)</p>	<p>1) Families that were able to act openly, express feelings and solve problems effectively had lower levels of depression. 2) Direct communication within the family was associated with lower levels of anxiety</p>

1. **ACS**: Appraisal of Caregiving Scale; **AIS**: Appraisal Illness Scale; **BDI**: Beck Depression Index; **BHS**: Beck Hopelessness Scale; **BPDQ**: Bereavement Phenomenology Questionnaire; **BSI**: Brief Symptoms Inventory; **CES-D**: Center for Epidemiological Studies-Depression Scale; **DAS**: Dyadic Adjustment Scale; **DI** or **DIS**: Demands of Illness Inventory (Scale); **DOT**: Directory of Occupational Titles (a form of SES); **F-APGAR**: Family APGAR; **FACES-II** and **-III**: Family Adaptability and Cohesion Evaluation Scale; **FCOPEs**: Family Crisis Oriented Personal Evaluation Scales also known as F-Copes Scale; **FDIM**: Family Dynamics Measure; **FDQ**: Family Dynamics Questionnaire; **FDS**: Family Dimension Scale (a form of FACES); **FHI**: Family Hardiness Index; **FES**: Family Peer Relationship Questionnaire; **FRI**: Family Relationship Index; **LCS-ES**: Lewis Cancer Self-Efficacy Scale; **MUIS**: Mishel Uncertainty in Illness Scale; **NLEQ**: Norbeck Life Events Questionnaire; **NSSS**: Norbeck Social Support Scale; **OSQ**: Omega Screening Questionnaire; **PAIS**: Psychosocial Adjustment to Illness Scale; **SAS**: Social Adjustment Scale; **SDAS**: Spanier's Dyadic Adjustment Scale; **SEMs**: Structural Equation Models; **SSS**: Smilkstein Stress Scale; **SSSC**: Social Support Scale; **SSQ**: Social Support Questionnaire; **STAI**: State-Trait Anxiety Inventory

Table 4. Reviews on family functioning in cancer patients' families

Researcher, year of publication, country	Topics dealt with	Conclusions	Comments
Pederson LM, Valanis BG. 1988, USA	<ol style="list-style-type: none"> 1. Coping problems related to breast cancer 2. Dealing with the patient's needs - coping with the patient's needs 3. Dealing with family member's emotional reactions 4. Obtaining information and assurance from professionals 5. Maintaining the family's integrity 6. Communication within and outside the family 7. Coping with other special problems 8. Maintaining the marital relationship 9. Approaches to assessment and intervention 	<ol style="list-style-type: none"> 1. Most of the studies place primary emphasis on the patient's problems rather than on families 2. Most of the assessment or intervention aimed at the effect of cancer 3. In cases where assessment and intervention were proposed the results were not evaluated 4. Breast cancer is the most studied area 5. No researchers have attempted to identify the families whose coping mechanisms are inadequate for handling the stress of cancer and thus requiring intervention 6. Studies that predict families at risk are needed 	<ul style="list-style-type: none"> - 73 references, of which 11 books - no information on how the review has been performed
Visser A, Huizinga GA, Van der Graaf WTA, Hoekstra HJ, Hoekstra-Weebers JEHM. 2004, Netherlands	<ol style="list-style-type: none"> 1. Impact of parental cancer on children' mental health 2. Marital functioning 3. Family structure 4. Changes in role 5. Family functioning and children' impact 6. Family communication 7. Parental agreement 8. Intergenerational agreement 	<ul style="list-style-type: none"> - results for school-aged children were inconsistent - no general pronouncement can be made about the impact of parental cancer on pre-school children - the majority of studies reviewed found a positive relationship between the psychological functioning of the parent and the child - non-uniformity in results may be due to heterogeneity in research questions, methodology, illness-related characteristics and different informant perspectives 	<ul style="list-style-type: none"> - 52 studies included in the review and 57 references - the methods and procedure for including studies are carefully described

2.5 Mental health of children with a parent who has cancer

As the mean age for first childbearing has risen in Finland (28 years, www.stat.fi 2006) more children may be affected by parental cancer. In this dissertation, the word “child” has been used to refer to all children under eighteen

The youngest children exposed to parental cancer are pregnant cancer patient’s foetuses. However, available studies on the outcome of cancer patients’ offspring are exclusively medical and no study from a psychological and/or an early-relationship perspective could be found.

Children before school-age have not been included in studies exploring the mental health of children of cancer patients. For instance, in Osborn’s review (2007) the first time the word “dependant child” is used, a foot-note has been added stating that “the term child or children refers to children of cancer patients from 5 to 18 years. The term “adolescent” is used to refer to children aged 11 and over. The term “younger children” is used to refer to children aged 10 and below” (Osborn 2007, p.123). Thus, pre-schoolers have been excluded, and no study concerning them could be found.

The effect of parental cancer on children’s and adolescent’s mental health has been explored mainly in the United States, but during the 21st century, studies have also been conducted in Europe (Osborn 2007).

Across previous studies, connections have been found between children’s perception of their family functioning and their own mental health. Good family functioning and open communication between family members were associated with less distress among the children (Harris and Zakowski 2003; Huiziga et al. 2003; Visser et al. 2004, Osborn 2007). Flexibility among family members was also important (Brennan 2004), due to the incapacity of the ill parent to engage in activities previously performed (Fitch et al. 1999; Elmberger et al. 2002).

Previous studies are unanimous that girls were at increased risk of anxiety and depression when their mother was diagnosed with cancer (Osborn 2007). Less distress was experienced by boys when either parent had cancer (Huizinga et al. 2005a) and by girls when their father had cancer (Compas et al. 1994; Grant and Compas 1995; Welch et al. 1996). As a consequence of the illness of their mother, the distress in girls was directly due to increased family responsibilities (Grant and Compas 1995).

Children’s distress has been found to fluctuate with the phase of the parental illness. The adjustment period after the parent’s initial diagnosis was often particularly distressing (Huizinga et al. 2003; Welch et al. 1996). The period before the death of the ill parent is understandably highly stressful. Six months before the death of their ill parent, children aged 7–16 showed significantly higher levels of anxiety and depression, as well as behavioural problems, compared to children in a normative sample (Siegel et al. 1992, 1996).

Children’s mental health has also been explored in relation to characteristics of the parent’s cancer. Children experienced increased distress in relation to a poorer prognosis, and to their perception of the severity and stressfulness of their parent’s cancer. Recurrent cancer (Huizinga et al. 2005a; Visser et al. 2006) and treatment-related complications

were also associated with increased distress (Huizinga et al. 2005a), as was decreased mental health in the ill parent (Hoke 2001; Visser et al., 2005; Watson et al. 2006) and in the ill parent's spouse (Visser et al. 2005). However, treatment, severity of cancer (Hoke 2001), time since diagnosis (Compas et al. 1994; Watson et al. 2006), stage of cancer (Compas et al. 1994) and type of cancer (Welch et al. 1996; Hoke 2001) were not related to children's adjustment.

Findings regarding the connection between the level of physical impairment of the ill parent and the mental health of children are contradictory. One study reported a significant positive association between them (Visser et al. 2006), whereas another did not (Compas et al. 1994). As many studies have been conducted without a control group (e.g. Compas et al. 1994; Welch et al., 1996; Huizinga et al. 2005a), it is still uncertain whether children with an ill parent actually differ in the amount of their symptoms compared to children of healthy parents. Some studies have suggested that children of ill parents were more distressed than controls (Siegel et al. 1992; Welch et al. 1996), whereas others reported similar levels of psychological distress in both groups (Harris and Zakowski 2003; Huizinga et al. 2003).

Hoke (2001) found that children aged 8–16 actually experienced less anxiety and fewer behavioural problems than did children in a comparison sample. Similar results were reported by Harris and Zakowski (2003), as children of an ill parent showed fewer symptoms of post-traumatic stress disorder than the controls did.

Cancer may sometimes serve a positive function in that it brings family members closer together (Brennan 2004; Huizinga et al. 2003). However, the apparent inconsistencies between different studies might suggest that some children are more vulnerable to psychological distress than others. Moreover, the latest study (Watson et al. 2006) suggested that the most relevant factor for the mental health of the children of cancer patients is parental depression. A summary of previous studies is presented in Tables 5 and 6.

Table 5. Main studies on mental health of adolescents of a parent who has cancer between 1996 and 2007¹

Researcher, year of publication, country	Aims of study	Material and Methods	Main results
Compas BE, Worsham NL, Ey S, Howell DC. 1996, USA	- To examine cognitive appraisals and coping in children, adolescents and young adults facing parental cancer	- 134 participants (6-32 years old) - 32 preadolescents 6-10 years (M age 7.8, SD 1.6); 59 adolescents 11-18 years (M age 14.6, SD 2.3) and 43 young adults 19-32 years (M age 22.9, SD3.4) - children living at home - young adults frequent contacts - cognitive appraisals and coping interview - R-CMAS - YSR-BSI - IES - correlations - ANCOVA	- Adolescents and young adults reported more emotion-focused coping and dual-focused coping than did preadolescent children - Stage and prognosis of parent's cancer were related to greater seriousness and stressfulness, and to more avoidance - Emotion-focused coping was related to greater avoidance and to higher symptoms of anxiety-depression
Weich AS, Wadsworth ME, Compas BE. 1996, USA	- To examine the level of distress of children exposed to parental cancer.	- 54 patients (M age 39.9, SD 5) and 36 spouses (M age 41, SD 7.2) - 55 adolescents (M age 14.5 SD2.2) and 34 pre-adolescents (M age 7.9, SD 1.6) - CBCL - CDI - R-CMAS - YSR - ANOVA	- Parents reported only little or no emotional distress or disruptive behaviours in their children (boys and girls/ father ill vs. mother ill) - children reported significantly differently from parents, especially girls - Adolescent girls whose mothers were ill reported the highest level of distress
Hoke LA. 2001, USA	- To explore the relationship of maternal breast cancer and children's adjustment	- Breast cancer mothers N = 28 (M age 43.7, SD 5), healthy mothers N = 24 (M age 41.5, SD4.6) - 14 boys and 21 girls of ill mothers, 17 boys and 17 girls of healthy mothers (M age 11.6, SD 2.4, age range 8.-16) demographic - PAIS-SR- STAI - CDI- RCMAS - YSR - CBCL - t-tests and Fisher's ET - ANCOVA	- Children of ill mothers reported fewer level anxiety symptoms than normative sample, and mothers reported fewer behaviour problems in their children - No evidence of distress and adjustment problems
Harris, C.A., & Zakowski, S.G. 2003, USA.	- To examine anxiety and depression in adolescents with parents diagnosed with cancer in comparison to adolescents of healthy parents	- 27 adolescents with a parent who had cancer and 23 adolescents with a healthy parent (12-19 year, M age 15.7) - demographic- CDI - RCMAS - IES - PTSD(PCL-C) - FES - t-tests - correlations	- Groups did not differ on anxiety and depression, but adolescents with a cancer ill parent perceived their own risk to develop cancer - Positive family environment was correlated with higher anxiety and depression (sic)
Huizinga GA, van der Graaf WTA, Visser A, Dijkstra JS, & Hoekstra-Weebers JEHM. 2003, The Netherlands	- To explore the psychosocial consequences for children with a parent who has cancer	- 14 ill parents, 12 partners, 15 children age 7-18 year (no mean age provided) - CBCL- YSR-FDS- qualitative interviews	- No significant differences in behavioural and emotional problems between these children and normative samples - Parents reported more problems than children did - Families with poor family functioning were more vulnerable (chaotic and disengaged families are at risk)

Researcher, year of publication, country	Aims of study	Material and Methods	Main results
Huizinga GA, Visser A, van der Graaf WTA, Hoekstra HJ, Klip EC, Pras E, & Hoekstra-Weebers JEHM. 2005a, The Netherlands.	- To assess stress response symptoms in children of parents diagnosed with cancer 1-5 years prior to the study	- 30 ill fathers, 139 ill mothers, 139 healthy fathers, 28 healthy mothers (M age 46.4, SD 5.4), 120 sons and 164 daughters (M age 16.4, SD3.1) - demographics - IES - PTSD - YSR - STAI-C - t-tests – correlations – ANOVA -	- 21% of sons and 35% of daughters reported clinical stress response symptoms - Daughters whose mothers were ill reported more distress than sons - Daughters of parents with a recurrent disease were more distressed than daughters of a parent with the first diagnosis - 1/5 of the boys and 1/3 of the girls expressed clinically elevated stress response symptoms
Huizinga GA, Visser A, van der Graaf WT, Hoekstra HJ, Hoekstra-Weebers JEHM. 2005b, The Netherlands.	- To examine 1) parent-adolescent communication in families of cancer patients 2) relationships between parent-adolescent communication and posttraumatic stress symptoms (PTSS) in adolescent children 3) the associations between parents' illness characteristics and parent-adolescent communication.	- 30 ill fathers, 139 ill mothers, (M age 45.7, SD 4.5) – 107 healthy fathers, 28 healthy mothers (m age 46.4, SD 5.4), 120 sons and 164 daughters (M age 16.4, SD3.1) - 232 girls and 178 boys (age range 13–17 years) from six secondary schools in town = control group - demographics - PACS - IES - PTSD - YSR – STAI-C - t-tests – correlations – ANOVA – multivariate analysis and regression analysis	- Adolescents communicated less openly with mothers with cancer than controls - Daughters communicated more openly with ill parents than with healthy parents. More open communication with healthy parents was related to fewer PTSS in daughters. More problem communication with both parents was related to more PTSS in both sons and daughters. - Sons reported more problems in communication with ill parents in case of more intensive treatment or recurrent disease. Daughters experienced less open communication with both parents when ill parents received more intensive treatment. - - Time since diagnosis was not related to parent-adolescent communication. - Problem communication with the healthy parent was the strongest predictor of intrusion, while problem communication with the ill parents was the strongest predictor of avoidance. - Parent-adolescent communication in families of cancer patients differs little from that in families not confronted with parental cancer.
Visser A, Huizinga GA, Hoekstra HJ, van der Graaf WT, Klip EC, Pras E, Hoekstra-Weebers JEHM. 2005, The Netherlands.	To investigate emotional and behavioural problems in children of parents diagnosed with cancer and to examine the relationship with demographic and illness-related variables - Cross-sectional	- 180 ill parents (M age 44.3, SD 5.1), 145 spouses (M age 44.8, SD 7.2), 114 children (age 4-11, M age 7.8, SD 1.6) and 222 adolescents (12-18 years, M age 15, SD 2.3) - Demographics - CBCL – YSR - One sample and independent T-tests, ANOVA - ICC	- More emotional problems were reported for latency-aged sons and adolescents girls, who had more problems than boys - Spouses reported better functioning in adolescents compared to the norm group - Adolescent daughters and latency-aged sons are at risk of emotional problems.

Researcher, year of publication, country	Aims of study	Material and Methods	Main results
Visser A, Huizinga GA, Hoekstra HJ, van der Graaf WTA, & Hoekstra-Weebers JEHM. 2006, The Netherlands.	<ul style="list-style-type: none"> - To investigate the impact of characteristics of 180 parents diagnosed with cancer, along with 145 spouses, and the prevalence of emotional and behavioural problems in children - Cross-sectional 	<ul style="list-style-type: none"> - 180 ill parents (M age 44.3, SD 5.1), 145 spouses (M age 44.8, SD 7.2), 114 children (age 4-11, M age 7.8, SD 1.6) and 222 adolescents (12-18 years, M age 15, SD 2.3) - Demographics - CBCL – YSR- RAND-36 - univariate analysis and T-tests, hierarchic multiple regression 	<ul style="list-style-type: none"> - Family situation (single parents, no or few siblings, oldest child) was one of the most important predictors of reported problems at latency age - For adolescents, the parental treatment and complications, as well as decrease in physical functioning in the parents affected more mental health - Parental mental health of the ill parents affected both groups of children
Visser A, Huizinga GA, Hoekstra HJ, van der Graaf WT, Gazendam-Donofrio SM, Hoekstra-Weebers JEHM. 2007a, The Netherlands.	<ul style="list-style-type: none"> - To examine the prevalence of problems in children within four months after a parent's cancer diagnosis (T1) six (t2) and twelve months (T3) afterwards. - longitudinal design 	<ul style="list-style-type: none"> - 69 ill parents (m age 43, SD 5.1), 57 spouses (M age 43, SD 5.7), 57 school age children (M age 8, SD 2.1) and 66 adolescents (M age 15, SD 2) - Comparisons to norm group and a sample of families who was exposed to cancer 1 to 5 years previously - Demographics - CBCL – YSR- T-tests, ANOVA, correlations - 	<ul style="list-style-type: none"> - No differences between groups - Reported problems decreased with time but initially vulnerable children remained vulnerable - Fathers and mothers agree in their perception of children's behaviour except for adolescent girls (mother and daughter agreement high, father and daughters/sons and mother and sons agreements was moderate)
Watson M, James-Roberts IS, Ashley S, Tilney C, Brougham B, Edwards L, Baldus C, & Romer G. 2006, UK.	<ul style="list-style-type: none"> - To identify factors associated with emotional and behavioural problems in children (6-17 years) of women with breast cancer - Cross-sectional 	<ul style="list-style-type: none"> - M time since diagnosis 11 months. Median age (no mean age provided) for adults participants was 45 , children male 46, female 64 and for adolescents male 17 and female 39. - 28 single families - CBCL – YSR- TRF – CHQ-MH: CF 87 and PF 98) – BDI-II – FAD – SF-8 - multivariate logistic regression analysis 	<ul style="list-style-type: none"> - Risk of problems with children was linked with low levels of family cohesion, low affective responsiveness and parental over-involvement - Adolescents reported family communication issues, which were associated with externalising behaviour problems - Maternal depression was related to internalising problems especially in girls - state of disease, time since diagnosis was irrelevant - maternal depression and poor communication are crucial

Researcher, year of publication, country	Aims of study	Material and Methods	Main results
Visser A, Huizinga GA, Hoekstra HJ, van der Graaf WT, Hoekstra-Weebers JEHM. 2007b, The Netherlands.	To examine the relationship between temperament and internalising and externalising problems among children of parents diagnosed with cancer, beyond the effects of socio-demographics, illness-related variables and life events.	- 340 adolescent children (149 sons and 191 daughters), between the ages of 11 and 18 years (M age=14.9 years, SD=2.3) and their 212 ill parents (80% mothers, M age=45.4 years, SD=4.7). Nine percent of the children were from single-parent families. Parents (43 fathers; 169 mothers, M age=45.4 years, SD=4.7) had been diagnosed with various types of cancer. The mean time since diagnosis was 2.6 years (SD=1.2). Twenty-nine percent of the parents had suffered relapses. EATQ-R- CBCL- YSR - REE – RLCQ	- Daughters of parents with cancer were reported as having more internalising problems than their counterparts - Prevalence of problems did not depend on children's and parents' age or educational level. - Recurrent disease and number of life events experienced by children and parents affected the problems reported. - The most important temperament dimensions in the prediction of internalising problems in children were shyness and fear/worry; to a lesser extent, frustration and perceptual sensitivity (children only) and lower scores on pleasure intensity (parents only). - Externalising problems were associated with effortful control and in children's reports with frustration. - Temperament seemed to be a more important predictor of problems as reported by children than by parents.
		Factor analyses of the EATQ-R were performed using simultaneous Confirmatory Analysis (SCA) and Exploratory principal Component Analysis (PCA) Chi-square and t tests - One-sample t tests - Univariate statistics (t tests and Pearson correlation analysis) - Hierarchical regression analyses -	

1. **BSI** : Brief Symptoms Inventory; **CBCL** : Child Behavior Check List; **CHQ-MH**: Mental Health subscale of the Child Health Questionnaire (CF 87 Child Form and PF 98 Parent Form); **EATQ-R**: Revised Early Adolescent Temperament Questionnaire; **FES** : Family Environment Scale; **FDS**; Family Dimension Scale (a form of FACES); **IES** :Impact of Event Scale; **PAIS**: Psychosocial Adjustment to Illness Scale; **PTSD (PCL-C)**:The Post traumatic Stress Disorder checklist-civilian version; **RAND-36**: a variant of the SF-36 of Ware and Sherbourne (GQL); **R-CMAS**: Revised Children's Manifest Anxiety Scale; **REE** : Recently Experienced Events; **RLCQ** : Recent Life Change Questionnaire; **PACS**: Parent- Adolescent Communication Scale; **RS(CPAS)**: Relationship Scale (Child-Parent Attachment Subscale); **STAI**: State-Trait Anxiety inventory; **STAI-C**: State-Trait Anxiety Inventory for Children

Table 6. Reviews on the impact of parental cancer on children and adolescents

Researcher, year of publication, country	Topics dealt with	Conclusions	Comments
Romer G, Barkmann C, Schulte-Markwort M, Götz T, Riedesser P. 2002, Germany	<ul style="list-style-type: none"> -Methodological review of studies on children of somatically ill parents - considers sample sizes, age group definition, instruments used, parental diseases studied - cancer (15), haemodialysis (9), aids (2), multiple sclerosis, pain syndromes, heart disease (13). 	<ul style="list-style-type: none"> - Lack of relevant keyword which makes it difficult to track studies - theoretical shortcomings: lack of theoretical framework and of models explaining the modes of transmission of psychopathology - ethics are not discussed in reviewed studies - multivariant complexity: integrating numerous variables involved - subjective dimension of experience of children and adolescent is difficult to grasp - cross-sectional studies do not grasp the process: a need for longitudinal, retrospective and prospective research 	<ul style="list-style-type: none"> - Method of review clearly defined - reported on articles and book sections, three academic theses, three theoretical articles, five case studies and 39 empirical studies published 1983-1998
Visser A, Huizinga GA, Van der Graaf WTA, Hoekstra HJ, Hoekstra-Weebers JEHM. 2004, The Netherlands.	<ul style="list-style-type: none"> - Impact of parental cancer on the psychosocial functioning of children: emotional, social, behavioural, cognitive functioning and school performances, physical symptoms - Relationships between study variables and child functioning: child variables (age and gender), parental variables (illness-related variables) - parental psychological functioning), family variables (parent-child relationship, marital functioning, family structure, changes in roles, family functioning and family communication) - Informant agreement (between parents and between children and parents) - Also reviewed intervention studies (7); all papers revealed positive effects of the intervention including less anxiety and more communication 	<ul style="list-style-type: none"> - Emotional problems in school-aged children (≤ 11 years) were reported in several qualitative studies, but only in one quantitative study (sic) - quantitative and qualitative studies reported anxiety and depression in adolescents (≥ 12 years) in particular in adolescent daughters - quantitative studies showed no behavioural and social problems in school age children and adolescents - qualitative studies revealed behavioural problems and described cognitive and physical functioning of children at all ages - the most consistent variables related to children' functioning appeared to be parental psychological functioning, marital satisfaction and family communication 	<ul style="list-style-type: none"> - Method of review clearly defined - reported on 52 studies between January 1980 and March 2004

Researcher, year of publication, country	Topics dealt with	Conclusions	Comments
<p>Grabak BR, Bender CM, Puskar KR, 2007, USA</p>	<ul style="list-style-type: none"> - An analysis of descriptive studies, interventions studies, and book chapters published between 1996 – 2006 that examine the impact of parental cancer on adolescents - emotions and behaviours - perceptions and knowledge of parental cancer - changes in roles - ways of coping 	<ul style="list-style-type: none"> - methodological problems: 1) small samples ranging from 3 to 55; 2) many samples combine school-age, adolescents, young adults, and age ranges not consistent for developmental stage; 3) half of the studies were limited to women with breast cancer; the majority of studies cross-sectional ranging from 2 months to 5 years after the parent's diagnosis – little is known about changes - conceptual issues: conceptual clarity was lacking for the meaning of "children", "distress", "fear" etc. - recommendations for further research: define "children" more exactly, adolescence is characterised by three distinct periods (early, middle and late) which should be considered because the developmental tasks are so different <p>As many studies concentrated on white, well-educated, middle-class people, there is a need for more diversity in socio-economic, racial and ethnic background of samples</p> <ul style="list-style-type: none"> - limitations in methodological quality and numbers of studies 	<ul style="list-style-type: none"> - Method of review clearly reported - 45 studies, three book chapters
<p>Osborn T. 2007, UK.</p>	<ul style="list-style-type: none"> - The study aimed to identify 1) whether early stage parental cancer is associated with an increased risk of psychosocial difficulties among children and adolescents, and 2) which factors are associated with impairment of psychosocial functioning in children and adolescents 	<ul style="list-style-type: none"> - Overall the evidence suggests that children and adolescents do not present more psychosocial problems compared to control groups - slight increase of internalising problems - adolescent daughters more affected - family variables like communication and expressiveness are consistently associated with impairment in child/adolescent psychosocial functioning - the role of maternal depression /adjustment and parenting variables are important predictors - little evidence that medical/treatment variables could be important for the child's outcome 	<ul style="list-style-type: none"> - Method of review clearly defined and reported - Reported on 40 studies (10 for question 1 and 30 for question 2)

2.6 Cancer during pregnancy

Cancer during pregnancy is not an uncommon problem. Approximately one per 1000 pregnant women develops cancer. Several types of cancer have been observed during pregnancy (Antonelli et al. 1996 a, b; De Carolis et al. 2006). The most frequent cancer during pregnancy is breast cancer, with an incidence of one in 3000 to one in 10.000 (Eedarapalli and Jain, 2006) and, it is estimated that the incidence of breast carcinoma during pregnancy will increase as more women delay child-bearing (Loibl et al. 2006). Acute leukaemia (Chelghoum et al. 2005), Hodgkin disease (Woo et al. 1992; Korkontzelos et al. 2005), and lymphoma have been reported during pregnancy (Ward and Weiss 1989; Janov et al. 1992). Additionally, melanoma (Daryanani et al. 2003; Schwartz et al. 2003), colonic cancers adversely affecting pregnancy (Woods et al. 1992), and carcinoma of the cervix or of the ovary have also been reported (Antonelli et al. 1996a, b).

When someone is diagnosed with cancer, he/she has to face the fear of imminent death, although, in the developed West, almost 50% of cancer patients can be cured: cancer is a crisis (Brennan 2004). Transition to parenthood, as a transformation process occurring with time, implying integration of new knowledge, changes in roles, changes in identity, and changes in patterns of behaviour is also a crisis (Benedek 1959; Anthony and Benedek 1970; O'Neill and Ruddick 1979; Cohen and Slade, 2000).

2.6.1 *The developmental tasks of pregnancy and early mother-infant relationship*

For women, the first stage of this transition process is pregnancy. Pregnancy can be seen as a developmental task with maturational phases. Raphael-Leff (1991) describes three phases. In the first stage, before the movements of the foetus are perceived, the pregnant mother goes through several processes including changes in her body and strange bodily perceptions, changes in her self-image and readjustment of her identity, changes in emotional states like overreaction to minor incidents, inappropriate oversensitivity and heightened emotionality and anxiety. The second stage of pregnancy is initiated by the perception of foetal movements. The expectant mother's concentration is divided between the demands of the external world and her growing attention toward what is happening within her. She elaborates fantasies and representations about the baby, sometimes communicating with him/her, and she reassesses her relationship toward her own mother. The third stage, during the last trimester is labelled by concerns for the growth of the baby and worries about labour and birth-giving (Raphael-Leff 1991). However, the process is always individual, unique and private enhancing the transition to motherhood.

As a result of transition and adjustment, parenthood is seen as a new mental state totally affecting the self and the identity of the adult. The concept of maternal preoccupation by Winnicott (1956) implies a transformation in the mind of the mother, while Fonagy and Target (1996) argue that parenthood leads to a transformation in the mind and the mental state of an adult, which is occupied by "holding the baby in mind". Stern (1995) described the concept of "motherhood constellation", which emphasizes that the psychic structure of the mother-to-be is going through the process of total re-organization, which lasts from a few months to two years.

Therefore, parenthood as a transformation and as a new state of inner life in the adult is related to the inner world of the newborn through emotional commitment to the foetus and

attachment. The concept of the attachment bond and the attachment system (which includes behavioural, exploratory and emotional systems) introduced by Bowlby (1969/1982) is central (Zeanah et al. 1993; Seifer et al. 1996). The mother's representations of her unborn child (Benoit et al. 1997) or the mother's representations towards her attachment figures (Fonagy et al. 1991) predict the quality of the infant's attachment pattern.

The representation of self as a mother or as a father, as well as the representation of the child in the adult's mind, reflects, at the same time, the quality of flexibility, and of consistency of the parents (George and Solomon 1996). These representations are highly influenced by one's own childhood experiences and mental health (Fraiberg 1980; Slade et al. 1999). Moreover, Fonagy and Target (1997) suggested that the relationship between attachment processes and the development of the capacity to envision mental states in self and others is a key determinant for the organization of the self. The development of "reflective functioning", which emphasizes the ability to anticipate and to mentalise, starts in early infancy, and this function may develop through life and later plays an important role in parents' sensitivity to understand the needs of their developing children.

The transition prepares the parents to adequately and sensitively meet the infant's developmental needs within the relationship with the infant. During the first three years of life, the infant is going through tremendous developmental changes on a biological, emotional, cognitive and social level, including acquisition of new skills such as walking and speaking (Zeanah et al. 1997). According to Stern (1985), the infant is born with the capacities to be in a relationship; the capacities mature, become organized and structured into a sense of subjective self and of being in relation with others. Stern (1985) defines four senses of self; 1) the emergent self (0-2/3 months), 2) the sense of a core self (2/3 months-7/9 months), 3) the sense of subjective self (7/9 months-18 months) and 4) the self of a verbal self (18 months onwards). To develop these senses of self and being-with-others, the baby needs the caregiver's emotional availability, the regulation of his/her needs like hunger, sleep, state of arousal, affect intensity, the correct perception and interpretation of his/her signals, the appropriate timing in fulfilling the needs, affectionate behaviour, vigilance and protectiveness (Stern 1985; Brockington 1996).

Moreover, the infant also has the resources to develop attachment relationships. This emotional bond between the caregiver and the infant develops during the first years of life and is seen as including four developmental stages: 1) around ten weeks of age the baby discriminates differences between caregivers and strange people, 2) in the second stage, around six months, the baby shows more attention and preferential attachment behaviour toward the mother, 3) the third stage, in the second part of the first year, is characterised by the development of motor skills, and the baby is able to approach the mother and to use language. This phase consolidated while the child's skills increase until the last stage occurring approximately during the third year of life: the attachment figure is maintained in the child's mind, in time and space, even when the attachment figure is not present. The attachment relationship is internalized as a model of-being-with, representations of others in the child's mind and remaining there for the rest of his/her life (Bowlby 1969/1982; Lieberman and Zeanah 1999).

2.6.2 Management of cancer treatment during pregnancy

The first medical challenge when a woman is pregnant, and she is suspected to have cancer, is diagnostic imaging and other investigations. The effects on the baby of imaging procedures have not been studied much (Liberman et al. 1994; Ahn et al. 2003). However, with adequate shielding, diagnostic imaging such as mammography should present few risks to the foetus, and fine-needle aspiration can be used (Loibl et al. 2006).

The next step is treatment. Ebert and colleagues reported (1997) 217 cases of cytotoxic therapy during pregnancy, for different malignant and rheumatologic diseases. In their review, 18 newborns (0.06%) had multiple anomalies of variable severity, and miscarriages occurred in 15 cases (0.06%), with the majority of them occurring after methotrexate administration. Chemotherapy for breast cancer during pregnancy has been reported without serious adverse consequences for the mothers or the babies (Ring et al. 2005). In some studies, safe use of chemotherapy during the second and third trimester has been reported without definite neonatal harm, but chemotherapy exposure in utero can also lead to risks of foetal loss, neonatal death or malformations of the newborn. Nine of the 11 reported malformations occurred when chemotherapy was given in the first trimester (Cardonick and Iacobucci 2004). Gwyn (2005) reported on data including 89 pregnancies that foetuses were exposed to chemotherapy in utero during the second and third trimesters; the pregnancies were carried to term without evidence of congenital abnormalities. Hahn and colleagues (2006) reported that all women in their study (n = 57) delivered live babies: one child had Down syndrome and two had congenital anomalies. At the time of their study, the children's age ranged from 2 to 157 months and they were healthy (Hahn et al. 2006). More data on the children born to women undergoing treatment for cancer should be collected (Gwyn 2005). Results seem to be to some extent contradictory, which can be frightening for the oncologist when he/she tries to deliver good-enough information to the patient.

The monitoring of the pregnancy and the timing of the delivery are optimized in relation to the cancer treatment of the mother. The mother and the baby can be monitored with standard prenatal care, but Doppler ultrasound of the cord vessels should be performed to screen any growth retardation, or oligohydramnios (Loibl et al. 2006). When the maturation of the foetus is sufficient, labour is induced. It is recommended that delivery could occur approximately three weeks after the last dose of chemotherapy (Loibl et al. 2006). Additionally, the delay of delivery for 3 weeks after chemotherapy allows foetal drug excretion via the placenta (Cardonick and Iacobucci 2004). Chemotherapy should not be given after 35 weeks' gestation because spontaneous delivery may occur (Loibl et al. 2006).

Minimizing the risk of maternal and foetal neutropenia and subsequent infection is of paramount importance. Additionally, the platelet count should be sufficient to avoid bleeding complications (Loibl et al. 2006). The gestational age at delivery was in the range 30 to 40 weeks, with a median of 37 weeks, in the studies of Ring and colleagues (2005) and of Hahn and colleagues (2006). Vaginal delivery is recommended, because, if it is planned to continue chemotherapy, the delay is shorter compared with a caesarean section. However, previous obstetric history and individual variations should be taken into consideration. Delivery should take place in a hospital with a neonatal unit, in case of complications (Loibl et al. 2006). Breast feeding is not possible if chemotherapy is continued.

2.7 The psychosocial support of cancer patient's children

Although the results of the studies on families and children of cancer patients reviewed above are to some extent contradictory, most authors of these studies agree that families and children are in need of support when confronted with parental cancer. Additionally, authors unanimously advocate family-centred psychosocial support, especially, if parental cancer is associated with depression in the ill or healthy parent, or in the case of single parenthood (Visser et al. 2004).

A few studies have focused on supporting the children of cancer patients (Greening 1992; Lewandowski 1996; Heiney and Lesesne 1996; Lewis et al. 2006). Lewandowski (1996) emphasized primary and secondary prevention of psychosocial disturbances and psychological problems in children in a primary care setting. The nurse is seen as an educator, who broaches the subject of parental illness, and challenges the assumptions that children do not notice their parent's illness. The nurse is also considered as a screener for specific stressors in families affected by parental cancer. Other ways to intervene included 1) assisting parents in thinking through what information to give their children, and how and where to give it, 2) supporting parents' parenting, 3) enhancing communication between family members, and 4) being a facilitator and "interpreter" between the systems involved with the family (school, health care, hospital, social welfare services). Finally, paediatric nurses working in a primary care setting are in a key position to identify and help children dealing with parental illness.

The "Bear Essentials" programme by Greening (1992) aimed to help families to understand how children perceive illness, separation, and loss, to discuss the concerns of family members in an emotionally supportive environment, and finally, to develop strategies to cope with emotional difficulties linked with parental illness. In this programme, children and parents met separately in concurrent monthly support groups led by a team including a social worker, nurses and a chaplain. The groups met eight times, and had a theme for each meeting, including visiting the hospital, and explaining the medical equipment by giving the children the opportunity to experiment with it on a large teddy bear, who served as the patient.

The "Quest" programme, by Heiney and Lesesne (1996) was designed to support children and adolescents whose parent or grandparent had cancer. After an initial parent interview, the children were allocated into age groups, and participated in one three-hour meeting including a dinner, a lecture and a tour of the different units of the cancer clinic (radiotherapy, laboratory, pharmacy, patient room) followed by a group discussion, and an evaluation. The "bear essentials" and "quest" have been carried out in the United State with a psycho-educative perspective, but the theoretical framework remained unspecified.

Moreover, in the United State, Rauch and Muriel (2003) described a parent guidance programme in a general hospital to provide expert consultation for adults with cancer and their families. Two child psychiatrists and two child psychologists provided consultation on the needs of children in families in which a parent has cancer. The families could be referred by any member of the cancer treatment team, and they were seen without assigning a psychiatric diagnosis. The focus of the consultation was to support parental competency, and children were seen in individual or family sessions. Some families needed only one to three sessions, while others required weekly sessions for several months. Children with

pre-existing psychiatric problems or in need of more intensive treatment were referred to child psychiatry clinics. In addition, the staff members were available to the parent and children surviving the loss of the other parent for some periodic consultations. Finally, in their recommendations for oncologists, Rauch and Muriel emphasized 1) up-dating the knowledge about children's normal development, 2) supporting families to maintain children's normal life routines, and allowing children to visit the sick parent, 3) protecting family time, and 4) enhancing communication within the family by promoting clear, appropriate and honest information. The guidelines for clinicians working with parents with cancer were comprehensive, and included recommendations about children, families, parents, social support, and communication (Rauch et al. 2003).

The Enhancing Connection Program by Lewis and colleagues has also been developed in the United States to reduce cancer-related distress and morbidity in children of cancer patients. The programme included five, one-hour educational counselling sessions delivered at 2-week intervals by trained clinicians. This intervention was found to be helpful both for ill mothers, whose mood became less depressed and whose self-confidence to assist the child improved, and for their children, who were found to present less anxiety and fewer behavioural problems (Lewis et al. 2006).

In Europe, Altschuler and Dale (1999) recommended that professionals should pay more attention to the fact that their patients are also parents. They suggested verbal or written guidelines, and a parent's room on adult wards, but, above all, they called for a change in mentality; being a parent deeply affects the individual, and the role of being a parent cannot be suspended by severe illness.

In a study on the implementation of a child-centred consultation and counselling for cancer patient's children in Germany some recommendations were set: firstly, physicians need practical evidence of the value of a new mental health intervention, secondly if possible, child-centred interventions should not be offered too soon following the parent's initial diagnosis, thirdly, in a high-risk treatment setting, the intervention should be offered prior to, and as a preparation for the critical phase of the treatment and should be implemented as a standard procedure. Furthermore, referrals to the child-centred counselling service were better accepted if made by physicians, not by other staff members. Finally, unresolved family conflicts that existed prior to the onset of a parental disease must be carefully explored and considered (Romer et al. 2007).

In Denmark, within the COSIP project, a focused short-term and needs-based preventive counselling was offered to families with a cancer ill parent. The counselling comprised a maximum of 5–6 sessions in variable settings with the family members. As a standard, the first session was with the parents (both parents if two parents were available) where the setting for the following sessions was discussed. The counselling took place in the family home, unless the family preferred otherwise. In addition to the family sessions, the children were offered group counselling with other children participating in the project. Parents who received counselling were significantly more depressed before the counselling than a nonrandomized control group who did not receive counselling, but participated in another part of the project. For the parents, there was a significant decrease in depression and increase in family functioning scores from before to after the intervention. For the children, a significant pre- to post-decrease in depression score was

found. Reasons for seeking counselling were insecurity in relation to the children, problems with communication, high level of conflict, and change of roles. Parents benefited from the counsellor's feed-back, e.g. confirmation about being a 'good-enough' parent, while family members gained more understanding of the emotions and reactions of other family members, and validation of their own feelings (Thastum et al. 2006).

The interventions are mostly designed for school-age children and adolescents, and ignored the needs of pre-school children.

Finally, to our knowledge, there is no specific model of psychosocial support for pregnant cancer patients and their infants. However, to be diagnosed with cancer during pregnancy might be the most painful and terrifying crisis a pregnant woman can encounter. As a consequence, all the aspects and features of crisis management are relevant in pregnant cancer patient's psycho-social needs (Catherall 2004; Kendall-Tackett 2004).

2.8 Summary of previous research

The results of studies on family functioning in cancer families present several problems, which make them difficult to review and to compare. Many studies concentrated on couples (Northouse et al. 1998, 2000, 2001, 2002) and the family view was secondary. In many other studies, where family members were involved, family members were often adults and not necessarily living under the same roof with the cancer patient. Family members were also patient's siblings or friends, as in Northouse's study (2002). In Kissane's studies (1994, 1996a, b), the children's mean age was 28.2 years, and in Edwards and Clarke's study (2004), the children's mean age was about 44 years. However, Lewis and colleagues (1989, 1993) and Lewis and Hammond (1992, 1996) included latency-aged children and adolescents. The samples were of variable size and were described in various ways: data were provided on background characteristics quite differently (age, mean age, status of "relatives", socioeconomic status, family structure, number of children). The instruments and the concepts used in the studies, like psychosocial adjustment, marital satisfaction, coping, family adjustment, appraisal, concurrent stress referred to very different theoretical frameworks, making the integration of results difficult. Moreover, children's own opinion is neglected and, finally, the concept of family remains unspecified in all previous studies.

The results of studies on children's mental health showed, in conclusion, that overall, children and adolescents do not generally experience elevated levels of severe psychological problems, but they are at a slightly increased risk of internalising problems, especially adolescent daughters (Visser et al. 2004, Osborn 2007). Family variables like quality of communication, and parental functioning especially maternal depression or level of adjustment are consistently associated with child/adolescent mental health. These findings indicate that there is a need to identify families at risks. Moreover, Grabiak and colleagues (2007) advocate for conceptual clarity, which is missing in previous studies.

The process of adjustment to motherhood and to early mother-infant relationship can be affected by several risk factors such as maternal psychopathology (Zeanah et al. 1997), maternal depression (Glover et al. 1999; Rich-Edwards et al. 2006; Gjerdigen and Yawn 2007), mother's own childhood experiences (Fraiberg 1980), marital relationship, and social support (Belsky 1984). Women's psychosocial needs have been only seldom studied,

and the few published references on the psychological aspect of cancer during pregnancy are, as Shover stated (2000, p. 699), “anecdotal”. Furthermore, cancer during pregnancy has not been examined from an infant psychiatric and early relationship perspective.

In Finland, the family functioning of cancer patients with dependant children, the mental health of children who have a cancer ill parent compared to children of parents without cancer and cancer during pregnancy have not been studied before. Psychosocial support for cancer patient’ children may have been provided by the Finnish Cancer Association; however, to our knowledge, psychosocial support for children of cancer patients has not reported within a University Hospital setting.

3 AIMS OF THIS STUDY

The aims of the present study were:

1. To examine factors associated with family functioning in cancer patients' families with dependant children:
 - a) in a sample of Finnish families compared to a community sample (Study I)
 - b) in a large sample of European families (Study II).
2. To examine 11-17-year old children's mental health when they are exposed to parental cancer. More specifically the research questions were:
 - a) to examine the children's perception of their family's functioning, and the association between family functioning and children's self-reported symptoms of psychological distress (Study III).
 - b) to examine the prevalence of self-reported symptoms and the factors associated with them in children of ill parents compared to a control group (Study III).
3. To explore the subjective experience of having cancer during pregnancy (Study V).
4. To explore the implementation of a child-centred family intervention for cancer patients' families with dependant children, and the reception of such an intervention in an adult oncology setting (Study IV).

4 PARTICIPANTS, METHODS AND ANALYSES

4.1 Procedure

4.1.1 Recruitment procedure

The participants of this present study were simultaneously recruited in six of the eight European centres involved in the COSIP project: Basel (Switzerland), Hamburg (Germany), London and Sutton (United Kingdom), Turku (Finland), Vienna (Austria), and Århus (Denmark) between May 1st 2002 and April 30th 2004. Each country independently collected its own sample, which, at the end of the project, was pooled together (Figure 3). *Study II* is based on this compilation and, thus, includes the Finnish sample.

The participants of *studies I, III and IV* (Finnish sample), were recruited from the Department of Oncology and Radiotherapy of the Turku University Central Hospital as follows: eligible patients were asked by their oncologists for permission to be contacted by the author of this thesis, who had personal face-to-face contact with every patient meeting the inclusion criteria (Appendix 1).

The common inclusion criteria for all samples, both international and Finnish were:

- A new or relapsed cancer diagnosed within 12 months (for *studies I, III, IV* in Finland), and at least two months but not more than 60 months (for the multi-site *study II*) before the start of the study.
- At least one biological child, between 4 and 17 years living with the cancer patient.
- Fluency in own mother tongue.

The patients for *study V* were included after the end of the formal data collection via the clinical work provided for the oncology clinic as a continuation of the COSIP project and no specific inclusion criteria were set.

Patients with haematological and gynaecological cancers were not included, because they belonged to other clinics, and the available resources for providing counselling did not extend to them.

The Finnish studies included a control group which was collected during autumn 2003. Six classes (three third-grade classes and three eighth-grade classes) of six different schools in Turku were randomly chosen. Pupils were given the same set of questionnaires, return-stamped envelopes and instructions as the clinical sample. For ethical reasons, collection of the pupils' addresses was not allowed. Therefore, the main teacher of each class was called twice to remind the children to send the completed set of questionnaires to the researcher.

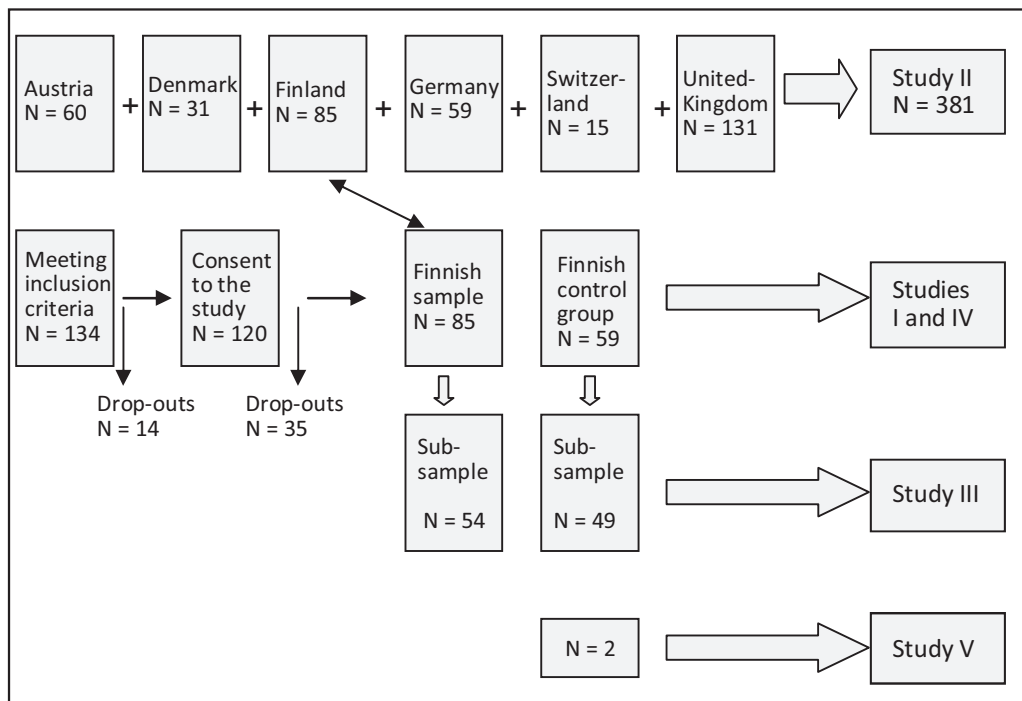


Figure 3. Flow-Chart of data collection (N = number of families)

4.1.2 Procedure for proposing and delivering counselling (Study IV)

The COSIP project included the implementation of services for children of cancer patients. Therefore, counselling was offered to all successive new or relapsed cancer patients who had at least one dependant child living with the patient (Appendix 2). The sessions were briefly summarized in the hospital files of the cancer patient, and an ICD-10 diagnosis Z71.8 ‘Other specified counselling’ was used.

Previous research and descriptions of interventions for cancer patients’ children, clinical experience as a family therapist working with children and expertise in child psychiatry were used for designing a model of counselling for cancer patients and their family members. It was designed to be child-centred. Two theoretical moves were made: 1) a move from the individual approach to the family approach, and 2) a move from the patient perspective to the parent perspective, i.e. the cancer patients were seen primarily as parents.

The purpose of the therapeutic intervention was to provide time and space for each family member individually, for the couple, the siblings, and for them all together as a family. The principles were these of the need-specific approach developed by Alanen and colleagues, which are: 1) the therapeutic activities are planned and carried out flexibly and individually in each case so that they meet the real and changing needs of the patients as well as of their family members. 2) the psychotherapeutic attitude is emphasized, 3) the different therapeutic activities should support and not impair each other, 4) the process quality of therapy is clearly perceived (Alanen 1975, 1997; Alanen et al. 1990; Alanen et al. 1991).

The main goals of the model were defined as follows:

- (1) Establishing a strong therapeutic working alliance between the therapist(s) and all family members (Minuchin and Fishmann 1981).
- (2) Supporting parenthood and parenting by alleviating parents' concern about the children, and children's worries about their parents. This was mainly achieved by providing parents, children and the whole family with space and time to elaborate on cancer: how it felt to be informed about the diagnosis, how it felt to have to deal with the "bad news", how every family member was able to cope during the time of the treatment, and finally, how it was when the treatment ended.
- (3) Helping parents to see the emotions and needs of their children by emphasizing the uniqueness of the experience of each family member, and by validating the children's feelings and thoughts. If parents had difficulties understanding their children's reactions, the therapist acted as an interpreter. Children's feelings and thoughts were validated.
- (4) Reducing feelings of guilt and promoting hope by facilitating communication among family members.
- (5) Assessing the need of family members for more help in the case of psychological distress (if the counselling intervention was insufficient).
- (6) In the case of a fatal prognosis, accompanying the family members in their process through loss and grief.

Technically, the counselling model consisted of 5-6 different sessions including 1-2 family sessions, 1-2 couple sessions, one sibling session, and an individual session for each child (Appendix 3). Additionally, one follow-up session was scheduled if the family wished it, or if the therapists wanted to check the development of the situation. Families could choose how (with the whole family or with a couple session), and when they wanted to start. Each session took about 50-60 minutes and was conducted by two experienced family therapists, with special competences to work with children (one therapist had experience in somatic treatment of cancer patients; one was a child psychiatrist). The counselling sessions took place in a cosy, friendly room, especially equipped for working even with small children with a doll's house, toys, drawing paper and pencils. However, if the cancer patient's situation required it, the counselling sessions could take place at the parent's bedside. Clinical supervision for the therapists was provided twice a month.

4.2 Participants in the European multi-site study (study II)

The European multi-site sample consisted of 381 families making 1128 participants in total. Details about possible bias in data collection and drop-outs are provided, besides Finland, only for Germany and the UK. Families were included if all eligible family members participated and at least 80% of the questionnaires were properly completed. Return rates are only known for Germany: 55%, Finland: 70% and the UK: 63% (COSIP Final report, 2005). A summary of the sample characteristics is presented in Tables 7 and 8.

Table 7. Participants in study II

	N	(%)	Mean (SD)
Family structure			
Two-Parents Families	276	72	
Single-Parent Families	79	20	
Missing data	26	7	
Number of children			
One child	60	16	
Two children	192	50	
Three or more children	114	30	
Missing data	15	4	
School education (years of school*)			
Low (< 9)	127	33	
Middle (> 9 and < 13)	125	33	
High (> 13)	87	23	
Missing data	42	11	
Family members			
Healthy fathers	184	29	
Age			44.4 (6.3)
Cancer fathers	85	13	
Age			45.3 (7.5)
Healthy mothers	74	12	
Age			41.3 (5.9)
Cancer mothers	287	45	
Age			43.4 (6)
Missing data	9	2	
Boys			
Age	228	47	10.8 (3.1)
<11v.	107		
> 11v.	121		
Girls			
Age	261	53	11.7 (3.4)
<11v.	94		
> 11v.	167		

* The socio-economic status of the family was expressed by choosing the educational level of the more educated parent

Table 8. Characteristics of the disease of the patients in study II

	N	(%)	Mean (SD)
Diagnosis			
Breast cancer	235	62	
Hodgkin disease and leukemia	45	12	
Others	101	27	
Time since diagnosis (months)			25.2 (69.4)
Lower quartile	4.8		
Median	10.7		
Upper quartile	24.5		
Number of patients diagnosed			
< 12 months	185	49	
> 12months	159	41	
Missing data	37	9	
Quality of life (SF-8 PCS)			
Cancer patient mother			43.9 (10)
Cancer patient father			42.3 (11.6)
Cancer patients			41.9 (10.2)

4.3 Participants in the Finnish studies

4.3.1 The participants of the clinical sample in studies I, III and IV

During the data collection period, 2063 cancer patients visited the Oncology Clinic for the first time and 134 patients fulfilled the inclusion criteria (6.4%). However, fourteen patients refused to be contacted. Data on age, gender, diagnosis and occupation were collected from files about these patients. These were seven women and seven men (mean age 45.8) and they had 19 children (mean age 12.7 years). This group did not differ significantly from the study group with regard to diagnosis, gender, age or occupation. Finally, the questionnaires were given to 120 patients and their family members, and 85 families returned the set of completed questionnaires (71 %). Data on the drop-out group (29%) are not available.

A summary of the sample characteristics is presented in Table 9.

Table 9. Participants in the Finnish studies I and IV

	Clinical sample N (%)	Control group N (%)	p-values
Families	N = 85	N = 59	
Two-parent families	69 (81)	47 (79)	
Single-parent families	16 (19)	12 (20)	p = 0.83*
Number of children in the family			
One	16 (18)	13 (22)	
Two	36 (42)	33 (56)	
Three or more	33 (38)	13 (22)	p = 0.10***
Adults	146	105	
Mothers	82 (56)	58	
Fathers	64 (43)	47	p = 0.80*
mean age (SD)	42.97 (6.77)	43.6 (6.09)	P = 0.45**
Ill Parents	85		
Mothers	63 (74)		
Fathers	22 (25)		
mean age (SD)	43.2 (6.53)		
Healthy parents	61	105	
Mothers	19 (31)	58 (55)	
Fathers	42 (68)	47 (45)	
mean age (SD)	42.60 (7.17)	43.6 (6.09)	
Children all	143	104	p = 0.12*
Girls	73 (51)	49 (47)	
Boys	70 (49)	55 (52)	
mean age (SD)	10.7 (3.9)	10.6 (3.8)	p = 0.18 **
Children ≥ 11 year			
Girls > 11y.	41 (28)	30 (28)	
Boys > 11y.	27 (19)	35 (33)	
mean age (SD)	13.76 (1.99)	14.17 (1.47)	

* Fishers Exact-test

** T-test

*** Cochran-Mantel-Haenzel test

For *study III* a sub-sample was segmented consisting of 54 families. A summary of the sample characteristics is presented in Table 10.

In *studies I and III* a control group was used. A sub-sample of the control group was segmented for *study III*. The questionnaires were given to 172 control group families and were returned by 59 families (32%). A summary of the sample characteristics is presented in Tables 9 and 10. The control group did not differ statistically from the clinical sample (Table 9).

Table 10. Sub-samples of study III

	Clinical sample N (%)	Mean age (SD)	Control group N (%)	Mean age (SD)
Female				
All mothers	52	44.8 (5.9)	48	43.3 (4.6)
Ill mothers	41 (76)			
Girls	30 (56)	13.5 (1.8)	19 (39)	13.7 (1.5)
Male				
All fathers	39	45.7 (6.9)	40	46.3 (7.1)
Ill fathers	13 (24)			
Boys	24 (44)	14. (2.)	30 (61)	14.1 (1.3)
Illness-related variables				
Diagnosis				
Breast cancer	33			
Others	21			
First diagnosis	48			
Recurrence	6			
Treatment on-going				
Chemotherapy	33			
Radiotherapy	15			
Treatment finished	5			
Data missing	1			

4.3.2 The participants of study V

Study V is a qualitative study on two pregnant cancer patients' subjective experiences and their psychotherapy.

Lisa

Lisa was a 35-year-old pregnant woman. During week 25 of pregnancy she was diagnosed with a Hodgkin disease (mixed cellularity stage II). She was given two courses (course 1A, 1B, 2A and 2B) of chemotherapy before the delivery. The pregnancy was monitored at the gynecologic clinic at weeks 25, 29+1, 31+2, 33+2 and 35+2. Each time the patient underwent an ultra-sound examination. At pregnancy week 37 +2, the labour was induced, and she gave birth (vaginal delivery) to a healthy infant girl: 2925 gr, 49 cm, and apgar point 9/9/9. Two weeks after the delivery, the chemotherapy was continued and she was given six more chemotherapy courses within five months. The infant was seen in the pediatric clinic and her heart was examined, because the medication which was given to her mother could have been toxic for the foetus. However, the infant was healthy. At the end of chemotherapy, the patient was given 23 days of consolidating radiotherapy on the mediastinum. The patient was seen in the oncology clinic two, six, ten, fourteen and eighteen months after the termination of the treatment for a follow-up control. The mother was in remission, and the child was found to be healthy.

Helen

Helen, a 28-year-old healthy mother was diagnosed with a T-cell lymphoma (lymphoma malignum non-Hodgkin anaplastic large T-cell stage IIB, IPI 0). At that time she was in the 24th week of pregnancy. She was given four courses of “lightened” chemotherapy before the delivery, which was planned to happen at week 37 of pregnancy. The pregnancy was monitored almost weekly and the foetus was examined by ultra-sound. At week 37 of pregnancy, the patient entered hospital for induction of the delivery. Despite one week of effort, first with vaginal preparations (five days and one day rest), and then with intravenous oxitocin, the delivery did not start. Pregnancy was at 38 +5. Finally, the obstetrician decided to proceed to an emergency caesarean, eight days after the process of induction of the delivery had started. A healthy infant boy was born, 3090 gr, 51 cm, apgar points 9/10/10. Breast feeding was not allowed, but the infant was immediately given to his mother.

Helen was given more chemotherapy. After chemotherapy, she was admitted to the haematological ward for autologous cell transplantation. At the end of the treatment the baby was three months and two weeks old. Helen was seen in the oncology clinic for follow-up visits: she was in remission, and the baby was found to be healthy.

4.4 Methods

Quantitative and qualitative methods were used separately and/or in combination in the studies of this dissertation. Only quantitative methods were used in *studies I, II, and III*. Quantitative and qualitative methods were used *in study IV*, and qualitative methods were exclusively used in *study V*.

Study IV examined the use of services, and *study V* the experience of having cancer during pregnancy in a naturalistic clinical setting over a period of one year. The naturalistic setting allowed the examination of the medical practice in the broadest sense within the actual clinical context of patients’ cancer treatment.

Triangulation was used. Triangulation is the use of multiple methods, theories, data sets in the study of a common phenomenon (Jick 1983; Ely 1991). Theoretical triangulation involves the use of several frames of reference or perspectives (theories on family, individual development, early infancy, mental health etc.), data triangulation attempts to gather data through various methods (self-report, interviews, observations, counselling) from different participants (patient, spouse, children, staff of the oncology clinic) and, finally, methodological triangulation which analyses the same set of data with different methods (Eskola and Suoranta 1998, p. 69-70). The goal is to increase reliability (Tuomi and Saajärvi 2002, p.141-142).

4.4.1 Quantitative methods: questionnaires used

The instruments were chosen within the European multi-site consortium before the project started. Some instruments were commonly used in Finland and Finnish translations were available.

Background information and demographic data were collected using a questionnaire designed for this purpose by the coordinator of the project. This background questionnaire was a set of modules modified to fit the specific composition of each family involved in the study (Appendix 5 – 8). The author of this thesis translated these questionnaires from German and English into Finnish and they were pre-tested during the spring 2002, but not back-translated. One module was designed for the oncologist in charge, and was delivered in English (Appendix 9). These questionnaires were used in *studies I, II, III, and IV*.

Family functioning measure

Family functioning was measured by the Family Assessment Device (FAD, Epstein et al. 1983). A Finnish translation of the instrument was available (Appendix 10). The FAD is a self-report questionnaire constructed to collect information on the various dimensions of the family system as a whole. The FAD was used in *studies I, II, and III*. FAD is made up of seven scales measuring Problem Solving, Roles, Behaviour Control, Communication, Affective Responsiveness, Affective Involvement, and General Functioning. There is no cut-off score but higher scores (>2) indicate greater family dysfunction. The reliability and validity of the instrument have been assessed in several studies, also in an oncology setting (Epstein et al. 1983; Byles et al. 1988; Miller et al. 1985; Kabacoff et al. 1990; Miller et al. 1994). Kabacoff and colleagues (1990) investigated the FAD using data from large psychiatric, medical and non-clinical samples, and they showed that six out of seven FAD scales demonstrated adequate internal reliabilities with alpha coefficients ranging from .57 to .86. The FAD was completed by both parents and children 11 years and older. In *studies I and III*, the Cronbach alphas ranged between .67 and .90, and for the European multi-site study (*study II*) .89.

Depression measure

Parental depression was assessed by the Beck Depression Inventory (BDI-IA, Beck and Steer 1993). The BDI is a 21-item self-report questionnaire used to measure depressive attitudes. An official translation of the instrument was available. The BDI was used in *studies I and II* (Appendix 11). There are four possible responses to each of the 21 items (symptoms and attitudes), which could be rated from 0 to 3 in terms of intensity of depression. The total range is thus 0-63, and usually the sum score of the total scale is used. The instrument is widely used in Finland (Hintikka et al. 2001; Korkeila et al. 2005) and internationally (Beck et al. 1988). In their review article, Beck and colleagues (1988) indicated that the BDI has high internal consistency in psychiatric and non-psychiatric samples. The Cronbach alpha for all samples used (clinical and control) was .90.

Family resilience

Family resilience as a family resource was measured by the *Sense of Coherence* (SOC, Antonovsky 1983) questionnaire which measures the perception of family members of their capacity to deal with the challenge of their life situation (Appendix 12). An official translation of the instrument was available. The sense of coherence (SOC) was used only in *study I*, as a descriptor of resilience seemed meaningful in the context of psycho-oncology. The SOC is a questionnaire consisting of 13 multiple-choice questions developed and validated by Antonovsky (1983). It is the shorter version of a 29-item semantic differentials

questionnaire. The components of SOC are Comprehensibility, Manageability and Meaningfulness. The subjects are asked to select a response, on a seven-point semantic differential scale: the higher the sum score, the higher the sense of coherence. Individuals with a strong SOC perceive their lives as comprehensible, manageable, and meaningful. The questionnaire is designed to be applicable cross-culturally and it has been used by research teams in at least in 33 languages and in 32 countries (Erikson and Lindström 2005). The SOC measure has previously been used in Finnish studies (Suominen et al. 2001, Suominen et al. 2004). High internal consistency has been found in a considerable variety of populations (Antonovsky 1993). The SOC was completed both by parents and children aged 11 years and over. The Cronbach alpha for the SOC of all participants was .57 and this was considered moderate.

Quality of life

Patient's *quality of life* was measured by the short-form questionnaire of the Medical Outcomes Health Survey, SF-8 (Ware et al. 2001), which assesses the perception of health status of the respondent (Appendix 13). The questionnaire was translated into Finnish by the researcher, but not back-translated. Only the ill parents filled in the forms. The questionnaire was used in *studies II* and *III*. The SF-8 consists of a physical component summary (PCS) and a mental component summary (MCS). The PCS measures physical functioning, physical role and bodily pain, whereas the MCS measures mental health, emotional role and social functioning. When analysing the data, the items are reversely scored so that high scores indicate better functioning (Ware et al. 2001). In *study II*, only the PCS scale was used, because the MCS correlated highly with the BDI. In *study III*, Cronbach alpha was .87 for the PCS, and .77 for the MCS, and in *study II*, the Cronbach alpha for the PCS was .88.

Children' mental health measure

The children' (age 11 to 17 years) mental health was measured by the Youth Self-Report (YSR, Achenbach and Rescorla 2001) and was used only in *study III* (Appendix 14). The YSR is a questionnaire on psychological symptoms for children aged 11-18 (Achenbach and Rescorla 2001). The YSR measures the following symptoms: 1) internalizing problems (anxiousness, withdrawal, depressive and somatic symptoms), 2) externalizing problems (rule-breaking and aggressive behaviour), and 3) the total score of all the symptoms mentioned above (Achenbach and Rescorla 2001). The reliability and validity of YSR have been found to be high (Belter and Foster 1996; Achenbach and Rescorla 2001). In *study III*, the Cronbach alphas ranged between .85 and .89.

4.4.2 Qualitative data collection methods

Methods for assessing the use of counselling (Study IV)

The use of counselling was assessed both by quantitative and qualitative methods.

To assess the use of the service, data were collected on patients who did not want to participate in counselling and more data were gathered by phone interviews which were documented in memos. Quantitative data about the types and the timing of sessions

provided for the patients who participated were collected. Opinions about the counselling were asked for during the last session and the follow-up session and were recorded on videotapes. Finally, the steps of the implementation process were documented in project memos.

Method for assessing the impact of the COSIP-project among the staff of the Oncology Clinic

In order to explore the level of connectedness with and attitudes to the COSIP - project among the staff of the Oncology Clinic, a one-page questionnaire was distributed (n = 148) (Appendix 15). Background information and information about experiences concerning the COSIP project were gathered.

Data collection methods used in study V

Data for *study V* were collected during psychotherapy sessions and mother-infant interaction observation, using the Ester Bick method. Bick developed, in Tavistock Clinic, her method of infant observation, which encouraged observers to watch and listen to infants during their early development, and focused on in-depth analysis of the capacity for attention and psychic transformation (Bick 1964, 1968; Haag and Haag 1995). The collected material consisted of sessions' memos, mother-infant observation memos, personal reflective diaries, memos used for supervision, and patient's files.

4.5 Analyses

4.5.1 Analyses used in studies I and II

The data for the Finnish studies were stored and analysed with SPSS for Windows 12.0.1, and the data of *study II* were analysed with SAS for Windows, release 9.1.3/2004. For *study I*, differences between the clinical sample and the control group regarding the gender and age of the ill parent, family structure and number of children were examined by Fishers Exact test for gender and family structure, T-test for age, and the Cochran-Mantel-Haenzel test for comparing the number of children in the families (Table 9). For *Study II*, descriptive statistics were used to describe the participants.

The statistical method used for *studies I and II* was a multilevel analysis model formulated for use with the SAS[®] mixed procedures applied to family functioning (FAD, Family Assessment Device, Epstein et al. 1983). Family Functioning (FAD) was the outcome variable. This procedure requires a normal distribution which was verified. The multi-level approach is appropriate for data with nested sources of variability, which means involving units at a lower level or micro-units (in this case individuals) nested within units at a higher level or macro-units (in this case, families). This multilevel analysing technique allows the simultaneous examination of the effects of group level and individual level variables on individual level outcomes, while accounting for the non-independence of observations within groups (Singer 1998; Roux 2002). Multilevel analysis also allows the examination of both between-group and within-group variability, as well as how family level and individual level variables are related to variability on both levels (Singer 1998; Roux 2002). The procedure allows a mixture of fixed effects (or

fixed coefficients) and random effects (or random coefficients). In mixed models, some of the regression coefficients are allowed to vary randomly across the higher level but others are not. The term, mixed, is also related to the fact that it is a correlation between lower level units (individuals) within higher level units (families). This procedure is an answer to the problem of analysing data from multiple informants. The models were tested in two master theses in statistics before they were used (Saunisto 2004, Saarelainen 2008, in press).

The explanatory variables used in the analysis were the same for *studies I and II* with some differences, which are presented along with the variables concerned.

The explanatory variables were included on two level; individual and familial.

On the individual level, the explanatory variables involved in the analysis were:

1. The role of the respondent, which was coded into two categories parent (1) and child (2).
2. The age of the respondent was included as a categorical variable in *study I* (adult/child) and as a continuous variable in *study II*.
3. The gender of the respondent was coded into two categories, male and female.
4. The score of the SOC, (sum variable), was used as a continuous variable, and only in *study I*.

The variables used *on the family level* were:

1. The BDI score for the ill parent, for the mother, and for the father. The BDI score was selected as a family level variable, because the data were collected only from the parents, and therefore, the score discriminates between families affected by parental depression or not. The variable was used as a continuous variable in *study I*, and as a categorical variable in *study II*. In *study II*, the caseness of depression was defined according to Berard et al., (1998) who confirmed that a score of ≥ 16 discriminated “true” cases of depression in cancer patients. The non-depressed were coded (0) and the depressed (1).
2. The SF-8 PCS for the ill parent was used as a continuous variable in *study II*.
3. The family structure was coded into two categories: (0) two-parent family, (1) single-parent family
4. The number of children in the family was coded into three categories: (1) one child, (2) two children, (3) three or more children.
5. The gender of the ill parent (1) male and (2) female.
6. The state of the disease was coded into two categories (1) new cancer and (2) relapsed cancer, for *study I*. This dichotomy was not possible for *study II* due to the large amount of missing data, and another solution had to be found. Therefore, the

diagnosis was used as a categorical variable and coded: (1) for breast cancer, (2) for Hodgkin disease and leukaemia, and (3) for other cancers.

7. In *study II*, the time since diagnosis was used and was coded: (1) < 12 months from diagnosis, and (2) \geq 12 months (at the time the study was conducted). This variable was included to give some knowledge about the effect of longstanding exposure to cancer.
8. Because the data were larger in *study II*, it was possible to include socio-economic status (SES) of the family (1) low, (2) middle, and (3) high defined by choosing the level of education of the more educated parent; this was a pragmatic solution given the diversity of the six countries involved in the study.

The restricted maximum likelihood method was used for estimating parameters of models using the statistical program SAS 9.1. At baseline a model without any explanatory variables was used in order to obtain the ratio of between-respondent to within-respondent variability. After that, the main effects of all theoretically important variables, as defined above, were added. The model was further refined in an exploratory way by excluding non-significant effects. The aim of this procedure was to extract the variables significantly associated with perceived general family functioning and, additionally, with each separate subscale.

4.5.2 Analyses for study III

For the sample of *study III*, descriptive analyses were used for the clinical and control groups. The group comparisons between the clinical and control group were performed using T-tests (variables normally distributed), and Mann Whitney U-tests (not normal distribution). Depending on the particular research aim, data from the YSR, FAD, SF-8 and the demographic questionnaires were analyzed. The seven subscales of FAD were included in the analyses. When analyzing SF-8, the scores of each subscale were used. Children with missing values on any of the subscales in the FAD or YSR ($n = 5$ in the clinical group; $n = 4$ in the control group) were left out of every analysis. When analyzing the effects of disease characteristics and SF-8, families with missing values on any of these variables were also left out of the analyses ($n = 1$). Due to the small size of some categories describing the onset and prognosis of the patient's illness, some of the original categories were added together. Onset was divided into acute and sub-acute/lingering, and prognosis was divided into curable/static and progressing/uncertain/lethal.

Before conducting correlation analyses, the distributions of the variables were explored. Depending on whether the variables were normally distributed or not, Pearson's or Spearman's correlations (two-tailed) were computed for YSR, SF-8, FAD and evaluations of illness. In the clinical group, regression analyses (stepwise) were performed to find out which FAD scales were able to independently contribute to the correlations with the YSR scales. The subscale, general functioning, was removed, as it is compiled of all other subscales in FAD, and therefore correlates highly with them ($r > 0.60$). Other scales showing a high inter-correlation (problem solving, communication and roles, all $r > 0.60$) were in turn included in the regression analyses, and the one subscale making the most significant prediction was finally included in the results. In order to explore the interaction

between the symptoms in daughters/sons and the sex of the ill parent, two-way analysis of variance (ANOVA) was performed. Since the YSR variables in this study were not normally distributed, non-parametric Mann–Whitney U-tests were computed to confirm the results of the ANOVA. Group comparisons were conducted between the clinical group and the control group, to determine whether the two groups differed significantly from each other with regard to the children's mental health and family functioning. If the variables were normally distributed, t-tests for two independent samples were used, and if they were not, non-parametric tests for two independent samples (Mann–Whitney U-tests) were computed.

A summary of the use of the variables used in *studies I, II, III, IV* is presented in Table 11.

Table 11. Summary of variables used in studies I, II, III and IV

	Study I	Study II	Study III	Study IV
Explanatory variables				
Family structure:	x	x	x	two-parent/ single/ recomposed
Two-parent family				
Single parent family				
Number of children:	x	x	x	x
1/ 2 or 3+				
Role in the family: parent/ child	x	x	x	x
Gender: male/female	x	x	x	-
Age of the respondent	child/adult	continuous	-	-
Socio-economic status:	-	x	x	x
high/middle/low				
Depression (BDI) of the mother, the father, the ill parent	continuous	BDI < 16 and BDI ≥ 16	-	-
Sense of Coherence	continuous	-	-	-
Quality of life (SF-8)	-	PCS scale continuous	PCS and MCS scales continuous	-
Onset and prognosis of the patient's illness	new/relapse	-	new/relapse	-
Time since diagnosis	continuous	<12m/>12m	-	
Diagnosis: breast cancer/ Hodgkin-leukaemia/other	-	Breast cancer/ Hodgkin/other	breast cancer/ other	breast cancer /other
Patient/control	x	-	x	comparisons between the group who participated in counselling vs. the group who did not
Country	-	x	-	-

4.5.3 Analyses for study IV

In *study IV*, descriptive statistics were used to describe the participants' characteristics and the quantitative aspect of the counselling. The statistical significance of differences between variables in the groups of all patients, the group of patients who participated in counselling, and the group of patients who did not participate was examined. Variables

such as gender, diagnosis and occupation were compared using the Pearson chi-square, and age was compared using ANOVA variance analysis.

Likewise, descriptive analyses were used to examine the variables of the questionnaire addressed to the staffs of the oncology clinic. To evaluate the connectedness with the project, the answers to questions 1-3 were pooled. The answers to questions 4-6 were combined to describe the attitude toward the project. Cross-tabulations were used to examine associations between variables.

4.5.4 Qualitative analyses for studies IV and V

The material collected for *studies IV and V* consisted of memos of phone interviews, memos of psychotherapy sessions, memos of the content of sessions and videotaped sessions, memos of observed interaction between mothers and their infants, diaries of conversations with the staff of the Oncology Clinic, and personal memos used in supervision. Memos were analysed using content analysis. Content analysis is a process used to systematically analyse documents with the aim of describing a phenomenon in a conceptual form (Cavanagh 1997). Content analysis aims to classify and describe phenomena within a process involving several steps: firstly, the units of analysis were defined according to the research question to be answered, secondly the material was read or viewed (for videos) several times asking specific questions: who is involved, when, how, how many times, where, what is happening and why? New memos were generated. Observations were reduced, simplified and grouped, exploring similarities and differences. The classifications and the observations were abstracted into new categories. Reliability was checked by another researcher.

4.6 Ethical considerations

This study and the implementation of the clinical work with cancer patients were approved by the Ethical Committee of Turku University Hospital and Turku city (for the collection of the control group). Written informed consent was required from parents and children (Appendix 4). The patients of *study V* provided written consent for describing their cases.

For the European multi-site sample, the ethics review boards of each locally involved hospital approved the study and the coordinator of the COSIP project guaranteed the EU commission compliance with ethical requirements.

5 RESULTS

5.1 Family functioning in cancer patients' families with dependant children (I, II and III)

In the studies included in this thesis, families were well functioning: the FAD mean scores of each sub-scale were not on a clinical level (< 2). When focusing on differences between groups, there were no differences between the clinical sample and the control group in *study I*, and no significant differences among the six countries in *study II*. The main results are summarized in Table 12.

Table 12. Summary of results: Factors associated with Family Functioning sub-scales in studies I and II

Variables	General Functioning	Problem-solving	Communication	Roles	Affective responsiveness	Affective involvement	Behaviour Control
Family structure:							
- two-parent family					p < 0.01 (study I)		
- single-parent family							
Role in the family:							
- Child		p < 0.001 (II)	p < 0.001 (II)		p < 0.01 (II)	p < 0.001 (II)	p < 0.001 (II)
- Parent		p < 0.01 (I)	p < 0.01 (I)		p < 0.01 (I)		
Gender:							
- Male	p < .0001 (I)	p < 0.01 (I)	p < .0001 (I)	p < 0.01 (I)	p < .0001 (I and II)	p < 0.01 (I)	p < 0.01 (I)
- Female			p < 0.05 (II)	p < 0.01 (II)			
Age of the respondent							
- Child							p < 0.05 (II)
- Parent	p < 0.05 (II)				p < 0.01 (II)		
BDI of the:							
- Mother	p < 0.01 (I)	p < 0.05 (I)		p < 0.05 (I)			
- Father							
- Ill parent	p < .001 (II)	p < .001 (II)	p < .001 (II)	p < .001 (II)	p < 0.01		p < 0.05 (II)
SOC							
	p < .0001 (I)	p < .0001 (I)	p < .0001 (I)	p < .0001 (I)	p < .0001 (I)	p < .0001 (I)	p < .0001 (I)
SF-8 - PCS							
				p < 0.05 (II)			
Time since diagnosis							
Diagnosis							
- Breast cancer							
- Hodgkin-leukaemia							p < 0.05 (II)
- Other cancers							

5.1.1 Depression

In *study I*, the BDI score of the mother was associated with FAD General Functioning, with FAD Problem Solving, and FAD Roles. The scores of FAD scales increased as the maternal BDI score increased, indicating increasing impairment in family functioning. This was true for the clinical sample, as well as for the control group.

In *study II*, where depression was categorised, each FAD subscale except Affective Responsiveness was significantly associated with the ill parent's depression: General Functioning, Problem Solving, Behaviour Control, Roles, Communication, Affective

Involvement. The depression of the ill parent was the most significant variable associated with impairment of family functioning in *study II* (Table 12).

The prevalence of depression in the sample of *study II* is presented in Table 13. Among cancer patients, 35% of the mothers and 28% of the fathers were depressed. Among healthy parents, 28% of the mothers and 13% of the fathers were depressed.

Table 13. Prevalence of depression in parents of study II

Depression (BDI score)	N	%	Mean (SD)
Healthy mothers			
BDI < 16	49	71	
BDI ≥ 16	20	28	
Mean (SD)			12.4 (8.9)
missing data	2	2	
Healthy fathers			
BDI < 16	153	86	
BDI ≥ 16	24	13	
Mean (SD)			7.7 (7.1)
missing data	7	4	
Cancer mothers			
BDI < 16	182	68	
BDI ≥ 16	95	35	
Mean (SD)			13.4 (8.9)
missing data	10	3	
Cancer fathers			
BDI < 16	43	71	
BDI ≥ 16	16	28	
Mean (SD)			9 (7.8)
missing data	8	11	

5.1.2 Other factors

No associations with FAD scores were found with the number of children, the socioeconomic status or the time since diagnosis (*Studies I and II*).

Family structure was found to be associated with FAD Affective Responsiveness, but only in *study I*. Belonging to a two-parent family was significantly associated with better FAD Affective Responsiveness ($p < 0.01$).

Significant associations were found with *gender*. Males (fathers and sons) perceived impairment in family functioning on all subscales in *study I* while, in *study II*, males perceived impairment in family functioning on FAD Role ($p < 0.01$), FAD Communication ($p < 0.05$) and FAD Affective Responsiveness ($p < 0.001$).

Significant associations were found with *roles in the family*. Parents perceived more impairment in FAD Problem Solving ($p < 0.01$), FAD Communication ($p < 0.01$) and FAD Affective Responsiveness ($p < 0.01$), as did children in *study I*, but in *study II*, children, more than parents, perceived significant impairment of family functioning on five subscales: FAD Problem Solving ($p < 0.001$), FAD Behaviour Control ($p < 0.001$), FAD Communication ($p < 0.001$), FAD Affective Responsiveness ($p < 0.01$), and FAD Affective Involvement ($p < 0.001$).

Age was significant for adults and children on some subscales in *study II*: the age of the parents was associated with FAD General Functioning ($p < 0.05$) and FAD Affective Responsiveness ($p < 0.01$). The older the parents were, the stronger the association with impairment of family functioning; 5-year coefficient 0.048 (SE 0.020), and 10-year coefficient 0.096 (SE 0.040). The same result was observable for children on the FAD Behaviour Control subscale ($p < 0.05$): coefficient for 5 years was 0.067 (SE 0.026).

Two variables related to the *disease* were found to be significantly associated with family functioning in *study II*: the physical status of the patient (SF8-PCS) was associated with impairment on the FAD Roles subscale ($p < 0.05$) and Hodgkin disease or leukaemia was associated with impairment on the FAD Behaviour Control subscale ($p < 0.05$).

Finally, in *study I* where the *Sense of Coherence (SOC)* was included, *SOC* was associated with FAD General Functioning, as well as with each FAD subscale ($p < .0001$). A strong Sense of Coherence was associated with improvement in family functioning in the clinical group, as well as in the control group.

Family functioning was also studied in *study III* where children of both groups, clinical and control, reported healthy and unhealthy family functioning to the same extent. All correlations indicated that *healthy family functioning* ($FAD < 2$) was associated with fewer symptoms in the children (Table 14).

Table 14. Correlations between Family Assessment Device and Youth Self -Report in the ill parent group (1) and the control group (2)

		Internalizing Problems	Externalizing problems	Total score
Problem solving	(1)	.371**	.442**	.457**
	(2)	.256	.277	.281
Communication	(1)	.446**	.394**	.465**
	(2)	.415**	.361*	.394**
Roles	(1)	.280	.383**	.387**
	(2)	.373*	.318*	.377*
Affective Responsiveness	(1)	.252	.257	.313*
	(2)	.083	.241	.157
Affective Involvement	(1)	.285*	.511**	.435**
	(2)	.275	.443	.372*
Behaviour Control	(1)	.173	.362*	.288*
	(2)	.265	.226	.290
General Functioning	(1)	.404**	.474**	.502**
	(2)	.203	.386**	.271

* Correlation significant at .05 level

** Correlation significant at .01 level

The regression analyses (stepwise) showed that the most significant predictors for children's symptoms were FAD Communication for internalizing problems ($p < 0.001$), FAD Affective Involvement for externalizing problems ($p < 0.001$), and FAD Problem Solving for the total score of symptoms ($p < 0.001$) (Table 15).

Table 15. Regression analysis (stepwise) of family functioning and symptoms in children of ill parents (n = 49)

FAD variable	B	SE B	β	t
	Internalizing problems			
Communication	1.024	.299	.446	3.419***
	Externalizing problems			
Affective involvement	1.116	.274	.511	4.076***
	Total score			
Problem solving	3.429	.973	.457	3.523***

$R^2 = .21$ for problem solving; $R^2 = .22$ for communication; $R^2 = .15$ for roles; $R^2 = .10$ for affective responsiveness; $R^2 = .19$ for affective involvement; $R^2 = .08$ for behaviour control; $R^2 = .25$ for general functioning
 * $p < .05$, ** $p < .01$, *** $p < .001$

5.2 The children exposed to parental cancer (III)

There were no significant differences in the levels of symptoms between the clinical and control group: both groups reported equal levels of internalizing and externalizing problems, as well the same total score of symptoms.

The effects on the three YSR scales with regard to (1) the gender of the child, (2) the gender of the ill parent, and (3) the interaction between the gender of the child and the gender of the ill parent were measured with two-way ANOVA. All effects were statistically non-significant. Neither boys as a group nor girls as a group showed more symptoms of distress compared to the other, regardless of the sex of the ill parent. The non-parametric Mann–Whitney test confirmed the results of ANOVA. Further, it showed that daughters ($n = 27$) did not react more strongly when a parent of a specific gender was diagnosed with cancer. Sons ($n = 22$) did not react differently when their mother or father was diagnosed with cancer either.

Spearman correlation coefficients were computed for evaluations of illness and the YSR variables ($n = 48$). No correlation between onset and prognosis of illness and the symptoms of children was found. Nor was correlation found between first or recurrent cancer and YSR. Spearman correlation coefficients were computed for SF- 8 and YSR. The only significant correlation found was that between the SF-8 *physical component summary* and the YSR *total score* ($n = 48$, $r = 0.288$, $p < 0.05$). The results indicated that a lack of physical incapacitation in the ill parent was associated with increased symptoms in the children.

5.3 The subjective experience of having cancer during pregnancy (V)

The findings of the qualitative analyses have been clustered around the following themes, (which are developed in the original paper), and a synopsis of the events during treatment are presented in Table 1 and 2 of article V.

The main topics processed by the two mothers during pregnancy were:

1. The experience of spending their pregnancy in the hospital. Being diagnosed with cancer and being in intensive treatment constitute an overwhelming situation for the pregnant mother, and the shadow of cancer extended to the beginning of the pregnancy although the diagnosis was made during the second trimester.

2. The worries about their bodily perceptions. Mothers had difficulties to make a distinction between bodily changes deriving from pregnancy, cancer or/and treatment and this may complicate the developing mother-infant relationship.
3. The lack of fantasies related to the baby-to-be. Mothers did not report fantasies about their baby.
4. The intensive fears during pregnancy. Mothers reported how they tried to protect their baby by strong fighting fantasies. These statements disclosed how life and death really are competing within the body of a pregnant cancer patient, and this is not only a subjective experience but a very concrete and unavoidable reality.
5. Childbearing and the experiences related to provoke delivery were an important topic. Delivery was a culmination of two concurrent but contradictory processes of life and death within the body of the mothers.

After childbirth, the main topics were:

1. The discrepancy between taking care for herself and nurturing an infant. After the infant was born the painful contradiction of taking care of the infant and of herself is a core question in the mind of the mother. After the delivery the mother, still in the middle of a psychic crisis, will face many concrete challenges in dealing with the everyday routines.
2. The emergent early relationship with the infant. The breast-feeding prohibition is one obstacle to ensuring the relationship with the infant; the other is the cancer treatment, requiring long hospital stays at frequent intervals. However, the early mutual mother-infant relationship seemed to be developing successfully. The mothers were not depressed and the new-borns were well regulated.
3. The relationship with the other family members. Pregnancy and cancer rouse different kinds of feelings, positive and negative, in the mind of the mother towards the family members.
4. The termination of the treatment. The termination of the treatment was as well a crisis. The possibility of a relapse – on an experienced and existential level – for the mother, the father, the new-born and the other children in the family means that they have to live in the shadow of cancer for the rest of their life.

5.4 Clinical work with cancer patients and their dependant children (IV and V)

5.4.1 The implementation process of the COSIP project and the outcomes at present

Before the COSIP project, no psychosocial support was given in the Oncology Clinic for cancer patients and their dependent children and co-operation with the Child Psychiatry Clinic was non-existent. The identification of patients with children was laborious because

no information on cancer patients' families was available. During spring 2003, the Oncology Clinic amended the questionnaire given to each new patient starting his/her treatment. Questions concerning spouse and children were added, and through this simple procedure, the staff got a clear picture of the family situation of their patients (Appendix 16).

Pre-existing ideas in the Oncology Clinic about providing psychosocial support for the patients were strengthened. On the request of the Oncology Clinic a series of training seminars on psychosocial issues (five seminars, each four hours) was carried out by the author of this thesis for the whole oncology staff (12 physicians, 105 nurses) during autumn 2004. During 2005, financial and staffing resources were investigated in order to set up a psychosocial team on a regular basis, which led also to the work presented in *study V*. In 2006, a multi-professional psychosocial team, including some of the Oncology Clinic's oncologists and nurses, the physiotherapist, the social worker and the chaplain, met on a regular basis about once a month for a case conference. The author of this thesis was invited to be a permanent member of this team. Presently, the author of this thesis is able to devote one day a week to clinical work with cancer patients and their children (Schmitt et al. 2007).

5.4.2 The experiences among the staff of the Oncology Clinic

At the end of the COSIP project, 74 % of the staff members responded to the questionnaire, (44 % physicians, 78 % nurses and 76 % of auxiliary staff members). On average, they had 16.5 years (SD 10.6) of experience in the profession and had been working in the Oncology Clinic about 13.3 years (SD 9.9). The staff members of the Clinic were slightly younger (43.4 years, SD 10.3) than the patients in counselling.

About 52 % of the oncology staff had personal contact with the family therapists working in the project. Most of the staff members, who had no contacts or had not referred patients, were radiotherapists or were working in the radiotherapy unit. Half of the staff members thought the patient benefited from the counselling. Negative feed-back has not been reported.

About 39 % of staff members considered that they are now more aware of the children of the patients than before, while 53 % thought about the children of their patients as much as before.

Personal contacts (informal discussion, coffee breaks) with the therapists were described as an experience of being nurtured, and were beneficial for professional life as well as for personal life.

5.4.3 Participation in counselling

Between May 1st 2002 and April 30th 2004, 2063 new patients were admitted to the Oncology Clinic, of whom 134 (6.5 %) were found to have children. Fourteen patients (10 %) did not want any information about the counselling. This group consisted of seven women and seven men (mean age 45.8 years) who had 19 children between 4 and 17 years of age (mean age 12.7 years). With regard to diagnosis, gender, age and occupation, this group did not differ significantly from the patients who gave permission to be contacted by the researcher/psychotherapist.

Altogether 120 patients gave permission to be contacted personally, of whom 83 (69 %) did not want to participate in the counselling. However, 48 of them gave the background information and could be interviewed by phone on the reasons for not wanting counselling. These 48 patients (31 mothers, 17 fathers) had 39 healthy spouses (25 husbands, 14 wives) and 73 children (34 girls, 40 boys). The main reason (11 cases, 23 %) was the accumulation of at least three obstacles such as travelling difficulties, exhaustion, and small children. The resistance of the healthy spouse or child (ren) was the reason in 11 cases. Two patients said they were not in need of psychological support and two patients were already in psychiatric care.

Altogether 37 patients, 23 healthy spouses and 69 children were seen in counselling. Comparing the 37 counselled families and the 48 families refusing counselling, the parents in the counselled group were significantly older (45.8 years, SD 6.7, versus 40.9 years, SD 5.8, $p < 0.0001$), while in the counselled group there were significantly more single parents (32 % versus 2 %, $p < 0.0001$). There were many recomposed families (29 %) among those who did not participate in counselling. There were no significant differences between the groups in gender or cancer type of the patient, socioeconomic status of the parents, or gender and age of the children (Tables 16 and 17).

Table 16. Background characteristics of cancer patients and their spouses in counselling and those not in counselling

	Counselled group n = 37				Non-counselled group n = 48				p-value
	Cancer patient n=37		Healthy spouse n=22		Cancer patient n=48		Healthy spouse n=39		
	n	%	n	%	n	%	n	%	
Gender									0.233
Female	32	86	5	23	31	65	14	36	
Male	5	14	17	77	17	35	25	64	
Type of cancer									
Breast	22	59			22	46			
Other	15	41			26	54			
Socioeconomic status									0.572
High	6	16	4	18	6	13	8	21	
Medium	23	62	7	32	22	46	13	33	
Low	7	19	10	45	16	33	14	36	
Data missing	1	3	1	5	4	8	4	10	
Family structure									<0.0001
Nuclear	23	62			33	69			
Recomposed	2	0,5			14	29			
Single	12	32			1	2			
Mean age, years (sd)									<0.0001
	45.2 (6.9)		45.6 (6.8)		41.4 (5.7)		40.0 (6.0)		

Table 17. Background characteristics of children (4-17 years) of cancer patients in counselling and those not in counselling

	Children in counselling		Children not seen in counselling		p-value
	n = 69		n = 74		
	n	%	n	%	
Gender					0.206
Girl	39	57	34	46	
Boy	30	43	40	54	
School status					0.849
Day care	14	20	14	19	
Elementary school (children 7-13 years)	30	43	33	45	
Secondary school (children 13-15 years)	16	23	18	24	
College or professional school (children 16-19 years)	6	9	8	11	
Data missing	3	4	1	1	
Mean age, years (sd)	10.7 (3.9)		10.6 (3.8)		0.925

During the two years, 239 sessions and 21 follow-up family sessions were provided. Half of the families chose to start with a whole family session. About a third of the sessions were family sessions (n = 75) and a third were individual adult sessions for the ill parent (n = 81), while couple sessions were provided 34 times. Individual sessions for adults are explained by the rate of single parents in the counselled group. Sibling sessions accounted for 8 % (n = 20), and child individual sessions 12 % (n = 29). Individual sessions for children were not wanted in six families.

The most usual time to start the counselling was around 3 months after the diagnosis (N = 11, 29%), while 30 families (81 %) started between 1 to 7 months (range 1-19 months) after diagnosis. Twenty-one patients out of 37 (56%) considered the timing of counselling to be right. One patient felt that the support came too late because information about counselling was given when the treatment was already over. Two patients would have liked to have had some counselling just after they were told the diagnosis. The remaining 13 patients had no preferences for the timing of the intervention.

Twenty-eight patients out of 37(75%) expressed the wish (6 in the last counselling session and 21 in the follow-up session) that at least one whole family counselling session should be included in the treatment routine of each new cancer patient with children. The family session should be scheduled by the physician in charge of the patient.

5.4.4 Clinical work with pregnant patients

The type and number of psychotherapy provided for both pregnant cancer patients are summarized in Table 18. Several theoretical frameworks and several types of sessions (individual, couple, mother-infant, family, and extended family) were provided by the same psychotherapist, the author of this thesis. The starting point for psychotherapeutic work was the current situation, the location and the persons who were present.

Table 18. Psychotherapy (number of sessions) provided during pregnancy and after childbirth.

Type of sessions	Lisa	Helen
Psychotherapy during pregnancy	Pregnancy weeks 22- 37 (15 weeks)	Pregnancy weeks 22-38 (16 weeks)
Individual sessions	16	14
Couple sessions	-	3
Family sessions	4	2
Psychotherapy after childbirth	Within 18 months after child birth	Within 13 months after childbirth
Individual sessions (father at home with baby)	-	1
Family sessions: patient - husband – children/ member of family of origin	2	8 (all at home)
Mother-infant sessions	30	11

6 DISCUSSION

The aim of this dissertation was to capture a contextual view of the phenomenon: “families affected by cancer”. The interpretation of the present study findings requires considering first the limitations and the strengths regarding design, samples, methods and analyses.

6.1 Methodology

6.1.1 Design

This study included quantitative analyses in a cross-sectional design (*studies I, II, III*) and qualitative analyses, where the same patients were followed for almost one year (*studies IV and V*). The cross-sectional design was imposed by the multi-site collaboration and the specific dead-line imposed by the European Union financing the project. The cross-sectional design allowed the collection of a larger sample, but one of the major limitations was that it was not possible to grasp the later effects of cancer on family functioning or children’s mental health. Likewise, cross-sectional designs have been used in previous studies; therefore, further studies should be longitudinal. There was an attempt in Finland to collect follow-up data, but the drop-out rate was too high to continue. However, the qualitative data used in this present dissertation provided a limited overview on what can happen in a family during the first year after a cancer diagnosis, but nothing can be stated about the later outcome of families and children.

6.1.2 Samples

The samples of this study were good in size but varied in quality. To our knowledge, the multi-site EU sample was the largest sample ever collected on cancer patients with dependant children. However, nothing can be stated about the quality of the sub-samples of the EU multi-site sample, except for Finland. No data have been collected about how representative and from what population it had been produced in each country. The response rates were only known for three countries. Therefore, at the beginning of a multi-site collaboration, it is recommended to ensure a set of rules for reporting data collection bias.

In Finland, great attention was paid to data collection. At the beginning, no data were available on the prevalence of cancer patients with dependant children. The collection of 85 families took two years and 6.5% of cancer patients in Turku University Hospital were found to have dependant children. However, the department of gynaecology and haematology were excluded, since resources for providing counselling were too limited and this may affect the final rate. The rate in Turku was low compared to estimations in the USA, where the prevalence of cancer patients with dependant children was estimated to be 24% (Muriel and Rauch, 2003). So far, the rate for Finland as a whole remains unknown (personal communication from leader of cancer registry centre in Finland, Eero Puukkala), and a research project could be set up to clarify this question.

In Finland, the drop-out rate was 30% (vs. 57% in Huiziga et al. 2005 and Visser et al. 2006). This was due to the fact that the author of this dissertation had a personal face-to-face contact with each eligible family through the cancer patient to whom the possibility of counselling was offered. However, the personal contact may have helped to

get a good response rate, but it could also have had some negative effects such as, people participating in the research to please the researcher. No data are available on the group of patients who did not answer. The response rate of the control group was poor, only 32%, despite the efforts to motivate people.

For *study IV*, the sample consisted of data from 37 families, and this was a large sample for qualitative studies. However, the material collected was only superficially examined to answer a few very specific questions. In *study V*, there were two cases of pregnant women: this kind of sample and design is adequate for deep qualitative analysis.

6.1.3 Methods

The methods were imposed by the EU multi-site consortium. The general background questionnaires were quite extensive including too many items, which led to missing data even on important issues. Some questionnaires were translated from German or English to Finnish by the author of this thesis and they were pre-tested but not back-translated. Although the questions were simple and the translations were checked, this was not the optimal procedure.

The Family Assessment Device (FAD) as a measure instrument for family functioning was available in each country's language, also in Finnish. The FAD has been previously used in Finnish studies (Räihä et al. 1997) and the quality of the instrument was to some extent confirmed by the results of *study II*: there was no difference between countries (which means that the instrument was working in almost the same way in the different countries). Moreover, only on the FAD Behaviour Control subscale, was the difference close to significance, which reflects the differences in discipline in each country. However, self-report procedures reflect the individual's perceptions – perceptions, which can be biased by several factors (Jacob and Tennenbaum 1988). Furthermore, reports were given by several different family members. However, this handicap was compensated by sophisticated statistical analysis.

Although the evaluation of depression was based only on a self-report questionnaire, the scale of the Beck Depression Inventory (BDI) has been assessed as a valid measurement of depressiveness in a population (Lasa et al. 2000). The concurrent validities of BDI with a clinical diagnosis have been found to be good (Beck et al. 1961). In *study II*, the cut-off point of depression was set at a level whose reliability and validity for cancer patients has been studied (Berard et al. 1998).

The Sense of Coherence (SOC) is a valuable descriptor of resilience. From a systemic perspective, the individual's resilience is relevant for the whole family. Antonovsky (1988) designed a study to demonstrate that such a construction as "family sense of coherence" is meaningful, since the SOC of disabled husbands and their healthy wives, taken separately and taken together, was significantly associated with the level of satisfaction with family life.

Qualitative methods were appropriate to answer the research questions about the implementation and the reception of the counselling, and for the exploration of a topic like cancer during pregnancy which has not previously been studied from an early relationship perspective.

6.1.4 Analyses

Besides classical descriptive analyses and conventional analyses like ANOVA, correlations or regression analysis, a sophisticated statistical method was used in *studies I and II*. The use of this analysis method was challenging, and allowed the simultaneous use of data from different members of the same family belonging to different groups. Thus, it was possible to give a voice and space to the children in a way which has not been used in previous studies. However, only children over 11 were able to complete the questionnaires as this required sufficient cognitive skills. There is a need to develop adequate methods to integrate younger children into the analysis to gain knowledge about pre-schoolers' mental health or their perception of family functioning, when they are exposed to parental cancer. The qualitative analysis extended the knowledge gained from the quantitative analysis.

6.1.5 Combining research and psychotherapy

One of the main strength and limitation of this dissertation was linked with the identity of the author: a psychotherapist carrying out research. The psychotherapeutic training included psychoanalytic adult individual psychotherapy (3 years), child-centred family therapy (5 years), and mother-infant psychotherapy (4 years). The role of researcher required standing back and recording objectively what occurred, while the role of psychotherapist required being inside the events.

The author of this thesis had the opportunity of being involved in all the steps of the COSIP project, including application for the participation, preparatory phase, research design, data collection, recording, saving, cleaning, analysing the data and writing the reports. To ensure more reliability quantitative data was always gathered before counselling could start.

This dual role, being a psychotherapist carrying out research, of course had an impact on the collection and the analysis of the qualitative data. The researcher was not a neutral and outsider observer of some phenomenon, but an active participant involved in the process of "being in the shadow of cancer". This was the background to the exploration of the counter- and complementary feelings but this process has not been reported and some data have voluntarily not been disclosed to respect confidentiality.

For *study V*, the naturalistic perspective was predominant. Nevertheless, this kind of combination is called participant observation research (Ely 1991; May 2002). The researcher-psychotherapist may feel pulled in two directions, in the precarious balance of the two very different demands of two roles. However, a psychotherapist's memory is trained to hold conversations long enough to make reasonably good notes, to keep diaries, to process analyses from a theoretical point of view, while the data collection was still ongoing. Moreover, the trusting relationship with the participants may have contributed to getting deeper information. On the other hand, reliability and objectivity had to be maintained by triangulation with quantitative methods, verification in peer groups and supervision (Tuomi and Saarjärvi, 2002).

This situation of being a psychotherapist and a researcher, of being at the same time outside and inside the study object, of moving "between" two worlds (research and psychotherapy) and two cultures (oncology and child psychiatry) required flexibility and multicultural proficiency, but as such, is common in qualitative studies (May 2002).

6.2 Results

6.2.1 Family functioning in cancer patients families with dependant children

The purpose of *studies I and II* was to identify factors associated with family functioning in cancer patients' families with dependent children. The purpose was to identify families at risk of dysfunction, to provide adequate psycho-social services and/or to identify the resources of the families.

Overall, the families were functioning well and in *study I*, there was no difference between cancer families and families belonging to the control group. However, many studies show that family functioning is vulnerable and susceptible to risk: for instance, Lewis and colleagues (1996b) showed that single mothers compared to married mothers reported a significantly higher number of illness-related pressures on their family and lower quality in parenting their children.

In *studies I and II*, family structure, number of children, and additionally in *study II*, socio-economic status, were not associated with impairment in family functioning. Single parenthood, and lack of economic resources are traditionally associated with family dysfunction and children's mental health (Conger et al. 1994; Luoma et al. 1999; Leinonen et al. 2003; Taanila et al. 2004), but in the families of the clinical sample (Finnish and multi-site sample) and the control group, this was not the case.

The gender issue was relevant: in *study I*, males (fathers and sons) perceived more dysfunction in family functioning on all subscales than females, and in *study II*, fathers and sons perceived impairment in FAD Roles, FAD Communication and FAD Affective Responsiveness. As the majority of the patients in both studies were mothers, it is not surprising that males found it difficult to adjust to new roles, and had problems in communication and affective responsiveness. However, this can also be interpreted as a sign of male sensitivity to the gravity of the situation. The gender of the ill parent was not found to be associated with impairment of family functioning. However, in *study II*, children perceived more impairment in FAD Affective Responsiveness when the father was the cancer patient. This could be interpreted as a consequence of crisis in the family; the ill father is requiring more attention, and the mother may be overwhelmed by the father's illness, everyday duties, work and worries. Additionally, the prevalence of depression in *study II* showed that when the father was ill, in almost 30% of the families the mother was depressed. It is not surprising that children perceived impairment in Affective Responsiveness.

Among variables related to the disease, stage of cancer (new/relapse) in *study I*, and time since diagnosis in *study II* were not associated with family functioning. However, the groups were too small: there were only nine patients in *study I* whose cancer was relapsed, and this information was missing for the patients in *study II*. In *study II*, the group "Hodgkin disease or leukaemia" was associated with impairment in Behaviour Control. Compared to breast cancer or other cancers, Hodgkin disease or leukaemia usually requires longer hospitalisations, and sometimes even barrier nursing in isolation that restricts family contacts (cell or marrow transplantations) and makes family life very demanding for several months; this could explain impairment in Behaviour Control, but then again, it could be interpreted as a strategy of adaptation to the situation. Nevertheless,

sometimes cancer treatments last for many years: the effects of this long-lasting and burdensome cancer on family functioning need to be assessed using a longitudinal design which was outside the scope of the present study.

In the multi-site sample of *study II*, the prevalence of depression was high: 35% for the ill mothers, 28% for the healthy mothers, 28% for the ill fathers and 13 % for the healthy fathers. The prevalence rates in the literature vary from 20 to 50% (Pasquini and Biondi 2007). In the multi-site sample, the depression of the ill parent was the most significant factor associated with impairment in family functioning, while in the Finnish study, it was the mother's depression rather than the ill parent's depression. However, in the multi-site sample most of the patients were mothers (287 ill mothers - 77% of all patients - vs. 85 ill fathers) and in the analysis of *study I*, all mothers (including control mothers) were included. This could explain this slight difference. The "ill parent" and the "mother" in these samples were often one and the same person. However, the results suggest, that cancer "per se" was not associated with impairment of family functioning, but that depression in the family, and specifically the mother's depression, was decisive. The mother's mental health seems to be the most meaningful resource of the family, and additionally, mothers are more likely to be depressed when the father has cancer than fathers when the mother is ill.

Miller and colleagues (1986) and Keitner and colleagues (1987) showed that depression significantly discriminates healthy and unhealthy functioning in families between samples of psychiatric patients and non-clinical families. Furthermore, the impact of parental depression on children's mental health has been described in numerous studies. Parental depression affects family functioning, which in turn is likely to impact adversely on the children. According to Beardslee and colleagues (1998), almost 40% of children of severely depressed parents are likely to develop a psychiatric disorder before age 20, and the risk grows to 60% by age 25. In a 20-year follow-up study, the risk of anxiety disorders, major depression, and substance dependence was approximately three times as high in the children of depressed parents as in the children of non-depressed parents. The children of depressed parents constitute a high-risk group for psychiatric and medical problems, which begin early and continue through adulthood (Weissman et al. 2006). Furthermore, a recent study on cancer families showed that maternal depression and poor family communication, rather than mother's treatment stage or time since diagnosis were associated with their school-aged children's behavioural and emotional problems (Watson et al. 2006).

Overall, children in the multi-site sample perceived more impairment than parents on five of the seven subscales in the multilevel analysis. Children were sensitive to dysfunction in their family. These results are new because children's opinion has not been registered before. Nevertheless, the mothers' depression may affect their capacity to perceive impairment in their families. Furthermore, it seems that the perception and the identification of distress are not only problems for the patients themselves, but also for their oncologists and nurses (Söllner et al. 2001; Piha and Virtanen 2003). More analyses and further studies are required to identify the profile of those families in which the parents are more likely to become depressed.

In the Finnish study, the Sense of Coherence (SOC) was used and the results are worth commenting on. The SOC is a reflection of the quality of a person's mind and his/her

ability to master the life situation, and a valuable descriptor of resilience. From a systemic perspective, the individual's resilience is relevant for the whole family. According to Bednar and colleagues (1988), family functioning is the classic model of a social system, where family members receive and give reciprocally, continually affecting each other. In the Finnish study, SOC was associated with improvement in family functioning, and was also found to be associated with improvement on each FAD sub-scale in the clinical group, as well as in the control group. Antonovsky (1988) designed a study to demonstrate that such a construction as "family sense of coherence" is meaningful, since the SOC of disabled husbands and their healthy wives, taken separately and taken together, was significantly associated with the level of satisfaction with family life. Additionally, a Chinese study showed that SOC significantly correlated with quality of life and coping ability after a critical illness (Fok et al. 2005). Moreover, Gustavsson-Lilius and colleagues (2007) confirmed, in a longitudinal design including couples where one partner was diagnosed with cancer, that a strong SOC at diagnosis predicted significantly lower levels of anxiety and depression at 14-month follow-up, even when the baseline levels of distress were controlled for.

In a large Finnish study (Suominen et al. 2001) a strong SOC predicted good health in both women and men, and was interpreted as an autonomous internal resource contributing to the favourable development of a subjective state of health. Furthermore, the study by Volanen et al. (2004) showed that among both genders, psycho-emotional resources rather than socio-economic factors were associated with SOC. These resources included the quality of the partner relationship, social support, the quality of work and previous experiences of one's own childhood living conditions. However, childhood adversities (including severe illness of a family member) have an impact on later depressiveness in adults. Combined with recent life events, childhood adversities were associated with depressiveness in an additive manner (Korkeila et al. 2005).

Nevertheless, the family resilience perspective might shed light on why the results of so many studies on family functioning in cancer families are in some cases contradictory or difficult to interpret. Adults and children are active, developing and thinking beings who are assessing their life: the same risk factor (having a family member with cancer) may have a totally different meaning and totally different consequences for individuals according to his/her coping strategies, previous experiences and/or environmental factors (Rutter, 1999). Moreover, the Family Resilience Perspective should be further explored in order to gain information about how to screen families at risk. Therefore, SOC seems to be a good instrument for screening strengths in the family with parental cancer.

6.2.2 Children exposed to parental cancer

As stated above, this dissertation failed to include pre-school children in the analysis. However, the results of *study III* about the mental health of children exposed to parental cancer were in line with previous studies, and in line with the conclusions summarised in the reviews presented above. In a cross-sectional design, it seems that cancer does not affect the mental health of children. The family is a resource for the children: open communication, flexible problem-solving skills and an appropriate amount of affective involvement were found to be significantly associated with better mental health both in the group of children with ill parents and in the children of the control group. Although

this study was the first in Nordic countries, longitudinal studies should be preferred to the duplication of cross-sectional designs using the same measures.

The results of *study V* showed that both babies were physically and mentally healthy. However, the long-term outcomes have not been assessed and only a longitudinal design could provide more information on this issue.

6.2.3 Cancer during pregnancy

Keeping the cancer patient alive, successfully providing a delicate treatment, carrying on the pregnancy and protecting the foetus, giving safe birth to the infant, keeping both the mother and the infant alive after childbirth while cancer treatment is in its most intensive phase, and finally, carrying out the treatment to defeat cancer, are extremely challenging issues for oncologists, obstetricians, neonatologists, and all the professionals involved in the medical system. This is the context in which the mother has to start to establish a relationship with her baby-to-be.

Both of the mothers involved were exposed to very high and long-standing anxiety. Data by Glover and colleagues (1999) suggest that maternal prenatal anxiety and depression may have different effects on the foetus and may operate by different mechanisms. Research supports the notion that adverse early experiences, including prenatal maternal stress have an influence on the developing foetus that may persist after birth, as assessed by measures of temperament and behavioural reactivity in the first years of post-natal life. The findings of these studies suggest that maternal distress compromises the regulation of hormonal activity and increases the amount of free corticotrophin-releasing hormone (CRH). Excess CRH and other hormones (cortical and met-enkephalin) that pass through the placenta have been associated with impairment in foetal habituation to stimuli and temperamental difficulties in infants (Wadhwa et al. 2001; Wadhwa 2005; Weinstock 2005). Moreover, distressed women have shown elevated cortisol levels during the middle of their pregnancy, and this was related to lower foetal weight as showed in a study by Diego and colleagues (2006).

Depression in cancer patients is quite common, ranging from 20 to 50% (Pasquini and Biondi 2007). Additionally, postpartum depression occurs in 10 to 20% of women who have given birth, although fewer than half of such cases are diagnosed (Gjerdigen and Yawn 2007). The strongest risk for postpartum depression was depressive symptoms during pregnancy or a history of depression before pregnancy (Rich-Edwards et al. 2006). Two or more stressful life events in the year prior to pregnancy, (Ruberstsson et al. 2005), financial hardship and unwanted pregnancy (Rich-Edwards et al. 2006), were significant risk factors for the development of post-partum depression. In *study V*, both mothers had experienced several risk factors, the accumulation of which could have led to depression. But they were not depressed. Grote and Bledsoe (2007) found that when mothers experienced high frequencies of financial, spousal, and physical stress during pregnancy, those who were optimistic were much less at risk of developing clinically significant depression at six months and 12 months postpartum compared with the pessimistic mothers. Validating resilience and enhancing optimism were recommended (Grote and Bledsoe 2007).

In conclusion, anxiety and depression should be considered when working with pregnant cancer patients, but at the same time, the validation of resilience should not be neglected. These findings of these two cases were in line with the results of the statistical analysis of the others studies: depression and sense of coherence are central. However, the preventive effect of the compassionate and empathic presence of the psychotherapist/researcher on the mother's mental health cannot be evaluated. Nevertheless, respectfulness of the patient's own coping systems, the timing and the nature of psychotherapeutic intervention should be carefully assessed.

6.2.4 Clinical work with cancer patients and their dependant children

The collaboration between the clinics of oncology and child psychiatry was friendly despite the earlier sparse co-operation. However, only 52% of the oncology clinic staff had a personal contact with the author of this thesis. About half of the staff thought that counselling was helpful. However, being more aware of cancer patients' families and children might complicate the work of doctors and nurses and be a burden to them (Piha and Virtanen 2003). Nevertheless, some COSIP project imprint was left: the author of this thesis has been invited to provide clinical work for the oncology clinic (Schmitt et al. 2007).

Although Rolland (2005) mentions some features of the relationship between families and health professionals (pp. 2591-2592), his model fails to address explicitly the issue of the interaction between the family system and the medical system (Imber-Black 1988), including different professionals with their belief systems, myths, taboos, and communication skills (Figure 4). The medical system is always in interaction with the patient and the family members (Baile et al. 2000, 2002; Maguire et al. 2002; Burkitt Wright et al. 2004; Fallowfield 2004; Oh et al. 2004).

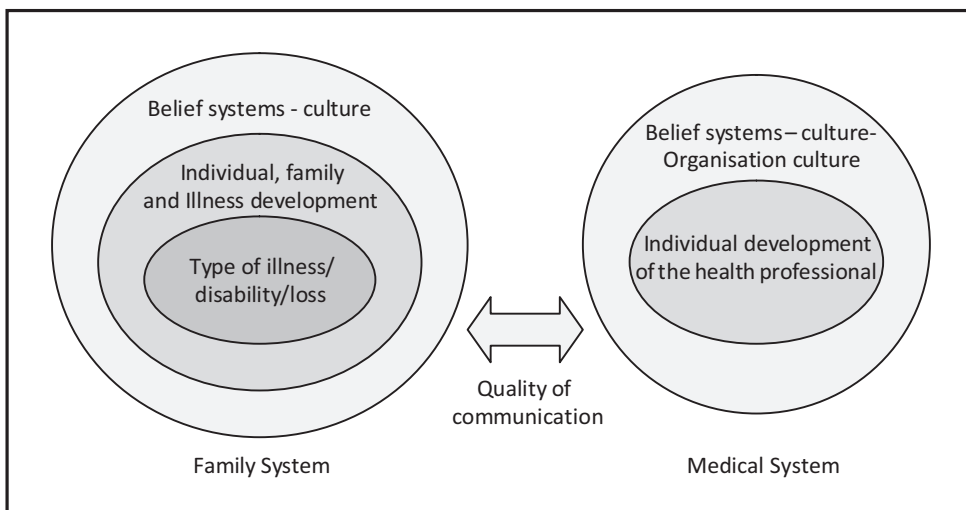


Figure 4. The FSI and the interaction with the medical system

However, the present study failed to address the issue of communication between the medical system (physicians, nurses, radiologists and other staff) and the family members. Every patient, and almost every family member described fragment of conversations

with the medical system's members, for instance, how the patient was informed about diagnosis, procedures and treatments. The quality of communication between the patients and the medical system's members (doctors etc.) is an important factor for coping with cancer (Brennan, pp. 295-355, 2004; Katainen et al 2005).

According to the literature in the field of psychosocial support for cancer patients, family-oriented support is uncommon (Newell et al. 2002). The Turku Model of counselling (see procedure section 4.1.2) was designed to be family-oriented and child-centred aiming to be helpful for all family members, but especially children. It was not designed to be psycho-educational like the interventions described in the review, although some elements of education were perceptible, as when a child asked questions related to the location of the cancer or to the parent's treatment. The spirit of the model was more to offer a safe space and empathic compassionate listening to families' experiences. This form of counselling combining family, parental couple, siblings and individual sessions was flexible and feasible, easily adjustable to the specific needs of families. Furthermore, it seems that this kind of clinical work enhanced a sense of coherence; family members created meanings for what happened to them by developing shared narratives about their experiences (Freeman et al. 1997)

According to Beardsee and McMillan (1993), a preventive intervention is meaningful for children whose parents are depressed. The literature underlined the psychological distress of the cancer patients (e.g. Ritterband and Spielberger 2001) and the results of *studies I and II* confirmed that depression is a core issue. In a parallel Danish study, Thastum et al. (2006) found that parents seeking counselling were significantly more depressed than those who did not want counselling.

During the preparation phase of the COSIP project, it was expected that a large proportion of parents would want counselling (cf. Rauch and Muriel 2004). In fact, this was not the case. In the group of 120 cancer patients with children at home, 30 % participated in the counselling, while most of the patients refused it. However, the phone interviews showed that distances, accumulation of at least three obstacles, and the resistance of the spouse or the children should be considered. In a geographically large country, the services should be available closer to the domicile of the patients, and the timing should better fit the needs of families. Otherwise support can become just an additional burden.

The counselling was offered by the child psychiatry clinic. Prejudices towards psychiatry, and the fears of possible stigmatization make it difficult to be perceived as support providers, and this may explain the poor participation in counselling. The families seen in counselling found it important to get psychological support in the cancer clinic itself. The establishment of a psychosocial team within the oncology clinic, and the integration of child psychiatry as a discipline focusing on children's mental health in the oncology clinic team could be a useful solution.

Some families might legitimately balk at what they see as an unwanted intrusion into their efforts to cope with a difficult situation, although others welcomed the counselling as a response to their needs. Studies should focus on clarifying the sub-groups of patients who need psychological support. Furthermore, the timing of offering services should coincide with the time of seeking for help, and the proposed help should meet the need of the help-seekers.

The proportion of single parents among cancer patients (15 %) was the same as among Finnish families in general in 2003 (13 %, Statistics Finland, <http://www.stat.fi/til/perh/index.html>). However, single parents were very significantly over-represented in the group of counselled families (32 %) compared to families who refused the counselling (2 %). Single parenthood is a risk both for the parent (often the mother), and for the children (Ringbäck et al. 2000; Ringbäck et al. 2003; Taanila et al. 2004). Awareness of their own vulnerability may have led the single mothers to seek counselling.

Female cancer patients were over-represented: this is in line with the epidemiologic reality. In 2005, in the age group 20-64 years, 5499 females were found to have cancer, which is 44% of all women diagnosed with cancer (N = 12415). Among males of the age group 20-64 years, 4828 developed cancer, which represents 34% of all male cancer patients from 0-85 years (N = 14046) (Finnish Cancer Registry, Table 3, 4, 7, 8 p. 12-19).

The patients and family members who participated in the counselling were extremely positive, and they suggested that at least one family session should be included in the routine of every cancer patient seen in the oncology clinic. This procedure could have several benefits. By proposing a family-oriented and child-centred approach to psychosocial counselling for cancer patients, the needs of each family member are validated. Additionally, Martire and colleagues (2004) confirmed this idea, and showed that family interventions are not associated with psychological negative outcomes for either the patient or family members. Moreover, patients and family members in need of psychiatric consultation and/or social support could be easily identified, and routine family session could lower the threshold for asking for further help by providing a nurturing experience of being understood. Given and colleagues (2001) advocated a periodical assessment of family members in order to identify specific sources of distress. Finally, standard practice protects from fears of stigmatization. Trief and Schiller (2001) stated that “they chose to see all patients, rather than only those at risk, because it is hard to define “at risk” patients” (p. 340). However, the disadvantages should also be considered. Families are in special need of support, but also of protection from intrusive practices.

It should also be remembered that children should be informed in an age-appropriate way about their parents' illnesses and their treatments (Kroll et al. 1998; Muriel et al. 2003). Moreover, children need the help and support provided by parents or other adults to cope with the information about the illness.

However, looking at the intervention from a clinically oriented perspective is not in itself enough; the usefulness and efficiency of the intervention should be studied using an intervention study design. Owen's and colleagues' (2001) review of outcomes in psycho-oncology interventions emphasized that, although there is a substantial body of literature, it remains difficult to define what should be the focus of improvement. Should the focus of this kind of psychosocial intervention be the mental status or quality of life of the cancer patient, the well-being of the children and the prevention of mental health problems in the children, the quality of family life, the coping of the healthy spouse, or the functioning of the family? For instance, Thastum and colleagues (2006) showed that, in Denmark, a similar kind of intervention was useful: the parent's and children's depression decreased significantly after the intervention, and family functioning (also measured by FAD) improved.

As a consequence of the collaboration between the oncology and the child psychiatry clinics, the oncologist in charge of the pregnant patients sought psychosocial help for them. Besides ethical delicacy, psychotherapy with pregnant cancer patients requires mastering several theories and clinical techniques to be used with the patients, the family members, significant others, the helping system, and finally, the mother-infant dyad. The attitude was of compassionate curiosity, an attitude of learning from the patients and their babies, and also of “watching, waiting and wondering” (Muir 1992).

There was no model available for psychotherapy with pregnant cancer patients. The following procedures were found to be useful: first, the psychotherapist joined the patient when she was in the hospital for examination, treatment or some other reason. The first contact was short (20-30 minutes), emotionally intensive, and led to an appointment for a further session (see the concept of joining, Minuchin and Fishmann 1981, pp 28-49). Stern suggests that a therapeutic alliance-transference framework will “permit the therapist to become a special form of supporting matrix that can validate, support, and appreciate the mother and thus “hold” her so that her maternal functions are liberated, discovered and facilitated” (1995, p.188).

The psychotherapist visited the patient wherever she was when she was in the hospital. As a result, the psychotherapeutic session took place in the waiting room of the radiology ward, or just after the ultra-sound examination in the hospital café, or on the ward when the patient was being given chemotherapy, where nurses or doctors could at any time interrupt the conversation. Consequently, the time-frame within which the sessions occurred was difficult to regulate, and the duration of the sessions was very flexible within a range of 10 minutes to 50 minutes. The sessions were always scheduled according to the routine of other medical procedures. There were several practical reasons for this procedure; firstly, the patients often had one or two different appointments every week, secondly, the geographical distances between home and hospital were great, and finally, psychotherapy should not be an additional burden.

The psychotherapist’s starting point was to use all these settings, conditions and environments as resources rather than as a handicap. Additionally, the timetables were sometimes modified because, in the case of leucopenia, the treatment was delayed from one to seven days. For Lisa only one home visit was possible, and for Helen, it was possible (her home was close to the hospital) to implement eight home visits, which enabled working with all family members and with the mother-infant dyad. Home visits were helpful to emphasize “normality” and the well-being of family members (Stern 2006). Additionally, it was possible for the parents to bring up more intimate issues because there was no risk that a nurse or another staff member would suddenly interrupt the conversation.

Often, when the psychotherapist came to see the patient, it was almost impossible to know in advance who would be present. This very special setting imposed flexibility, creativity and tolerance of anxiety and vicissitudes. It also required a correct balance between being available and keeping a non-intrusive stance. Technically, when the patient was alone, intra-psychic phenomena, like the mother’s representations, fears or fantasies, perceptions and trauma of delivery were focused on.

When other people were present (family members, friends, staff), the psychotherapeutic approach shifted to family therapy and network therapy. On the systemic level, theories

on couple relationship and family's development and functioning, on communication and larger systems (relatives, friends, relations with the nursing staff and medical system) were used. However, the starting point was always the present situation, and what was currently active in the mother's mind. Outside and concrete help from relatives and authorities was very important.

However, the main work was mainly to be the container of very intensive anxiety, to listen to the suffering and the fears of the family members, but also to enhance the pleasure and joy of having a baby. Despite the worries and difficulties, there were also joyful and playful times with the mothers and their infants and other children.

6.3 Ethical aspects of this study

This study required specific ethical sensitivity; patients and their family members were in a vulnerable phase of their life and overwhelmed by the crisis, the treatment and many other life events, which have not been reported within the frame of this study. This is the first study in Finland devoted to clarifying the functioning of families of cancer patients with dependant children, and the first study to present a model of psychosocial support for children of cancer patients. However, raising the issue of children's coping with parental disease may have had an adverse effect on the patients and the children: the patients, spouses, children, medical staff members may have experienced more anxiety since the study raised threatening questions. Therefore, it was important to provide psychotherapeutic support in parallel with the research. Although, the data collection finished in May 2004, the author of this thesis continued to be available to the patients requesting help as long as was necessary. Furthermore, the emphatic interest of the researcher may also have been also therapeutic for the patients and their family members. However, concern remains concerning the 14 patients and their 19 children who never gave permission to be contacted by the researcher, the 30% of patients who were too ill or too overwhelmed to participate in the study, and the patients who declined counselling. They may have been more in need of help than other patients, but this is difficult to state and impossible to prove. Finally, this study suggested that screening depression in cancer patients is of paramount importance for the well-being of their family and their children. However, one should remember the recommendations of the World Health Organisation (Wilson and Junger 1968) concerning the screening of diseases: the harms and the benefits of screening should be considered, the principles of voluntariness and equality should be respected also for children, and finally, resources should be provided for adequate treatment.

6.4 Implications and conclusion

In the studies included in this dissertation, it has been possible to demonstrate the following:

1. In the Finnish sample from Turku, the prevalence of cancer patients with dependant children was around 6.5%. Data on a national level are missing.
2. In the studies of this dissertation, cancer "per se" did not impair family functioning, children's mental health or the early relationship between cancer ill mothers and their baby.

3. Maternal depression or the ill parent's depression and the individual's sense of coherence are the main factors associated with family functioning in a cancer patient's family with dependant children, as well as in the families of the control group: depression was associated with impairment in family functioning and sense of coherence with the improvement of family functioning.
4. In the European multi-site sample (N = 381), the prevalence of depression was 35% for ill mothers and 28% for ill fathers, compared with 28% for healthy mothers and 13% for healthy fathers.
5. A child-centred family intervention which aims to give space for elaborating on cancer in the family, to validate the sense of coherence in family members, and to promote open communication among them, was positively welcomed by 30% of the patients. At least one family session conducted by an experienced clinician could be useful for early detection of depression in adults and/or children. Comprehensive psychotherapy of pregnant cancer patients should involve, besides the patient, her partner, her other children, the members of her family of origin and the significant others.

Clinical implications and recommendations for further studies can be summarized as follows:

1. On a national level, the prevalence of cancer patients with dependant children should be clarified.
2. Early screening and effective treatment of depression in cancer patients is of paramount importance for the well-being of their family and the mental health of their children.
3. In further studies, the sense of coherence and resilience should be focused on. More studies are required to discriminate the families who are in need of support from the families who can cope without the help of mental health professionals.
4. More studies are required to identify the cancer patients and the families where the patients are likely to become depressed.
5. Further studies should be longitudinal and should focus on identifying the children and adolescents for whom parental cancer is an unbearable life-event and, thus, are in need of the support of mental health professionals.
6. The effectiveness of a child-centred family intervention for the support of cancer patients and the prevention of children's psychopathology should be studied within an appropriate design.
7. More knowledge is required about the psycho-social development of infants born during their mother's cancer treatment.
8. A child-centred family intervention seems to be suitable in an oncology setting.

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9 APPENDICES

Appendix 1

SUOSTUMUS YHTEYDENOTTOON

Minulle on kerrottu EU:n rahoituksella toteutettavasta syöpään sairastuneita vanhempia ja heidän lapsiaan koskevasta tutkimuksesta ja neuvontakokeilusta.

Annan suostumukseni siihen, että tutkimusryhmä voi ottaa yhteyttä minuun kertoakseen asiasta lisää.

Turussa ____/____ 2003

Suostumuksen antajan allekirjoitus ja nimikirjoituksen selvennys

Suostumuksen antajan syntymäaika

Suostumuksen antajan osoite ja puhelin numero (puhelin numerot)

Appendix 2

KEVÄT 2003

Hyvä vanhempi

Olet juuri saanut tietoa sairaudestasi ja sen hoidosta. Tällainen tieto herättää monenlaisia tunteita ja huolia mm. perheen ja lasten selviytymisestä.

Vuoden 2002 alussa on TYKS:n lastenpsykiatrian yksikössä käynnistynyt **EU:n rahoittama kahdeksan eurooppalaisen tutkimuskeskuksen yhteinen tutkimushanke, jonka kohteena on vanhemmuus vakavan sairauden aikana.** Tutkimuksen yhteydessä aloitamme onkologian klinikan kanssa neuvontakokeilun. Neuvonnalla tarkoitetaan perheille ja perheenjäsenille tarjottavia **keskustelumahdollisuuksia.** Tutkimus koskee sellaisia syöpään sairastuneita vanhempia, joilla on **alle 18-vuotiaita kotona asuvia lapsia.**

Tutkimuksena tavoitteena on:

- **tutkia vanhemmuutta** eri näkökulmista silloin, kun perheessä on syöpään sairastunut vanhempi
- **saada tietoa perheen ja perheenjäsenten hyvinvoinnista ja selviytymisestä** tällaisessa tilanteessa
- **arvioida perheille antamamme neuvonnan hyödyllisyyttä**

Tietoa kerätään **lomakkeilla** ja **neuvonnan yhteydessä.** Saamamme luvan perusteella tulemme ottamaan Teihin **puhelimitse yhteyttä** lähiaikoina, noin kahden viikon sisällä.

Tutkimuksesta vastaa lastenpsykiatrian professori Jorma Piha.

Kohteliaiin terveisin

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Appendix 3

Hyvä vanhempi

Kerroimme puhelimessa tutkimuksestamme ja siihen liittyvästä neuvontakokeilusta. Keskustelussamme sovimme, että lähetämme teille tutkimukseen liittyviä kyselylomakkeita ja ohjeet niiden täyttämistä. Lisäksi toivomme perheenne osallistuvan neuvontakokeiluun, johon kuuluu kuusi keskustelukäyntiä.

Neuvontakeskusteluissa mukana olevilla tutkijoilla on perheterapeuttinen koulutus ja Terveystieteiden tutkimuskeskuksen antama oikeuspsykoterapeutin ammattinimikkeen käyttöön. Perheenjäsenet osallistuvat keskusteluihin eri kokoonpanoilla:

1. tapaaminen: **vanhemmat/koko perhe** (kaksi tutkijaa)
2. tapaaminen: **koko perhe** (kaksi tutkijaa)
3. tapaaminen: samanaikaisesti **vanhemmat** (yksi tutkija) ja **lapset** (yksi tutkija)
4. tapaaminen: **perheen yksi lapsi** (yksi tutkija)
5. tapaaminen: **koko perhe** (kaksi tutkijaa)
6. tapaaminen 6 kk:n kuluttua: **koko perhe** (kaksi tutkijaa)

Neljäs tapaaminen on tarkoitettu perheen yhden lapsen tutkimiseen. **Kansainvälisen tutkimussuunnitelman mukaan kyseeseen tulee se lapsi, jonka syntymäpäivä on lähinnä tutkimuslomakkeiden täyttämispäivää.** Neuvontakeskustelut videoidaan. Kaikkia tietoja käsitellään luottamuksellisesti. Videonauhat ja muu tutkimusmateriaali ovat vain tutkimusryhmän käytössä ja niitä säilytetään tietosuojalain edellyttämällä tavalla. Voitte luonnollisesti keskeyttää neuvontakäynnit milloin tahansa eikä keskeyttäminen vaikuta TYKS:n onkologian klinikan antamaan hoitoon eikä muuhun hoitoon, johon Te olette tai perheenne jäsenet ovat oikeutettuja. Tässä tapauksessa teillä on myös oikeus pyytää videonauhoitteiden hävittämistä.

Kiitämme etukäteen osallistumisestanne, joka antaa meille arvokasta tietoa hyvin vähän tutkitusta alueesta. Se auttaa meitä ymmärtämään paremmin perheitä, niiden tarpeita ja kehittämään parempia lapsiperheille suunnattuja palveluja tulevaisuudessa.

Tutkimuksesta vastaa lastenpsykiatrian professori Jorma Piha. Lisätietoja tutkimuksesta antavat:

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Appendix 4**SUOSTUMUSLOMAKE LAPSI JA VANHEMMAN VAKAVA SAIRAUS –
TUTKIMUKSEEN**

Lapsi ja vanhemman vakava sairaus tutkimukseen osallistuminen on vapaaehtoista, ja voitte keskeyttää osallistumisenne milloin tahansa ilman, että se millään tavalla vaikuttaa TYKS:n onkologian klinikan antamaan hoitoon tai muuhun hoitoon, johon te olette tai perheenne jäsenet ovat oikeutettuja.

Suostumme osallistumaan *Lapsi ja vanhemman vakava sairaus* tutkimukseen, joka on osa laajempaa eurooppalaista EU:n tukemaa hanketta. Olemme saaneet sekä suullisesti että kirjallisesti tietoa tutkimuksesta ja neuvontakokeilusta.

Annan myös luvan sairauskertomustietojen käyttöön.

Turussa ____ / ____ 2003

Suostumuksen antajan allekirjoitus ja nimikirjoituksen selvennys

Suostumuksen antajan syntymäaika

Suostumuksen antajan osoite

Puolison allekirjoitus ja nimikirjoituksen selvennys

Lasten nimet ja allekirjoitukset

Tutkimusryhmän edustajan allekirjoitus

Appendix 5

KYSYLYLOMAKE ÄIDILLE
PERHEEN LAPSIEN KOSKEVAT TIEDOT
 (Täytetään erikseen jokaisesta lapsesta)

Lapsen etunimi ja sukunimi _____
 Lapsen syntymäaika _____

Lomaketta täytetään äidin nimi _____

COSIP-ID numero (tutkijat täyttävät)

Yleistä tietoa lapsesta (rengasta oikea vaihtoehto)		
01 Lapsen nimi		
02 Lapsen syntymä aika	_____	
03 Biologisten sisarusten määrä	_____(88)
04 Lapsen sukupuoli		
Poika.....(1)		
Tyttö.....(2)		
05 Lapsen kansalaisuus		
Suomalainen.....(246)		
Muu.....		
06 Lapsen sairaus vanhempi on...		
Biologinen isä.....(1)		
Biologinen äiti.....(2)		
Isäpuoli.....(3)		
Äiti puoli.....(4)		
Adoptioisä.....(5)		
Adoptioäiti.....(6)		
Sjaisisä.....(7)		
Sjaisiäiti.....(8)		
Muu äiti/hahmo.....(9)		
Muu isä/hahmo.....(10)		

07 Terve vanhempi tai muu aikuinen, joka huolehtii lapsen arjesta.	Ei sovi, sellaista aikuista ei ole.....(98) Biologinen isä.....(1) Biologinen äiti.....(2) Isäpuoli.....(3) Äiti puoli.....(4) Adoptioisä.....(5) Adoptioäiti.....(6) Sjaisisä.....(7) Sjaisiäiti.....(8) Muu äiti/hahmo.....(9) Muu isä/hahmo.....(10)
▶ isän uusi partneri merkitään äiti puoleksi, vaikka he eivät olisi naimisissa, jos he asuvat saman katon alla.	08 Lapsi elää äidin/huoltajan kanssa Biologinen äiti.....(1) Äiti puoli.....(2) Adoptioäiti.....(3) Sjaisiäiti.....(4) Isäpuoli.....(5) Muu äiti/hahmo.....(6) Ei äiti/hahmo.....(7) Ei tietoa.....(8)
▶ äidin uusi partneri merkitään isä puoleksi, vaikka he eivät olisi naimisissa, jos he asuvat saman katon alla.	09 Lapsi elää isän/huoltajan kanssa Biologinen isä.....(1) Isäpuoli.....(2) Adoptioisä.....(3) Sjaisisä.....(4) Isäpuoli.....(5) Muu isä/hahmo.....(6) Ei isä/hahmo.....(7) Ei tietoa.....(8)
▶ jos lapsi asuu "normaalisti" vanhempiensa kanssa, niin kirjaa (98)	10 Lapsen muut mahdolliset elinolosuhteet <i>Jos lapsi elää vanhempiensa kanssa, kirjotaa:</i> Ei sovi.....(98) Lasten/nuorten koti.....(1) Kuntoutus-/terapeuttinen laitos/koti.....(2) Asuu yksin.....(3) Naimisissa tai avoliitossa.....(4) Ens- ja turvakoti.....(5) Asunnoton.....(6) Ei tietoa.....(7)
	11 Onko lapsi kutsunut tai kolkonnan? Ei.....(1) Kyllä.....(2) Ei tietoa.....(3)

12 Montako lasta asuu samassa kodissa?

Tässä lühitään tietää montako alle 18-vuotiasa asuu saman katon alla

Lapske kaikki lapset, myös kotou pois muuttaneet	13 lapsen asema perheessä Ainut lapsi.....(1) Nuori lapsi.....(2) Keskimääräinen lapsi.....(3) Vanhin lapsi.....(4) Ei tietoa.....(5)
LAPSEN KEHITYS	14 Äidin ikä lapsen syntymässä (vuosina) 15 Mahdolliset vaikeudet Ei Kyllä Ei tietoa 15a Raskauden aikana (1) (2) (3) jos oli, minkälaisia..... 15b Synnytyksen aikana (1) (2) (3) jos oli, minkälaisia..... 15c Synnytyksen jälkeen (1) (2) (3) jos oli, minkälaisia..... 15d Onko lapsella ollut pysyvä suhde vähintään yhteen ja samaan ihmiseen elämänsä kolmen ensimmäisen vuoden aikana? Sama henkilö(1) (2) (3)

LAPSEN KEHITYS Onko lapsi saanut kumitoutusta kehitysvaikeuden vuoksi? Ei Kyllä Ei tietoa 16a Motoriseen kehitykseen(1) (2) (3) ▶ Jos kyllä, mihin vaikeuteen?	Ei Kyllä Ei tietoa 16b Puhteen kehitykseen(1) (2) (3) ▶ Jos kyllä, mihin vaikeuteen?
16c Siirseydenkehitykseen (kastele/tuhrminen)(1) (2) (3) ▶ Jos kyllä, mihin vaikeuteen?	Ei Kyllä Ei tietoa 17 Vakava sairaus(1) (2) (3) ▶ Jos kyllä, mikä sairaus?
18 Aikaisemmat yhteydenotot psykologisten ongelmien vuoksi. Ei yhtään.....(1) Kasvatus ja perheneuvola.....(2) Lastenpsykiatrian poliklinikka.....(3) Lastenpsykiatrian osasto.....(4) Muu.....(5) Ei tietoa.....(6)	▶ Vakavalla sairaudella tarkoitetaan: a) sellaista sairautta, joka on vaatinut vähintään 2 x yhten viikon ajan sairaalahoitoa b) sellaista sairautta, joka vaatii jatkuvaa erikoislääkärin seurantaa. ▶ tässä kysytään onko kyseinen lapsi jostain turvinut psykologisia apua

<p>► onko sellaisia tapahtumia puolen vuoden sisällä</p>	<p>19. Elämän tapahtumat</p> <p>Pelottava kokemus tai omanarvon tunning menetäminen.....(1) Kyllä (2) (3) Ei tietoa (3)</p> <p>Siirtolaisuus tai muu suuri muutos.....(1) (2) (3)</p> <p>Taloudellinen tai aineellinen katastrofi.....(1) (2) (3)</p> <p>Fyysisen väkivallan uhriksi joutuminen.....(1) (2) (3)</p> <p>Pitempi ero äidistä tai isästä.....(1) (2) (3)</p> <p>Vakava rita jonkun kanssa.....(1) (2) (3)</p> <p>Syntipukiksi joutuminen.....(1) (2) (3)</p> <p>Muutto.....(1) (2) (3)</p> <p>Muuttuneet perhesuhteet.....(1) (2) (3)</p> <p>Rakkaan ihmisen menettäminen.....(1) (2) (3)</p> <p>Muu.....(1) (2) (3)</p> <p>mitkä.....</p> <p>20a. Kuukautiset</p> <p>Ei sovi, lapsi on poika..... (98)</p> <p>Ei vielä..... (1)</p> <p>Kyllä..... (2)</p> <p>Ei tietoa..... (3)</p> <p>► Jos ovat alkaneet, minkä ikäisenä? ____</p> <p>Ei tietoa..... (88)</p>
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<p>► jos lapsi on tyttö valitse 98 ja siirty etempään</p>	<p>20b. Äänen murros (mädäläntuminen)</p> <p>Ei sovi, lapsi on tyttö..... (98)</p> <p>Ei vielä..... (1)</p> <p>Kyllä..... (2)</p> <p>Ei tietoa..... (3)</p> <p>► Jos äänimurros on tapahtunut, minkä ikäisenä? ____</p> <p>Ei tietoa..... (88)</p>
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PÄIVÄHOITOA KOSKEVAT KYSYMYKSET

<p>► jos lapsi on vielä liian pieni ollaan missään hoidossa, siirty kysymykseen 35 ja valitse 98</p> <p>► jos lapsi ei ole nyt hoidossa (on liian iso ja käy koulu, min. valitse 10 (ei missään) ja siirty kysymykseen 23</p>	<p>21. Päivähoidon järjestelyt</p> <p>Lapsi on vielä liian pieni..... (98)</p> <p>Hötopaikat.....</p> <p>Ei missään hoidossa..... (10)</p> <p>Perhepäivähoitossa..... (41)</p> <p>Päiväkodissa..... (42)</p> <p>Ei tietoa..... (91)</p>
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<p>► äiti yrittää muistella millaista oli, kun lapsi oli hoidossa</p>	<p>22 Hoitoajan aikaiset ongelmat</p> <p>Eroahdistus..... Ei (1) Kyllä (2) Ei tietoa (3)</p> <p>Konaktihäiriö..... (98) (1) (2) (3)</p> <p>Leikkivaikeuksia..... (98) (1) (2) (3)</p> <p>Ylivillisuus..... (98) (1) (2) (3)</p> <p>Käytöshäiriö/aggressiivisuus..... (98) (1) (2) (3)</p> <p>Muu, mikä..... (98) (1) (2) (3)</p>
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KOULUKÄYNTIÄ KOSKEVAT KYSYMYKSET

<p>► äiti yrittää muistella millaista oli koulukäynnin, vaikka lapsi olisi jo lopettanut koulukäynnin</p>	<p>23 Koulun aloittaminen</p> <p>Ei sovi, lapsi ei ole vielä koulussa..... (98)</p> <p>Aloitti koulukäynnin ikänsä mukaisesti..... (1)</p> <p>Aloitti vuoden aikaisemmin..... (2)</p> <p>Aloitti vuoden myöhemmin..... (3)</p> <p>Ei tietoa..... (4)</p> <p>24 Koulukäynnin historia</p> <p>Ei sovi, lapsi ei käy vielä koulussa..... (98)</p> <p>Säännöllinen..... (1)</p> <p>Jäänyt kerran luokalle..... (2)</p> <p>Jäänyt monta kertaa luokalle..... (2)</p> <p>Siirretty erityisluokalle..... (4)</p> <p>Jäänyt luokalle ja siirretty erityisluokalle..... (5)</p>
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<p>► Vasta muistellen</p>	<p>25 Jättikö lapsi peruskoulun kesken?</p> <p>Ei sovi, lapsi ei käy vielä koulussa tai koulukäynti on kesken..... (98)</p> <p>Ei..... (1)</p> <p>Kyllä, koska tahoi itse..... (2)</p> <p>Kyllä, koska koulu erotti hänet..... (3)</p> <p>Kyllä, muista syistä, miksi?..... (4)</p> <p>Ei tietoa..... (5)</p>
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<p>► Vasta muistellen</p>	<p>26 Koulukäyntivaikeudet</p> <p>Onko tädin tai koulun aloitteesta pyydetty ammattilaisten apua seuraavien ongelmien vuoksi?</p> <p>Ei sovi, lapsi ei käy vielä koulussa..... (98)</p> <p>Ei tietoa.....</p> <p>Käytöshäiriö/aggressiivisuus..... Ei (1) Kyllä (2) Ei tietoa (3)</p> <p>Suorittamisen ongelmat..... (1) (2) (3)</p> <p>Sosiaaliset ongelmat..... (1) (2) (3)</p> <p>Keskittymisvaikeudet..... (1) (2) (3)</p> <p>Ylivillisuus..... (1) (2) (3)</p> <p>Kouluhäiriö..... (1) (2) (3)</p> <p>Koulupeko/robia..... (1) (2) (3)</p> <p>Muu, mikä?..... (1) (2) (3)</p>
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LAPSEN TERVEYDENTILA

<p>► lue ensin lapsi kohdat 30 ja 31 ja valitse lasta parhaiten kuvaava tilanne! On kyse kansainvälisestä tutkimuksesta ja sen vuoksi vaihtoehdot voivat tulla kummallistilaa!</p>	<p>27 Koulunkäynnin menestys: mikä on korkein saavutettu taso? Ei sovi, ei käy vielä koulua tai peruskoulu on kesken.....(98) Ei ole saanut päästötodistusta.....(100) Peruskoulu ja päästötodistus.....(401) Lukio jäänyt kesken.....(402) Ylioppilastutkinto.....(403) Opiskelee ammattikoulussa/opistossa.....(404) Opiskelee yliopistossa.....(405) Päätti väli vuoden /menee opiskelemaan.....(406) Ei tietoa.....(901)</p>
	<p>28 Nuorten muut mahdolliset tilanteet Ei ole vielä valmistunut tai on työkäytön.....(1) Työtön.....(2) Tilapäinen työ.....(5) Oppisopimus.....(4) Suojatyössä.....(4) Nuorisovankila tai valvonta.....(5) Nuorisovankila tai valvonta.....(6) Ei tietoa.....(7)</p>
	<p>29 Millä luokalla lapsi on tällä hetkellä? ———— Ei tietoa.....(98)</p>
<p>► katso viimeistä koulutustilaa</p>	<p>30 Koulumenestys Viimeinen arvosana: ———— Aidinkielen: ———— Matematiikassa: ———— Ei arvosanaa vaan kirjallinen arviointi.....(98)</p>
<p>► valitse millä luokalla lapsi on:</p>	<p>31. Millä luokalla lapsi on tällä hetkellä? Ei sovi, lapsi ei ole vielä koulussa.....(98) Ensimmäisellä luokalla.....(401) Toisella.....(402) Kolmannella.....(403) Neljännellä.....(404) Viidellä.....(405) Kuudennella.....(406) Seitsemällä.....(407) Kahdeksannella.....(408) Yhdeksännellä.....(409) Kymppiluokalla.....(410) Ammatikouluissa/tai opistossa.....(411) Lukion ensimmäisellä luokalla.....(412) Lukion toisella.....(413) Lukion kolmannella.....(414)</p>

	<p>32 Onko lapsi säännöllisessä seurannassa jonkun sairauden vuoksi; astma, allergia, diabetes, muu? Ei.....(1) Kyllä.....(2) ► Jos kyllä, minkä vuoksi?</p>
	<p>Ei tietoa.....(3) 33. Käyttikö lapsi säännöllistä lääkitystä sairautensa vuoksi Ei.....(1) Kyllä.....(2) ► Jos kyllä, mikä lääkitys?</p>
<p>Jos isä on sairastunut: Jos isä ei ole sairastunut, niin olet valmis. KIITOS! Isä ei sairas.....(98) Äiti ei sairas.....(98)</p>	<p>Jos äiti on sairastunut: Jos äiti ei ole sairastunut, niin olet valmis. KIITOS! Äiti ei sairas.....(98)</p>
<p>40. Sen jälkeen kun isä sairastui onko lapsen tilanteensa/käyttäytymisensä ollut muutoksia? Ei.....(1) Kyllä.....(2) ► jos on niin millaisia?</p>	<p>41. Sen jälkeen kun äiti sairastui onko lapsen tilanteensa/käyttäytymisensä ollut muutoksia? Ei.....(1) Kyllä.....(2) ► jos on niin millaisia?</p>
<p>Ei tietoa.....(3)</p>	<p>Ei tietoa.....(3)</p>

Appendix 6

KYSELY ÄIDILLE	
PERHETTÄ KOSKEVAT TIEDOT	
Äidin nimi _____	
01 Kumpi vanhempi on tällä hetkellä sairas Äiti (1) Isä (2) Molemmat (3)	
<i>Jos vain äiti on sairas täytää lomakkeen vasen sarake. Jos vain isä on sairas täytää lomakkeen oikea sarake. Jos molemmat ovat sairaita täytää molemmat sarakkeet.</i>	
Äidin sairautta koskevat tiedot	Isän sairautta koskevat tiedot
7a Mitä diagnooseja sinulle on tässä yhteydessä tehty? _____ _____ _____	7b Mitä diagnooseja on hänelle tässä yhteydessä tehty? _____ _____ _____
8a Milloin päädiagnoosi tehtiin? Kk/vuosi ____ ____ / ____ ____ Ei tietoa (88/88)	8b Milloin päädiagnoosi tehtiin? Kk/vuosi: ____ ____ / ____ ____ Ei tietoa (88/88)
9a Oletko ollut nykyisen sairauden vuoksi sairaalahoitossa? Ei (1) Kyllä (2)	9b Onko hän ollut nykyisen sairauden vuoksi sairaalahoitossa? Ei (1) Kyllä (2)
<i>Jos sairaalahoitoja ei ole ollut merkitse (98) ja siirry kysymykseen 70</i>	
10a Kuinka monta kertaa olet ollut sairaalahoitossa? 1 (1) 2-4 (2) 5enemmän (3)	10b Kuinka monta kertaa hän on ollut sairaalahoitossa? 1 (1) 2-4 (2) 5enemmän (3)
► kirja esim. toukokuu 2001: 05/01	11a Milloin ensimmäinen sairaalahoito oli? Kk/vuosi: ____ ____ / ____ ____ Ei tietoa (88/88)
12a Kuka silloin huolehti lapsesta/lapsista? (Esim. _____ isovanhempi, naapuri) _____	11b Milloin ensimmäinen sairaalahoito oli? Kk/vuosi: ____ ____ / ____ ____ Ei tietoa (88/88)
12b Kuka silloin huolehti lapsesta/lapsista? (Esim. _____ isovanhempi, naapuri) _____	12b Kuka silloin huolehti lapsesta/lapsista? (Esim. _____ isovanhempi, naapuri) _____

Appendix 7

KYSELYLOMAKE ISÄLLE**ISÄÄ KOSKEVAT TIEDOT**

isän nimi

COSIP-ID numero (tutkijat täyttävät tämän kohdan)

01 Isän syntymävuosi ____ _ _ _ _				
<p>► Tässä tarkoitetaan isänä toimivaa miestä tai muuta aikuista</p> <p>Ei tietoa(8888)</p>				
02 Korkein koulutaso				
Keskeytynyt _____ kansa-,perus- _____ tai keskikoulu(98)				
Kansakoulu(401)				
Perus- tai keskikoulu(402)				
Ylioppilas(403)				
Ammatillinen koulutus:				
Ei ammattikoulutusta(411)				
Ammattikurssi/kursseja(412)				
Ammattikoulu, kauppakoulu tai muu kouluasteen oppilaitos(413)				
Opistoasteen koulutus(414)				
Korkeakoulu(415)				
Muu, mikä?(416)				
Ei tietoa(88)				
03 Työllisyystilanne				
Täyspäiväisessä työssä(1)				
Vuorotyössä(2)				
Säännöllinen osa-aika työ(3)				
Yrittäjä/free-lance työ(4)				
Työtön(5)				
Työtön mutta koulutuksessa(6)				
Eläkeläinen(7)				
Koti-isä(8)				
Opiskelija(9)				
Ei tietoa(88)				
04 Mihin ammattiin olet saanut koulutuksen?				
Vasta tähän kysymykseen vaikka olet sairaslomalla, se on tilapäinen poissaolo.				

05 Missä työssä työskentelet tällä hetkellä?				

Appendix 8

KYSELYLOMAKE ÄIDILLE**ÄITIÄ KOSKEVAT TIEDOT**

Äidin nimi _____

COSIP-ID numero (tutkijat täyttävät tämän kohdan)

<p>► Tässä tarkoitetaan äitinä toimivaa naista tai muuta aikuista</p>	<p>01 Äidin syntymävuosi _____</p> <p>Ei tietoa(888)</p>
	<p>02 Korkein koulutaso</p> <p>Keskeytynyt kansa-,perus- tai keskikoulu.....(98)</p> <p>Kansakoulu.....(401)</p> <p>Perus- tai keskikoulu.....(402)</p> <p>Ylioppilas.....(403)</p> <p>Ammatillinen koulutus:</p> <p>Ei ammattikoulutusta.....(411)</p> <p>Ammattikurssi/kursseja.....(412)</p> <p>Ammattikoulu, kauppakoulu tai muu kouluasteen oppilaitos.....(413)</p> <p>Opistoasteen koulutus.....(414)</p> <p>Korkeakoulu.....(415)</p> <p>Muu, mikä?.....(416)</p> <p>Ei tietoa.....(88)</p>
<p>Vasta tähän kysymykseen vaikka olet sairaslomalla, se on tilapäinen poissaolo.</p>	<p>03 Työllisyystilanne</p> <p>Täysipäiväisessä työssä.....(1)</p> <p>Vuorotyössä.....(2)</p> <p>Säännöllinen osa-aika työ.....(3)</p> <p>Yrittäjä/free-lance työ.....(4)</p> <p>Työtön.....(5)</p> <p>Työtön mutta koulutuksessa.....(6)</p> <p>Eläkeläinen.....(7)</p> <p>Kotiäiti.....(8)</p> <p>Opiskelija.....(9)</p> <p>Ei tietoa.....(88)</p>
	<p>04 Mihin ammattiin olet saanut koulutuksen?</p> <p>_____</p> <p>_____</p> <p>05 Missä työssä työskentelet tällä hetkellä?</p> <p>_____</p> <p>_____</p>

Appendix 9

Basic Documentation (BADO-C)

Module for the ill parent's physician

Surname, First Name (of ill parent) _____

Date of Birth (DDMM/YYYY) _____

Name of person documenting _____

COSIP-ID for ill parent:

If (1) is coded, please answer questions 2-7 only if these numbers are marked with an "a" in addition.

01 Which parent is currently ill?
 Mother(1)
 Father(2)
 Both(3)

If (2) is coded, please answer questions 2-7 only if these numbers are marked with an "b" in addition.
 If (3) is coded, please answer all of the following questions.

<p>Regarding the illness of the mother: 02a What diagnoses according to ICD-10-No. were made? Please write full name(s) below: _____ _____ ICD-10-No.: _____</p>	
<p>Regarding the illness of the father: 02b What diagnoses according to ICD-10-No. were made? Please write full name(s) below: _____ _____ ICD-10-No.: _____</p>	
<p>03a When was the leading diagnosis made? Month/Year: _____ / _____ (88/88) unknown</p>	<p>03b When was the leading diagnosis made? Month/Year: _____ / _____ (88/88) unknown</p>
<p>04a Onset of illness acute(1) subacute(2) lingering(3)</p>	<p>04b Onset of illness acute(1) subacute(2) lingering(3)</p>

<p>► "genetic" = genetic defect identified (e.g. hereditary hemochromatosis, Huntington)</p>	<p>05a Aetiology of illness genetic(1) multifactorial (including genetic risk)(2) infectious(3) accident(4) other illness (please specify below):(5)</p>	<p>05b Aetiology of illness genetic(1) multifactorial (including genetic risk)(2) infectious(3) accident(4) other illness (please specify below):(5)</p>
<p>► "progressing" = worsening of health state over a period within the last 12 months</p> <p>► "static" = state of impairment remains stable over a period of one year or more</p> <p>► "stable" = stable and complete remission (no cancer cells in the last 5 years)</p> <p>► "stable" = impaired status can be expected over the next 12 months (e.g. remission after accident, patient stable under dialysis)</p> <p>► "progressing" = e.g. multiple sclerosis</p> <p>► "terminal" = all medical measures are palliative</p> <p>► "insure" = death, please code "insure"</p>	<p>06a Course of illness during the last 12 months: remission(1) improvement but not in remission(2) static(3) relapse after previous remission(4) progressing(5) evaluation not possible(6)</p>	<p>06b Course of illness in the past remission(1) improvement but not in remission(2) static(3) relapse after previous remission(4) progressing(5) evaluation not possible(6)</p>
<p>07a Prognosis cured(1) stable(2) progressing(3) insecure(4) terminal(5)</p>	<p>07b Prognosis cured(1) stable(2) progressing(3) insecure(4) terminal(5)</p>	<p>Karnovsky-Index _____ %</p> <p>100%=normal, no complain, no signs of illness. 90%= mild symptoms, daily activities not impaired 80%= daily activities possible under effort 70%=self-supply possible 60%=self-supply possible with occupational aid 50%=needs formal aid 40%=handicapped or in need of help, not hospitalised 30%= severely handicapped, bedridden 20%=severely ill, hospitalised 10%=moribund</p>

Appendix 10

Täysin samaa mieltä 1 - Samaa mieltä 2 - Eri mieltä 3 - Täysin eri mieltä 4	
1. Perheen yhteisten tekemisten suunnittelu on vaikeaa koska käsittämme toisemme väärin.	1 2 3 4
2. Selvitämme useimmat jokapäiväiset ongelmat kotona.	1 2 3 4
3. Kun joku on poissa toaltaan niin muut tietävät minkä vuoksi.	1 2 3 4
4. Kun pyydät jotakuta tekemään jotain, niin sinun pitää varmistaa että hän on tehnyt sen.	1 2 3 4
5. Kun jollakulla on ongelmia, niin muut sekaantuvat siihen liikka.	1 2 3 4
6. Kriisiaikoina voimme turvautua toistemme tukeen.	1 2 3 4
7. Emme tiedä kuinka toimia hätätilanteissa.	1 2 3 4
8. Joskus tarvitsemme tavarat pääsevät loppumaan.	1 2 3 4
9. Emme ole halukkaita näyttämään heitä tunteita toisillemme.	1 2 3 4
10. Pidämme huolen siitä, että perhejäsenet suorittavat velvollisuutensa.	1 2 3 4
11. Emme voi puhua toisillemme surullisista oloistamme.	1 2 3 4
12. Toimimme yleensä ongelmia koskevien päätöstemme mukaan.	1 2 3 4
13. Saat yleensä muiden huomion vain silloin kun jokin on heille tärkeää.	1 2 3 4
14. Et voi tietää mitä toisesta tuntuu, vain sen perusteella mitä he puhuvat.	1 2 3 4
15. Perheen töitä ei jaeta tarpeeksi.	1 2 3 4
16. Hyväksymme toisemme sellaisina kuin olemme.	1 2 3 4
17. Palkkiahästä pääsee helposti rikkomalla sääntöjä.	1 2 3 4
18. Puhumme toisillemme suoraan vihjailujen sijaan.	1 2 3 4
19. Jotkut meistä eivät kerta kaikkiaan reagoi tunteella.	1 2 3 4
20. Tiedämme miten toimia hätätilanteissa.	1 2 3 4
21. Vältämme puhumasta peloistamme ja huolen aiheistamme.	1 2 3 4
22. Meidän on vaikeaa puhua toisillemme hellistä tunteista.	1 2 3 4
23. Meidän on vaikeaa saada laskurme maksettu.	1 2 3 4

Appendix 10
PERHEARVIOINTILOMAKE.

OHJEET LOMAKKEEN TÄYTTÄMISEKSI

- Lomake on tarkoitettu vanhemmille ja 12 vuotta täyttäneille lapsille/nuorille.
- Vastaa kysymykseen sen mukaan, kuinka perheesi on Sinun mielestäsi toiminut viimeksi kuluneiden 12 kuukauden aikana.
- Täytä lomake yksin aluksi keskustele vastauksistasi muiden perhejäsenten kanssa.
- Olemme kiinnostuneita Sinun henkilökohtaisesta näkemyksestäsi perheestäsi.

Tässä lomakkeessa on välttämää perheitä. Lue jokainen välttämä huolellisesti ja mieti kuinka hyvin se kuvailee perhettäsi. Vastaa sen perusteella millainen kuva Sinulla on perheestäsi.

Jokaiseen välttämään on neljä (4) eri vastausvaihtoehtoa:

Täysin samaa mieltä 1 Vältise 1, mikäli välttämä sopii perheeseesi erittäin tarkasti.

Samaa mieltä 2 Vältise 2, mikäli välttämä kuvailee perhettäsi melko hyvin.

Eri mieltä 3 Vältise 3, mikäli välttämä ei kuvaile perhettäsi kovin hyvin.

Täysin eri mieltä 4 Vältise 4, mikäli välttämä ei sovi perheeseesi lainkaan

Nämä vastausvaihtoehdot 1, 2, 3, 4 ovat jokaisen välttämän vieressä, esimerkiksi:

41. Emme tydy mihinkään mikä ei ole täydellistä. 1 2 3 4

Vastaa jokaiseen välttämään ja merkise vastauksesi rengastamalla oikeaa vaihtoehtoa vastaava numero. Älä mielti vastaustasi liian pitkään, vaan vastaa niin nopeasti ja rehellisesti kuin voit. Jos jokin kohta tuottaa vaikeuksia, vastaa ensimmäisen ajatuksesi mukaan.

Vastaaajan nimi _____

Syntymäaika ____/____/____ Sukupuoli nainen mies

Lomakkeen täytötpäivä ____/____/2002

Suomenkielinen käännös on tehty Helsingin yliopiston lastenpsykiatrian klinikalla 1999 professori Fredrik Ahnqvistin johdolla depressiivisten lasten psykoterapiatutkimusta varten ja tarkistettu Turun yliopiston lastenpsykiatrian klinikalla 2002 professori Jorma Pihän johdolla Lapset ja vanhemman vakava sairaus tutkimusta varten.

Täysin samaa mieltä 1 - Samaa mieltä 2 - Eri mieltä 3 - Täysin eri mieltä 4	Täysin samaa mieltä 1 - Samaa mieltä 2 - Eri mieltä 3 - Täysin eri mieltä 4
24. Sen jälkeen, kun perheemme on yrittänyt ratkaista ongelman keskustelemme yleensä siitä toimikko se vai ei.	1 2 3 4
25. Olemme liian itsekeskeisiä.	1 2 3 4
26. Voimme ilmaista tunteita toisillemme.	1 2 3 4
27. Meillä ei ole selkeitä sääntöjä kylpyhuoneen käytöstä (yksityisyys).	1 2 3 4
28. Emme osoita sitä, että välitämme toisistamme.	1 2 3 4
29. Puhumme ihmisille mieluummin suoraan kuin jonkun kautta.	1 2 3 4
30. Meillä kaikilla on omat tehtävämmet ja velvollisuutemme.	1 2 3 4
31. Perheessämme on usein paha olla.	1 2 3 4
32. Meillä on säännöt siitä, saako toista yödyä.	1 2 3 4
33. Olemme kiinnostuneita toisistamme, vain silloin kun meillä on jokin yhteinen kiinnostuksen kohde.	1 2 3 4
34. Perheessämme on vain vähän aikaa omiin henkilökohtaisiin kiinnostuksen kohteisiin.	1 2 3 4
35. Usein meille käy niin, ettemme sano sitä mitä tarkoitamme.	1 2 3 4
36. Tuntemme, että meidän hyväksyttään sellaisina kuin olemme.	1 2 3 4
37. Osoitamme kiinnostusta toisiamme kohtaan silloin kun voimme itse hyötyä siitä jotenkin.	1 2 3 4
38. Selvitämme useimmat sellaiset asiat, jotka saavat meidät pois toisillemme.	1 2 3 4
39. Perheessämme muut asiat ovat tärkeimpiä kuin hellyys.	1 2 3 4
40. Keskustelemme siitä kenen tulisi tehdä kotityöt.	1 2 3 4
41. Perheessämme päätöksenteko on ongelmallista.	1 2 3 4
42. Perheessämme esotamme kiinnostusta toisiamme kohtaan, vain kun voimme hyötyä siitä jotenkin.	1 2 3 4
43. Olemme vilpittömiä ja suoria toisillemme.	1 2 3 4
44. Emme noudata mitään sääntöjä tai käyttäytymisnormeja.	1 2 3 4
Täysin samaa mieltä 1 - Samaa mieltä 2 - Eri mieltä 3 - Täysin eri mieltä 4	
45. Jos jotakuta pyydetään tekemään jotain, niin häntä täytyy muistuttaa siitä.	1 2 3 4
46. Pystyimme päättämään siitä, kuinka ongelmat ratkaistaan.	1 2 3 4
47. Jos sääntöjä rikotaan niin emme tiedä mitä siitä seuraa.	1 2 3 4
48. Mikä tahansa käy päinsä meidän perheessämme.	1 2 3 4
49. Osoitamme hellyyttä toisillemme.	1 2 3 4
50. Voimme käsitellä ongelmia, joihin liittyy tunteita.	1 2 3 4
51. Emme tule hyvin toimeen keskenämme.	1 2 3 4
52. Emme puhu toisillemme, kun olemme vihaisia.	1 2 3 4
53. Olemme yleisesti tyytymättömiä perheessämme jaettuun velvollisuksiin.	1 2 3 4
54. Vaikka tarkoitamme hyvää, niin puutumme liikaa toistemme elämään.	1 2 3 4
55. Meillä on sääntöjä vaarallisten tilanteiden varalta.	1 2 3 4
56. Uskoudumme toisillemme.	1 2 3 4
57. Itkemme avoimesti.	1 2 3 4
58. Meillä ei ole kunnollisia kuljetusjärjestelyjä.	1 2 3 4
59. Kun joku on tehnyt jotain sellaista, josta emme pidä, niin kerromme sen hänelle.	1 2 3 4
60. Yritämme miettiä erilaisia keinoja ratkaista ongelmat.	1 2 3 4

Appendix 12

8. Kuinka usein tunteesi ja ajatuksesi ovat oikein sekaisin?

Hyvin usein 1 2 3 4 5 6 7
erittäin harvoin tai ei koskaan

9. Kuinka usein koet tunteita, joita et sallisi itsellesi?

Hyvin usein 1 2 3 4 5 6 7
erittäin harvoin tai ei koskaan

10. Monet ihmiset – jopa lujaluonteiset – kokevat tiettyissä tilanteissa olevansa toisten tiellä. Kuinka usein olet kokenut näin?

En koskaan 1 2 3 4 5 6 7
hyvin usein

11. Kun jotain on tapahtunut, oletko jälkikäteen yleensä todennut, että

Olet yll- tai aliarvioinut asian merkityksen 1 2 3 4 5 6 7
näät asian oikeassa mittakaavassa

12. Kuinka usein sinulla on tunne, että päivittäiset tekemiseni ovat joksenteen merkityksettömiä?

Hyvin usein 1 2 3 4 5 6 7
erittäin harvoin tai ei koskaan

13. Kuinka usein sinulla on tunteita, joita et koe voivasi varmuudella pitäää kurissa?

Hyvin usein 1 2 3 4 5 6 7
erittäin harvoin tai ei koskaan

TUNTEET JA TUNTEMUKSET

Lomake on tarkoitettu vanhemmille ja 12 vuotta täyttäneille lapsille/nuorille. Kyselyllä halutaan selvittää, mitä sinusta tuntuu? Rastia se vaihtoehto 1-7, joka vastaa parhaiten käsitystäsi.

Vastaajan nimi _____

Syntymäaika ____/____/____ Sukupuoli nainen mies

Lomakkeen täyttöpäivä ____/____/2002

1. Tähän asti elämäni on ollut

Täysin vailla selvää tarkoitusta ja päämäärää 1 2 3 4 5 6 7
sen tarkoitus ja päämäärät ovat täysin selvät

2. Kuinka usein sinulla on tunne, ettet oikeastaan välitä, mitä ympärilläsi tapahtuu?

Erittäin harvoin tai ei koskaan 1 2 3 4 5 6 7
hyvin usein

3. Kuinka usein olet yllättynyt sellaisten henkilöiden käyttäytymisestä, jonka uskoit tuntevasi hyvin?

En koskaan 1 2 3 4 5 6 7
jaukavasti

4. Oletko joskus pettynyt ihmisiin, joihin luoit?

En koskaan 1 2 3 4 5 6 7
jaukavasti

5. Kuinka usein sinulla on tunne, että sinua kohdellaan epäoikeudenmukaisesti?

Hyvin usein 1 2 3 4 5 6 7
erittäin harvoin tai ei koskaan

6. Kuinka usein sinulla on sellainen tunne, että olet oudossa tilanteessa etkä tiedä, mitä tehdä?

Hyvin usein 1 2 3 4 5 6 7
erittäin harvoin tai ei koskaan

7. Koeeko, että päivittäisten tehtäviesi hoitaminen on?

Suuren mielihyvän ja tyydytyksen lähde 1 2 3 4 5 6 7
tuskallista ja ikävää

Appendix 13 SF-8

KYSELYLOMAKE SAIRASTAVALLE VANHEMMALLE

COSIP ID-numero (tutkijat täyttävät)

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Rastita oikea vaihtoehto

- Miten arvioisit terveydentilaasi yleisesti ottaen kuluneen 4 viikon aikana?
Erinomainen Oikein hyvä Hyvä Menettelee Huono Erittäin huono
- Kun ajattelet 4 viimeistä viikkoa, miten paljon sairauteesi liittyvät ongelmat ovat rajoittaneet liikuntakykyäsi, esim. kävelyä tai rappujen nousemista?
Ei yhtään Hyvin vähän Jonkin verran Aika paljon En voinut liikkua yhtään
- Kun ajattelet 4 viimeistä viikkoa, miten paljon sairautesi on vaikuttanut toimintakykyysi sekä kotona että työssä?
Ei yhtään Vain vähän Jonkin verran Aika paljon En voinut tehdä mitään
- Kun ajattelet 4 viimeistä viikkoa, kuinka paljon sinulla on ollut fyysisiä kipuja?
Ei yhtään Hyvin lieviä Lieviä Siedettäviä Vaikeita Hyvin vaikeita
- Kun ajattelet 4 viimeistä viikkoa, kuinka paljon energiaa sinulla on ollut?
Hyvinkin paljon Aika paljon Jonkin verran Vain vähän Ei yhtään
- Kun ajattelet 4 viimeistä viikkoa, kuinka paljon fyysinen tai psyykinen kuntosi on rajoittanut sosiaalista kanssakäymistä ystävien tai sukulaisten kanssa?
Ei ollenkaan Hyvin vähän Jonkin verran Aika paljon Täysin
- Kun ajattelet 4 viimeistä viikkoa, kuinka paljon koet olleesi vaikeiden tunteiden (kuten ahdistuneisuus, masentuneisuus, ärtyneisyys) kuormittamana?
Ei yhtään Hyvin vähän Keskipertaisesti Aika paljon Erittäin paljon
- Kun ajattelet 4 viimeistä viikkoa, kuinka paljon henkilökohtaiset tai tunnepuolen ongelmat ovat estäneet sinua tekemästä tavallisia jokapäiväisiä asioita työssä/koulussa tai kotona?
Ei yhtään Hyvin vähän Jonkin verran Aika paljon En voinut tehdä mitään

Appendix 14

KYSELY 11-18-vuotilaille NUORILLE
Harrastukset, koulunkäynti ja ongelmat

Luottamuksellinen

Sinun nimesi: _____

Sukupolkesi: Poika Tyttö

Päiväys: pv kk v

Äidinkielenesi: Suomi Ruotsi Muu, mikä?

Isä: _____

Äiti: _____

Sinun syntymäaikasi: pv kk v

Koulunkäynti tai opiskelu: En käy koulua, en opiskele

Oppilaitos: _____

Vastaa seuraavien kysymysten Sinun oman näköyksesi mukaan, vaikka toiset olisivat toista mieltä. Voit tarvittaessa kirjoittaa lisäkommentteja!

I. Luettelisitko urheilulajeja, joita mielestäsi harjastat (esim. uiminen, jalkapallo, voimistelu, jalkapallo jne):

En harjastaisi yhtään urheilua

Keskittämällä-räisiltä vähemmän	Keskittämällä-räisiltä enemmän	Keskittämällä-huonompi	Keskittämällä-voimempi	Keskittämällä-saimen	Keskittämällä-parempi
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

II. Luettelisitko muuta lempiharrastustuloksista, taitamisista ja taitoista (esim. lukeminen, peili, musiikki, käsityöt, postimerkkien jne. - tv:n katselu ei lasketa mukaan):

Ei tällaisia harrastuksia

Keskittämällä-räisiltä vähemmän	Keskittämällä-räisiltä enemmän	Keskittämällä-huonompi	Keskittämällä-voimempi	Keskittämällä-saimen	Keskittämällä-parempi
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

III. Luettelisitko mihin joukkueisiin, kerhoihin, yhdistyksiin tai ryhmiin kuulut (esim. urheiluseura/joukkue, harrastuskerho, kuoro jne):

Ei kerhoa tai seuraa

Ei yhtä aktiivinen kuin muut	Yhtä aktiivinen kuin muut	Aktiivisempi kuin muut
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

IV. Luettelisitko niitä tittelijä ja tehtäviä teet kotona (esim. oman huoneen siivous, muut kotityöt, maastoon jakaminen, lastenhoito jne):

Ei mitään

Keskittämällä-huonompi	Keskittämällä-saimen	Keskittämällä-parempi
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

V.1. Kuinka monta läheistä ystävää sinulla on? (Sisällyttää ei-läheisiä mukaan) 1 2 3 4 tai enemmän

2. Kuinka monta kertaa viikossa tapaavat ystäväsi koulun ulkopuolella? (Sisällyttää ei-läheisiä) Vähemmän kuin kerran 1 tai 2 3 tai useammin

VI. Verrattuna muihin samankäsitisiin kuinka hyvin miltästäsi:

Huonompiin	Keskittämällä-saimen	Parempiin
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

VII. Koulunestisyys

Kuinka menestyit seuraavissa asioissa verrattuna muihin samankäsitisiin (Jos et löydä koulua, niin vastaa sen tilalleen mukana, kaivattomiksi listat koulut)

En käy koulua. Seitä miksi:

En ole sisaruksina Ei ole sisaruksina

Ei yhtiään 1 2 3 tai useammin

Vähemmän kuin kerran 1 tai 2 3 tai useammin

Verrattuna muihin samankäsitisiin

Keskittämällä-huonompi	Keskittämällä-saimen	Keskittämällä-voimempi	Keskittämällä-parempi
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Onko Sinulla joku sairaus, ruumiillinen vamma tai terveysongelma?

Ei Kyllä - kerrositko tarkemmin:

Onko Sinulla joku ongelma tai huoli opiskelussa?

Ei Kyllä - kerrositko tarkemmin:

Onko Sinulla joku muu ongelma tai huoli?

Ei Kyllä - kerrositko tarkemmin:

Kuivalitko parhaita ominaisuuksiasi:

Ei Kyllä - kerrositko tarkemmin:

Suorassa on luettelo lapsilla ja nuorilla jostakin esiintyvistä ominaisuuksista ja ongelmista. Arvioi miten paljon välttämättä sopii sinuun, kun ajattelet tätä hetkeä ja viinoksi kututtua puolta vuotta. Ympyröi sopivan vaihtoehdon (0, 1 tai 2). Ole ystävällinen ja vastaa kaikkiin kysymyksiin, myös vaikka joku vastaus ei ole sinun siviilille.		2 – Sopii erittäin hyvin tai usein	
0 = Ei sopi lainkaan		1 = Sopii jossain määrin tai toisaan	
0 1 2 1. Käyttyköön käsistäsi nuoremalla tavalla	0 1 2 37. Joutuu usein appelpuun	0 1 2 66. Toistan tiettyjä toimintoja uudelleen ja uudelleen. (Kuvaile)	0 1 2 93. Puhun liian paljon
0 1 2 2. Juon alkoholia liian vanhempieni lupaa (Kuvaile)	0 1 2 38. Minua kiusataan paljon	0 1 2 67. Karkailen kotoa	0 1 2 94. Kiusaan aika paljon muita
0 1 2 3. Väitän usein vastaan	0 1 2 39. Läkän selvitän kavereiden kanssa, jotka joutuvat usein vaikkeuksiin	0 1 2 68. Huudan paljon	0 1 2 95. Olen kiivestunut
0 1 2 4. En pysty tekemään leppuun aloittamaan tehtäviä	0 1 2 40. Kuiden ääniä, joita muiden mielestä ei ole olemassa. (Kuvaile)	0 1 2 69. Olen väkiloiva, pidän asiat itselläni	0 1 2 96. Ajattelen liikaa seksisovaa
0 1 2 5. Väin harvat asiat tuntuva minulle rautina	0 1 2 41. Toinen heiken mieltöijäsesta tai ajatelmasta	0 1 2 70. Näen asioita, joita muut eivät näe. (Kuvaile)	0 1 2 97. Uhdellen satuttavasti muita ihmisiä
0 1 2 6. Pidän elämistä	0 1 2 42. Olen mieluummin yksin kuin muiden kanssa	0 1 2 71. Meneen helposti hamilleni	0 1 2 98. Minusta on mukava auttaa muita
0 1 2 7. Kerskailem, leikkim, nauttien	0 1 2 43. Vähdellen tai peikkun	0 1 2 72. Syyttelen tulppajaa	0 1 2 99. Tupakoim tai käytän nukaaka
0 1 2 8. Olen huono keskittymään	0 1 2 44. Puuskelen krysantti	0 1 2 73. Osaan tehdä hyvin asioita kessilläni. (Kuvaile)	0 1 2 100. Minulla on mukamissongelmia. (Kuvaile)
0 1 2 9. En saa postia mielestäni tiettyjä ajankausia. (Kuvaile)	0 1 2 45. Olen hermostunut, kireä tai jännittynyt	0 1 2 74. Pelkään ja yrittän tehdä vaikkauken	
0 1 2 10. Olen levoton, en pysty istumaan hiljaa	0 1 2 46. Minulla on hermostuneita liikkaita tai rytmisiä. (Kuvaile)	0 1 2 75. Olen up	
0 1 2 11. Olen liian riippuvainen aikuisista	0 1 2 47. Näen painajaisia	0 1 2 76. Näkän päivällä joku yllä enemmän kuin useimmat muut lapset tai nuoret. (Kuvaile)	
0 1 2 12. Tunnen olevani yksinäinen	0 1 2 48. Muut nuoret eivät pidä minusta	0 1 2 77. En pysty keskittymään, häiriintyn helposti	
0 1 2 13. Olen hämmetynyt tai ymmällinen	0 1 2 49. Tiettyjä asioita teen paremmin kuin useimmat nuoret	0 1 2 78. En pysty keskittymään, häiriintyn helposti	
0 1 2 14. Iken paljon	0 1 2 50. Olen liian pelkäs tai ahdistunut	0 1 2 79. Minulla on puhevankaisia. (Kuvaile)	
0 1 2 15. Olen rehellinen	0 1 2 51. Tunnen huumausta	0 1 2 80. Puuskelen oikeuksiini	
0 1 2 16. Olen ilmeä, kusaan muita	0 1 2 52. Minulla on liian vomakkaita syölysyöndönetuä	0 1 2 81. Vanstian kotoa	
0 1 2 17. Uhdellon ja haaveilen paljon	0 1 2 53. Syön lihaa	0 1 2 82. Vanstian kodiin ulkopuolella	
0 1 2 18. Väingoinen itsestäni läheisesti tai läheisiin yrittäi isemättä	0 1 2 54. Olen liian väsynt	0 1 2 83. Kerään tavaroita, joita en tarvitse. (Kuvaile)	
0 1 2 19. Yritän saada paljon huomusta	0 1 2 55. Olen ylipainoinen. Paino: _____ kg. Pituus: _____ cm.	0 1 2 84. Teen asioita, joita muut pitävät outona. (Kuvaile)	
0 1 2 20. Rikoon omia vaaroitani	0 1 2 56. Minulla on seuravia vavojia ilman tunnettuä seittä tu:	0 1 2 85. Minulla on ajatuksia, joita muut pitävät outona. (Kuvaile)	
0 1 2 21. Rikoon muiden vaaroita	0 1 2 a. Särkyä tai kipuja (ei päänsärky)	0 1 2 86. Olen itsepäinen	
0 1 2 22. Olen totelematon kotona	0 1 2 b. Päänsärkyä	0 1 2 87. Mielillään tai tunteen vaihtelevat äkillisesti	
0 1 2 23. Olen totelematon kouluissa	0 1 2 c. Pahoivomia	0 1 2 88. Pidin tai maan muiden seurassa olemisesta	
0 1 2 24. Syön liian huonosti	0 1 2 d. Silmävavojia. (Kuvaile)	0 1 2 89. Olen epäluulubien	
0 1 2 25. Tulen huonosti toiseen muiden lasten tai nuorten kanssa pitäytyä lähellä	0 1 2 e. Ihottumaa tai muita iho-ongelmia.	0 1 2 90. Kiroilen tai käytän rivoa kieltä	
0 1 2 26. En tunne syyllisyyttä, kun olen tehnyt jotain, mitä ei olisi pitänyt tehdä	0 1 2 f. Vätsäkipu	0 1 2 91. Ajattelen itseni tappamasta	
0 1 2 27. Olen kateellinen muille	0 1 2 g. Oksentelua	0 1 2 92. Minusta on mukava saada muut tuuraamaan	
0 1 2 28. En noudata sääntöjä kotona, kouluissa tai muualla	0 1 2 h. Muuta (Kuvaile):		
0 1 2 29. Pelkään tiettyjä eläimiä, tilanteita tai paikkoja - muuta kuin koutia. (Kuvaile)			
0 1 2 30. Pelkään koulun menoa	0 1 2 57. Käyn harkasta toiseen kempuun (esim. tonaisen, yön)		
0 1 2 31. Pelkään ajattelevani tai tekäväni jotain pahaa tai huonosti. (Kuvaile)	0 1 2 58. Nyrpin ihonni tai muita ruumiinosiani. (Kuvaile)		
0 1 2 32. Koen, että minun on oltava ajattelinen	0 1 2 59. Osaan olla ystävällinen		
0 1 2 33. Minusta tuntuu, että kukaan ei pidi minusta	0 1 2 60. Minusta on hauska kokeilla uusia asioita		
0 1 2 34. Minusta tuntuu, että oisit tihkaavat tai väinovat minua	0 1 2 61. Selvitydyn huonosti koulutyöistä		
0 1 2 35. Tunnen olevani arvoton tai huonompi kuin muut	0 1 2 62. Olen kempelö		
0 1 2 36. Joutuu usein vaihokohiin, jossa säntään itseni	0 1 2 63. Olen mieluiten itseäni vanhempien lasten tai nuorten kanssa		
0 1 2 65. Kieittyköön puhumassa	0 1 2 64. Olen mieluiten itseäni nuorempien lasten kanssa		

Ok ystäväillinen ja kirjotia vielä lisää itsestä ja elämästä, jos haluat:

Ok ystäväillinen ja tarkista, että olet vastannut kaikkiin kysymyksiin. Aiktevaa mitä kullakin, josta olet huolissasi, jos sellaisia on!

KIITOS VASTAUKSISTA!

Mikäli vielä haluat kertoa jotain, voit käyttää alla olevaa tilaa siihen.

Appendix 15

Hyvä syöpätautien klinikan henkilökunta – huhtikuu 2004 -

Toukokuun alussa vuonna 2002 aloitimme Lapsi ja vanhemman vakava sairaus-projektin eli COSIP-projektin aineiston keruun ja samalla käynnistimme syöpään sairastuneiden potilaiden ja heidän lastensa ja perheidensä neuvontakokeilun klinikallanne. Aineiston keruu päättyy nyt tämän kuun lopussa. Projektin raportointia varten kartoitamme myös teidän kokemuksianne ja mielipiteitänne. Olisimme kiitollisia, jos voisitte täyttää tämän lyhyen, yhden sivun kyselyn ja palauttaa sen viikon sisällä.

Vastauksista etukäteen kiittäen

Jorma Piha
Professori, ylilääkäri

Sukupuoli	nainen	mies	Ikä
Ammatti	Osasto (rengasta) 810 – 811 – 816 – 820 – 821		
Kuinka monta vuotta olet toiminut ammatissasi	Kuinka monta vuotta olet työskennellyt TYKSin syöpäklinikalla		
Onko COSIP-projekti mielestäsi ensisijaisesti painottunut	tieteelliseen tutkimukseen psykososiaaliseen neuvontaan molempiin yhtä paljon		
Olen osallistunut COSIP-projektia koskeneeseen infotilaisuuteen	kyllä	ei	
Olen henkilökohtaisesti ollut tekemisissä COSIP-projektin terapeuttien kanssa (Florence Schmitt, Hanna Manninen)	kyllä	ei	
Potilaat ovat kertoneet COSIP-terapeuttien antamasta neuvonnasta	kyllä	ei	
Olen ohjannut potilaita COSIP-projektin terapeuttien neuvontaan	kyllä	ei	
Onko COSIP-projektin terapeuttien antamasta neuvonnasta mielestäsi ollut hyötyä potilaille	kyllä	ei	en osaa sanoa
Nykyisin työssäni ajattelen potilaiden perheitä ja lapsia	enemmän kuin aikaisemmin yhtä paljon kuin aikaisemmin vähemmän kuin aikaisemmin en osaa sanoa		
Jos olet ollut tekemisissä COSIP-projektin terapeuttien kanssa, niin minkälaista kanssakäyminen on ollut?			
Tarvittaessa jatka kääntöpuolelle			

Appendix 16

Tupakkaitteko tai oletteko tupakoinut?
 Ei: _____ Kyllä: _____ Montako vuotta: _____ Määrä/vnk: _____
 Lopettanut v. _____
 Alkoholin käyttö (mitä, montako pulloa/vnk, vko tai kk)

Samassa taloudessa:
 Puoliso: Ei: _____ Kyllä: _____
 Lapset: Ei: _____ Kyllä: _____ Syntymävuodet: _____

Naisilla,
 kuukautistoiminta:
 Alkoi _____ vuoden ikäisenä Kohdun poisto, vuosi _____
 Loppui _____ vuoden ikäisenä
 Säännölliset _____ Epäsäännölliset _____

Syntytykset _____ vuosina _____
 Raskaus normaali Kyllä: _____
 Ei: _____
 Keskenmenot _____ vuosina _____
 Raskaudenkeskeytys _____ vuosina _____

Gynekologinen hormonihoito
 Kyllä: _____ Milloin _____ Syy _____
 Ei: _____ Mitä _____

Oletteko käyttänyt E-pillereitä?
 Kyllä: _____ aika _____ Mitä _____
 Ei: _____

Turun yliopistollinen keskussairaala, Onkologian poliklinikka
Haastattelulomake

Pyydämme teitä ystävällisesti tuomaan tämän lomakkeen täytettynä poliklinikalle.

Sukunimi, etunimet: _____
 Henkilötunnus: _____ Pituus: _____ Paino: _____
 Anamatti: (myös entiset): _____
 Onko lähisukulaisilla todettu syöpää (mikä syöpä, kenellä)? _____

Oletteko ennen ollut sairaalahoitossa (sairaalat, vuosi, syy sekä leikkaukset)? _____

Sairastatteko tai oletteko sairastanut

1. Sydäninfarkti Kyllä: _____ Ei: _____ 6. Astmaa Kyllä: _____ Ei: _____
2. Kohonnutta veren-
paineetta Kyllä: _____ Ei: _____ 7. Sokeritautia Kyllä: _____ Ei: _____
3. Sappitautia tai
munuaistautia Kyllä: _____ Ei: _____ 8. Muuta pitkä-
aikaisrauhaa Kyllä: _____ Ei: _____
Mitä? _____
4. Keuhko- tai muuta
tuberkuloosia Kyllä: _____ Ei: _____
5. Epilepsiaa Kyllä: _____ Ei: _____ 9. Yliherkkyys Kyllä: _____ Ei: _____
Mikä? _____

Käytättekö lääkkeitä (lääkkeen nimi ja määrä)? _____

Käännös