



AINO-LIISA JUSSILA

## Stabilising of Life

A Substantive Theory of Family Survivorship  
with a Parent with Cancer



ACADEMIC DISSERTATION

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the Faculty of Medicine of the University of Tampere,  
for public discussion in the Paavo Koli Auditorium of the University,  
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*To Mother and Father*

# ABSTRACT

Aino-Liisa Jussila

Stabilising of Life - A Substantive Theory of Family Survivorship with a Parent with Cancer.

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The purpose of this grounded theory study was to explore families' living with a parent with cancer and to develop a substantive theory to explain how these families solve the main concern in their lives. The study design was prospective using 32 joint couple conversations with the parents of 13 families (N=26) which were had during different stages of the cancer trajectory as well as observations of 26 hours of five families, including in total ten parents and nine children (N=19), collected during a boarding course on psychosocial rehabilitation. The data was collected and analysed according to the grounded theory methodology and consisted of 2377 incidents and the memo fund of 97 pages.

The main concern of families living with a parent with cancer was *stabilising of life* through facing of hardships and assuming an attitude towards the future which patterned out as detaching from the disease, fighting against the disease, adjusting to life with the disease and submitting to the disease.

When hardships were faced in the family of a parent with cancer in a life-embracing, persistent and active manner and the family's attitude towards the future emphasised positivity, hopefulness, meaningfulness, balancedness and trust, the family was *detaching from the disease*. This consisted of maintaining of hope, living trustingly, changing of the concept of self, progressing of recovery and continuing the habituated life. Then, during detaching from the disease, apart from changing of the concept of self, the life of the parent and his/her family members returned back to normal.

In the family of a parent with cancer, the stabilising of life involved *fighting against the disease* when the family was facing hardships in a life-embracing, persistent and active manner, and nevertheless, assuming a negative and hopeless, anxious and fearful as well as doubtful attitude towards the future. Fighting against the disease involved the stages of deliberating about falling ill, rebelling against the change in life, overcoming adversities, preparing for worse and ensuring the functionality. During fighting against the disease, the family uniformly resisted the disease and wanted to struggle against it.

When hardships were faced in a powerless, dejected and passive manner, but the manner of assuming an attitude towards the future was nevertheless underlined by positivity, hopefulness, meaningfulness, balancedness and trust, the family was *adjusting to life with the disease*. Therefore, adjusting to life with the disease comprised clarifying of facts, resorting to help, returning to life, intensifying of togetherness and maturing through hardships. In adjusting to life with the disease, the family learned to live with the changes in life brought about by the disease.

Stabilising of life entailed *submitting to the disease* in the family with a parent suffering from cancer when hardships were faced in a powerless, dejected and passive manner and the family assumed a negative, hopeless, anxious, fearful and doubtful attitude towards the future. Submitting to the disease included the stages of life coming to a standstill, succumbing to fear, being burdened by concerns, life turning more difficult and getting caught in being ill. During submitting to the disease, the family in a way further attached itself to the adverse reputation of the disease and the difficult circumstances it had inflicted.

The substantive theory of family survivorship is a middle range theory which provides researchers, health and social care professionals and educators with a greater understanding of the perspectives of families' living with cancer which may be used in developing the health and social care of families and in developing the education of health and social care professionals.

**Key words:** Stabilising of life, family survivorship, a parent with cancer, caring for the family, the grounded theory methodology.

# TIIVISTELMÄ

Aino-Liisa Jussila

Elämän vakautuminen – Substantiivinen teoria perheen selviytymisestä vanhemman sairastaessa syöpää.

Tampereen yliopisto

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Tämän grounded theory -tutkimuksen tarkoituksena oli tutkia perheiden elämää vanhemman sairastaessa syöpää ja kehittää substantiivinen teoria selittämään, kuinka nämä perheet ratkaisevat keskeisimmän huolenaiheen elämässään. Tutkimus oli prospektiivinen ja koostui 13 perheen vanhempien (N=26) 32 samanaikaisesta haastattelusta potilaan sairastamisen eri vaiheissa sekä 26 tunnin havainnointiaineistosta, joka kerättiin sopeutumisvalmennuskurssilla, johon osallistui viisi perhettä: yhteensä kymmenen vanhempaa ja yhdeksän lasta (N=19). Aineisto kerättiin ja analysoitiin grounded theory -metodologian mukaisesti. Aineisto koostui 2377 tapahtumasta ja memoista, joita oli 97 sivua.

Syöpään sairastuneen vanhemman perheen kohdatessa eteen tulevia vaikeuksia ja asennoituessa tulevaisuuteensa se selvittää elämäntilannettaan *elämän vakautumisen* avulla, joka ilmenee sairaudesta irtautumisena, sairautta vastaan taistelemisena, sairauden kanssa elämään totuttelemisena ja sairauteen alistumisena.

Kun vaikeudet kohdattiin syöpään sairastuneen vanhemman perheessä elämänhaluisesti, peräänantamattomasti ja aktiivisesti, ja perheen tulevaisuuteen asennoitumisessa korostuivat myönteisyys, toiveikkaus, mielekkyys, tasapainoisuus ja luottamus, perhe *irtautui vanhemman syöpäsairaudesta*. Sairaudesta irtautuminen koostui toivon ylläpitämisen, luottavaisesti elämisen, minäkäsityksen muuttumisen, tervehtymisen etenemisen ja totutun elämän jatkumisen vaiheista. Tällöin vanhemman ja perheenjäsenten elämä palautui entiselleen sairaudesta irtautumisen kuluessa lukuun ottamatta minäkäsityksen muuttumista.

Elämä vakautui *sairautta vastaa taistelemalla* syöpään sairastuneen vanhemman perheessä silloin, kun vaikeudet kohdattiin perheessä elämänhaluisesti, peräänantamattomasti ja aktiivisesti, ja perhe asennoitui tulevaisuuteen kielteisesti, toivottomasti, huolestuneesti sekä pelokkaasti ja epävarmasti. Sairautta vastaan taistelemisen sisälsi sairastumisen pohtimisen, elämänmuutosta vastaan kapinoimisen, vastoinkäymisten voittamisen, nykyistä

pahempaan varautumisen ja toimivuuden varmistamisen vaiheet. Sairautta vastaan taistelemisen aikana perheessä vastustettiin yhtenäisesti sairautta ja haluttiin kamppailla sitä vastaan.

Kun vaikeudet kohdattiin syöpään sairastuneen vanhemman perheessä voimattomasti, lamaantuneesti ja passiivisesti, mutta tulevaisuuteen asennoitumisessa korostuivat kuitenkin myönteisyys, toiveikkuus, mielekkyys, tasapainoisuus ja luottamus, perhe *totutteli sairauden kanssa elämiseen*. Tällä tavalla sairauden kanssa elämään totuttelemisen muodostui tosiasioiden selkiytymisen, apuun turvautumisen, elämään palaamisen, yhteenkuuluvuuden vahvistumisen ja vaikeuksissa kypsymisen vaiheista. Sairauden kanssa elämään totuttelemisen aikana perheessä opeteltiin elämään sairauden mukanaan tuomissa elämänmuutoksissa.

Elämä vakautui *sairauteen alistumalla* syöpään sairastuneen vanhemman perheessä silloin, kun vaikeudet kohdattiin perheessä voimattomasti, lamaantuneesti ja passiivisesti, ja perhe asennoitui tulevaisuuteen kielteisesti, toivottomasti, huolestuneesti, pelokkaasti ja epävarmasti. Elämän vakautumiseen liittyvän sairautteen alistumisen vaiheita olivat elämän seisahtuminen, pelon valtaan joutuminen, huolista kuormittuminen, elämän hankaloituminen ja sairastamiseen juuttuminen. Sairauteen alistumisen aikana perhe ikään kuin kiinnittyi yhä lujemmin sairauden huonoon maineeseen ja sen tuomiin vaikeisiin olosuhteisiin.

Tämä substantiivinen teoria antaa perheiden elämästä syöpäsairauden kanssa tutkijoille, terveys- ja sosiaalialan työntekijöille ja kouluttajille uuden näkökulman, jota voidaan käyttää kehitettäessä perheiden terveydenhuoltoa ja sosiaalihuoltoa sekä terveys- ja sosiaalialan ammattihenkilöiden koulutusta.

**Avainsanat:** Elämän vakautuminen, perheen selviytyminen, syöpään sairastunut vanhempi, perheen hoitaminen, grounded theory –metodologia.

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# 1 INTRODUCTION

Cancer is a disease influencing not only one person in the family; instead, it can be perceived as a family disease since the falling ill of one family member affects the entire family and its well-being (Anderson and Tomlinson 1992, Åstedt-Kurki *et al.* 1999b, Anderson 2000). Therefore, when one of the parents falls ill with cancer, it impacts the everyday life of the diagnosed persons and their family members. In addition, the cancer patients' relatives or significant others find that the disease is a part of their lives (Hietaranta and Jokinen 1989, Eriksson 1996, Kuuppelomäki 1996b, 2000, Eriksson and Lauri 2000a, 2000b, Eriksson 2001, Lindholm *et al.* 2002).

In 2001, 11,066 women and 11,364 men, altogether 22,430 people fell ill with cancer, and in 2004, the predicted number of new cancer patients in Finland is approximately 23,206 people in total (Finnish Cancer Registry 2003). Accordingly, the disease touches the lives of several persons, not only the patients. Moreover, living with cancer in a family is worth studying since many patients survive. The currently predicted five-year relative survival rate for those fallen ill during 1997–1999 is over 50% for men and over 60% for women in Finland according to the prognoses of lung and breast cancers (Pukkala *et al.* 2003). In the end of 2003, there were some 160,000 Finnish persons who have suffered from cancer sometimes during their lives. Some of them have recovered but some have disabilities or inconvenience caused by the disease or its treatment. (Pukkala *et al.* 2003.)

Individual adult cancer patients experience anxiety at different stages during the course of their being ill (*cf.* Bottomley 1998, MacBride and Whyte 1998) and feel great stress especially during the stages of treatments, relapse, or metastasis or the terminal stage (Heim *et al.* 1997). The time between noticing a symptom, attending a health care provider and receiving a cancer diagnosis is full of fear due to what might be discovered (Leydon *et al.* 2003). This influences the entire family as well. It is already known that elderly people perceive living with cancer as a bodily, mental, social and existential experience but their responses to cancer are more related to their greater life experiences and the aged may already have started coming in terms with their own mortality (Thome *et al.* 2003). Nevertheless, there is a need to study the adult cancer patients' and their families' everyday life with cancer. Because the patient's disease has an effect on all other family members, it is valuable to know what living with cancer is like from the point of view of the entire family. This knowledge could be used in the identification of those families with cancer who are likely to require

emphasised or continued interprofessional health and social care during or even after the completion of treatments.

As Feldstein and Rait (1992) and Yates (1999) state, there is evidence that families are affected by cancer and that living with a family member who is suffering from cancer is a difficult coping challenge to other family members and that the disease has a significant impact on the family members' lives. It is also known that the experience of cancer for families often has been described as burdensome and stressful since it has an impact on many dimensions of the family members' individual life. For example, physical symptoms, managing uncertainty, concerns, tension and emotion adjustment, role conflict, economic burden, work adjustment and sleep disturbances are common among individual cancer patients. Despite this evidence, there is little knowledge about the nature of the family's experience with cancer and what kind of impact the disease has on the family relationships and interactions in order to care for the entire family. (Yates 1999.) In addition, there is topical demand (McClement and Woodgate 1998, Dow 2003, Lewis 2004) for studies in this area. Research is also required because nowadays more and more cancer patients and their families are actively seeking information, knowledge and support on their own. Hence, this inductive grounded theory research is very actual.

According to Lewis (1997), cancer patients have been treated in studies as a homogenous population, not as persons who vary both in the disease trajectory and in the cancer-related issues with which they have difficulties. For instance, studies of coping with cancer in accordance with the coping model (Lazarus and Folkman 1984, 1991) involve the actions and thoughts of the patients in response to merely the stress caused by cancer and emphasise methods of coping which manage the cancer-related threats. In studies conducted in relation to the existential issues, the emphasis is on facilitating the psychoemotional processing of the cancer event. The studies conducted according to the relational issues, such as the parent-child and parent-spouse relationship, emphasise the importance of relationships in mediating or moderating the diagnosed person's response to cancer and of including the patient and his/her significant other as the recipients of the behavioural interventions. (Lewis 1997.) According to their starting points, these different preconceived studies try to give an answer to how to help entire families with cancer without first knowing what it is actually like to live in a family with cancer. Thus, this inductive grounded theory research is of great importance.

The purpose of this research is to explore families' living with a parent with cancer and to develop a substantive theory to explain the manner in which they solve the main concern in their lives. The resulting theory provides researchers, health and social care professionals and educators with a greater understanding of the perspectives of families living with cancer. This substantive theory presents several challenges for further research on families' health and social care and interprofessional education of health and social care professionals.

The concept of a family in this research is defined as a unit of a mother and a father with a child or children, who live together at home and are bound together

with strong emotional, biological, social and juridical bonds and with a history and a future as a group. The characteristics of family relationships are the following: they persist over time, they are emotionally intense and they involve high levels of intimacy in day-to-day life. (Åstedt-Kurki and Hopia 1996, Keurulainen 1998, Åstedt-Kurki *et al.* 1999a, Åstedt-Kurki *et al.* 2001a, Weihs *et al.* 2002.)

This research is significant since the character of cancer in a family affects the condition of a family. Nowadays, in addition to the formal health and social care, family caregiving is common in the context of cancer. It poses challenges to health and social care professionals who should pay attention to family caregivers and all family members. Thus caring for an entire family with cancer as a patient should be seen as a principle also in the formal health and social care since cancer is a family disease and influences the lives of all family members.

## 2 FAMILIES LIVING WITH CANCER

In this chapter, I present the context in which an individual family member and the entire family with cancer live. The following sections (2.1–2.6) will discuss their living according to the character of cancer in a family and the condition of a family with cancer. Further, family caregiving, and health and social care professionals' challenges of treating an entire family with cancer as a patient and caring for an entire family with cancer will be considered. These areas emerged in the literature search conducted during the phases of memo sorting and theoretical writing.

### 2.1 The Character of Cancer in a Family

The demands of the treatments and the fear of recurrence and of death are characters of the cancer which belong to the everyday life of cancer patients and their families (Richer and Ezer 2000). Thus, patients and their families view the cancer very negatively and look at the future with great anxiety and little hope (Lowdermilk and Germino 2000). For example, women with breast cancer and their significant others describe how the disease influences their inner existence and values (Arman *et al.* 2002). This affects everything in their lives including their views of themselves and their relationships. Their lives may be described metaphorically as a “field of force”, since at the same time, life and death as well as the meaning of life and the dependence on the significant others become paramount to them. (Arman *et al.* 2002.) Accordingly, in the literature a review by Kristjanson and Ashcroft (1994) identifies four major dimensions of the family's journey through cancer such as the developmental stage of the family, the trajectory of cancer, the family's responses to cancer, and the behaviour of the health care providers.

Despite the advances of treatment, cancer is still the most feared disease also among the public and health care professionals in oncology. Early detection, provision of screening programmes and scientific advances in treatment have not yet changed the threatening connotations regarding the belief that it entails a fate few escape. (Aro *et al.* 1999, Miller *et al.* 2000.) According to Taylor (1995), explanations, such as God's will, heredity, chance, life-style and personal factors, the environment and the patient's acknowledgment of responsibility are clarifying the cancer experience. In addition, positive significance, such as re-prioritisation of goals, changed lifestyles and values, increased appreciation

towards others and nature, and spiritual development are also meaningful (Taylor 1995). In fact, long-term survivors can view the disease even as a positive and insightful experience leading to expansive and renewing interaction with their environment (Utley 1999). This changes the nature of the cancer.

As Lederberg (1998) states in Baum (2000), the character of the disease renders cancer a family disease, and the family members of cancer patients are like “second-order patients”. Therefore, the disease of one member of the family changes the emotional balance, the division of responsibilities, and social activities in the family, since distress levels tend to correlate positively between the family members (Manne 1998 in Baum 2000). The cancer may be a family disease also due to its genetic character, although inherited cancers account only for approximately 10% of all diagnosed patients (Li 1995 in Baum 2000). For instance, family caregivers of ovarian cancer patients feel considerable anxiety regarding the genetic nature of the disease (Ferrell *et al.* 2002). It has also been found that families with experience of cancer change over time and are characterised by various phases, while the trajectory of cancer extends from the point of prevention of cancer through the early diagnostic phase, acute care, remission to rehabilitation or to possible recurrence or terminal stage. Accordingly, the impact of cancer on families and their responses to cancer are family requirements, demands on the family, role changes among the family, communication within the family, coping responses of the family and health changes in the family. (Kristjanson and Ashcroft 1994.)

## 2.2 The Condition of a Family with Cancer

There are many reasons why the family with cancer should be treated as a whole in health and social care. For example, women who have close relatives such as daughters or sisters with breast cancer regard information and support as important, especially concerning the personal risk of breast cancer (Chalmers *et al.* 2003). Furthermore, Eriksson and Lauri (2000a) found that the importance of informational and emotional support to the relatives of cancer patients is evident, since relatives consider it important to receive information from health care professionals. However, relatives receive only very little information in relation to their demands, although they should wish for information throughout the patient’s disease period. It is especially important to pay attention on whether or not the patients want their relatives to be informed, which relatives are allowed to be informed and what type of information would be given and in what way. However, all relatives do not want emotional support from health care professionals, although the support provided for relatives seems to be very weak (Eriksson and Lauri 2000a).

The family with cancer should be treated as a whole in health and social care since the diagnosis of cancer may also be a threat to the whole family. According to Heath (1996), the threat of a childhood cancer correlates with indicators such

as an overall family reaction, information and communication, position within the disease continuum, prognosis and the presence of a metastatic disease. Paying attention to the entire family is important, especially in the treatment of childhood cancers (Bryant 2003). As mothers and fathers have different roles in the transition to adult life, lack of paternal encouragement and higher maternal involvement may cause poor close relationships in the adulthood for the survivors of childhood cancers (Hill *et al.* 2003). Thus, cancer may be a family affair and affect the condition of the entire family in a number of ways.

Since cancer is a family disease, it affects the condition and the lives of all family members. There is evidence that childhood cancer and its treatments have psychosocial consequences for the entire family and some of them have either problematic or positive outcomes in the child's and the family's everyday life. When the entire family is living in a situation dominated by the stresses of long lasting uncertainty and uncontrollability due to a parent's or a sibling's life-threatening disease, *e.g.*, the family members' personalities and social support are focal in their survival process. The most difficult situation for parents is telling children bad news about their own cancer or that of other relatives. Therefore, attending support groups and counselling, communicating among the family and paying attention to family members' quality of life seem to help them and improve their family's overall condition. (Patenaude and Last 2001.)

The situation of a family with paediatric cancer involves knowledge and understanding of the nature of the disease, being truthful, medical responses to the disease as well as changes in the family's relationships and family life. The effect of paediatric cancer on the child, parents and siblings during different stages of the disease may constitute an overwhelming family crisis and significantly change the family life. However, the family members' lives might be improved by being straightforward about the disease and by telling the truth in sharing information with other family members. Nevertheless, there is a gap in communication between parents and children which weakens the condition of the family with cancer. (Yin and Twinn 2004.) Furthermore, the health status among primary caregivers of children with cancer is positively associated with the quality of life in terms of physical health, psychological status, social relationships and environmental factors (Chien *et al.* 2003), which should be recognised in health and social care. Therefore, especially family-oriented interventions are needed. In addition, matters such as interaction with the health care providers, medical information, health care utilisation and psychosocial support are important throughout the stages of diagnosis, hospitalisation, post-hospitalisation and recurrence or terminal care (Freeman *et al.* 2000) in order to improve the condition of families with cancer.

According to Helseth and Ulfsæt (2003), a parent's suffering from cancer is dominant and causes major changes within families while there are obvious, covered and behavioural reactions on and under the surface. Families also make great efforts to manage the situation by escaping from and returning to it in order to face the disease intermittently, to put the disease aside for a while and to gain positive experiences. Moreover, families are covering up difficult feelings,

balancing information and feeling good most of the time with rocked balance, context-related well-being and well-being as a function of time and periodical variations. (Helseth and Ulfsæt 2003.) These features bring about perspectives to the condition of a family with cancer as well as challenges to treat the family as a whole in health and social care.

## 2.3 Family Caregiving in the Context of Cancer

Nowadays, family members are increasingly often taking care of the patient at home, *e.g.*, due to an early discharge from hospitals. Caregivers might feel stress, and those perceiving a higher subjective burden show lower health-promotion behaviour of their own compared to those who have a lower subjective burden (Sisk 2000). Their subjective burden is also negatively related to their self-care (Schott-Bear 1993). For instance, sleep and depressive symptoms of the caregivers may vary greatly from week to week, when the quality of sleep and depressive symptoms are affected by the status of the patient's disease, the patient's symptoms and the caregiver's anxiety (Carter 2003). There is also evidence that caregivers have more stress symptoms, which have an impact on the increased difficulty in managing caregiver tasks (Chan and Chang 1999b). Caregivers may perceive caregiving as either living an ideal, an ordinary or a compromised life. Family members, who are compromising their lives by caregiving, set unrealistically high expectations for themselves and the recipients. When these expectations are not met, their life is unbalanced and compromised for attention, acknowledgement, and affirmation and their life seems to provide little satisfaction. (Ayres 2000a.)

As caregiving becomes a more common experience for families, the family members assume substantial responsibilities the meanings of which are complex, yet related to the responsibilities themselves (Ayres 2000b). Caregivers living an ideal life explain that their lives are improved, but not saved, by caregiving. Benefits result from love between the caregiver and the recipient and from events emphasising the positive aspects in the recipient's conditions while minimising or ignoring the negative ones. Caregivers living an ideal life stress the importance of their lifelong relationship with the recipients of care. Caregivers with ordinary lives deny that their situation is taxing, even if they acknowledge that other people might consider caregiving to be burdensome. Although they do not worry about the future, they possibly see disappointments ahead and use this potentially darker future as a downward comparison in order to better appreciate the present situation. (Ayres 2000a.)

Caregiving tasks are demanding especially for the spouse. Although gender roles might be essential in selecting the caregiver, the intimacy inherent in the role of the caregiver renders an emotionally close relationship an important criterion in the selection of spouse as the caregiver. Wives are only one third as likely as husbands to select their spouses as caregivers. People suffering from

cancer who name their spouses as confidants are three times more likely to name them also as caregivers than those who do not. (Allen *et al.* 1999.) If the relationship has been mutual in the past, restriction of activities is foreshadowed by loss of intimacy and affection, which in turn is indicated by caregiver becoming distressed. On the other hand, in less mutual relationships, restriction of activities is brought about by the severity of the patient's symptoms. Especially older spousal caregivers may even feel that restriction in the caregiver's own activities mediate the associations between the stress and resentment evoked by caregiving and the depressed effect since the severity of the patient's symptoms associates with negative effective outcomes for the caregivers largely to the extent that disrupt the caregivers' normal activities. (Williamson *et al.* 1998.) Caregiving tasks, such as direct care, interpersonal tasks and overall tasks, are perceived difficult among caregivers who have little caregiving experience (Chan and Chang 1999a). For example, participants of a special education programme on family caregiving do not feel overwhelmed and are able to cope with the caregiving experience (Robinson *et al.* 1998). This kind of programmes are needed since compensation for personal time, updating knowledge of the reimbursement mechanism and emotionally accepting the likelihood of a progressive downward course of illness are perceived extremely difficult among caregivers (Chan and Chang 1999a).

Family caregiving skills are defined as being able to engage effectively and smoothly in the processes of monitoring and interpreting, making decisions and taking action, providing hands-on care, making adjustments, accessing resources, working together with the receiver of care and negotiating the health care system (Schumacher *et al.* 2000). For example, caring for a terminally ill patient at home is described as having the potential to increase the caregiver's vulnerability as well as risk for fatigue and burnout in addition to requiring continuous balancing between burden and capacity (Proot *et al.* 2003). Nevertheless, the role transition that leads to becoming a family caregiver means the transition to a new life situation of him/her and bearing responsibility of and providing care for their relatives, which may also have positive implications for cancer patients and their families (Wennman-Larsen and Tishelman 2002). On the other hand, adult children and spouses themselves think that their most difficult duties are, in particular, emotional support, behavioural management, monitoring symptoms and doing household tasks (Bakas *et al.* 2001). Thus, co-operation between family caregivers and health care professionals may be described as complex, dynamic and multifaceted (Ward-Griffin and McKeever 2000) and should be based on the typology of family care developed by Nolan *et al.* (1995).

## 2.4 A Family with Cancer as a Patient

Cancer is not a disease influencing just one person in the family; instead, it involves moving through the family's psychosocial transition that facilitates the

cancer experience (Lewis 1993). When one family member suffers from cancer, the others may easily be left without attention in health and social care. The entire family undergoing the cancer experience should be viewed as a patient, since cancer in the family has a great impact on all family members, especially on children. The meanings of this disease to children with cancer, to siblings of children with cancer and to children of parents with cancer are related to their cognitive level of development and to the specific nature of the disease. Its cognitive meaning involves the children's understanding and knowledge of the disease, and its personal meaning depends on the children's concept of self, physical functioning and feelings, while its social meaning rests on the family's relationship and lifestyle. (Hymovich 1995.) Sometimes children who have a parent suffering from cancer, may feel lonely and unsupported, and their feelings and reactions may remain unrecognised even by their parents (Lewandowski 1996). Therefore, health care professionals working with families need to have at least basic knowledge of the different dimensions of the family's health in order to identify the individual ways in which the families work for promoting their health and well-being (Åstedt-Kurki *et al.* 1999a, 1999b). Moreover, health care professionals need to recognise the family members', especially the children's feelings, and act as their advocates (McPherson and Thorne 2000) in order to treat the entire family as a patient.

According to Nelson *et al.* (1994) some children of cancer patients experience problems and anxieties in their home, school and social lives as well as difficulties with social and personal relationships that are related to the parent's cancer diagnosis and treatment. These children might be unable to discuss the patient's cancer with parents, have less time to spend with friends or in sport and leisure activities, face deterioration in schoolwork and feel continuing anxiety over the parent's disease. (Nelson *et al.* 1994.) Therefore, entire families with cancer should be assessed and helped in health and social care. Furthermore, the parents of an adult son or daughter suffering from cancer feel helplessness and frustration if the parents suspect that their child is receiving less than optimum care or if they are excluded or not informed by the health care professionals (Grinyer 2004). Thus, the entire family should be regarded as a patient or a client in health and social care. There is evidence about a lack of knowledge concerning individual cancer survivors (Ferrell *et al.* 2003) and their families, although according to Baum (2000), the individual survivors describe that they are forever changed by cancer. For instance, the psychological outcomes in long-term survivors of paediatric brain cancer and the siblings of childhood cancer survivors do not show increased psychological distress; instead, distress appears to be associated more with the diminished social functioning that may be related to type of cancer or treatment (Zebrack *et al.* 2004). Hence, to facilitate helping not only individual patients, there is a need to know how entire families live with cancer in order to help all family members because paying attention on entire families in health and social care might have far-reaching effects on all family members.

In family-oriented cultures, for example, in the Southern European and Latin American countries, the family has played a central role in cancer patient's health care. However, nowadays there are early signs of the desired trend towards greater diagnostic disclosure by families. For example, telling the truth to patients may still be controlled by the family, although the trend towards the provision of more diagnostic information directly to the cancer patient is desired. It is significant that the patient's health care is strongly culture-oriented and the role of the family in health care relies on that. (Arraras *et al.* 1995.) On the other hand, individualism has separated the family from caring for the patient in many countries. Respecting the autonomy of cancer patients when talking with their families in health care emphasises respecting the patients' views rather than those of their families. Patients favour openness towards their family, but they can also refuse unconditional disclosure of information without their consent and exert their influence of what information would be provided to them. In that way, patients may value the respect for their autonomy and consider that their own needs take priority over those of their family. (Benson and Britten 1996.) On the other hand, the information priorities of patients often differ from those of their families, although it is important to ensure that the patient's entire family is informed in order to maximise the patient's benefits (Feldman-Stewart *et al.* 2001).

A whole family should be seen as a patient, since family members are touched in many ways by their family member's disease (Åstedt-Kurki and Paavilainen 1999) and medical care. For instance, the spouses' perceptions of and living with a partner who has been diagnosed with rectal cancer followed by surgery resulting in stoma are depressive and suffering. The spouses feel anxiety about the partner's serious condition and the possible spread of cancer. They live with difficulties of being involved in the partner's disease and hospital care, with uncertainty, with learning to live in a new way with an altered body and with searching for explanations. Furthermore, they share the fear of recurrence with the patient. Therefore, spouses want to be included together with the patients in the information sessions with health care professionals and to be regarded as patients in that way. (Persson *et al.* 2004.) Families also need help for learning positive coping skills, for recognising that they are not alone, for discovering how to enjoy living in the present and for attaching a different meaning to the words of hope and healing (Johnson 2000). Hence, the whole family with cancer truly needs varying psychosocial care throughout the cancer experience. However, health and social care professionals should pay thorough attention on how family members view the patient's symptoms since opinions expressed by the professionals on the reliability and validity of the family members' responses to the patients' illness events, such as symptom experiences, are based on assumptions, stereotypes or broad generalisations derived from anecdotal experiences rather than on actual symptoms (Lobchuk and Degner 2002).

Patients and their families have a great number of needs regarding information and support which are unmet in the health and social care because the entire families are not dealt as patients. According to the literature review by

Echlin and Rees (2002), men suffering from prostate cancer have distinct needs for information and manifest information-seeking behaviour throughout their cancer experience, and their partners carry out an information-seeking pattern comparable to the patients' information-seeking behaviour. Their need for information seems to increase immediately before and after brachytherapy as information about the treatment and the side-effects become pertinent. (Echlin and Rees 2002.) Moreover, adolescent children of women suffering from breast cancer find that their needs for information are poorly met, since they have fears, uncertainties and a feeling of isolation in response to their mothers' cancer diagnoses. Thus, the emotional impact of breast cancer on adolescents is significant. They want to know, especially, whether their mothers are going to survive, which extends beyond the direct impact of their mothers' disease. Since assessment of their needs is minimal, specific interventions are needed. Further, their mothers think that both of them are like patients and have a need for family-related health care interventions. (Kristjanson *et al.* 2004.) These could be answers to the families' universal needs, such as receiving high-quality information and having good relationship to the health care professionals, or to the families' situational and personal needs, such as managing daily life, emotions and social identity (Soothill *et al.* 2003).

## 2.5 Caring for a Family with Cancer

Because the family has a great importance to the cancer patient, it is essential to include the family in caring for the patient and to treat the entire family as a patient. This involves not only caring for the patient, but also helping the family members to enhance their quality of life in order to support the patient (Rustøen *et al.* 2000). The fact is that family issues, like family's health, family's happiness, relationships between spouses and children, as well as control over life and physical independence are the most important issues related to the quality of life of the cancer patient (Rustøen *et al.* 1999, Rustøen *et al.* 2000). In addition, since nowadays families themselves may have great parental responsibilities during treatment periods due to geographic isolation from the extended families, it creates demands on health and social care and poses a challenge to treat the entire family as a patient (Rayson 2001).

Paying attention to the quality of the cancer patients' care is important. For instance, cancer patients' perceptions of the quality of nursing care are characterised by professional knowledge, continuity, attentiveness, co-ordination, partnership, individualisation, rapport and caring (Radwin 2000). In particular, interaction between the patient's family and health care providers in an acute care environment is considered very important among the hospital staff and marked by dissemination of information and support to the family members (Åstedt-Kurki *et al.* 2001c). Hence, the staff can use themselves as instruments to create contacts and feel confident in working with the family members instead

of having little time for them, being afraid of coming too close to them and having problems with establishing relationships (Söderström *et al.* 2003). For instance, in out-patient departments, the staff's views on interaction with the adult patient's family members is defined by providing information for relatives, discussing and creating contacts between staff and significant others as well as working together (Åstedt-Kurki *et al.* 2001b).

Patients treated with chemotherapy perceive that professionals are more prone to focus on the medical-technical aspects of the treatment than on the psychosocial sequence of the treatment (Uitterhoeve *et al.* 2003), although the emotional aspect of cancer patient's care should be valued in the same way as physical and technical aspects (Bolton 2000). For example, within the process of bone marrow transplantation, the family may even be ignored and misunderstood by health care professionals, although these families have many issues to be addressed in order to be able to decrease their anxiety and to be able to offer the emotional support that the patient requires (Wocha 1997). On the other hand, health care professionals may sometimes even unconsciously overlook the emotional care in favour of routines or physical aspects of care in order to protect themselves (Jones 2001). That is why families' life with cancer should be studied to improve health and social care of the cancer patients and their families.

From the relatives' point of view, caring for cancer patients involves emphasising both the content of the care and the way in which it is provided. Professional skills and trustworthiness of staff members and the safety of care are highly appreciated among the cancer patients' relatives. Therefore, they are very pleased with the standards of care, professionalism, professional skills and friendliness of the staff in oncology wards, although there may be little encouragement for patients to take part in decision-making concerning their care. (Eriksson 1996, 2001, Eriksson and Lauri 2000b.) Furthermore, the family members perceive that there are obvious problems and shortcomings in family orientation in health care in terms of being seriously interested in the family's well-being as well as telling what relatives could do in the hospital (Åstedt-Kurki *et al.* 1997). Family members may spend a lot of time at their relative's bedside, and the daily routines of families and their ways of life are very much affected. Family members may be supported and informed, but not without their active interest and involvement. The relatives think that they are expected to be there and offer help to their family member. Hence, there is much to do for facilitating the integration of relatives into the patients' care (Åstedt-Kurki *et al.* 1997) in order to take care of the whole family. It is possible to describe family caring even as sailing through troubled waters of learning the meaning of the disease and finding comfort through the care or learning to care for families and living with the fears of others (Meiers and Tomlinson 2003), which is a challenge to health and social care professionals.

## 2.6 Summary of families living with cancer

According to previous research, *the character of cancer in a family* (Appendix 1) affects *the condition of a family with cancer* (Appendix 2). Nowadays, in addition to the formal health and social care, *family caregiving is common also in the context of cancer* (Appendix 3), which poses challenges to family caregivers and health and social care professionals who take care of patients in their homes. Moreover, health and social care professionals should pay attention to all family members. *An entire family with cancer as a patient* (Appendix 4) and *caring for the family with cancer* (Appendix 5) should be seen as the principles in the formal health and social care since cancer is a family disease and influences the lives of all family members. International family research in the cancer context seems to focus on all these aspects (Appendices 1–5) but not clearly from the entire families' point of view since in many of them the data was collected just only from one family member. This became clear in the course of the literature search which I conducted during the phases of memo sorting and theoretical writing in order to avoid preconceiving information.

Recent Finnish family-related research in the cancer context has focused on *family functioning* (Murtonen *et al.* 1998) and *family coping* (Savela 2000). However, studies conducted in Finland have examined *living with cancer from the viewpoint of cancer patients' relatives or significant others* (*cf.* Hietaranta and Jokinen 1989, Eriksson 1996, Eriksson and Lauri 2000a, 2000b, Eriksson 2001, Lindholm *et al.* 2002) and from *the individual cancer patients' point of view* (*cf.* Krause 1991, Suominen 1992, Krause 1993, Suominen *et al.* 1994b, Linden 1995, Lindvall 1995, Suominen *et al.* 1995, Kuuppelomäki 1996a, Lindvall 1997, Kuuppelomäki 1998, Kuuppelomäki and Lauri 1998a, Lindvall 1998, Aakala *et al.* 2000, Kyngäs *et al.* 2000, Kyngäs *et al.* 2001, Lindvall 2001, Virtanen 2001, Arman *et al.* 2002, Karhu-Hämäläinen 2002, Kekäläinen 2002, Sarvimäki *et al.* 2003). In addition, there are studies on *cancer patients' participation in the decision-making concerning their own care* (*cf.* Suominen *et al.* 1994a, Juvonen and Lauri 1994, Sainio *et al.* 2001a, 2001b, Sainio 2002, Sainio and Eriksson 2003) as well as on *cancer patients' and their relatives' views on death* (Kuuppelomäki 1996b, Kuuppelomäki 2000). In conclusion, more research is needed concerning the entire families' living with a family member with cancer.

### 3 THE PURPOSE AND THE RESEARCH QUESTIONS

The purpose of this study is to explore families' living with a parent with cancer and to develop a substantive theory to explain how they solve the main concern in their lives. The resulting theory may provide researchers, health and social care professionals, educators and others with a greater understanding of perspectives of families' living with cancer.

The research questions for this study are:

1. How do families live after one of the parents has fallen ill with cancer and what are the concepts for explaining their lives?
2. How do these concepts of families' living with a parent with cancer relate to each other?
3. What kind of substantive theory emerged explaining families' living with a parent with cancer?

# 4 GROUNDED THEORY AS A RESEARCH METHODOLOGY

The classic grounded theory methodology (Glaser and Strauss 1967, Glaser 1978) was selected as the research methodology for this research since it is a general research methodology using different types of data, it has the power to generate concepts and conceptual hypotheses in the form of an emerged theory, it can be used without testing in the substantive area from which it was generated, and it is conceptually modifiable as the reality in the form of new data shapes it. I rejected the different remodelled grounded theory methods due to their preconceptions which should have forced the research into description. (Glaser 1999, 2001, 2002a, 2002b, 2002c, 2003.) In the following sections (4.1–4.2), I present the background assumptions of the grounded theory methodology (Glaser and Strauss 1967, Glaser 1978) and the discovery process of this substantive theory.

## 4.1 The Background Assumptions of the Grounded Theory Methodology

Barney Glaser and Anselm Strauss discovered the grounded theory methodology in studying the awareness of and time for dying (Glaser and Strauss 1965, 1968, 1993, Glaser 1995a) in California in the 1960's. The methodology was not invented; its discovery and methodological and theoretical underpinnings were rooted in their educational backgrounds. Barney Glaser was trained in quantitative research methodology by Paul Lazarsfeld and in theory construction by Robert Merton at Columbia University, while Anselm Strauss was trained in qualitative research by Herbert Blumer and Everett Hughes at Chicago University. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Glaser 1998, Siitonen 1999, Glaser 2001, 2003.)

The grounded theory methodology is an open, generative and emergent research methodology which lets the natural social organisation of substantive life emerge. Often, the research area is significant in general. Studying an area of life-cycle interest is interesting also for the researcher, thus maintaining motivation to get through the study. This kind of fields are related to, *e.g.*, health and health care, education, business, management and marketing. They are dealing with relevant problems of substantive areas of concerns and need this

methodology to grasp the underlying processes of what is going on in order to help professionals to resolve the participants' main concerns. The use of this methodology involves a risk of losing the goal of theory generation in favour of full conceptual description. The grounded theory itself does not entail findings; rather, it is an integrated set of conceptual hypotheses or probability statements about the relationship between concepts that account for the behaviour emerged in a substantive area. The grounded theory methodology is a multivariate generating process which is taking up several overlapping conceptual phases. They all feed into each other and somehow integrate to be discovered. The package of the grounded theory methodology consists of data collection and coding through memoing, theoretical sampling, sorting and writing and using the constant comparative method. Memos keep track of the subintegration, which will facilitate sorting and writing, as they are theoretically coded. (Glaser and Strauss 1967, Glaser 1978, 1992, 1994, Lowe 1996, Glaser 1998, Siitonen 1999, Glaser 2001, 2003.)

Concept generation, specifically categories and their properties, is based on the constant comparative method. It means firstly generating a theory by *constant comparison of incidents* which emerged in Glaser's studies in the psychological index formation approach taught by Lazarsfeld. Constant comparison of incidents yields far more concepts and relationships between them than the psychological index formation where the indicators were summed. Concept generation takes place through the constant comparison of incidents when the researcher keeps asking "What category does this incident indicate?" or "What property of what category does this incident indicate?", and a category or its property is emerging. (Glaser and Strauss 1967, Glaser 1978, 1992, 1994, Lowe 1996, Glaser 1998, Siitonen 1999, Glaser 2001, 2003.)

Secondly, the constant comparative method means *explication of texts*. It is a skill of reading texts line by line to ascertain what the informant is exactly saying without imputing what was said, interpreting it or reifying its meaning. Moreover, according to Glaser, reading texts line by line means that the researcher is interested in the concepts and the patterns of behaviour which the characters found in themselves in the texts. These analytic roots are essential in the grounded theory methodology. I also used the constant comparative method to let the found matters emerge. I conducted the concept generation by continually comparing each incident to all the other incidents and to each category as well as by generating properties of categories in reading observations, field notes and data collected in conversations line by line. This helped me to generate concepts which closely fitted into what was going on in the substantive area. (Glaser and Strauss 1967, Glaser 1978, 1992, 1994, Lowe 1996, Glaser 1998, Siitonen 1999, Glaser 2001, 2003.)

Furthermore, concept generation is based on the *interchangeability of indices* which was taught by Lazarsfeld at Columbia University. As the concepts emerge and the constant comparative method proceeds, the researcher begins to see the same thing over and over again in different ways. Saturation occurs when the incidents become interchangeable, and it is not any more worth collecting the

same data yet again with no more relevant properties of the category. The constant comparative method is limiting the amount of data needed and keeps concepts emerging from which to build a theory. Interchangeability of the indices convinced also me that the concepts were saturated and I finished the theoretical sampling. (Glaser and Strauss 1967, Glaser 1978, 1992, 1994, Lowe 1996, Glaser 1998, Siitonen 1999, Glaser 2001, 2003.)

*The latent structural pattern* emerges after one of the categories seems to be consistently related to other categories and their properties time and again after the researcher has constantly coded and theoretically sampled for more data. This category is classified as a core category of the theory which Lazarsfeld termed as a latent structure of the theory. A core category shows the continual multivariate processing of what is going on in the substantive area and explains the resolving of the participants' main concern. The latent structural pattern discovered in the beginning of the research is surrounding the core category and is the prime mover in solving the main concern of the participants. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Glaser 1998, Siitonen 1999, Glaser 2001, 2003.)

Theory construction through *theoretical coding*, taught by Robert Merton at Chicago University, becomes essential in that the substantive concepts are related to each other through theoretical codes in order to generate the concepts into a theory. Whereas Merton had emphasised his pet theoretical codes in the data analysis, Glaser turned to *induction* because he could not find any of them in his own data, which would have yielded different results. Because he wanted to make a grounded theory that fits, works and is relevant, he combined the best parts of both the theoretical and the empirical approaches in the grounded theory methodology. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Glaser 1998, Siitonen 1999, Glaser 2001, 2003.)

*Property space analysis* (Barton and Lazarsfeld 1969) is one of the quantitative analytic techniques which Glaser learned from Lazarsfeld's inductive quantitative analyses. It was the interaction of the effects of variables on other variables either quantitative or qualitative. It meant inducing the meaning of what was going on and not bothering with the empty logic of what one wished was going on. It was a short step for Glaser to see that this inductive approach had evolved into an integrated set of hypotheses or a theory to the grounded theory methodology. Property space in a form of a typology emerged also as a theoretical code for this research when the implicit criteria of the typology emerged. The other theoretical code of this research was a process that emerged and occurred within the typology. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Glaser 1998, 2001, 2003.)

The influence of the Chicago school and Anselm Strauss to the grounded theory methodology was how *social construction of realities* in qualitative research was perceived. Working with Strauss in the research on the awareness of dying provided Barney Glaser with a chance to apply the quantitative ideas mentioned earlier to qualitative data analysis. Moreover, he started grasping the social construction of realities through symbolic interaction and creating

meanings through the participants' indications towards themselves and others. Glaser's view of applying symbolic interaction was not forcing meanings on participants but rather listening to their genuine meanings, grasping their perspectives and studying their concerns. He was combating the "impressionistic" influence of the Chicago school by tying the emerging theory generation and the grounded theory methodology tightly to the data by constant comparison. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Glaser 1998, Siitonen 1999, Glaser 2001, 2003.)

## 4.2 The Discovery Process of the Substantive Theory

The discovery process of the substantive theory of family survivorship involved research activities chronology of which explains the research design of this research (Table 1). The use of the grounded theory methodology itself contained three different perspectives of conceptual levels. The first was *the theoretically sampled data*, the second was conceptualisation of the data into *categories and their properties* and the third was the overall integration of the data into *the integrated theory* through sorting according to the emerged theoretical codes. At each conceptual level, the abstraction was raising and polishing. (Glaser 1998, 2002a.)

According to Glaser (1978, 1998), working with grounded theory entailed a personal pacing of the researcher and a package of five S's: subsequent, sequential, simultaneous, serendipitous and scheduled which did not occur in this or any other predetermined order. Subsequent meant what must be done next in this study, sequential what was to be done later as a part of the current activities. Simultaneous was doing many activities at once, such as theoretical sampling, coding, memo writing, memo sorting and writing. In addition, the concept involved keeping in mind that the relative emphasis may change while proceeding towards the completed theory. Serendipitous meant being constantly open to the emergence of new aspects in and from the data and the analysis. The new aspects came as surprising realisations. Scheduled meant that the project had an overall rough and flexible schedule with periods set out for collecting the data, analysing it, sorting memos and writing the emergent grounded theory. As a consequence, the grounded theory process was multivariate, instead of linear, since it was based on a process discovery rather than on a description or a measurement of units. The research activities of this research and their occurrence (Table 1) are explained in the following six sections (4.2.1 - 4.2.6).



### 4.2.1 Theoretical Sampling

Theoretical sampling was the prime mover in the process of collecting and analysing the data, deciding what data to collect next and where to find the data in order to develop the substantive theory as it emerged. Theoretical sampling was both directed by the emerging substantive theory and it directed its further emergence. Theoretical sampling was the “where to next” in collecting data, the “for what” according to the codes, and the “why” in the analysis in theoretical memos. The contents of the data collected in the conversations with the couples, the data acquired through observing the families and, later, of the data received during the further conversations with the couples depended on the concepts emerging from the evolving theory. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

I started the collection of data by interviewing cancer patients and their spouses because the purpose of this research was to explore a substantive theory of families’ living with a parent with cancer. I wrote field notes after having conversations and observing, as well as theoretical memos during the coding of the data. The process of constant comparison and category development began as a consequence. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

As I coded the transcripts and the field notes from each interview and from each observation and made comparisons in the collected data, I wrote memos, *i.e.*, notes of varying length on theoretical ideas, connections, insights or overviews. As the interviews and observations continued and the couples and their children continued to provide me with new information, I continued coding data and making constant comparisons as well. At the same time, the memo fund proliferated. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

Theoretical sampling consisted of the conscious, grounded deductive aspect of the inductive collecting, coding and analysing of data. Theoretical sampling was grounded on deductions which fed into data for more induction as the growing theory directed me. It focused and delimited the collection and analysis of data constantly, so that I was not collecting the same data over and over again based on the same questions, which could have ignored the interchangeability of indices. Theoretical sampling limited data collection to a minimum, instead of allowing it to pile up. Moreover, it responded to the need for more data that was relevant for the emergence of new categories and their properties. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

As the data collection progressed, the focus was less on the families’ living with a parent with cancer and more on the conceptual categories which were emerging in the data on the couples. I continued collecting data on the couples near to the point of saturation and moved on to the next group of informants and collected the data by observing entire families. Next, I resumed having

conversations again the same couples as earlier. The purpose of this was to generate data for defining the emergent categories and their properties as well as to substantiate the presence of the substantive theory through saturation. Saturation meant that the concepts were completed and, thus, the gap in the emerging theory was almost, if not completely, filled. Furthermore, it meant that I was no longer hearing anything new, and I began to notice redundancy in the concepts yielded by the data. No additional data were needed since I saw similar instances over and over again. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

Consequently, theoretical sampling brought about collection of data to the saturation of categories and their properties until they reached theoretical completeness. It focused questions more and more on the direct emergence of the theory. Questions changed constantly in accordance with the requirements of the emergent theory and theoretical sampling. Once saturation occurred, new questions were asked which were appropriate to the new emergent issues of the main concern of the new interviewees. Thus, I avoided the problem that the theory could have run thin if the same data would have been collected over and over again. By responding to the need for theoretical completeness, theoretical sampling directed me to new data sources which constantly generated the parsimony and the scope of theory as it accounted for how the main concern of the families was constantly resolved. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

Saturation brought dullness and boredom but theoretical sampling sustained the motivation to continue with data collection. As I wrote memos and put down an idea of where to take the growing theory or how to question it, this became a motivated occasion for theoretical sampling on a category or its property regardless of how short or long the foray into the field might have been. There followed then more data, more coding and analysis and yet more theoretical sampling until the entire substantive theory in the memos was saturated. After that I turned to sorting the memos. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

Theoretical sampling resulted in an ideal sample which consisted of 32 conversations with 13 couples and observation of five families including nine children during the boarding course on psychosocial rehabilitation. The sample was conceptual about an area of interest, *i.e.*, families living with a parent with cancer, not a representative one. That is why an exact sample size was impossible to predict beforehand since sampling was based upon the developing theory and data saturation. The criterion for judging when to stop sampling different groups pertinent to a category was the theoretical saturation of the categories. Data saturation was reached after interviewing 13 couples from one to three or four times and after observing five families during the three-day boarding course on psychosocial rehabilitation. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

Data completeness of this study was based only on theoretical completeness, not numbers or lengths of interviews or observation. There was no number,

merely sampling for saturation completeness, which yielded a well-integrated grounded theory with parsimony and scope. A concrete number of sampling included in this study could not be presented in advance, because the shape and size of the theoretical sampling was not known beforehand. As a grounded theory researcher, I could not know by preconception what the informants' problem was and how they were going to solve it, what the core category and the other categories were, which would later have emerged, and where the theoretical sampling was going to lead. Hence, including a set number of people of a specific population did not make sense in this study. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

## **Conversations and Field Notes as Data**

Both parents were representing their entire family in this study and interpreting their family members' views concerning living with a parent with cancer. The parents were informants in the data collected in conversations during this study (Table 1) since they were sharing the family's day-to-day life, and were tied together as a unit with emotional bonds, which might have made it easier for them to talk about personal and sensitive matters. Only one parent may not necessarily have represented the views of all the family members. (Åstedt-Kurki and Hopia 1996, Åstedt-Kurki *et al.* 2001a.)

The participation and recruitment in this interviewing part of the study met several eligibility criteria. Cancer patients and their spouses were deemed mentally and physically competent to participate by health care professionals, were willing to participate and able to speak and express their experiences and feelings, were from 21 to 62 years of age, had children, were outpatients, were able to participate in conversations together several times during their hospital visits, and were treated with radiation therapy and/or chemotherapy.

I recruited the participant couples with the assistance of nurses at the outpatient clinic and radiographers at the radiation therapy department in the Oulu University Hospital. After receiving the permissions from the head of the Oncology Clinic of The Oulu University Hospital (dated March 20, 1998) and from the Ethical Committee of the Medical Faculty in the Oulu University (dated April 27, 1998), I described the eligibility criteria to the staff of the outpatient clinic and the radiation therapy department in the Oncology Clinic of the Oulu University Hospital. Later, I reminded the nurses and the radiographers of the patient eligibility criteria for this study and they made suggestions to me as to whom they could ask for this study. The nurses and the radiographers approached potential patient participants, briefly described the study, gave the information sheet (Appendix 6) to them and asked permission for me to meet them. Subsequently, I explained the study, answered questions, invited them and their spouses to the research, and they and their spouses signed the consent forms (Appendix 7). I took privacy into consideration and encouraged it and helped patients and their spouses to decide on a mutually acceptable place and time for

the first conversations. After signing the consent forms, I assigned codes to the couples (F1, F2, F3, etc.) in the order in which they were recruited (Table 2).

Demographic information of the families was obtained at the end of the first conversations with the 13 couples. In six families, the father was the patient and in seven, the mother was the patient. The patients' ages ranged from 39 to 59 and their spouses' from 31 to 60 years. Their children, 42 altogether, were from 6 months to 36 years of age. (Table 2.)

**Table 2.** The characteristics of families.

Family	Patient	Spouse	Age Patient/Spouse	Number of children	Children's ages
F1.	wife	husband	41/44	3	8,11,12
F2.	wife	husband	59/60	2	36, 34
F3.	wife	husband	54/55	3	19, 24,24
F4.	husband	wife	46/41	3	10, 14, 18
F5.	wife	husband	40/40	2	2, 4
F6.	wife	husband	38/31	2	3, 6
F7.	wife	husband	52/52	3	21, 26, 29
F8.	husband	wife	51/50	2	20, 24
F9.	husband	wife	43/40	9	½, 4, 6, 7, 9, 11, 14, 16, 17
F10.	wife	husband	56/58	4	29, 30, 32, 34
F11.	husband	wife	44/42	2	13,14
F12.	husband	wife	54/54	3	18, 20, 22
F13.	husband	wife	42/40	4	3, 6, 10, 13

I had conversations with the parents of the 13 families from one to three or four times. Both parents were present at each conversation (Moriarty 1990, Anderson and Anderson 1999). The total number of joint couple conversations (Morris 2001) was 32. The *first* step conversations occurred either at the hospital or in their homes as soon as the family members had heard that the one of the parents has been diagnosed with cancer. The *second* step conversations of the same nine couples took place during the radiation and/or chemotherapy phase, and the *third* step conversations of eight couples and the *fourth* step conversation of one couple at the hospital during the phase of follow-up visits or in their homes during their follow-up periods. Each discussion lasted between 45 minutes and 2 hours, 30 hours in sum. The length of these conversations allowed the participants to describe their lives openly and in depth, which in turn provided me with rich data. (Table 3.)

The taped conversation transcripts were typed by a radiographer in verbatim in order to make every attempt to maintain accuracy, including the couples'

voices and individuality. Wives' speech was marked with W, husbands' with H, and mine with A. I verified the transcripts for accuracy by listening to the tapes and checking what I heard with what was printed. The transcripts had the font (Times New Roman, size 12) with the following margins: 1,5 cm left and 3,5 cm bottom, 2,5 cm top, and 3,5 cm right. The right margin was left for writing incidents. The total amount of interviewed data was 389 pages. I made corrections when necessary while listening the recorded tapes, and then printed a final copy of the transcripts for open coding. Although time-consuming, reading the transcripts and verifying the tapes helped to increase my theoretical sensitivity of the data. (Table 3.)

**Table 3.** The characteristics of the data collected in conversations.

Family	Both parents Present	Duration (minutes)	Times	Place	Field notes (pages)	Taped
F1.	Yes	180	4	hospital	3	yes
F2.	Yes	120	3	hospital	2	yes
F3.	Yes	180	3	hospital	2	yes
F4.	Yes	210	3	hospital	3	2 x yes
					3	1 x no
F5.	Yes	240	3	hospital	3	yes
F6.	Yes	220	3	2 x hospital	2	yes
				1 x home	3	yes
F7.	Yes	200	3	hospital	2	yes
F8.	Yes	120	1	home	2	yes
F9.	Yes	100	3	hospital	3	yes
F10.	Yes	60	1	hospital	1	yes
F11.	Yes	60	3	hospital	1	yes
F12.	Yes	50	1	hospital	2	yes
F13.	Yes	60	1	home	2	yes

The preconceived theme interviews during the two first couple interviews were related to coping in the families, *e.g.*, matters which were promoting or preventing coping in the family's new life situation. In the end of these two interviews, the couples wanted to expand the conversations and tell more extensively what the main problems in living in a family with a parent with cancer were and how they were solving the problems. Fortunately, I soon realised that preconception in the form of a coping theory (Lazarus and Folkman 1984, 1991) was going to steer the discussions which is absolutely against the principles of data collection in the grounded theory methodology. Therefore, I changed the interviewing strategy from the theme interview to an open

conversation. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

From the third couple conversation onwards, during the first step of data collection, I gave to the couples enough space to explain freely and openly what their families' main problems in living with a parent with cancer were and how they solved them. The conversations with participants were open and honest in order to find out what was going on in families regarding their living with mother's or father's cancer (Appendix 8). I continued data collection according to this principle, and I finished it after having conversations with the 13 couples from one to three or four times since the categories and their properties saturated, although I had the ethical permission for having conversations with up to 20 couples.

In addition to the data collected in conversations, I wrote a total of 34 pages of field notes by hand to supplement the data because even substantively trivial data could help in generating the theory (Glaser and Strauss 1967). Immediately after the conversation had ended, I wrote these detailed field notes about the content of interviews or audiotaped my comments concerning the content of discussions. I documented the appearances of informants, the details of the settings, the individuals' verbal and non-verbal communication and action providing as much detail as possible (Table 3). This example represents my field notes of data received in conversations:

I meet the couple in the radiation therapy ward. The man has difficulties speaking because of his illness; the voice is hoarse. Both are willing to talk about their situation, and they are motivated in participating in the study. The wife starts to cry every now and then. The family's two daughters and their boyfriends are there to escort the patient and his wife to the radiation therapy. They are emotional. The patient seems weak, moves with difficulty. Nevertheless, I get the impression that it is important to him to take part in this study. After the interview the patient goes to the isotope ward to receive his isotope injection.

The parents live alone, but the oldest daughter is unemployed and moves back home so that she can help her father during the day. The younger child gets a driver's licence soon and can then take them to the treatments by car. The family seems tightly connected and they are pulling together. The spouses talk openly, are not bitter, but state that the family's father's illness has made them more serious. The symptoms had been there earlier, but they had been treated as asthma until now. The asthma medication had not helped. A month ago he went to the doctor's because of a headache, and the tests made then revealed changes in the lungs. F12, 24.7.1998.

## **Observation and Field Notes as Data**

As awareness of the core category grew, theoretical sampling and collection of data during selective coding directed me towards observing entire families (Table 1), because I realised that the views of the parents did not necessarily represent the views of the entire families. The focus of attention during the observation was not on who was speaking in the family but rather, what the family was saying together since in this study, the family was perceived as a coherent unit of people who were tied together with emotional, biological, social

and juridical bonds. The family made a coherent, homogenous group but within that, the group opinions might vary quite widely. (Åstedt-Kurki and Hopia 1996, Åstedt-Kurki *et al.* 2001a.)

The observational data of this study were collected during the boarding course on psychosocial rehabilitation of cancer families organised by the Cancer Society of Northern Finland between 13<sup>th</sup> and 15<sup>th</sup> of August 1999. I was a member of the staff and my data collection method during this course was participant observation. It was a process in which the aim was to collect scientific data through the observer's presence in social situations. I used participant observation fruitfully to gather a variety of information on, *e.g.*, verbal communication, social behaviour, activities and environmental conditions. The method was based on intensive interaction between the observer and the informants. It was essential that the interaction occurred on the informants' terms and that the observer influenced the ongoing events as little as possible. (Spradley 1980, Liukkonen and Åstedt-Kurki 1994, Polit and Hungler 1999, Savage 2000.)

Fieldwork was carefully prepared beforehand in order to avoid the observer's influence on the data. I participated in the planning meeting of the boarding course on psychosocial rehabilitation and got familiar with the programme, environment and the other staff members in advance. I was also familiarised with the aim and the content of the boarding course on psychosocial rehabilitation and my role by the head of the course. Moreover, she introduced the enrolled families to me. They were informed beforehand about my role as a staff member and as an observer for the research purpose. Additionally, their permission for the use of that kind of data collection method was asked in advance by the head of the course.

The Cancer Society of Northern Finland recruited participants according to the eligibility criteria set by the cancer society. The criteria were that one of the parents had cancer, the family had children under the age of 16, it was living in the Northern Finland and the family members were willing to share their life experiences with other families and staff members. The course participants, ten parents and nine children in all, consisted of five families (F14, F15, F16, F17 and F18). In three families, the mother was the patient and in two the father was the patient. The patients' ages ranged from 33 to 46 and their spouses' ages from 37 to 48 years. Their children were between 1 and 11 years of age. (Table 4.) The staff members were: a public health nurse as the head of the course, a family therapist, a physiotherapist and two students of early childhood education. I worked as the staff members' partner both in the joint programme for adults and children as well as in their separate programmes. Moreover, all staff members were aware of my role as an observer.

**Table 4.** The characteristics of the families who participated in the boarding course on psychosocial rehabilitation.

Family	Patient	Spouse	Ages Patient/Spouse	Number of children	Children's ages
F14.	husband	wife	35/37	2	7, 9
F15.	husband	wife	33/40	1	1
F16.	wife	husband	41/41	3	2, 8, 10
F17.	wife	husband	46/48	1	9
F18.	wife	husband	41/40	2	9, 11

The general aim of the three-day boarding course on psychosocial rehabilitation was to help families in living with cancer. The specific objectives for parents were to obtain possibilities to concentrate on the couple's mutual relation, to share experiences of living with cancer with other couples, to get rid of the everyday routines and to pick up and gain resources for the future. The adults' programme consisted of individual, pair and group works and discussions guided by the family therapist. The specific objectives for children were to get possibilities to speak about the cancer, if needed, to deal with the disease by various activities, *e.g.*, role playing or drawing, to meet other children in the same situation, to get enough space for their feelings and to find channels to express them, as well as to have fun together with other children. They were divided into two different age groups and their programmes differed. Due to their ages, the two youngest children did not participate in the discussion and action groups. Furthermore, the families shared the leisure time with the other families and the staff members as much as possible.

The observational data were comprised of field notes written as soon as possible after the different events included in the content of the programme. My focus was to observe without any preconceived structure, and I wrote detailed field notes and documented the appearances of informants, the details of the settings, the individuals' verbal and non-verbal communication, social behaviour and action providing as much details as possible. I wrote, *e.g.*, what was happening among the families, what was essential and how informants behaved in their life situations, or what family members expressed in the situation concerning their living with a parent with cancer. The amount of field notes of observational data was 30 pages altogether. I also audiotaped my comments, 60 minutes in total, regarding different events and used them as field notes. This example illustrates my field notes of observational data:

Each person both in the adults' and in the children's group got to draw the cancer in their family; what it is like? After that the groups gathered together, and the drawings were hung up to the walls for everybody to see, and the children as well as the adults told each other about their drawings. Here included is one example:

The woman has a thyroid cancer: She describes her drawing so that there is nothing good to be found in the illness, although there is hope and light in getting away from it. It is an obscure lump in one's life, although it is debarred from her mind. She continues that in her own life there are many question marks and that the door outwards is in a sense closed. The illness restricts the life. They have medically gotten rid of the illness, but it is on her mind every day. The spouse drew a small clump on a large piece of paper, and explains that it depicts the small size of the tumour when they found it, and he also hopes that its meaning will remain small in their lives. That is why he left so much empty, free space around it in his drawing. The children of the family tell briskly about the illness in their drawings, which they explain is like one new family member. F16, 14.8.1999.

#### *4.2.2 Substantive Coding*

Substantive coding comprised the activities of open coding and selective coding (Table 1). Substantive codes were the categories and their properties of the theory which represented the substantive area concerning families' living with a parent with cancer and conceptualised the empirical substance of the research area. Substantive codes were used later on together with theoretical codes to build up the conceptual theory. (Glaser 1967, 1998.)

Substantive coding took place with concept generation through the constant comparative method. Accordingly, I first compared an incident to another incident and then, as a category or its property emerged, I compared the concept to the next incident while asking the analytic questions: "What category does this incident indicate?" or "What property of what category does this incident indicate?" and "What is the participant's main concern?". Constant comparison verified the concept as a category denoting a pattern in the data. It also verified the fit of the category nomenclature to the pattern. Constant comparison generated properties of the category as well as saturated the category and its properties through the interchangeability of indices. (Glaser and Strauss 1967, Glaser 1978, 1992, 1994, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

The mechanics of substantive coding (Glaser 1978) started by writing a transcript title on each document of 32 tape-recorded conversations with the parents of 13 families. The transcript title included the family code number (from F1 to F13), the conversation number (from 1 to 3 or 4) and the date of conversation. Field notes and memos concerning data yielded from the conversations of the same family were also labelled with the family code number (from F1 to F13), with the conversation number (from 1 to 3 or 4), and with the date of conversation. Field notes and memos of observations were identified by the running family code number (from F14 to F18) and the date of observation. These transcript titles, field note titles and memo titles were useful in making constant comparisons of open and selective coding and also facilitated the later theoretical memo sorting.

The data yielded from the conversations contained altogether 1591 incidents, the observational data 684 incidents in total and the field notes 102 incidents in all. An incident could be found in a phrase, in one or two sentences or some times in as much words as a paragraph. Each incident was labelled with the family code number (from F1 to F18), with the conversation number (from 1 to 3 or 4) and with the page number of the transcribed data or with the date of observation. This facilitated making constant comparisons. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

Glaser (1998) contributes a typology of data that a grounded theory researcher might encounter in substantive coding. They are: baseline, interpreted, proper line, vague and conceptual data which all were evident in this study. These five types are all data but may affect the conceptualisation differently. In baseline data, which is usually perceived as typical data, the participants were describing their lives. It was specific and it was possible to check it from other sources. It also stimulated new questions as “Why did the informant speak about these details?” or “What the informant really wanted to say?” This example illustrates the baseline data:

”It is the last week as far as this chemotherapy goes, but I don’t know yet, so after this chemotherapy week the surgeon will see whether to operate or what. Next week I have two more radiation therapies and then after that there are eight boosters planned for those rash areas. The surgeon will check now at this stage to see what the results of this treatment have been, whether to operate or continue with this radiation therapy.” 4.2.1.

Interpreted data included the participants’ describing what was going on in a way that revealed to the researcher how to see their experience or behaviour (Glaser 1998). In the following example, the informant interpreted the concept of searching for positive aspects:

”It is the positivity that is the thing that makes one try to find from the bad things, try to find the positive side. In my opinion he is better at it than me. He always tries to find it... “just think about it, that thing is also like that it isn’t that bad“, even though it looks like it.” 6.2.19.

Proper line data comprised the participants’ saying what they believe they were supposed to say, and when the participants’ expressions were supporting a particular line about the topic as proper to the researcher. In addition, there was a difference between the adopted and the actual information. (Glaser 1998.) This example describes it:

”We live just like normal, like nothing had happened at all.” 4.3.3.

Vague data were imprecise, secretive and disclosed as little as possible. A participant may have mumbled as little as possible about what was going on, and no one was supposed to know what was going on. It also may have been vague in order to conceal an aspect of behaviour, which required further investigation. (Glaser 1998.) In this example of the data, the spouse mumbles very little about the alternative of what if the patient really would have died:

”One does here sort of... think differently about things now that this continuation treatment has lasted for a month already since the operation. So that one has adjusted there, and happen what may, it is not all that dramatic in that sense, when one thinks that what if... a couple of days

there and comes so that now the life ends there and then. It is so dramatic when one is not at all prepared for it, so that now that I have had a month to weigh all the options and adapt myself to the thought that one either survives and the life continues happily. The family has been doing quite well and... but then if the operation hadn't succeeded so well, so that had come to that... dying so..." 1.2.5.

Conceptual data involved the participants' rhetorical and hypothetical describing without empirical references. There were many in vivo concepts which have been generated so that they dominated the manner in which everything was talked about. (Glaser 1998.) Following is an example of that:

"It (falling ill) does make one grow. One can think about things a little differently. Everything is not so clear and obvious. I don't know how to say that any better. One day at a time." 4.3.6.

The constant comparative method was the fundamental operation in concept generation, and there were several ongoing matters during it. Fitting meant validity which referred to the fact that the naming of the category or its property suited well to the data. The naming sometimes occurred quickly and sometimes took a long time, and it was based on naming a pattern that emerged in incident after incident. Comparing incident after incident meant constantly returning to the data and, in that way, correcting and verifying the emerging pattern. As comparing more incidents yielded no more properties of the category and the category was verified, saturation was achieved by the interchangeability of indices. This meant that I could cease collecting and coding more data on the category and its properties. Further collecting became useless since, although the incidents were empirically different, they indicated the same concept and its properties. Therefore, the category had "earned its way" into the theory and theoretical sampling continued aiming to saturating other categories and establishing relations to them. (Glaser and Strauss 1967, Glaser 1978, 1992, 1994, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

## **Open Coding**

Open coding (Table 1) belonged to substantive coding. It was the first stage of grounded theory development and involved analysis by fracturing the data into categories and their properties which became the initial building blocks of the theory formation. I conducted the open coding according to its rules which were: asking the analytic questions during coding, analysing the data line by line, doing open coding myself, interrupting coding in order to write memos when needed and not assuming the relevance of any variable, *e.g.*, age, gender or education, until it emerged as relevant. Open coding came to an end when it reached the core category. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

I started the open coding by reading the data collected in conversations (Table 5, Appendix 10), by observation (Table 6, Appendix 12) and by writing field notes (Table 7, Appendix 25) line by line and by listening to the tape-recorded conversations. I continued the open coding by writing incidents in the

markings of the raw data. This meant that the dense data of interviews and participant observation was divided into pieces.

**Table 5.** The example of an open code of the data yielded from the conversations.

The indicators in the data	The incidents of the data	The properties of the category	The category as an open code
<p>“I for one would experience it like that that falling ill in a way makes the family and, kind of, our whole system stronger so that others take responsibility of doing those tasks. Yes, I’d see it like that that although this is a negative matter as such, it involves quite a lot of positive aspects as well. We cannot necessarily appreciate them yet, and that might come at a later stage. And especially the kids cannot do it.” (4.2.8.) A father with cancer.</p>	<p>Possibly appreciating later the positive aspects of falling ill. (4.2.8.)</p>	<p>Searching for positive aspects.</p>	<p>Thinking optimistically.</p>

Open coding could not consist of holistic reading of interviews or field notes for an overall impression because it would have neglected the details and their comparative meaning for concept generation. An overall impression might have fitted but would have had no systematic relevance to the theory and to systematic concept generation. Instead, concepts had to be rigorously generated and verified as to pattern and fit, which I guaranteed by line-by-line analysis. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

**Table 6.** The example of an open code of the data yielded from the observation.

The indicators in the data	The incidents of the data	The properties of the category	The category as an open code
<p>The small things lose their significance, things have been put into a new perspective. The manner of spending time has changed, we're focusing more on the family now and spending less time outside home, we do things among the family, it keeps us busy as such but we've cut down the activities outside home. Life is family-oriented activities. We act natural, are ourselves in the family, being natural. It means that everyone can be himself or herself, and therefore there are fewer fears, so that the sense of security has increased since we have been living a family-oriented life. (F16, 14.8.1999.)</p>	<p>The manner of spending time becoming family-oriented. (F16, 14.8.1999.)</p>	<p>Concentrating on the family.</p>	<p>Changing of life values.</p>

Concepts emerged after a while. The categories were concepts of a higher level than the properties and captured the underlying patterns in the data, while the properties were concepts about the categories (Tables 5, 6 and 7). I wrote incidents in the gerund form of a verb, if possible, and looked carefully at the informants' use of language. The use of gerunds meant that I was drawn to the recognition of psychosocial processes of the informants' behaviour. Indicators, which were pieces of raw data and examples from where the categories and their properties emerged, illustrated the grounding of the theory. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

**Table 7.** The example of an open code of the data yielded from the field notes.

The indicators in the data	The incidents of the data	The properties of the category	The category as an open code
<p>The husband has osteosarcoma. The wife interprets her drawing so that her life seems black, a big knot somewhere that causes the life to be continuous uphill and downhill. She started to cry. The husband told that the illness is a black thing; although there are many good things in life, this illness is like an ugly potato in which there is nothing good to be found. Therefore, he drew into the dark soil of the potato patch a big potato, one he would like to smash and destroy with his feet. F15, 14.8.1999, The boarding course.</p>	<p>Having feelings of uphill and downhill. (F15, 14.8.1999.)</p>	<p>Experiencing moments of weekness.</p>	<p>Being upset by the gravity of the disease.</p>

After having the conversations with the 13 couples from one to two or three times, I realised by constantly comparing the data and by writing theoretical memos that the core category, stabilising of life, had emerged among the categories. Stabilising of life as a core category was proven over and over again through its prevalent relationship to other categories and, thereby, it integrated them together. It also fulfilled the criteria of core category according to Glaser (1978).

Based on the criteria of core category, stabilising of life was related to as many other categories (Figure 1) and their properties as possible and more than other candidates for the core category. It reoccurred frequently and took more time to saturate than other categories. It related meaningfully and easily with other categories, and these connections came quickly and intensely. It had clear and grabbing implication for a formal theory, *e.g.*, stabilising of life of families in their different life situations concerning facing of hardships in the family and assuming an attitude towards the future. This meant that the core category did not lead to dead ends in the theory; rather, it brought me through the analyses of the processes, which I was working on, with its relevance and explanatory power. Stabilising of life was entirely a variable since its frequent relations to other categories made it highly dependently variable in degree, dimension and type. Emergent conditions which were the criteria of its two dimensions, facing

of hardships in the family and assuming an attitude towards the future, varied it easily. It was readily modifiable through these dependent variations. While accounting for the variation in the families' problematic behaviour, it was also a dimension of the problem. In addition, the core category of stabilising of life was a theoretical code of process. (Glaser 1978.)

The open coding came to an end when it reached the core category. Moving from open coding to selective coding was achieved by the interplay of theoretical memos and the constant comparison method. After the core category among the categories emerged, I essentially had the ingredients for writing the substantive theory.

## **Selective Coding**

The data collected after the core category had emerged were for the purpose of selective coding (Table 1). It meant that I continued theoretical sampling by observing the families during the boarding course on psychosocial rehabilitation and by interviewing again the couples interviewed earlier, for the third or fourth time. Simultaneously, I delimited the coding of new data yielded in conversations and by observation only to those categories that related to the core category in a sufficiently significant manner to be used in the parsimonious theory. Selective coding was used to enrich the developing theory by the upcoming data collected in conversations and by observation and to expand the concepts already established as well as to help solidify the categories and their properties. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

The selective codes were saturated when no new properties of the categories emerged through the constant comparison method (Table 8). As the selective codes became saturated by evidence, they formed a foundation based on which to ask further questions about the underlying pattern as a theoretical code. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

**Table 8.** The example of a selective code.

The incidents of the data	The properties of the category	The category as a selective code
Trusting in the Treatments Living today “to the full“ Maintaining the mental balance Occasionally forgetting the disease Disappearing of the disease’s sensation value Receiving future from God	Prevailing of equilibrium	Living trustingly
Minimalising the time for consideration Detaching from the circumstances of being ill Focusing thoughts and attention elsewhere Avoiding Isolating	Evicting concerns	
Yielding of conceding Trusting in recovering Increasing of gratitude Seeing past the present	Trusting in the future	

### 4.2.3 Theoretical Coding

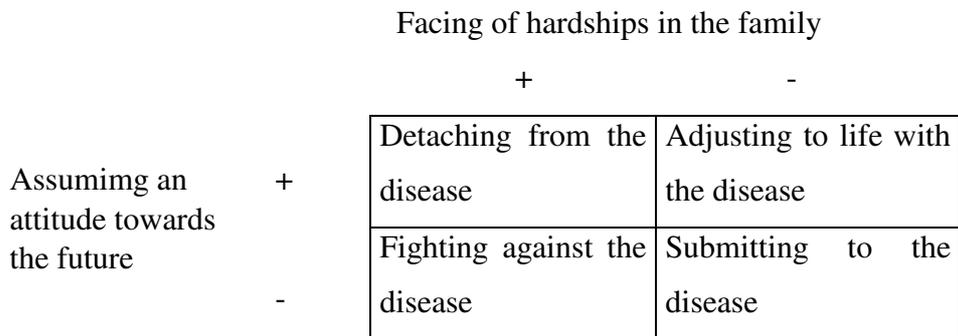
Theoretical coding implicitly conceptualised in which manner the substantive codes related to each other as interrelated, multivariate hypotheses in accounting for resolving the main concern of families in living with a parent with cancer (Table 1). *Theoretical codes of a typology and a process* were emergent and wove the fractured story turned into concepts back to an organised complete substantive theory. Theoretical codes provided the models for generation of theory and emerged during substantive coding, writing memos and, especially, in sorting. Theoretical codes were also patterned out to be verified to provide grounded integration. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

The substantive codes were used together with the theoretical codes to build up the conceptual theory since substantive codes are not theoretical codes. However, without them, theoretical codes would be empty abstractions. Moreover, substantive codes could be related without theoretical codes but the result would be confused, theoretically unclear or typically connected by descriptive topics but not going anywhere theoretically. That is why the

integration between substantive and theoretical coding was used in this grounded theory and characterised through the analytical inductive research methodology. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

Theoretical codes of a typology and a process were emergent in the data and earned their way into the theory as much as also the substantive codes did. The operation in the construction of a typology was *substruction*, which was moving from the typology to its criteria. It entailed looking for the implicit criteria from which the typology was unintentionally constructed. The variation of the typology based on the emerged criteria which related to the dimensions of the core category, facing of hardships in the family and assuming an attitude towards the future. They expressed the activities and emotional atmosphere of the family, as either active actions in a life-embracing and persistent atmosphere or passive actions in powerless and dejected emotional atmosphere. Furthermore, either trusting actions in a positive, hopeful, meaningful and balanced emotional atmosphere or doubtful action in a negative, hopeless, anxious and fearful emotional atmosphere were expressions of that. (Figure 1.)

The typology of stabilising of life indicated the variation in the entirety based on the combination of the categories. The variation of the typology consisted of detaching from the disease, fighting against the disease, adjusting to life with the disease and submitting to the disease. (Figure 1.) (Glaser 1978.)



**Figure 1.** The typology of stabilising of life as a theoretical code.

In addition, the typology of stabilising of life contained a process as an emerged theoretical code. The process of each type of the typology had different stages and referred to something occurring over time in a family concerning facing of hardships in the family and assuming an attitude towards the future. Detaching from the disease in a family of a parent with cancer consisted of the stages of maintaining hope, living trustingly, evolving of the concept of self, progressing of recovery and continuing the habituated life. Fighting against the disease in a family of a parent with cancer contained the stages of deliberating about falling ill, rebelling against the change in life, overcoming adversities, preparing for worse and ensuring the functionality. Adjusting to life with the disease in a family of a parent with cancer was composed of the stages of

clarifying of facts, resorting to help, returning to life, intensifying of togetherness and maturing through hardships. Submitting to the disease in a family of a parent with cancer contained life coming to a standstill, succumbing to fear, being burdened by concerns, life turning more difficult and getting caught in being ill. (Glaser 1978.)

It took time to understand as many theoretical codes as possible by reading the literature of the grounded theory methodology but staying away from the literature of the substantive area being researched in order to avoid preconceived theoretical codes. This was a very important part in developing my theoretical sensitivity since my goal was to develop a repertoire of as many theoretical codes as possible. The more theoretical codes I learned, the more variability I gained for seeing them emerging and then fitting into the theory. An increased understanding to theoretical codes (*cf.* Glaser 1996) empowered my ability in generating theory and kept it at the conceptual level. Without this, the outcome may have been simply a topical conceptual description since this would limit the discussion on how concepts relate to each other. It also enabled the development of my theoretical model. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

#### 4.2.4 Memo Writing

Theoretical memo writing by co-varying with coding, other memoing, theoretical sampling and memo sorting provided the integrative binding and power to put it all together into a grounded theory (Table 1). Theoretical memos were theorising write-ups of ideas about open and substantive codes and their theoretically coded relationships as they emerged. Writing them was like a vehicle with the help of which concepts and ideas poured out, were saved and grew. Theoretical memos ensued from constant comparison and tracked substantive and theoretical code emergence and their integration, conceptual levels as they became more abstract, saturation, delimiting, density, and the perspective level. Theoretical memos provided through this process led to theoretical sampling and captured and kept track of the emerging theory. As they accumulated and matured, they increased to the point of saturation and needed to be sorted for writing up a theory. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

I wrote theoretical memos by following the basic goals of memoing in order to theoretically develop *ideas* with complete *freedom* into a *memo fund* which was *easily sorted*. The memos were used to capture the moment since their goal was to portray theoretical ideas for the growing theory at the moment they occurred. The memos were my ideal and conceptual writings which occurred to me during the different research activities and which I wrote down so that they were not lost. They were writings on anything when capturing a theoretical idea as it emerged and also, but not necessarily, on theoretical coding of its link to other categories and their properties. The memos were totally free and emergent,

and they did not have any preconceived structure or form. They just flowed out with total freedom and matured on during the research process when I was constantly stopping to get the ideas down in writing and, thus, kept the memo fund growing. Moreover, I noted memos of the concepts and their locations in the data yielded in conversations, by observation and by writing field notes and labelled the memos for the upcoming theoretical sorting by the family code number (from F1 to F18), the conversation number (from 1 to 4) and the page of the transcript or the date of the observation. Hence, the memos were ready to be sorted later on for the concepts. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

The memos varied from being a jot of a few words to writing a full memo later on around an idea all the way through theory bits of one or two pages. The memo fund was 97 pages altogether. Memos consisted of anything that captured conceptualised ideas, where they went theoretically and how theoretical sampling was to be continued. They were illustrated and annotated to field notes when appropriate. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.) This example represents the memos of the data yielded in conversations:

Fighting against the disease aiming to stabilising of life:

The family includes, in addition to the mother and the father, two small children who during the interview either played among themselves in their own room or came out to drink juice with us. The illness of the wife has lead the parents to start fighting the disease as unanimously. The husband has had a hard time as he has taken care of the housework and the children during the wife's intensive treatment phase. In the beginning of the illness the children were dependent on the father, but now as the treatments are over they have returned to their mother's "apron-strings". At times the atmosphere in the family has been tense and hopeless, and the spouses have argued with one another. Also the obstinate ages of the children are testing the family. Fear of death and anxiety arises among the parents, and because of this they still wake up at nights. The children sense the mother's illness, and one of the children wouldn't like to go to daycare anymore, but misses her mother there.

The reason for falling ill and the bad reputation of the disease still trouble the parents' thoughts. Becoming ill feels like a great injustice in their lives, and it awakes rebelling against the current situation. The feeling of panic clears away as the treatments have started. The patient rather discusses the illness with her female friends than with her husband, because she fears that he will become distressed. For the sake of the functioning and the maintaining of the family community it is for the time being better that they do not dwell on the trouble caused by the disease between the two of them.

The everyday life of the family moves on controlled by fear which is at times, due to the effect of the treatments, lessened by a feeling of being in a sense given a new life. The spirit of togetherness helps, and also the fact that they have to keep going on from here with the help of everyday routines and three-week treatment periods. In a sense they have to fight, moving on gradually with their lives with the attitude that they have to overcome this because they have two small children to raise. In the future the patient does intend to change her relationship to work, and focus on the things she feels good about or that are necessary for the job, without taking on too many extra challenges. (F5.3, 25.5.2001)

As categories and their properties patterned out, memos kept track of the patterning, *i.e.*, validity or fit, workability and relevance. This tracking naturally led to theoretical sampling. Memos tracked the interchangeability of indices and saturation of categories and their properties. They explained the ongoing delimiting. Furthermore, they explained, for later reference, the transition from open to selective coding, the delimiting of the study and the naming or the tentative naming of the core category. The memos explained where the study was being taken next. These explanations grew more formulated and the memoing continued. I had an ideal record of the twists and turns of the research. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

The conceptual level, theoretical coding integration, theoretical completeness and saturation increased as I became more absorbed into the study and the memo fund accumulated. Delimitation became more precise and concepts became clearer. Theoretical formulations abounded. Memo maturity resulted in a rich fund which was later sorted. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

As memos matured, I started to hear the same thing over and over again in the interviews and to see it in memos. The pattern was conceptualised and the relevance was assured. The core category and its resolving of the main concern of the participants was confirmed over and over again. Saturation and delimiting occurred. The theory worked and fitted at this stage and it was best to write it soon. Thus, memos were getting better, more to the point and theoretical codes were emerging more frequently. The memo fund started becoming large to handle. Theoretical sampling no longer seemed relevant. The memos became repetitive, there were, particularly, memos on memos and memoing became dull, even boring. Theoretical completeness with parsimony, scope, depth and breadth of conceptualisation had emerged. It was time to start sorting. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2002a, 2003.)

#### *4.2.5 Memo Sorting*

After substantive coding and achieving the rich and comprehensive memo fund, I started to sort the memos according to the emerged theoretical codes which integrated the saturated categories and their properties into the substantive theory of stabilising of life in a family. The theoretical memo sorting (Table 1) was one of the delimiting properties of the grounded theory methodology and produced a dense substantive theory. The theoretical memo sorting was conceptual sorting of theoretical ideas written in the memos, not sorting of raw data, and had many important benefits for the ensuing theoretical writing since it produced the first draft of the manuscript. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

The theoretical memo sorting was conducted according to the emerged theoretical codes, a typology and a process which were the organisers in this substantive theory. I based my theoretical sorting on the assumption of the grounded theory methodology that the world is empirically integrated, not logically modelled. The grounded theory methodology struck the empirical integration and the multivariate nature of living in a family with a parent with cancer but modelling beforehand would have crushed it. Therefore, I avoided preconceived outlines for sorting the memos of this substantive theory and let the emergence of theoretical codes and the constantly verified outline of this theory emerge. Thus, I avoided staying at the categorisation level and only describing them in the topical form without relationships between the concepts. Upon comparison, they related empirically in the fashion of the typology and the process and the substantive area was integrated. The theoretical memo sorting generated an integrated outline according to which I wrote the substantive theory. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

The sorting process provided a dense theory with theoretical completeness and prevented the regression back to writing up with descriptive raw data. All this was controlled by the analytic rules of theoretical sorting (Appendix 9). They were also emergent, not proliferated beyond control to force the integration. The analytic rules concerning *starting to sort, sorting on the basis of the core category, writing memos, reaching theoretical completeness, using mechanics of sorting, following theoretical pacing and maintaining integrative fit and conceptual level* guided the theoretical sorting of this study and the construction of the emerged substantive theory and its subsequent theoretical writing. (Glaser 1978, 1998.)

I started sorting anywhere in the memo fund and picked a memo which I placed somewhere on the table. Then I picked another memo and saw in comparison how it was related to the first one picked. I continued doing comparisons manually for which it was important to have a great deal of space. That is why I had large tables for spreading out all memos to grasp the integration. I just kept on picking a memo of the original memo fund and constantly comparing it to others. Integration emerged when the memo related theoretically and substantively to the other memos. Re-sorting of the memos occurred if they fitted somewhat differently. I kept on sorting, comparing and re-sorting, and the integration of the theory emerged. (Glaser 1978, 1998.)

I sorted only those categories and properties which related to the core category. Otherwise, the concept was left out of the theory since it obviously had no use in it. Theoretical coding helped decide on and figure out the relation of the concept to the core category. When necessary, I stopped sorting for writing a memo if sorting on the core category generated new ideas which I then sorted into the integration. The mechanics of sorting entailed me cutting up memos as much as necessary in order to increase sortability. It meant that the memos on the codes and the codes along with the data which indicated it were cut out of the memos with scissors for sorting. I also wrote “pass on” notes on memos to be

carried forward and kept a paper nearby the sorting piles on which I wrote new memos, if needed. From the beginning of the sorting, I started to use envelopes as files in which I put the memos which were already sorted. I organised uninterrupted time for my theoretical pacing, which balanced the cumulative build-up of theoretical memos and the maturing process of the emerging theory. The sorting was written up when the theoretical integration to a larger picture was completed. (Glaser 1978, 1998.)

I reached the integrative fit and conceptual level of the substantive theory by constantly questioning and comparing each idea to the emerging outline. The question “Where does this fit in?” made the underlying pattern, integration and multivariate relations between concepts emerge. In addition, theoretical completeness was reached, when concepts fitted, worked, had relevance and were saturated. I could be sure that the substantive theory with parsimony, scope, depth and breadth of conceptualisation had emerged. It was time to cease sorting. (Glaser 1978, 1998, 2002a.)

#### *4.2.6 Theoretical Writing*

Theoretical writing involved the writing up of the sorted memo piles according to the conceptual construction of induction (Table 1). The memos were ordered after theoretical memo sorting due to which I knew what to write next in this writing phase when I was ending the grounded theory package. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

Funnelling down was the first step in the writing phase. It is one aspect of delimiting in the grounded theory methodology. The results started out according to it with the logic implicit in the theory. First, I brought out the continued resolving of the participants main concern with the core category, stabilising of life, and delimited it to its dimensions, facing of hardships in the family and assuming an attitude towards the future. They accounted for the variations of the typology in resolving the problem. Then, I stated the integrative outline established through the sorting. The outline discussed each section and how they related to each other so that it was known what was expected in the theory. After that, I wrote four substantive sections of detaching from the disease, fighting against the disease, adjusting to life with the disease and submitting to the disease which followed from the sortings. (Glaser 1998)

I applied the conceptualisation rules to the writing phase and wrote substantive codes and thought of theoretical codes. I was keeping the emerged theoretical codes in my mind while writing the substantive codes as theoretical codes were implicitly presented. The theoretical outline directed me in writing substantively how two categories related into a hypothesis. This tracked the conceptual integration on the substantive theory and made the flow hang together. I related concept to concept instead of concept to people, which should have lowered the conceptual level. This kept the substantive theory generalisable

to the conceptual core category and the general problem which brought out the formal theory implications. Moreover, I used illustrations to lighten the density of this substantive theory. Their task was to facilitate integrating the theory and maintaining its conceptual level. I designed the balance between illustrations and concepts and avoided using too many illustrations because they could have diluted the substantive theory. (Glaser 1998, 2002a.)

# 5 THE SUBSTANTIVE THEORY OF THE FAMILY SURVIVORSHIP WITH A PARENT WITH CANCER

In the first section (5.1) of this chapter, I will present the structure of *the substantive theory of family survivorship* with a parent with cancer and its core category, stabilising of life, as well as the connections between its subcore categories: *detaching from the disease*, *fighting against the disease*, *adjusting to life with the disease* and *submitting to the disease*. The four following sections (5.2-5.5) will discuss the structures and contents of the subcore categories of stabilising of life.

## 5.1 Family Survivorship through Stabilising of Life

The sudden falling ill with cancer of a family's mother or father is a *shock* to all family members which begins the *process of stabilising of life* in the family as they continue their life with the disease. The core category of this substantive theory, *stabilising of life*, involves psychosocial behaviour brought on by a parent falling ill in a situation in life that is new for the family members. In the family, stabilising of life manifests itself as *detaching from the disease*, *adjusting to life with the disease*, *fighting against the disease* and *submitting to the disease* which are the four subcore categories of stabilising of life and constitute the typology of psychosocial behaviour of the family.

The dimensions of stabilising of life are *facing of hardships* and *assuming an attitude towards the future*. They are related to the feelings and actions prevailing in the family which in turn indicate that the family's stabilising of life, as regards facing of hardships and assuming an attitude towards the future, entails either detaching from the disease, fighting against the disease, adjusting to life with the disease or submitting to the disease. (Figure 2.)

Stabilising of life is manifested in the family based on different criteria depending on whether facing of hardships and the associated feelings and actions are life-embracing, persistent and active or powerless, dejected and passive, and whether assuming an attitude towards the future and the feelings and actions related to it are positive, hopeful, meaningful, balanced and trusting or negative, hopeless, anxious, fearful and doubtful. (Figure 2.)

Stabilising of life of a family with cancer either *follows* the behaviour in accordance with the subcore categories or *varies* between the four behavioural patterns. The variation of stabilising of life depends on the situation-specific realisation of criteria representing the various feelings and actions involved in facing of hardships and assuming an attitude towards the future. The variation of stabilising of life is manifested as variation of the different stages included in its four different behaviour patterns. (Figure 2.)

STABILISING OF LIFE		FACING OF HARDSHIPS IN THE FAMILY	
		Life-embracing attitude Persistence Activity	Powerlessness Dejection Passivity -
ASSUMING AN ATTITUDE TOWARDS THE FUTURE IN THE FAMILY	Positiveness Hopefulness Meaningfulness Balancedness Trust  +	<b>Detaching from the disease:</b> 1. Maintaining of hope 2. Living trustingly 3. Changing of the concept of self 4. Progressing of recovery 5. Continuing the habituated life	<b>Adjusting to life with the disease:</b> 1. Clarifying of facts 2. Resorting to help 3. Returning to life 4. Intensifying of togetherness 5. Maturing through hardships
	Negativity Hopelessness Anxiety Fearfulness Uncertainty  -	<b>Fighting against the disease:</b> 1. Deliberating about falling ill 2. Rebelling against the change in life 3. Overcoming adversities 4. Preparing for worse 5. Ensuring the functionality	<b>Submitting to the disease:</b> 1. Life coming to a standstill 2. Succumbing to fear 3. Being burdened by concerns 4. Life turning more difficult 5. Getting caught in being ill

**Figure 2.** The substantive theory of family survivorship with a parent with cancer.

When hardships are faced in the family of a parent with cancer in a life-embracing, persistent and active manner and the family's attitude towards the future is emphasised with positivity, hopefulness, meaningfulness, balancedness and trust, the life of the family stabilises through *detaching* itself from the parent's cancer. Detaching from the disease is related to stabilising of life and in this way, it consists of maintaining of hope, living trustingly, changing of the concept of self, progressing of recovery and continuing the habituated life. Then, during detaching from the disease, apart from changing of the concept of self, the life of the parent and the family members returns back to normal. (Figure 2.)

Life is stabilising in the family of a parent with cancer through *fighting against the disease* when the hardships are faced in a life-embracing, persistent

and active manner in the family, and the family is nevertheless assuming a negative and hopeless, anxious and fearful as well as doubtful attitude towards the future. Fighting against the disease involves the stages of deliberating about falling ill, rebelling against the change in life, overcoming adversities, preparing for worse and ensuring the functionality which are essential in stabilising of life. During fighting against the disease, the family uniformly resists the disease and wants to struggle against it. (Figure 2.)

When hardships are faced in a powerless, dejected and passive manner, but the manner of assuming an attitude towards the future is nevertheless emphasised by positivity, hopefulness, meaningfulness, balancedness and trust, the family is *adjusting to life with the disease*. Along these lines, adjusting to life with the disease which is involved in stabilising of life consists of clarifying of facts, resorting to help, returning to life, intensifying of togetherness and maturing through hardships. During adjusting to life with the disease, the family learns to live with the changes in life brought about by the disease (Figure 2).

Stabilising of life entails *submitting to the disease* in the family of a parent with cancer when hardships are faced in a powerless, dejected and passive manner and the family assumes a negative, hopeless, anxious, fearful and doubtful attitude towards the future. Submitting to the disease is connected to stabilising of life and it includes the stages of life coming to a standstill, succumbing to fear, being burdened by concerns, life turning more difficult and getting caught in being ill. During submitting to the disease, the family sort of further attaches itself to the adverse reputation of the disease and the difficult circumstances it has inflicted. (Figure 2.)

## 5.2 Detaching from the Disease in a Family of a Parent with Cancer

Motto: “*Disease has left from our lives.*”

Detaching from the disease is connected to stabilising of life in a family of a parent with cancer, and it is actualised in the ways of facing of hardships and assuming an attitude towards the disease. When stabilising of life involves life-embracing, persistent and active facing of hardships and assuming a positive, hopeful, meaningful, balanced and trusting attitude towards the future, the family detaches itself from the cancer on the level of both feelings and actions. Apart from the changing of the concept of self, during the process of detaching, the life of the family returns back to normal. Detaching from the disease is manifested in the lives of the parent and his/her family as a process of psychosocial behaviour, which begins with maintaining of hope and continues through living trustingly, changing of the concept of self and progressing of recovery to continuing the habituated life (Figure 3).

<b>STABILISING OF LIFE</b>		FACING OF HARDSHIPS IN THE FAMILY
ASSUMING AN ATTITUDE TOWARDS THE FUTURE IN THE FAMILY	<b>Criteria:</b> Positiveness Hopefulness Meaningfulness Balancedness Trust	Life-embracing attitude Persistence Activity
		<b>Detaching from the disease:</b> 1. Maintaining hope 2. Living trustingly 3. Changing of the concept of self 4. 4. Progressing of recovery 5. Continuing the habituated life

**Figure 3.** The process of detaching from the disease in the family of a parent with cancer.

Detaching from the disease in the family of a parent with cancer begins with *maintaining of hope*, which is essentially connected with persistent facing of hardships and assuming a balanced attitude towards the future. In the stabilising of the family's life, maintaining of hope is fluently followed by a phase of *living trustingly*. In addition, it is connected to persistent facing of difficulties, with assuming a hopeful attitude towards the future. As detaching from the disease advances, the family members observe in themselves *changing of the concept of self*, which is connected to both active overcoming of hardships and assuming a balanced and trusting attitude towards the future. As detaching from the disease continues, the family members emphasise *progressing of recovery* as a turn for the better. It is connected with life-embracing facing of hardships and assuming a positive attitude towards the future. Within *continuing the habituated life*, the life-embracing, persistent and active facing of hardships by the parent and the family members combined with their hopeful and trusting attitude towards the future are significant as the family is detaching itself from the disease (Figure 3, Table 9).

**Table 9.** The stages and their categories of detaching from the disease in a family with a parent with cancer.

The subcore category	The stages of the subcore category	The categories of the stages of the subcore category
Detaching from the disease	1. Maintaining of hope	Awakening of hopes of recovering Dispelling concerns Thinking optimistically
	2. Living trustingly	Prevailing of equilibrium Evicting concerns Trusting in the future
	3. Changing of the concept of self	Changing of life values Spiritual growing Reinforcing self-esteem
	4. Progressing of recovery	Becoming motivated in self care Increasing of treatment satisfaction Restoring the zest of life Facilitating of life
	5. Continuing the habituated life	Resuming the former life Maintaining the same relationships Continuing with everyday routines

### 5.2.1 *Maintaining of Hope*

The life of a family detaching from cancer is marked by maintaining of hope, which is characteristic of the atmosphere in the family throughout the process of detaching from the disease. Maintaining of hope includes feelings and actions connected with *awakening of hopes of recovering*, *dispelling concerns* and *thinking optimistically* in the family of a parent with cancer (Table 9, Appendix 10). As hopes of recovery have been awoken, the family maintains hope, which is supported by the recognition of dispelling concerns and optimistic thinking. This is manifested in the family’s positive attitude towards life and their active role in detaching from the disease. Maintaining of hope in the family of a parent with cancer is included in stabilising of life, and it is fundamentally connected with persistent facing of hardships and assuming a balanced attitude towards the future.

### **Awakening of Hopes of Recovering**

Awakening of hopes of recovering, which is interlinked with maintaining of hope (Appendix 10), is characterised by *being aware of the recovering*, which

means realising the possibilities of recovering and detaching from the disease in the family of the parent with cancer, *e.g.*, as a result of an early diagnosing of the tumour. In addition to this, the parent's having an opportunity to receive treatment encourages the strengthening of hopes amidst the family members. Further, this is supported by the family members' familiarising with the treatments and actually witnessing the treatments while, *e.g.*, visiting the cytostate and radiation therapy wards. The gradual increase in the level of *living on the patient's terms* and the increasing of his/her strength nourish the awakening of hopes of recovering among the family members. This is characterised also by *being encouraged by the treatment results*, which motivates one in detaching from the disease and brings about awakening of hope. Talking with other patients and their families, and, *e.g.*, reading books written by fellow patients contribute in giving hopes of recovery. Additionally, *trusting in the improved reputation of cancer* ties in with awakening of hopes of recovering, because cancer is no longer considered solely as a terminal disease, since developing of the forms of treatment has added to the possibilities of recovery. This is reflected, *e.g.*, in one spouse's views on trusting in the improved reputation of cancer during his wife's disease:

*"So far it has of course changed, that thing, so that cancer is not such a bogey anymore as it was still about twenty years ago, because the treatments have improved. I have two sisters who have been ill, one eight years ago and the other later, she has breast cancer." 2.1.1.*

## **Dispelling concerns**

Dispelling concerns (Appendix 10) is linked with maintaining of hope. It is characterised by *gradual advancing* of life in the family with the help of the parent's improving health and the feeling of relief among the family members. A further aspect of dispelling concerns is *viewing the future positively*, when the family's life is marked by a positive atmosphere and assuming a hopeful attitude towards the future. The parent and his/her family members may at times contemplate on the patient's returning to work or even acquiring a new profession.

A further factor of dispelling concerns is *trusting in the shared life* despite a family member's being seriously ill. The predominating optimism towards the continuing of life together keeps the family from sliding into despair or depression. Such trusting in the shared future despite the wife's disease is supported by the opinion of one spouse:

*"Yes, we believe that everything will turn out all right, the treatments are taken care of and we trust in the future that we will carry on together." 3.2.13.*

Although the family's life is in an undulating motion and the thoughts about the future obviously fluctuate from hopeful to desperate, the family members nonetheless come into contact with *life becoming brighter*, which is a part of dispelling concerns. Regarding the parent's falling ill as a less important factor in relation to the other aspects of the family life and considering it irrelevant help the family members feel better. The family has experienced acclimatising both to

the disease and to living with it. Furthermore, the family has several other things to think about instead of focusing on the disease. Therefore, as detaching from the disease is in progress, thinking about being ill is avoided. If life focuses too much on one family member being ill, it is perceived that life comes to a standstill and also the others fall ill.

A further aspect included in dispelling concerns is *using humour* which, for its part, results in lightening of living and creating an atmosphere that maintains hope in the family. When joking and laughing at the expense of being ill is possible among the family, detaching from the disease is felt as more concrete.

A factor essential in the atmosphere of the family detaching from the disease is *anticipating the future*, which is characteristic of dispelling concerns. Making plans for the future and perceiving the next day as better than the current situation results in forgetting the concerns. For instance, the parent feels confident of work issues being settled and his/her finding a new role at work after returning from the sick leave.

## Thinking Optimistically

Supported by thinking optimistically, which is linked to maintaining of hope (Appendix 10), the family believes that *pulling through honourably* from the disease is possible. It means trusting in overcoming the disease due to treatment and thereby trusting in the withdrawing of the disease from the life of the family. A father with cancer commented on the issue as follows:

*“I think we’ll pull through this all right. It hasn’t really crossed my mind, the sort of a situation where we wouldn’t make it.” 4.2.8.*

Characteristic of thinking optimistically, which is prevalent among the family members, is also *trusting in recovering*. The parent’s own will to recover and the family’s confidence in recovering are important factors in maintaining of hope. Instead, giving up and having a pessimistic attitude would result in faltering of hope and the feeling of perishing taking over. Living optimistically and the family members’ trust in recovering facilitate living with cancer.

Thinking optimistically involves *searching for positive aspects*, which means rejecting the feeling of life coming to a standstill as a result of a parent falling seriously ill. Instead of the family’s life coming to a standstill, emphasising the positive aspects facilitates the lives of the family members and creates grounds for an optimistic way of thinking amongst the family.

The atmosphere in a family detaching from a disease is also characterised by *turning negative aspects into positive*. Creating a positive atmosphere in the family indicates thinking optimistically and results in creating hope instead of focusing on emphasising the negative aspects.

*Distinguishing between great and small problems*, which is emphasised by a mother’s or father’s falling ill is one aspect of thinking optimistically helpful in relating realistically to the different problems that arise in a family. Thinking optimistically is also linked with emphasising of optimism, with which one can avoid grieving in advance over bad news that may possibly come up in the

future. This *avoiding of grieving in advance* alleviates the family's life and emphasising it helps the family members in detaching from the circumstances of being ill.

In addition, *emphasising of optimism* is characteristic of thinking optimistically. It means stressing the meaning of hope in the family and accentuating the view that in the future, life will go well both for the parent and the family members. Emphasising an optimistic viewpoint is, in this case, essential in the atmosphere of the family.

### 5.2.2 Living Trustingly

In the family's process of detaching from the disease, maintaining hope is followed by living trustingly. In this phase, the family members live in the present as fully as possible trying to avoid the effects resulting from being ill. Living trustingly involves feelings and actions connected with *prevailing of equilibrium* and *evicting concerns*, as well as with *trusting in the future* in the family of the parent with cancer (Table 9, Appendix 11). When the family is balanced and shares an atmosphere that evicts concerns, the family members live trusting in the future. In this case, there is trust among the family members in detaching from the disease and dispelling concerns, and they strive actively and trustingly for the future. Living trustingly is included in the stabilising of life, and it is connected to both persistent facing of hardships and assuming a hopeful attitude towards the future.

### Prevailing of Equilibrium

Prevailing of equilibrium within the family (Appendix 11) is connected to living trustingly. It is characterised by *trusting in the treatments*. It contributes to the developing of a positive outlook toward the different treatments for cancer and their beneficial influence. In the family, trusting in the treatments is expressed as giving positive feedback on the treatment received. Consoling oneself with good treatment results and trusting in the recuperative effects of the treatments bring about the prevailing of a harmonious atmosphere in the family and encourage one in detaching from the disease. The relevance of good treatment results is also accentuated in the children assuming a balanced attitude towards a parent's disease.

*Living the day "to the full"* is an aspect of prevailing of equilibrium in the family of a parent with cancer. As this contented state prevails, the family members do not feel that the disease is restricting their lifestyle. Instead, they attempt to continue living trustingly. Therefore, staying in touch with life is important both to the parent and to the family members when detaching from the disease. A mother with cancer expressed it in the following manner:

*"I think children are one factor, like that they sort of keep one connected with the everyday life. Have to look for a mitten or a shirt, just like it ought to be."* 1.3.2.

Characteristic of prevailing of equilibrium is also *maintaining* the family members' *mental balance*. It is more important than the limitations in the parent's physical condition when living trustingly in a family of a cancer patient, because the reflecting of the family members' balanced outlooks on life in each others' lives, *e.g.*, prevents the faltering of the children's basic sense of security. It is very important to the parents that the children can continue living their carefree childhood despite the disease of a mother or father.

In addition to maintaining a good mental balance, *occasionally forgetting the disease* is a part of prevailing of equilibrium in the family, thereby facilitating the family members' detaching from the disease. When the disease is left without attention, it is easier to lead a balanced life. A father described how the children occasionally forget about their mother's disease as follows:

*"When there are such days that the wife has no pains, I think it's quite good that the children have been able to pretty much forget about that disease – if there haven't been headaches or anything like that." 1.4.1.*

The easing of the shock caused by the disease among the family, *e.g.*, in the children's assuming a natural attitude towards the parent, brings about prevailing of equilibrium within the family. The family members' feeling relieved enables talking about their situation also with other people close to them. The closest relatives and friends knowing about the serious disease that has been encountered by the family facilitates both other people's assuming an attitude towards the family, as well as the family itself. Therefore, *disappearing of the disease's sensation value* is not only of importance in the prevailing of equilibrium within one's own family, but also in the close relatives' and friends' living trustingly despite the serious disease in a family close to them.

In families emphasising religion, prevailing of equilibrium is characterised by *receiving future from God*. It involves trusting in God's guidance, which renders being balanced possible. The family members feel that faith in life being a gift from God, who alone knows whether the disease is curable or about to take over, is a safe and balancing factor.

## **Evicting concerns**

Evicting concerns (Appendix 11) is closely linked with living trustingly within the family. It is characterised by *minimalising the time for consideration*, which means actively avoiding thinking about the concerns brought by being ill in order to enable living trustingly. *Detaching from the circumstances of being ill* in its turn means deliberating about the requirements brought about by the changed situation and looking for new solutions for evicting concerns. In the course of being ill, instead of being victimised by the situation, the family thinks about the new options it has in this unexpected situation. Here included is a spouse's example of the family's conversations about detaching from the circumstances of being ill:

*"I personally don't believe in it, if someone says that you are victims of circumstances, I don't believe it because we create our own circumstances. That is why I believe, that it has been*

*largely in this situation of the wife being ill, about the fact that we've been able to talk about things the way they are. So it's not like yeah, I understand, and when somebody asks 'what did I say?' they don't have a clue but debate what this situation demands from me, what it demands from her, what it demands from the children, what it demands from us to the children."* 6.2.18.

*Focusing thoughts and attention elsewhere, e.g.,* by following a certain routine day schedule, working or having a holiday, is a part of evicting concerns, and linked to living trustingly. For example, actively engaging in hobbies enables distancing from the concerns caused by the disease. Respectively, meeting friends and the children's circle of friends is needed to help in detaching from the concerns so that living trustingly with the disease would be possible.

*Avoiding of isolating* is included in evicting concerns and living trustingly. Instead of huddling into oneself and contemplating on the disease, the family's situation is made easier by taking into consideration the things that happen around them and to others close to them. Decreasing isolating and retreating to one's own company, and putting emphasis on discussion and intercommunication between the family members and other people is essential, since contemplating on the disease on one's own and retreating into solitude would result in the increasing of anxiety, thus preventing the evicting concerns.

## **Trusting in the Future**

Living trustingly is connected with trusting in the future (Appendix 11), a part of which is *yielding of conceding* among the family. It includes zest for life and persistence prevailing among the family. Moreover, *trusting in recovering* is characteristic of trusting in the future, and it means believing strongly in detaching from the disease. It is, *e.g.*, having confidence in the recuperative effect of the treatments and in the knowledge of experts. A wife with cancer described trusting in recovering as follows:

*"But apparently this nursing staff's professional skills are and such, so I haven't doubted that for a second, and I haven't been worried about that. We've just been positively surprised about this aspect of how well and diversely they give the treatment."* 3.1.8.

Moreover, a part of trusting in the future is *increasing of gratitude* that prevails among the family members. It means perceiving life as a value in itself, or, *e.g.*, satisfaction about having a new lease of life. Trusting in the future involves also *seeing past the present*, when the family that expresses living trustingly does not live solely for the moment, but trusts also in tomorrow and in detaching from the disease.

### *5.2.3 Changing of the Concept of Self*

Despite detaching from the disease, suffering from cancer does not pass without effects in the family, for it changes the parent's and his/her family's concepts of themselves. The changing of the concept of self involves feelings and actions connected with *changing of life values, spiritual growing and reinforcing of self-*

*esteem* among the family of a cancer patient (Table 9, Appendix 12). When the family members' life values change while living with the disease, and spiritual growth and reinforcing of self-esteem take place, the family's concepts of themselves change. In this case, the active pursuit of meaningfulness in life, which is built on a new set of values, is now more pointedly evident in the family members' lives as they strive for detaching from the disease. The changing of the concept of self is included in the stabilising of life, and it is connected both to active facing of hardships and to assuming a balanced and trusting attitude towards the future.

## **Changing of Life Values**

The changing of the parent's and his/her family members' concept of self includes changing of life values that takes place during the course of being ill (Appendix 12). Characteristic of it is *concentrating on the family* and perceiving it as important among the family members. For example, living focused on the children and emphasising surviving and recovering of the patient are now more important to the parent and his/her family than investing on their work and careers. *Looking after one's health* is also considered more significant than before. Appreciating the patient's own well-being instead of the others' self-sacrificial caring and overly bearing other people's concerns are new aspects in the family's life. A mother with cancer described the matter as follows:

*"My aunt called yesterday, and we also talked about this granddaughter, so she said that listen, now she as a relative and as a friend will say that from now on you'll just take care of yourself and leave all the worries to other people. Now I must think selfishly and be so, but it is just that to be like that, too, carrying the worries of the whole flock of kids around with me (laughter) and taking care of them all, it is like that, and then all the rest of that load is with me as well. When just one of them has problems with their brood, I have a tendency to carry the weight of too many worries on my shoulders." 10.1.10.*

Included in the changing of the life values may be also the *clarifying of the outlook on life*, which involves, *e.g.*, increasing religiousness compared to the previous life. This is exemplified by deliberating about one's own religiousness or its coming up more pronouncedly, praying more often, or relying on God's help. Furthermore, clarifying of the outlook on life may mean discussing with higher forces and receiving help and balance from them.

## **Spiritual Growing**

Spiritual growing is connected with the evolving of the concept of self which takes place during the disease (Appendix 12). This comprises the family or its members *becoming independent*, or getting, in a way, a new grip on their lives. For instance, it is manifested in the parents of the family in dissociation from their own parents, whereby living with the disease is mainly a matter of the core family. Discussing the changed situation of the family with friends or relatives becomes less significant. On an individual level, becoming independent means,

*e.g.*, maturing and spiritual growing of a child towards realising that in the future, s/he may have to cope without one of his/her parents. With children, the spiritual growing means an increase in taking one's own initiative and responsibility for their own everyday matters, such as waking up in the morning and issues associated with school.

*Increasing openness* is characteristic of spiritual growing in the family. It includes maintaining a conversational atmosphere, increasing the level of taking the children into consideration and avoiding the hiding of issues relating to mother's or father's disease as well as adopting a more open manner of looking at things in the family and in its vicinity. For example, telling the children about the parent's disease in a more open manner than before illustrates the spiritual growing of the parents. Moreover, increasing openness affects the relatives and other close ones as it is also felt important that they are taken into consideration when discussing the disease since it influences the way they approach the parent and since a family member's falling ill with cancer may be thought to affect all of them.

A part of the spiritual growing of the family is *realising the uniqueness of health*. The manner of taking health for granted is withdrawn and replaced by the understanding of cherishing health. By detaching from the disease, the family members feel joy of life due to the fact that the parent is able to go on with his/her life in the same way as before and therefore, they appreciate life in quite a new manner.

Understanding another person who has undergone the same and increasing sensitivity towards the respective condition of the parent constitute *increasing empathy* which is characteristic of the spiritual growing of the family members during the disease. Here, the family members discover that, *e.g.*, attentiveness has increased among them. A closely related issue is *learning humility* that consists of acceptance towards disposal of the axioms related to life and alterations of stable life, even towards the possibility that they may suffer a relapse. Additionally, *assuming a more relaxed attitude towards life* is involved in the spiritual growing occurring during the disease in, *e.g.*, attitudes towards issues related to job and raising the children.

*Searching for the purpose of being ill* is also linked to the process of spiritual growing launched in the family through the event of a family member falling ill. Growing through a disease is very burdensome and involves a number of disconsolate questions such as: why did this happen to the family and what meaning or value could the suffering have. Searching for the purpose of being ill is highlighted when one detaches oneself from the disease since only life turning difficult makes one see what is truly valuable in life. The spouse recalled the searching for the purpose of being ill during his wife's disease as follows:

*"This kind of things, well, I don't think it's a coincidence that causes them. This teaches us a lesson in life, the meaning of which I don't get or understand yet at this point, but I will some day."* 6.1.10.

## Reinforcing Self-esteem

Reinforcing self-esteem is connected with the evolving of the concept of self (Appendix 12) which is characterised in *re-planning life*. The family becomes more courageous in making plans on a perhaps longer term and in reorienting, *e.g.*, spending the free time studying or in hobbies, which promote detaching from the disease. Success in *managing in everyday life* leads to reinforcing self-esteem among the family members. When the parent strives for, *e.g.*, coping with household work within the limits of his/her condition, or when the spouse or children succeed in completing tasks formerly unfamiliar or more demanding to them, the joy of succeeding introduces reinforcing self-esteem. In addition, *realising a dream* and accomplishing a change that has been in planning for a long time support the reinforcing self-esteem. For instance, the family may make the trip or the purchase for which they have been planning. As one of the spouses described it:

*"This kind of thing is always... when you make your dream come true, no matter how desperate the survival seems or you feel that you won't be here much longer and that's it, and then you do something you've been dreaming of your whole life."* 8.1.29.

### 5.2.4 Progressing of Recovery

Progressing of recovery is, in a way, a turning point towards better in the process of detaching from the disease for the parent and his/her family, as it consists of feelings and actions associated to *becoming motivated in self care, increasing of treatment satisfaction, restoring the zest of life and facilitating of life* in the family with (Table 9, Appendix 13). When the family members take care of the parent and promote his/her recovery, the treatment satisfaction increases, which in turn contributes to restoring the zest of life and thus facilitating the life of the family. The active nature of the family and a positive attitude in treating the ill family member and a feeling of meaningful life promote the patient's feeling of recovery and detaching from the disease. At the same time, facilitating of life amidst the disease appears more and more real. Progressing of recovery is included in the stabilising of life and it interconnects both with facing difficulties in a life-embracing manner and with assuming a positive attitude towards the future.

## Becoming Motivated in Self Care

Becoming motivated in self care (Appendix 13) is an essential part of the progressing of recovery and it is characterised by *appreciating the treatment* of the parent with cancer in the family. It involves motivation from the patient in participating in his/her own treatment and encouraging from the family for him/her to do so. Although undergoing exhausting treatment occupies the minds of the patient and his/her family members, appreciating the treatment is more

significant than giving up the treatment. Receiving treatment is considered fundamentally important and the family emphasises the importance of exact complying with the treatment plan.

Becoming motivated in self care strives towards *avoiding exertion*, which renders possible the continuation of the treatment. During the treatment period, it is required that the patient concentrates on his/her own volition on avoiding exertion and that the family members are willing to help and support him/her. To become motivated towards *tending to side-effects* ensures that the side-effects do not hinder the treatment from progressing as planned. Therefore, e.g., guaranteeing normal mobility for the hand after a breast cancer operation, treating the reddening of skin in connection with radiation therapy and treating fatigue and nausea are familiar to patients with cancer and their families. In addition, emphasising mental coping and stability in becoming motivated in tending to the side-effects make the patient feel more at ease and facilitate living with the side-effects. Patients with cancer and their families are also familiar with *comparing forms of treatment* which facilitates the proportioning of side-effects to each other and adapting to them. For some patients, radiation therapy is easier than cytostatic treatment whereas some people feel that radiation therapy as exhausting and that cytostatic treatment hardly causes them side-effects.

Characteristic for becoming motivated in self care is also *taking care of the personal well-being* of the patient during and after the treatment, which means that all family members take part in promoting the recovery of the patient. This means, e.g., organising possibilities for the patient to rest during his/her recovery period and doing household work on his/her behalf. One couple reflected on the ways on taking care of the personal well-being of the wife as follows:

*Husband: "Well, with that (remodelling) we had suddenly this situation that the radiators were torn off and everything was... We had to finish it; otherwise it would have been a disaster... It was taken care of. The autumn was coming and we had to install the isolation and everything... the summer taught us to... take care of things... They will sort themselves out when you take them one by one and when you don't take in too big a chunk at one time. This applies also to the cancer... if it reoccurs or spreads."*

*Wife with concert: "You had a clear plan, remember. You wrote down everything: what next and after that and so on. Come to think of it, I had a sort of a plan too: I take these three things: walks outdoors, rest and nourishment. Those are the things I can do. And then I've read quite a lot of these [books about] how one can enhance one's own well-being." 5.2.14.*

Moreover, taking care of the personal well-being comprises the patient taking the responsibility for his/her own recovery and pondering what would be the best way to promote one's own recovery. Taking care of the personal well-being may come forth after the treatment as a mental gathering of oneself and relaxing.

## **Increasing of Treatment Satisfaction**

Increasing of treatment satisfaction (Appendix 13), the properties of which include *consoling in the early diagnosis of the disease*, is linked to the progressing of recovery in the family. The family members' feelings of relief

when they find about the small size or the early discovery of the tumour leads to the increasing of treatment satisfaction. A closely related issue is *being aware of the importance of screenings* which is manifested in satisfaction about the availability of screenings and about participating in them.

*Consoling in the immediate starting of treatments* also forms a part of increasing of treatment satisfaction. Immediate starting of treatments stops the progressing of the disease and speeds up the alleviating of the distress. This is important for the entire family as they are striving towards detaching themselves from the disease. It is also felt that *being relieved for receiving treatment* is important because of the fact that awareness of the patient receiving treatment alleviates the distress and facilitates the life of the family when considering the disease.

One of the properties of increasing of the treatment satisfaction is *emphasising positive treatment results* since successful treatment consoles the parent and his/her family. The progress in the patient's condition obtained through treatment emphasises the importance of treatments for the personal recovery of the parent in the minds of the parent and his/her family. Presenting positive treatment results in media promotes and enlarges the awareness among the population about the development of treatment for cancer and the various possibilities of surviving which in turn increases the general satisfaction towards treatments for cancer.

Increasing of treatment satisfaction also involves *giving positive feedback* about screenings, examinations or treatment. It is satisfaction for receiving expert treatment, polite service and personal guidance as well as dissemination of information and maintaining a supportive atmosphere towards recovery at the ward or the polyclinic. A mother who was receiving radiation therapy gave positive feedback for the personnel of the radiation therapy department:

*"In my opinion, the staff has been very nice here. We were just talking with one of the patients and s/he said that they've probably chosen these people here very carefully. Everybody is so friendly and ready to give information. Yes, in there, in the radiation therapy unit, I've received information that the doctor or anybody else hasn't given. You only see the doctor for such a short period at a time. The radiographers have clarified things for me. They take the patient well into consideration and if you've got a problem, they answer your questions."* 7.2.12.

## **Restoring the Zest of Life**

Progressing of recovery also comprises restoring the zest of life (Appendix 13) which is characterised by *improving of physical condition* of the patient. It is shown in improving health which is supported by the stabilising of the patient's condition also assessed by medical standards. *Sensing the recovery* refers to the progressing of the patient's recovery and the on-going rehabilitation perceived by the parent or the family members. Thus, it also refers to restoring the zest of life.

As the restoring the zest of life continues, the family notices that the disease has not put a stop to the lives of the family members. Instead, they are

experiencing the withdrawal of the disease. The family goes through the stage of *getting past of being ill* which includes the withdrawing of the disease from the everyday life of the family and perceiving the disease as a temporary stage of life. Gradually, returning to the former ways of life is felt as a relief in the family.

*Becoming interested in everyday matters* is typical for restoring the zest of life of the patients and progressing of health. Taking care of one's physical condition and becoming interested in the everyday matters of the family illustrate this as well as continuing to take care of the children, starting the work or returning to the working rhythm do. Taking charge of the everyday life, detaching through work and progressing with the help of routines signify the return of the joy of living and progress in the patient's condition. The responsibility that the parent took for his/her family before s/he was taken ill increases again. As a couple discussed taking responsibility for the family which reflects becoming interested in everyday matters:

*Husband: "It's such a heavy responsibility for the children and everything, so that in a way it's... Like my wife said: somebody has to have the strength anyway. She has managed it well."*

*Wife with cancer: "It's coming from the subconscious; it's got to be... so that you don't start to just complain. You didn't complain much for having to stay up at nights." 5.2.8.*

Furthermore, *regaining concentration skills* is involved in restoring the zest of life. After the worst phase of the disease, the patients have the energy to concentrate on the continuation of their own everyday life. *Keeping up high spirits* is a part of restoring the zest of life and progressing of recovery which promote the developing of a safe state of affairs among the parent with cancer and the family members. It also comprises the emergence of a positive attitude towards life in the family despite the difficult stage of life.

Characteristic for restoring the zest of life and progressing of the recovery is *striving to get away from the disease* which refers to the patient's active detaching from the circumstances of being ill with the support and help of the other family members. The personal and active detaching from the disease is important also for the family members. One couple described in the following way, how the wife was striving to get away from the disease:

*Husband: "Like the fact that after the operation, you started to do things too quickly and you couldn't stress your left arm much, so even that felt great that... you could see the joy of living in that, too, that now we won't let this keep us down. In your trying to do housework then already."*

*Wife with cancer: "I didn't take it, didn't want to... I've never wanted the role of a patient really. I spent three days in the hospital during the operation and then wanted for them to come and take me home. I missed the children and my own home and bed so much and I knew that I'll be completely helpless at home but as I knew that my mother-in-law will be there to help and well... something like that like 'I don't want to just lie here', so it's good for the recovery that I do the things I can. It was mentally very restorative to just do things and to stay in touch with the life at home and not bury myself in the bed or just lie in the hospital. The situation wouldn't have improved there at all." 5.1.8.*

Striving to get away from the disease may also comprise supposing that the disease is withdrawing or denying the disease which involve getting past the

disease quickly and detaching from the circumstances of the disease. After the treatments have ended, the patient might think that s/he has overcome the disease instead of taking the follow-up period and rehabilitation into consideration.

## **Facilitating of Life**

Facilitating of life (Appendix 13) is connected with progressing of recovery. One of its properties is *surviving for the sake of the close ones*, whereby the significance of family members is stressed in the detaching from the disease, and there is no room for giving in or remaining in the conditions of the disease. Emphasising family ties and seeing the value of each other as a life-facilitating factor is important for the family members since, in their opinion, surviving alone would be much more difficult.

*Getting by with support* pertains to facilitating of life and it is important for the progressing of the patient's recovery. Supporting and helping facilitate the lives of the patient and the whole family. The support received by the family helps them to go on with their lives and acts as a factor detaching them from the disease. Moreover, *comforting in talking* to close friends and relatives gives the family strength in this difficult stage of life. An example of this is the viewpoint of one couple:

*Husband: "Well, it's the knowledge and as mentioned, by talking and discussing... So by processing those kind of hard questions. It all ripens in time, for some faster and for others slower. It's that they don't ripen if you don't think about this issue and I think it's the one in our family dealing better with this who was more attending and talked more. I chop wood. There are no things you can't talk about. We haven't had to go to bed so that something is left, like, unsolved, we have started to talk about things."*

*Wife with cancer: "The knowledge and then these treatments and all this emotional support from the family, those are the essential things I've felt that have helped me the most." 3.2.13.*

### *5.2.5 Continuing the Habituated Life*

Continuing the habituated life releases the family of a parent with cancer from the circumstances of the disease and enables the detaching from the disease and the continuing of normal life. It comprises the feelings and actions related to *resuming the former life, maintaining the same relationships* and *continuing with everyday routines* in the family of the parent with cancer (Table 9, Appendix 14). When the family's life returns back to normal and when the relationships have remained the same despite the disease, the family can resume its former life even with the normal everyday routines. Resuming the former life is also manifested in the positive attitude towards life and a balanced atmosphere in the family and in the feeling of meaningful life as the family detaches itself from the disease. A persistent and life-embracing attitude from the part of the parent and the family members as well as an active way of facing of hardships connected with a hopeful and trusting attitude towards the future are characteristics of continuing

the habituated life as the life stabilises in the family that is detaching from the disease.

## **Resuming the Former Life**

Continuing the habituated life is linked with resuming the former life (Appendix 14) which is characterised by *overcoming the worst phase* of the disease. An additional quality of this is *managing to avoid loss* of the parent experienced by the family members. Resuming the former life is also facilitated by the fact that the patient suffers no visible, *e.g.*, hormonal or other late side-effects caused by the treatment, and therefore, *managing to avoid late side-effects* has taken place.

*Normalising of life* and resuming former life refer to the family members resuming their everyday lives and forgetting about the disease. Furthermore, the resuming of former life for the children is manifested in *sparing the family members from difficulties*, and the children or their lives show, *e.g.*, no signs of problems caused by the disease of the mother or the father. Below is an example of one couple and their children concerning sparing the family members from difficulties:

*Husband: "I think that the children have survived well through this like... I think it's quite important that they've not stayed home mourning their mother's severe disease. They've got hobbies and friends. They don't remember it all the time, only then when mother isn't doing so well."* 1.4.8.

*Wife with cancer: "Children have even had some squabbles – it's a sign of life resuming its normal course."* 1.4.8.

## **Maintaining the Same Relationships**

Maintaining the same relationships (Appendix 14) is closely connected with continuing the habituated life. It is distinguished by *maintaining an intimate relationship* whereby the disease has not damaged the partnership between the spouses and the patient does not feel that s/he has been rejected by the spouse. As the disease has not damaged other relationships of the family either, *maintaining the same family connections* is achieved. Thus, the patient does not feel that s/he is rejected or shunned by the family because of the disease. Maintaining the same attitudes by the children is also maintaining parenthood, whereby the disease has not changed the relationship between the children and the parent with cancer. A father with cancer reflected on maintaining the same family connections:

*"It's important when the disease strikes, no matter who is the patient, that the family supports you and contributes in things. You don't feel that you're an outcast because of this. It's still felt that you're important although you're suffering from this disease in our family. If there was a situation where you'd have to think whether you belong in the family anymore or not, that would be tough. The family is the first and foremost supporter."* 4.3.10.

Maintaining the same relationships is for the parent with cancer and his/her family also *maintaining the same attitudes by the close ones* belonging to the

immediate circle of the family, which means that friends and relatives treat them the same as before. This co-supports the detaching from the disease by the family.

### **Continuing with Everyday Routines**

Continuing with everyday routines (Appendix 14) is a part of continuing the habituated life, and it is characterised by *taking part in everyday life* by the parent and the family members. Participating in the treatment while living at home and taking part in the everyday life of the family mollify the ill parent and his/her family. Gradually, they will reattach themselves in the everyday life and *filling the life with activities* and work will take place. *Keeping life stable* for the family illustrates the stability of life which is involved in continuing the life as before. This is rendered possible if, *e.g.*, the financial situation of the family remains the same in spite of the long-time disease of one of the parents.

A parent falling severely ill is demanding for the entire family. However, it is important that *continuing the former life* is possible for each of the family members and that detaching from the disease is realised. Implementing habitual daily rhythm and, *e.g.*, resuming former hobbies are representations of continuing the former life. One couple described continuing the former life as follows:

*Wife: "It's common everyday life like in every other family. Normal life, one day at a time."*

*Husband with cancer: "Surely it's best that way, but for me it's... let's say, if I think about you and the girls, then it should be so that you don't have to ponder on this a lot but that we're leading a normal everyday life. I'm also externally trying to lead such an everyday life, when it's possible and go to work if I can, etc." 8.1.31.*

## **5.3 Fighting against the Disease in a Family of a Parent with Cancer**

Motto: *"We do not permit the disease into our lives."*

Fighting against the disease is connected to stabilising of life in a family of a parent with cancer. It is implemented in the facing of hardships and assuming an attitude towards the future. While stabilising of life refers to a life-embracing, persistent and active facing of hardships, and assuming an attitude toward the future is nevertheless negative and hopeless, anxious and fearful as well as doubtful, the family fights against the disease on the level of both feelings and actions. During the process of fighting, the life of the family stabilises so that the family members stand united in fighting against the disease and want to struggle against it. Deliberating about falling ill and rebelling against the change in life, overcoming adversities, preparing for worse and ensuring the functionality are

different stages involved in the process of psychosocial behaviour of the family fighting against the disease. (Figure 4).

<b>STABILISING OF LIFE</b>		<b>FACING OF HARDSHIPS IN THE FAMILY</b>
<b>Criteria:</b>		Life-embracing attitude Persistence Activity
<b>ASSUMING AN ATTITUDE TOWARDS THE FUTURE IN THE FAMILY</b>	Negativity Hopelessness Anxiety Fearfulness Uncertainty	<b>Fighting against the disease:</b> 1. Deliberating about falling ill 2. Rebelling against the change in life 3. Overcoming adversities 4. Preparing for worse 5. Ensuring the functionality

**Figure 4.** The process of fighting against the disease in the family of a parent with cancer.

Fighting against the disease in the family of a parent with cancer begins with *deliberating about falling ill* which is, in stabilising of life, related essentially on one hand to the persistent facing of hardships and, on the other, assuming a fearful and doubtful attitude towards the future. *Deliberating about falling ill* is immediately followed by *rebelling against the change in life*. This too is involved in a persistent and active manner of facing of hardships and assuming an anxious and fearful attitude towards the future. As fighting against the disease proceeds, the family members observe *overcoming adversities* which is an indication of the family’s strength and interconnects both with life-embracing and persistent facing of hardships and assuming a doubtful attitude towards the future. As fighting against the disease advances, the family members start to emphasise *preparing for worse* which is related to the persistent facing of hardships and assuming a fearful, doubtful and even negative attitude towards the future. *Ensuring the functionality* means that the life-embracing, persistent and active attitude shown by the parent and the family members towards facing of hardships in conjunction with occasionally negative and hopeless life filled with worries and experiences of fear and doubt in assuming an attitude towards the future belong essentially in the fighting against the disease by the family. (Figure 4, Table 10).

**Table 10.** The stages and their categories of fighting against the disease in a family with a parent with cancer.

The subcore category	The stages of the subcore category	The categories of the stages of the subcore category
Fighting against the disease	1. Deliberating about falling ill	Becoming confused by the disease Seeking for reasons for falling ill
	2. Rebellling against the change in life	Deliberating about the life becoming more difficult Criticising the treatment
	3. Overcoming adversities	Taking responsibility of one’s own treatment Creating a fighting morale Processing the worries Blocking out the disease
	4. Preparing for worse	Getting accustomed to the after-effects of the treatment Preparing for a decline in the patient’s condition
	5. Ensuring the functionality	Securing the future Bearing responsibility Protecting the close ones Rationalising the facing of disease Adopting a new way of spending time

### 5.3.1 *Deliberating about Falling Ill*

In the atmosphere of a family fighting against the disease, becoming surprised by the disease and grieving over falling ill enter into the first stage of the process of fighting against the disease. Deliberating about falling ill, which starts the fighting against the disease, comprises the emotions and actions linked to *becoming confused by the disease* and *seeking for reasons for falling ill* in the family of a parent with cancer (Table 10, Appendix 15). After the family hears about the disease, they are perplexed and start to deliberate about the disease and seek reasons for it. Then, the fearful and anxious atmosphere prevailing in the family is strengthened by the active seeking for reasons for falling ill while fighting against the disease. Deliberating about falling ill is comprised in stabilising of life in the family of a parent with cancer and relates essentially to the persistent facing of hardships and, on the other hand, to assuming a fearful and doubtful attitude towards the future.

## Becoming Confused by the Disease

Becoming confused by the disease, which is connected to deliberating about falling ill (Appendix 15), is characterised by *becoming surprised by the disease*. An acute case of falling ill with cancer, diagnosed, *e.g.*, in a screening test, causes feelings of shock and surprise in the parent and his/her family and arouses fear and anxiety. Finding out about the cancer diagnosis shocks and surprises also the people in the immediate circle of the family since cancer is still thought to be a severe disease.

Becoming confused by the disease also comprises *lacking the feeling of being ill* which is manifested even by questioning the reality of the disease. Reflecting on the feeling of having no symptoms or connecting the symptoms with the severe disease also belong to lacking the feeling of being ill.

Moreover, *assuming an uncomprehending attitude towards the disease* is also typical for becoming confused by the disease as the family is faced with a new, unexpected situation which is slow to process. Assuming an uncomprehending attitude towards the cancer is a manifestation of ignorance and helplessness from the adult's part. As for children, an uncomprehending attitude towards the disease of the parent is one way of processing the matter threatening the family as children do not fully understand the emotions and effects the disease has on the family and on the behaviour of the family members. Therefore, children express their ignorance differently. Their expressions may include, *e.g.*, wondering at the anxiety of the parents, clinging to the 'healthy' parent, seeking support from the day care staff or throwing temper tantrums at their parents. One couple described the situation of assuming an uncomprehending attitude towards the disease:

*Husband: "Children don't know how to be discreet. When they are angry, they throw a tantrum... we've boiled over sometimes, there's a sign that it's been quite rough. Sometimes you blow up."*

*Wife with cancer: "Oh yeah, only sometimes (laughter). It's been rough, a good confrontation and battle. Of course, children sense if the parents are tired or if there's something, they notice and whine even more. For example, when I started this radiation therapy, our daughter, who is three years old, didn't want to go to day care and cried there when she knew that I went to [the hospital in] Oulu and there she talked about going to miss mom. Clearly, she clung to the day care nanny. She didn't want to climb to my lap before as much as then and sought more attention. Our other daughter is five; she hasn't reacted much or expressed anything unusual, she has gone on as before. They've learned quite a lot from all this." 5.2.3.*

Falling ill with cancer is also a subject of wonder for the friends and relatives in the immediate circle of the family. An uncomprehending attitude towards the patient's disease assumed by outsiders is shown in confusion and increases the level of anxiety of the parent and his/her family.

## Seeking for Reasons for Falling Ill

Seeking for reasons for falling ill (Appendix 15) is connected to deliberating about falling ill and it is linked with fighting against the disease. Seeking for reasons for falling ill, which is characterised by *pondering on the factors causing the disease*, *grieving over falling ill* and *posing questions*, is contemplating the origin of the cancer, grieving over its appearing and searching for answers to the questions among the family as well as in the thoughts of its individual members. Pondering on the past life and tracing the cause of the disease as well as connecting them with the patient's symptoms is seeking the concrete reasons for the disease. A mother with cancer stated the following about posing questions:

*"But could it be... I was just talking about this... for example, when I got this disease, I thought that could it be that I've got an overdose of something. Could it be the fact that we were eating lots and lots of cloudberries but then you don't buy oranges and such, we don't need them as the berries have vitamin C. I started thinking that perhaps I'd treated myself too well (laughs), so that it spills over somehow. I don't know. – And the thing with our child's disease mustn't have affected mine since I think it was only one month before when they diagnosed this... so that it came so quickly in spite of the hard feelings... Then we have this thing, well, they say that grieving has an influence on you. My mother's death was rather tough for me, that really was such a thing, and my daughter-in-law's father fell ill with cancer and died during that winter. I'm a bit like that, I take other people's... that they don't have to be real close to me and I still feel bad if I hear something bad has happened to them so that I take it too close to my heart..." 2.2.7.*

### 5.3.2 *Rebelling against the Change in Life*

In the family's process of fighting against the disease, deliberating about falling ill is followed by rebelling against the change in life. In this phase, the family members gather up all their resources in order to resist the disease and to prevent it from taking the upper hand. Rebelling against the change in life involves the feelings and actions relating to *deliberating about the life becoming more difficult* and to *criticising the treatment* among the family of the parent with cancer (Table 10, Appendix 16). When deliberating about the life becoming more difficult, the family rebels against the change in life brought about by the disease and criticises the patient's treatment in order to bring about changes. Then the prevailing critical, rebellious, but also guilty, atmosphere and on the other hand, unyielding and life-embracing behaviour aiming to evict troubles prevailing within the family intertwine with the feeling of hopelessness towards the future as the family fights against the disease. Rebelling against the change in life is a part of stabilising of life and closely related to the persistent and active facing of hardships as well as to assuming an anxious and fearful attitude towards the future.

## **Deliberating about the Life Becoming More Difficult**

Deliberating about the life becoming more difficult (Appendix 16) is linked with rebelling against the change in life. Its properties are *envying health* and *struggling against falling ill*. It is the expression of resistance within the family, during which accepting the disease is experienced as completely impossible. Reasoning “Why me?” is to some extent rebelling against becoming ill and searching for answers to explain why one has been “screened out” or become one of the diseased. Furthermore, the reasoning of the family seeks to explain why their family member became ill. One father with cancer described the situation as follows:

“Yes... *the children are now, the other of them has moved out, so that with them, now that this was found out, we talked and probably even cried together, that how can it be... why me?*”  
8.1.9.

Moreover, *doubting one’s own decisions* and *feeling guilty about falling ill* is characteristic of deliberating about the life becoming more difficult. The family members’ considerations may comprise questioning the decisions made and blaming the chosen ways of living as well as feeling guilty over the family’s life becoming more difficult that follows. Even the children can experience guilt over their parent’s disease. Deliberating about the life becoming more difficult can also be feeling guilty over the fact that the patient has not sought care early enough or that the others have not urged him/her to seek care. On the other hand, the family members feel that they have not paid enough attention to the changes in the patient’s condition, or may even feel that they themselves have caused the patient’s disease. This can also include doubting other self-inflicted decisions, such as smoking or the chosen diet.

## **Criticising the Treatment**

Criticising the treatment (Appendix 16) is interrelated with rebelling against the change in life that is manifested in the family’s behaviour of fighting against the disease. Questioning the necessity of treatment is characteristic of criticising the treatment. It involves perceiving the treatment as unnecessary because the patient feels that s/he has no symptoms or because s/he does not notice the alleviating effects of the treatment. Moreover, it comprises frustration towards the receiving of treatment when the side-effects arise, as well as being suspicious about its effectiveness.

One part of criticising the treatment is *criticising the timing of the treatment* when the family ponders whether the treatment should have been begun earlier. *Criticising the chosen line of treatment*, on the other hand, involves the parent and his/her family becoming worried about the suitability, adequacy or effectiveness of the chosen methods of treatment. Another characteristic of criticising the treatment is *expressing wishes for changes in the treatment*. In this situation, the patient expresses wishes and proposals for improvement regarding his/her treatment. The patient may criticise the lack of private doctors in special

health care, wish for the help of a support person already in the early phase of the disease or demand a more active approach from the health care personnel to discuss matters relating to being ill also in basic health care. Furthermore, *criticising the actions of the health care personnel* comprises criticising the treatment. The criticism can focus on providing information about the disease or the treatment, on impolite discussions or on the manner of presenting the diagnosis.

Criticising the treatment comprises also *complaining about the lack of complementary therapy*. The patient criticises the shortcomings in his/her treatment, e.g., that not enough attention is paid to diet therapies or that therapies complementing conventional treatments are not used. For instance, a father with cancer complained about the lack of alternative diet therapies:

“...when I lost over ten kilos, at the hospital they wrote down every day what I ate and ate only a half potato and kept losing weight, and they just wrote down that he had eaten or hadn't eaten almost anything, and yet nobody did anything... I asked them once, wasn't anybody really concerned about the fact that I'm running out of building blocks. This disease consumes really much and everything, but not in there... If you ask, you get painkillers immediately, you get sleeping pills immediately, but if you ask, if you could get some vitamin pills or something, it's impossible.” 8.1.2.

### 5.3.3 Overcoming Adversities

Overcoming adversities is an expression of the family's strength in the process of fighting against the disease in a family of a parent with cancer. It comprises feelings and actions relating to *taking responsibility of one's own treatment, creating a fighting morale, processing the worries and blocking out the disease* (Table 10, Appendix 17). When the family takes responsibility of the patient's treatment and creates fighting morale, the family members keep up the overcoming of adversities by processing their worries and by dispelling the feeling of disease among them. In this stage, the family overcomes the feelings of hopelessness with their own activity as they fight the disease. Overcoming adversities is included in the stabilising of life and is linked both with the life-embracing and persistent manner of confronting adversities as well as with assuming a doubtful attitude towards the future.

### **Taking Responsibility of One's Own Treatment**

Taking responsibility of one's own treatment (Appendix 17) is characteristically connected to the overcoming of adversities, and it is active fighting against the disease by the parent and his/her family. It is characterised by *acting in the limits of endurance* when the ill parent and the members of the family use the accustomed methods of treatment or medication on the patient's terms at discretion in order to improve his/her condition. Another significant characteristic of taking responsibility of one's own treatment is *seeking different*

*treatment alternatives* and taking part in the treatment in order to find different factors facilitating the condition of the patient. In the following, a father with cancer describes finding different treatment alternatives for his own treatment:

*“I spent a lot of time in the hospital at that time, when it was... the cytostatics made my health very poorly and otherwise, but no, they just looked that a-ha, mister has lost another kilogram weight, haven't you eaten anything today, but nobody noted that at all. I could probably have lost weight till I weighted 40 kilos, had I not looked for the solution. Of course, treating this disease is my own responsibility, and you can't make the doctor or the family or any friends or relatives responsible for it, you have to take a personal responsibility and take care of yourself. If you leave it and wait for something to happen, you probably are worse off.” 8.1.3.*

Taking responsibility of one's own treatment is also characterised by *turning to complementary therapy* which is adopting an open attitude towards all complementary therapy against cancer and using them without reservations. The ill parent and the family members aim to find relief and effects facilitating the condition of the patient from, for example, alternative hormone replacement therapy, diet therapy or trace element treatments.

## **Creating a Fighting Morale**

Creating a fighting morale among the family intertwines with the overcoming of adversities, which in turn is connected to fighting against the disease (Appendix 17). It is characterised by *clarifying the common goal* and pursuing it within the family because reaching this common objective relating, *e.g.*, to the children or to other things perceived as important is experienced essential in the fight against the disease. A couple described clarifying of the common goal as follows:

*Wife with cancer: “Yes, we have to, now we have to. Now it's no longer about our choices, whether we make it or not. We must make it. So this kind of a thought.”*

*Husband: “That's it.”*

*Wife with cancer: “That's it”*

*Husband: “There aren't really any other possibilities. We have to fight, it may sound a bit naïve, that to fight, but... what should... we have two sweet kids and yet everything is like, we have no other alternative.” 5.1.12.*

Creating a fighting morale is also characterised by *inspiring togetherness* and in *maintaining the unity* of the family. They involve understanding the seriousness of the situation and combining the resources in order to overcome the disease since the fight against the disease requires a great deal of unified and persistent activity by the family. Moreover, *wishing for an understanding and helpful attitude* from the family members helps the patient in his/her personal battle against the disease as adopting an evasive and fearful attitude towards the patient would only worsen the situation.

## **Processing the Worries**

Processing the worries (Appendix 17) is another aspect in the overcoming of adversities and fighting against the disease. It involves *hoping for another*

*diagnosis*, in other words, thinking that the disease may not be cancer after all. It is one of the methods of processing the worries, hoping to the last possible chance that the manifested symptoms are not related to a malignant disease. On the other hand, *blocking the bad news in advance* is to some extent processing the worries. In this case, people avoid grieving the possible future troubles and thinking about the disease taking a turn for the worse or the effects of treatment. By blocking the possible future grievances in advance, the parent and his/her family members aim to spare themselves and to lead a full life in spite of the disease. Processing the worries also comprises *erasing problems independently*, in which case the family members process the worries in different ways. For instance, enjoying the surrounding nature and reviving in the nature contribute to processing the worries. Furthermore, withdrawing into privacy and deliberating about difficulties are among the means used in the overcoming of adversities. A mother with cancer aimed to erase problems independently in the following manner:

*“I don’t think that it’s the right approach to put off all these worries right away, they then remain unprocessed in the background, but I should process them at least to a certain point, until I notice that I have made them too big or they get smaller as I work on them and become solved. But when should one process these worries. Just this walking and being in the fresh air. That’s for me... just walking along, that’s a good time to think about things in peace. I’ve read somewhere that that can help change thoughts. Discussing with others about these issues, with people with similar experiences, or with otherwise understanding people who are interested in one’s situation. They exactly are these ways to repel, to take part and go, and then there is something else than just the private circles. I was also thinking that what would it have been like if I had arranged to spend the nights here. They told me, that here is a kind of residential home, or to go with the option to come from home. I think that coming over from home treatments is definitely better, and I can continue with my normal life. In no occasion is it good to turn into a hermit and remain grieving by oneself. I still have some good friends, acquaintances who don’t know about this, and I haven’t told them. Should I really tell everyone in the first place. If the matter comes up naturally, perhaps then. You aren’t necessarily organising press conferences on all own diseases or other things.” 3.2.5.*

## **Blocking out the Disease**

Blocking out the disease (Appendix 17) is linked with the overcoming of adversities and closely related to the family’s behaviour of fighting against the disease. One of its properties is *appreciating the certainty of healing*. When the family wants to fight the disease and to block it out, it feels that it is important that the healing is being ascertained by monitoring and by seeking medical treatment, when necessary. They feel that living without the feeling of disease between the follow-up visits is extremely important, and aim to achieve that by consciously blocking out the thoughts about being ill of the family members’ minds. Furthermore, *blocking out the possibility of the disease recurring* is an important indication of blocking out the disease. The family is determined to believe that the disease has been overcome and that it will not return to their life.

*Preventing the disease from taking the upper hand, e.g., by reviving in work, enjoying the company of other people, or by focusing in one's own everyday life, is blocking out the disease among the family. The family does not let the disease to control their lives; instead, it is determinedly blocking the adversities attributable to the disease. The following is an example of one couple's aims to prevent the disease from taking the upper hand:*

*Wife with cancer: "You just have to start talking about it and then... I don't know if it's been some sort of depression about this thing, but I have so many different thoughts going through my mind that I have really tried to force myself away from all the worrying and to read books and to take up other activities and to talk with people, so that they could get me to think about something else."*

*Husband: "It's been the same for me, that I have repelled these worries by chopping a lot of firewood or by skiing or running. If you start thinking about the same thing too much, you must change to a different wave length or push the delete button." 3.1.7.*

#### **5.3.4 Preparing for Worse**

In the process of fighting against the disease, people prepare themselves, despite of overcoming many adversities, for the after-effects of treatments and for the deterioration of the patient's present condition. Preparing for worse involves feelings and actions in the family of the parent with cancer relating to *getting accustomed to the after-effects of the treatments* and to *preparing for a decline in the patient's condition* (Table 10, Appendix 18). When the family is preparing itself to the after-effects of the treatments, it is simultaneously preparing for worse by anticipating a decline in the patient's condition. In the fight against the disease, this is manifested in a feeling of anxiety in spite of active and life-embracing actions. Preparing for worse is included in the stabilising of life, and it is connected to the persistent facing of adversities as well as to assuming a fearful, doubtful and even negative attitude towards the future.

#### **Getting Accustomed to the After-effects of the Treatments**

Getting accustomed to the after-effects of the treatments (Appendix 18) ties in with preparing for worse and fighting against the disease. One of the properties of getting accustomed to the after-effects of the treatments is *becoming conscious of hormonal changes* when the patient is aware of the changes in his/her system caused by the late effects of cytostatic treatments and hormone treatments, among others. For example, the family members are preparing themselves in advance to live with factors such as disorders in the menstrual cycle, the expression of menopausal symptoms, childlessness or the manifestation of mood disorders. A husband with cancer described:

*"They told me when I left this ward in the beginning of August with my skin troubles, for the first time they disclosed that I will be impotent. I haven't really wanted to give in to the doctors, like, it can't be true, but they insisted that this will happen. When I've been to the urologist, it*

*doesn't really look like that now, but of course it might happen as life goes on. The doctor at the cancer ward told me that it will happen. And, like, in the urology ward the urologist said that it is possible, the treatment has been so intense that the testicles have suffered a lot. In the same evening we discussed the matters. We cried a bit, hoped for the best that it wouldn't happen. We talked about it, at home there was some tension and getting used to the idea, after I had first seen the urologist."* 4.2.14.

*Getting accustomed to incapacitation* involves getting accustomed to the physical after-effects of the treatments. Whether it is a question of getting accustomed to the condition resulting, *e.g.*, from a stoma operation or from an amputation, the family needs to remember that surgical care does not alter the parent's personality. Getting accustomed to the physical after-effects of the treatments comprises also *adapting to the changes in self-image*. The changing of the self-image both physically and mentally and the body becoming unfamiliar due to treatments require adaptation that demands special resources and support from the family *eg.* in getting used to the loss of hair and in wearing a wig in connection with cytostatic treatment.

## **Preparing for a Decline in the Patient's Condition**

Preparing for a decline in the patient's condition (Appendix 18) is interrelated to preparing for worse. It is characterised by *anticipating mental collapse*. After acknowledging the possible future changes in mental balance, the family is more capable of preparing for it and fighting for the well-being of the ill parent.

Another property of preparing for a decline in the patient's condition is *foreseeing the failing of health* during which taking care of the patient's general condition and increasing the bodily resources are essential factors in the fight against the disease. However, the family does not forget the realities because all members of the family are *realising the recurrence possibility of the disease*, which in turn refers to foreseeing the failing of health. Accordingly, a mother with cancer described:

*"I have somehow started to perceive this like so that this is just an disease from which I will recover and life will go on. There always is a little devil lurking in the background whispering that what if the cancer recurs, and what if it will appear in the other breast and such. You can't do anything about it. You'll have to start all over again. I'm sure it will be all right. Everything is possible."* 3.2.19.

### **5.3.5 Ensuring the Functionality**

Ensuring the functionality enables the parent's and his/her family's fight against the disease. It involves feelings and actions in the family of the parent with cancer relating to *securing the future, bearing responsibility* for the family, *protecting the close ones, rationalising the facing of disease* and *adopting a new way of spending time* (Table 10, Appendix 19). The family members are ensuring the functionality during the parent's disease by aiming in different ways

to secure the future. Moreover, they aim to bear the responsibility about each other, protect each other from the negative effects of the disease, rationalise their attitude towards the disease as well as adopt a new way of spending time. The life-embracing, persistent and active attitude shown by the parent and the family members towards facing of hardships, occasionally combined with negative and hopeless life filled with worries and experiences of fear and doubt in assuming an attitude towards the future, are features of ensuring the functionality as the life becomes more stable in the family fighting against the disease.

## **Securing the Future**

One of the aspects in ensuring the functionality is securing the future (Appendix 19). It is characterised by *combining treatments, childcare and work* with the objective of continuing treatments according to the plan. Ensuring the functionality is also manifested in *emphasising the coping of the children* because being the object of the parents' love and care is important especially regarding the children's feeling of safety. The parents may consider supporting the children in a new situation brought on by the disease even more significant than their own recovery. In addition to small children, children on the threshold of adulthood require special attention since the parent's becoming ill coincides with their own development phase. Moreover, securing the future includes *worrying over the children's lives*, even if the patient's condition deteriorates or s/he succumbs to the disease.

Among the properties of securing the future of the family is *preparing for the death of the patient*, as life is not necessarily taken for granted. It comprises taking into account the possibility of losing the parent and acknowledging the imminence of death in conversations between the family members or reacting to the actual fear of death as well as thinking about death even if it does not feel topical. As a mother with cancer described:

*"When you think about the kids, like, we've had to go over this matter a lot with our kids because I have changed externally and the children have through that... we've had had to talk these matters over with them. They have... at first we really talked about it a lot that what this is. Then we've talked about death too. The older one is in the age that he has been thinking a lot about death. He's been wanting honestly to know what the situation is."* 6.2.3.

## **Bearing Responsibility**

Bearing responsibility for the family (Appendix 19) is linked with ensuring the functionality and fighting against the disease. During the disease, *caring for the coping of the family members* means bearing responsibility for each other amongst the family. This is vital for ensuring the functionality in a situation where one of the parents is critically ill and where especially taking care of the children's coping and welfare is the responsibility of both of the parents. In this stage, the objective of the parents is to avoid, for instance, burdening the children with grieves and responsibilities as well as with caring for their siblings and

housework. Moreover, burdening the children might impair the mental well-being of the parent. *The helped turning into the helper* means that the ill parent bears responsibility for the coping of the spouse and the managing of the children during the disease. Indeed, comforting and supporting the spouse and the children changes the parent's role from the helped to the helper. *Preventing the anxiety of the family members* also comprises bearing responsibility for the family because the anxiety of parents or children hinders the functionality of the family in a difficult situation. In the following, a mother with cancer describes her means to prevent the anxiety of her spouse:

*"With us, it might be that I feel... I have told that we've had sleepless nights and stuff like that but then again I've noticed that he gets so distressed that I've spoken about these things with someone else. In a way, I've tried to spare you so that you can continue this everyday life. I've talked with my girlfriends about these feelings and sentiments... and with workmates and so on, what it feels like... because they don't live with it the whole time, like my husband lives with me every day. If he gets really anxious, what will come of this, then we'll be both sick."* 5.3.8.

Bearing responsibility for the family comprises also *providing for the family*. Providing for the family's economy is essential in bearing responsibility for the family and in fighting against the disease. Long sick-leaves may exacerbate the family's economic situation and, therefore, feeling economical responsibility is a part of ensuring the functionality. For instance, in an entrepreneur family, providing information for other family members and transferring the company know-how to others ensure economic well-being as well as the continuity of work or of the company.

## **Protecting the Close Ones**

Protecting the close ones (Appendix 19) is connected with ensuring the functionality and is part of the family's behaviour of fighting against the disease. Protecting the close ones involves *avoiding complaining*, avoiding the mutual deploring among the family members and being careful about creating a complaining atmosphere. Instead, the family consciously aims to create an atmosphere of fighting against the disease. Furthermore, *sparing the family members from emotional upset* is protecting the close ones, which is important in terms of ensuring the functionality. Relatives are spared by, for example, avoiding burdening the patient's elderly parents by telling them about the falling ill of their child in an alarming manner. Instead of burdening the close ones or making them sad, they are looked for support and encouragement in the family's fight against the disease. *Keeping the disease secret*, which is characteristic of protecting the close ones, supports the family in going on with their lives. Avoiding talking about the disease with people outside the family's intimate circles is necessary amongst both the parents and the children because sparing the patient himself/herself as well as the other family members from expressions of horror at the cancer diagnosis is perceived important. This means preventing outsiders interfering in the family's internal matters. Keeping the disease secret comprises protecting the close ones and it is part of ensuring the functionality, in

which case both others and oneself are spared. The objective of keeping the disease secret and keeping silent about the disease is to spare the family members and especially the children from the disadvantages of being ill. A mother with cancer justified keeping the disease secret as follows:

*“It worries me that how are the children coping with the questioning from outsiders. I’d like to add that the family would survive with as few scars as possible, my husband, the children and the relatives. This has been such a matter that it has shaken the entire family.” 1.2.5.*

Moreover, *refusing pity* and especially sparing the family from the outsiders’ excessive sympathy characterise protecting the close ones. On one hand, people outside the family and the children’s friends are perceived as important outlets for feelings, but on the other hand, lamentation from outsiders is not accepted. The family may experience the continuous questioning or repeated expressions of sympathy awkward. Furthermore, the family members do not need understanding as such, but natural interaction with their friends as before. Protecting the close ones also comprises dispelling self-pity since excessive sympathy would hamper the functionality of the family, and therefore the family members combine their resources in order to prevent that.

## **Rationalising the Facing of Disease**

Rationalising the facing of disease (Appendix 19) is interlinked with ensuring the functionality and fighting against the disease, in which case, *focusing on the essentials* and *avoiding to think about falling ill* are typical of the atmosphere within the family. The family members aim to focus on the essentials of their lives and to prevent thinking about the causes for the disease from dominating over their lives. Moreover, the spouses aim not to begin deliberating profoundly about factors relating to the disease amongst themselves. Concentrating on everyday life, reinforcing the unity of the family and drawing upon the realities in resisting the disease are perceived more important than falling back on emotional outbursts. A couple told about their avoiding of thinking in depth about falling ill:

*Wife with cancer: “Have we really talked much with each other, like it’s been more of the everyday conversations that now the leukocytes were down again and they can’t give treatments, or something like this. So that what I’ve read somewhere like people cry together and such, we haven’t actually had anything like that.”*

*Husband: “Crying.”*

*Wife with cancer: “Yes, crying. I don’t know if we’re somehow less emotional. We’ve lived this time one day at a time, so that we haven’t started thinking anything like that. Like it was said in the beginning, we must overcome it and take one day at a time, and so we have lived all this time.”*

*Husband: “There’s no denying that this has been a mechanical project, a treatment at a time, now we do this, like, see to it that next we do this and that. An emotional level, or whatever it is, like, we get through this with cold calculation, get this over with. Like we could of course cry together, but what would it be like in a family with children if we both started crying...” 5.2.7.*

One objective of the family is preventing the fear of death, which is characteristic of rationalising the facing of the disease. This is required in ensuring the functionality as well as in reinforcing the feeling of overcoming the disease. When fear of death does not become too dominant in the lives of the family members, the situation is more bearable and the healing feels more real.

## **Adopting a New Way of Spending Time**

Adopting a new way of spending time (Appendix 19) is linked with ensuring the functionality, which means reinforcing the family in its difficult condition as it fights the disease. One of its properties is *altering the family members' participation in everyday life*, in which case the family members bear or share responsibilities in a new way for different tasks amongst the family, such as housework or gardening. For instance, the spouse takes part in the everyday life of the family by doing more housework than before or by taking care of the children. In the following, a couple describes how they have changed their participation in everyday life:

*Wife with cancer: "There's that, that now... our lives have changed. Like, previously, I had experienced that I was the one mainly taking care of the children, who feeds them, puts them to bed and takes care of the normal stuff, but now in June, my husband has lulled them to sleep, put them to bed, so that these habitual routines, ways of doing things around the house, are quite different. The husband does a lot more of housework because he has to."*

*Husband: "I kind of have to (laughs)."*

*Wife with cancer: "Have to, yes, yes. But I think it's good. The kids feel now much closer to you, in really a different way. The younger one, when he wakes up at night, he might cry mommy but then he cries daddy. That's quite illustrative that a child, two years old, cries for daddy at night." 5.1.10.*

*Increasing co-operation* forms a part of adopting a new way of spending time. It means ensuring the functionality by working together as the family fights against the disease. Increasing co-operation comprises, for instance, sharing housework among all family members in order to prevent it piling up on the same persons. Simultaneously, it comprises increasing the parent's taking part in the chores of the family as his/her strength permits and reviving by being together. Moreover, *giving time for the family members* is considered a part of adopting a new way of spending time. It comprises increasing the time family members spend together. For example, the spouse spends more time at home with the children, instead of at work, when the patient takes treatments or the spouse reserves more time for the family when the patient is recovering from the fatigue caused by treatment. The children stand united and possibly spend more time with each other. For older children who are becoming adults, giving time can mean returning to the sphere of the childhood home and "standing up for each other".

## 5.4 Adjusting to Life with the Disease in a Family of a Parent with Cancer

Motto: “*We will manage with the disease.*”

Adjusting to life with the disease is linked with stabilising of life in a family of a parent with cancer, and it is realised in facing of hardships and assuming an attitude towards the future. When stabilising of life entails the powerless, dejected and passive facing of hardships, but the manner of assuming an attitude towards the future is positive, hopeful, meaningful, balanced and trusting, the family is adjusting to life with the disease on the level of both feelings and actions. During the process of adjusting, the life of the family stabilises through learning to live with the changes in life brought about by the disease. Adjusting to life with the disease is manifested in the lives of the parent and his/her family as a process of psychosocial behaviour that begins with clarifying of facts and continues through resorting to help, returning to life and intensifying of togetherness to maturing through hardships. (Figure 5).

<b>STABILISING OF LIFE</b>		<b>FACING OF HARDSHIPS IN THE FAMILY</b>
<b>Criteria:</b>		Powerlessness Dejection Passivity
		<b>Adjusting to life with the disease:</b> 1. Clarifying of facts 2. Resorting to help 3. Returning to life 4. Intensifying of togetherness 5. Maturing through hardships
<b>ASSUMING AN ATTITUDE TOWARDS THE FUTURE IN THE FAMILY</b>	Positiveness Hopefulness Meaningfulness Balancedness Trust	

**Figure 5.** The process of adjusting to life with the disease in the family of a parent with cancer.

Adjusting to life with the disease in the family of a parent with cancer begins with *clarifying of facts*, which is linked with both the powerless facing of hardships and assuming a cautiously balanced and trusting attitude towards the future. In the stabilising of life of the parent and his/her family, the clarifying of facts is immediately followed by *resorting to help*. It is linked, on one hand, with facing of hardships powerlessly and passively, and on the other, with assuming a hopeful and trusting attitude towards the future. *Returning to life* is an essential phase of adjusting to life with the disease, during which the family realises that

living with the disease is possible. It is connected to both facing of hardships in a dejected manner as well as assuming a positive and balanced attitude towards the future. Moreover, *intensifying of togetherness* is linked with facing hardships to some extent in a powerless manner. However, it also includes assuming a balanced and trusting attitude towards the future. The occasional feeling of powerlessness, dejection and passivity experienced by the parent with cancer and his/her family, as well as, on the other hand, perceiving life meaningful when assuming an attitude towards the future are essential features of *maturing through hardships* as the family adjusts to life with the disease. (Figure 5, Table 11).

**Table 11.** The stages and their categories of adjusting to life in a family with a parent with cancer.

Subcore category	Stages of the subcore category	Categories of the stages of the subcore category
Adjusting to life with disease the disease	1. Clarifying of facts	Becoming clear of the nature of the Living in realities
	2. Resorting to help	Feeling relieved for human contacts Leaning on the philosophy of life Gathering up the family's resources Calming down due to professional help
	3. Returning to life	Accustoming to changes in life Being perplexed by the ending of the treatment Attaching to the present Processing being ill
	4. Intensifying of togetherness	Strengthening of the intimate relationship Unifying of the family Coming closer of the immediate circle
	5. Maturing through hardships	Maintaining the equilibrium Looking after oneself Accepting the circumstances

#### 5.4.1 Clarifying of Facts

Clarifying of facts begins the process of adjusting to life with the disease in the family of the parent with cancer. In this phase, assuming a serious attitude

towards treatment and realising the limited scope of future are central features of the family's atmosphere. Clarifying of facts comprises feelings and actions relating to *becoming clear of the nature of the disease* and *living in realities* in the family with cancer (Table 11, Appendix 20). When the nature of the cancer becomes clear, the facts relating to the disease are clarified and the family starts to live according to the realities brought about by the disease. At first, the atmosphere in the family is dejected, but little by little, the family members begin to act according to the situation as they adjust to life with the disease. In the family of the parent with cancer, clarifying of facts is included in stabilising of life, and on the other hand, it is connected to the powerless facing of hardships and assuming a cautiously balanced and trusting attitude towards the future.

## **Becoming Clear of the Nature of the Disease**

The family is adjusting to life with the disease, whereby becoming clear of the nature of the disease (Appendix 20) is interlinked with clarifying of facts. Due to the insidious nature of the disease, it is characterised by *taking the treatment seriously*. Assuming an attitude towards falling ill with cancer is not superficial; instead, facing the disease demands special resources from the family members. Trusting in expert knowledge, appreciating different types of treatment and following the given treatment instructions conscientiously are prevalent among the family. The patient is motivated in undergoing the tough and lengthy treatment process which is a self-evident fact also to his/her family members. For example, everyone is prepared for postponing a family holiday or changing the family's other plans on grounds of one family member's treatment. Accommodating the family's everyday life takes place according to the demands of the disease.

*Investing in bravery* is essential in becoming clear of the nature of the disease because the increasing of bravery enhances the family members' tolerance and facilitates bearing the circumstances of being ill. Moreover, the fact that the parent and his/her family members notice in themselves *becoming serious in face of disease* is characteristic of becoming clear of the true nature of the disease. Falling ill brings about the family members' getting concerned, and in a way, it causes the life in other respects coming to a standstill. As the facts have clarified, the family stops to think about what really is happening. A spouse described becoming serious in face of his wife's falling ill in the following manner:

*"On the other hand, it is bothering that people talk about it too optimistically or say something like 'it'll be okay.' They too should say that it should be taken seriously and in some way to compose oneself with it. Everyone has their own way to deal with the disease and... Well, it's been a shadow on us the whole summer. Now we're monitoring the situation again."* 5.1.2.

## **Living in Realities**

Living in realities (Appendix 20) is connected with clarifying of facts. After becoming clear of the nature of the disease, the family members see that it is best

to learn to live with it. *Conforming to the disease* is characteristic of such a realistic attitude towards life whereby falling ill is perceived as a fact belonging to life. Understanding the paralysing effect of the disease is, in that case, a positive matter. Although the family is dealing with a serious disease, it may perceive falling ill also as “becoming hardened”, in the positive sense. For instance, in a family, the members of which have been healthy before and have thought that life can continue forever unchanged, taking the limited and unforeseeable nature of life into account has come up concretely due to the disease.

Moreover, living in realities entails *acknowledging the limited scope of future*. Waning of the patient’s resources and abating of will to live unavoidably give occasion to anticipating the scarcity of shared time left. Furthermore, the patient him/herself may have a realistic view on his/her own destiny and on the facts related to being ill. Having doubts about returning to work or recuperating give cause for hopes in terms of spending the remainder of the family’s time together. Below are thoughts of a father with cancer regarding the results of acknowledging the limited scope of future:

*“We did this deal with the kids when we sat down and talked about it that we’re not trying to change our normal life very much. For my part, on no account do I want to become some centre of attention, that people start to worry too much because I think that, like, I’m not so used to that. I’m just used to be an equal member of our family and so on, so we want our situation to change as little as possible. Of course, if I can’t do something, if I’m so ill, so I can’t do something in that sense, then in that case, it’s quite normal that someone can help me out. That, like in this everyday life, the change wouldn’t be such, like if I started to think about what should I do now, what should I do. Of course, my wife is really worried, and I too have bad days, like, what could my wife do and so on. I guess she’d like to do as much as possible but you can’t give any concrete advise, it’s like just bustle.” 8.1.9.*

*Living according to the situation* is characteristic of living in realities because the clarifying of facts relating to the disease points out the most suitable alternatives for continuing life. Taking the situation into account is, in a way, like the family’s central line of action as it is adjusting to life with the disease. For outsiders, falling ill of a family member may feel oppressing but within the family itself, the family members are assuming as realistic an attitude towards it as possible. The family realises that this is now the situation according to which they must live. Instead of not dealing with even the most difficult issues brought about by the disease, proportioning the shared resources according to them is essential.

Living in realities also includes *being annoyed at excessive optimism*, which means longing for assuming an unforced and fact-based attitude towards being ill among the family. The disease causes continuous feeling of fear in the family members, and therefore, all information concerning the disease is taken seriously. Tiring of too much optimism is possible, and in being ill, not even the drawbacks of the disease are ignored. Excessive optimism is perceived as diverging since being aware of the fact that a serious disease is unpredictable is a reality among the family members.

*Reserving time for adjusting* is characteristic of living in realities, and it is manifested in the fact that the situation met by the family is kept from outsiders. Treating the subject in conversations among the family is important, and talking with the children about being ill is open and increases the sense of security. Thereby, the disease turning in their minds to something more threatening and frightening than it is may be prevented. Gradually, increasing of openness is possible and being ill will be discussed with others outside the family. Making the disease public is relieving for both the parents and the children since the support and help from the immediate circle resulting from openness facilitate adjusting to the disease and living with it. In the following, a spouse describes reserving time for adjusting to his wife's being ill:

*"I for one think it was important that we managed to keep this information secret from outsiders until the wife got through the operation, and only then it sort of became public. In a way, we ourselves had time to get used to it and know what was going on." 1.1.1.*

### 5.4.2 *Resorting to Help*

In the family's process of adjusting to life with the disease, clarifying of facts is followed by resorting to help, during which the family members seek to find relief to their difficult situation. Resorting to help comprises feelings and actions relating to *feeling relieved for human contacts, leaning on the philosophy of life, gathering up the family's resources* and *calming down due to professional help* in the family of the parent with cancer (Table 11, Appendix 21). The family members experience that they find relief not only in contacts to others close to them or in their philosophy of life, but also in resorting to the individual resources and relying on the expertise of various professionals. In this phase, despite the prevalent anxious atmosphere within the family, the family members aim to overcome the feeling of powerlessness prevailing among them as they are adjusting to life with the disease. Resorting to help is included in stabilising of life in the family of the parent with cancer. It is connected, on one hand, to the powerless and passive facing of hardships, but on the other hand, also to assuming a hopeful and trusting attitude towards the future.

#### **Feeling Relieved for Human Contacts**

Feeling relieved for human contacts (Appendix 21) that is linked with resorting to help is an aspect of adjusting to life with the disease. In the family, it is characterised by *receiving help*. The ill parent may perceive being the receiver of help as a new, valuable thing in his/her life. Bearing responsibility for his/her tasks in the family and enabling rest or recovering from the treatment are priceless help from the family members for the ill parent. However, receiving help may be difficult for the patient who has been a responsible helper and provider in the family before. Receiving help is also supportive for the entire family since they receive help from outsiders or professional assistance provided

by the society, and are feeling relieved for human contacts when they are living in the circumstances of being ill. Moreover, this entails receiving help offered by the immediate circle of the family. In addition to relatives and friends, this group may include personal relationships established through work. Resorting to help provided by the immediate circle, *e.g.*, while going through the most difficult phase or when needing concrete help, is processing of concerns in the life of the parent with cancer and his/her family. Help from friends or neighbours is essential, and the practical assistance provided by them is felt irreplaceable. A mother with cancer recounted the following about her being the receiver of help:

*“Of course, we’d never like to be, or at least I’m such a person that I wouldn’t like to be the one who has to receive help or even to ask for it. Like, for me, it has been in that way a lesson, like it wouldn’t be so bad to be in the role of the receiver of help. We can’t determine our lives. It has to be sometimes our role, having to receive help. Naturally, it isn’t easy.”* 6.3.7.

Feeling relieved for human contacts is expressed also in *cheering up through friendship* felt by the family members. Experiencing true friendship is a significant help for the family, and relying on it makes it easier for the family members to live with the disease. The internal relationships among the family do not necessarily suffice while adjusting to being ill, and therefore, relaxing with friends is perceived as a factor having a bracing effect on life.

Furthermore, *feeling encouraged by fellow sufferers* is characteristic of feeling relieved for human contacts. Finding strength in peer support and encouragement is perceived by the family as an important help when living with the disease. Empirical information provided by other patients and support persons and, *e.g.*, making good use of adaptation training facilitate adjusting to life with the disease. Information on and experiences about suffering from cancer provided by fellow patients are significant resources for the families as they are living in a new situation.

## **Leaning on the Philosophy of Life**

Leaning on the philosophy of life (Appendix 21) is interlinked with resorting to help. It is characterised by *relying on faith* that is more marked in families emphasising religion as they are adjusting to life with the disease. Relying on God’s help is an alleviating factor in the situation of being ill, and the disease is considered as something given by God, as are the treatments and help. Relying on faith means also turning to prayers and receiving help from God since finding consolation and help in praying is important for the ill parent and his/her family members. Moreover, being aware of praying for the parent and his/her family is perceived as a facilitating factor when life with the disease continues. Praying for the parent is viewed as caring and looking after him/her, as well as something creating hope.

Leaning on the philosophy of life involves also *conversing with higher powers*, whereby reciprocal asking for help and receiving it ease the lives of the parent and his/her family members. A father with cancer described this as follows:

“Well, it’s basically about asking, and you can ask for many things and things for many people and things for others than yourself. Like I said, that I have experienced that I bear responsibility for my falling ill, and even if I know that God can cure me if he so wishes as he probably has done. He has given me evidence, like, I went there yesterday and that it has probably spread in my head, and then, well, there was nothing, so I said that hey, thanks a lot. This was yet another clear sign that... Like this sort of things, like I, of course, hope that there wouldn’t be anything but if you think, like, what if there is something, He would give good instructions and support and energy for me to carry on with the treatments, and I’ll do anything. So that sort of praying, I think it’s more like a conversation. Dialogue, I think, like I see it that way that I get certain answers.” 8.1.18.

## **Gathering up the Family’s Resources**

Gathering up the family’s resources (Appendix 21), which is connected to resorting to help, is characterised by *leaning on individual strengths*. Living with the disease is facilitated by leaning on factors concerning personality and characteristics, roles and organisational skills or educational background. Finding help in leaning on family members’ strengths is a factor facilitating life as the family is adjusting to being ill. Facing of hardships with dashing humour is one example of leaning on family members’ individual strengths. For instance, making good use of the cheerful and energetic characters of family members as the family’s resource helps, for its part, them in their difficult situation. A mother with cancer gave the following example of using humour that is one of her family’s strengths:

“Yes (laughs). We’ve been laughing about it, like because I’ve been operated everywhere, they have opened my leg and my stomach and taken my breast, they’ll probably open up my head next and see what’s wrong in there.” 6.1.11.

*Laying stress on empathy* that is characteristic of gathering up the family’s resources means taking care of one another and gathering the family together in order to render helping each other and learning to live with the disease possible. Furthermore, *striving for the unity of the family* gives the family strength and energy for overcoming the adversities. Banding together, avoiding arguments and keeping the atmosphere calm are examples of striving for the unity of the family.

## **Calming Down Due to Professional Help**

Calming down due to professional help (Appendix 21) is interlinked with resorting to help, which contributes to the family’s living with the disease. It is characterised by *trusting in knowledge*, and it means appreciating the work of the health care professionals or, *e.g.*, that when a family member notices symptoms s/he can rely on receiving competent help when turning to public health services. Furthermore, it entails calming down due to medical information, which alleviates the family members’ anxiety about the disease since knowing about existing effectual treatments abates the feeling of fear among the family. Being

informed of treatment results encourages the family members. Information about being able to continue life with the disease is good news to the parent. Trusting in professional help as well as in the competence and skilfulness of the health care professionals helps and calms down the family as they are adjusting to life with the disease. This was explained by a husband with cancer as follows:

*“Like, if someone falls ill, then he would at least get realistic information that this isn’t the end of life at least right away, that I’ve struggled on for over ten years. I’ve recovered from melanoma, like, you never know if even... and for once experience something else than cancer... (laughs).” 8.1.14.*

*Negotiating about the treatments* is characteristic of calming down due to professional help when the patient or his/her family members feel better when conversing with the health care professionals about either the new treatments or other factors concerning treatment. Moreover, *finding relief in reasoning* is a part of calming down due to professional help. The family finds help in thinking based on deliberating and seeking different facts, such as speculating about the quality of the treatment, the skills of the professionals or the surviving possibilities of the parent, as well as reading relevant literature and meditating.

### *5.4.3 Returning to Life*

Returning to life is an essential phase in the parent’s and his/her family’s process of adjusting to life with the disease, whereby the family members feel concretely that living with the disease is possible. Returning to life comprises feelings and actions related to *accustoming to changes in life, being perplexed by the ending of treatment, attaching to the present* and *processing being ill* in the family of the parent with cancer (Table 11, Appendix 22). As the family is accustoming to changes in life, the family members begin returning to life by means of being perplexed by the ending of treatment, attaching to the present and processing being ill. Thereby, the atmosphere in the family is hopeful and the feelings towards the future are trusting as the family members are adjusting to life with the disease. Returning to life is included in stabilising of life, and it is linked both with the dejected facing of hardships as well as with assuming a positive and balanced attitude towards the future.

### **Accustoming to Changes in Life**

Accustoming to changes in life brought about by falling ill (Appendix 22) is essentially interrelated to returning to life and adjusting to life with the disease. Habituating to changes in life, caused either by the disease itself or by its influences in the everyday life of the family members, requires *accepting the emerging of hardships* and contributes to the family getting on with their life. This is illustrated by a spouse’s view during his wife’s being ill:

*“There is always something bothering us. Of course, it keeps us on our toes. That’s the truth. Like, this thing is a lesson...” 6.1.7.*

Moreover, *experiencing the fluctuating of feelings* is characteristic of accustoming to changes in life. Even if the family step by step learns to manage with the disease, fluctuating of feelings from one extremity to another is usual in their everyday life. Changing of feelings of dejection into hopefulness and balancedness into anxiety is possible.

The family members find that life will not be the same, in which case *processing the changing of everyday life* is inevitable and characteristic of accustoming to changes in life. Changing of life that takes place during the course of being ill and that can be noticed in the mental atmosphere of the family gives cause for processing the changing of everyday life. For instance, altering the family members' own plans, focusing on the treatments, rearranging of the family's shared free time due to time required for recovering from the treatments, changing of the children's situations and changing of matters concerning working set demands on accustoming to changes in life. Furthermore, emerging of hardships is an indication of changing of everyday life in comparison with the former life.

### **Being Perplexed by the Ending of Treatment**

Connected to returning to life, being perplexed by the ending of treatment (Appendix 22) means learning to live again and adjusting to life with the disease. Ending of the treatment period is an important goal for the family in the process of being ill. Being perplexed by its ending is characterised by *becoming exhausted of the treatments*, which is the most important feeling among the family when the long-term daily treatment that has possibly caused side effects is about to be over. Ending of the treatment period and losing contact with the health care professionals create *experiencing insecurity*, which perplexes the family members. Despite the feeling of insecurity, *receiving a new life* for its part causes confusing, even if it increases satisfaction and joy in the family. A mother with cancer depicted her feeling of receiving a new life in the following manner:

“So, that’s because [I thought] just today, like, great, I get to have a holiday and get some rest. When the cytostatic treatment ended and I started to recover little by little, and then there was this radiation therapy coming and likewise now I have this weird feeling that... at times, my feelings vary from one extremity to another. At times, I feel like crying and then there is... my goodness, I feel like I’ve been given a new life, a new possibility now, to have been through such a thing and I’ve been to such treatments. I feel almost euphoric, like wonderful that I live, here and now.” 5.2.8.

### **Attaching to the Present**

Attaching to the present (Appendix 22), which is interlinked with returning to life, is characterised by living in the present day. It is a way of life tried and trusted by the family as the facts are clarifying and they are living with the disease since learning of being ill and returning to life takes place little by little

and living one day at a time. Living in the moment offers a possibility to see other dimensions in life besides the disease. A mother with cancer described living in the present day with the following example:

*“Well, I have noticed it, that I’ve learned and view things differently... like living here and now so... why worry about tomorrow, you have to learn it to be able to enjoy today. And, of course, you can’t change the past, it’s past and gone and now we’re moving on again. I’ve had these treatments and such, so my husband has well taken care of things at home and cooked meals, like the practical side is taken care of.”* 5.2.9.

Attaching to the present involves also *ignoring the disease*. In this case, a kind of alternating between remembering the disease and forgetting it is the atmosphere prevalent within the family. The everyday life of the family members is filled with adjusting to being ill and performing the daily functions relating to the family’s environment. Furthermore, setting goals for the future does not extend beyond tomorrow; instead, *striving for tomorrow* is the family members’ most important objective and a sign of living in the present.

Attaching to the present is characterised by *acting like a robot*. It is characteristic of the family members’ returning to life, which entails living in the present and getting through everyday routines, such as taking the children to day care, doing homework or taking care of the necessary housework without wasting too much energy on the tasks. Attaching to the present and following everyday routines establish a feeling of life remaining relatively similar when compared to times prior to the disease.

Attaching to the present means also *proceeding from treatment to treatment* and building the entire family’s life around the parent’s treatments and follow-up examinations. Receiving the treatments and fitting the family’s daily functions in with the parent’s treatments become the family’s way of life. Measuring time by using proceeding from treatment to treatment and dating different events to periods taking place either before the beginning of treatments or after their ending is typical of returning to life.

### **Processing Being Ill**

Processing being ill (Appendix 22) is connected to returning to life and the family’s adjusting to life with the disease. One of its properties is time-consuming *processing the reputation of the disease* since cancer is still considered an incurable disease. However, suffering from cancer involves negative attitudes. Processing is individual for each family member and takes place characteristically for each of them in that way that they nevertheless gradually reach equilibrium in the situation the family has encountered. Accustoming to the adverse reputation of cancer and overcoming the cancer diagnosis requires deliberating. Although the disease in question is a curable one, in the family members’ minds it is notorious and unpredictable. Therefore, suffering from the disease requires processing.

*Receiving the facts* is an element of processing being ill because hearing and discussing facts related to the disease and its treatment is difficult. However, the

family members' objective is assuming a realistic attitude towards the facts, not as much exaggerating them or underestimating their significance since it facilitates returning back to life and adjusting to life with the disease. A spouse depicted receiving the facts during his wife's suffering from the disease as follows:

*"Naturally, I hope that all goes well but I just have to learn to take the things as they come... although it's hard, very hard."* 6.1.10.

Additionally, processing being ill involves *comparing with fellow sufferers*. It means drawing a parallel between the family's own situation and those of fellow sufferers' families. For example, the family may find that there are several other families with similar disease, or that many have it even worse and even they have survived. Comparing with fellow patients means also realising that the health of patients who have succumbed to the disease may have been initially worse than that of their own family member. Clarifying one's own situation by deliberating about other patients' and families' conditions brings about learning of being ill and returning to life. The family thinks that the situation could be even worse.

Moreover, processing being ill is characterised by *monitoring the recuperating*, which involves meticulously paying attention to the gradual progressing of the healing process. Recovering little by little, varying of good and bad days or prevailing of the feeling of disease are subjects of monitoring the recuperating, and observing them is processing being ill among the family.

#### 5.4.4 Intensifying of Togetherness

As life is stabilising, the feeling of togetherness among the family is deepening with the process of adjusting to life with the disease. Intensifying of togetherness comprises feelings and actions relating to *strengthening of the intimate relationship, unifying of the family and coming closer of the immediate circle* in the family of the parent with cancer (Table 11, Appendix 23). Suffering from a disease strengthens togetherness both by strengthening the intimate relationship and unifying the family, as well as by bringing their immediate circle closer to them. Thereby, in the family's atmosphere, signs of hopefulness, but also helplessness may be detected as the family members are adjusting to life with the disease. Intensifying of togetherness is included in stabilising of life and connected to both the powerless facing of hardships and, nevertheless, assuming a balanced and trusting attitude towards future.

### **Strengthening of the Intimate Relationship**

Strengthening of the intimate relationship (Appendix 23) is linked with intensifying of the family's togetherness. It is characterised by *showing affection*, which is experiencing thoughtfulness and intimacy as well as showing tenderness. As the intimate relationship strengthens, the spouses do not avoid

talking with each other about even the most difficult issues caused by the disease. Discussing confusing matters that burden the relationship and processing falling ill together is necessary since feelings showing affection and caring dispel suspicions and fears caused by suffering from the disease that threaten the relationship.

Moreover, a characteristic of strengthening of the intimate relationship, *deliberating about the changes regarding sexuality* of the patient strengthens the togetherness between spouses because the effects of, *e.g.*, a breast removal or a post-treatment drop in the hormonal level of the patient's sexuality occupies the spouses' minds. Changes caused by the treatments may influence the patient's self-esteem and evoke insecurity concerning the endurance of the intimate relationship. Therefore, strengthening it by means of deliberating about the changes regarding sexuality is necessary.

Further, strengthening of the intimate relationship involves *deepening of love* between the spouses. The disease and its treatments change the patient or the spouse but the intimate relationship is noticed to strengthen since deepening of love in the course of being ill is a cohesive force in the intimate relationship. Deepening of love between the spouses is manifested in many ways that make it possible for the patient to convince him/herself of his/her spouse's feelings despite the changes caused by the disease and its treatments. Deepening of love includes also the spouses' committing themselves to each other and to their family despite the difficult disease that they have encountered. Strengthening of the intimate relationship enhances the feeling of togetherness and facilitates adjusting to life with the disease. A husband described deepening of love in his intimate relationship as follows:

*"It's of course one field, but in my mind, if you care about someone, like, if caring is based on what the person looks like, I think it's on a rather shaky ground because everyone of us gets older anyway and that caring should be based on something deeper, on what kind of character one has and everything... it's a terribly big... I can't now even list all the things that caring is really based on. If the other person has such features that are now impaired, whether it happens because of the disease or something, this appearance, well, it hasn't changed what's within, what love should really be based on. Indeed, it would show quite soon. My wife had long and thick hair that came down to her behind. If my love had been based on her hair life would be on shaky ground now. In my mind, it's not."* 6.2.13.

## **Unifying of the Family**

Unifying of the family (Appendix 23) is interrelated to intensifying of togetherness and adjusting to life with the disease. It is characterised by *strengthening of family ties*, which involves spurring the patient in recovering and perceiving recovering, in a way, as the family's common project, living focused on the children or being emphasised of the meaning of family. The family supports the patient amidst being ill, and suffering from the disease strengthens the togetherness between parents and children. Responsibility for caring is on the entire family or it is shared among the family members so that

also the children can each in his/her own way pay attention to the patient's well-being in the family. In addition, intensifying of togetherness is manifested in decreasing of disagreements in the family in comparison with previous or in avoiding causing them intentionally. A mother with cancer told the following about strengthening of family ties:

*"Yes, and they follow my going to the examinations always. It looks like they sigh with relief every time I get positive feedback that there's nothing to worry about. Sure enough, it's been a shared project, like we haven't kept it a secret from any family member."* 7.3.9.

*Adjusting to a way of life* is characteristic of intensifying of togetherness, in which case the family members adjust themselves to the changed situation in their life. It means introducing a new way of life among the different family members and adjusting to the changes caused by a parent's falling ill. *Harmonising decision-making* is a positive aspect of suffering from a disease. It leads to unifying of the family, which may be valued also afterwards. Harmonising decision-making involves deliberating together about the requirements of a new situation brought about by the disease and finding new solutions for the best of the entire family. Strengthening of unity means pulling together and feeling that the family is stronger than before in face of external threats.

### **Coming Closer of the Immediate Circle**

Also coming closer of the immediate circle (Appendix 23) is connected to intensifying of togetherness. It is characterised by *restoring the former situation*, whereby the family's friends and relatives and the children's playmates, in a way, bring the family messages from the life and surroundings outside of being ill and, at the same time, give rise to intensifying of togetherness with the family's prior life and facilitate returning to life. Furthermore, *giving assistance* is displaying such empathy that brings about coming closer of the immediate circle and extending the intensifying of togetherness also to the immediate circle of the parent with cancer and his/her family. Relatives and friends want to help the family, in which situation, *e.g.*, the grandparents take part in childcare, the mother-in-law comes to do the housework during the parent's operation or relatives take care of the farm work. In the family feeling powerless, giving assistance is perceived as relationships coming closer and, therefore, as something positive resulting from being ill.

*Showing attention* among the relatives means coming closer of the relatives in the immediate circle of the family as one of its members is suffering from a disease. The fact that a relative has encountered a serious disease is invoking feelings of sympathy among the relatives, and the family perceives inquiries about the parent's condition as caring about them. Moreover, empathy expressed by close friends illustrates coming closer of the family and its immediate circle, instead of deserting the family due to the disease. A mother with cancer gave the following example of attention showed by the immediate circle:

*“Yes, I’ve noticed that even the more distant relatives call nowadays and ask how’s it going... people with whom we haven’t really been in touch much. Indeed, on the other hand it’s warming.” 1.4.4.*

### **5.4.5 Maturing through Hardships**

Maturing through hardships enables the parent’s and his/her family’s adjusting to life with the disease. Maturing through hardships comprises feelings and actions relating to *maintaining the equilibrium*, *looking after oneself* and *accepting the circumstances* in the family of a parent with cancer (Table 11, Appendix 24). When the family maintains the equilibrium and realises the importance of looking after oneself, it matures through hardships after noticing a higher level of accepting the circumstances in comparison with the early days of suffering from the disease. Maturing through hardships is manifested within the family both as noticing the hardships caused by being ill and as realising the solution to them as the family is adjusting to life with the disease. The occasional powerlessness, dejection and passivity experienced by the parent and his/her family in facing of hardships and, on the other hand, considering life meaningful in terms of assuming an attitude towards the future are characteristics of maturing through hardships as the life stabilises in the family, which is adjusting to life with cancer.

### **Maintaining the Equilibrium**

Maturing through hardships is interlinked with maintaining the equilibrium (Appendix 24), which is characterised by *emphasising important issues* in the family’s life, *e.g.*, by having conversations about values of life. In addition to relieving the ill parent’s condition or ascertaining the managing of family members, eliminating unnecessary activities and focusing on the essential is central. *Striving for inner harmony* in the family’s life means maintaining the equilibrium. Suffering caused by being ill does not elevate the family members, but the parents and the children aim to find a balanced state of being in order to enable adjusting to life with the disease for their part. Balance in life helps the family members in adjusting to the changes brought about by the disease. Proportioning hardships to the positive things in life renders living with the disease in a balanced manner possible. A couple depicted their family’s striving for inner harmony as follows:

*Wife with cancer: “For me it means life.”*

*Husband: “Yes, life and that you survive, that you can enjoy the days we have. That you are able to turn as many negative things to positive as possible.”*

*Wife with cancer: “ And, on the other hand, one sees it, like, there are so many good things.”*

*Husband: “Because of this disease all negative things increase, if one scales the positive and the negative things, the balance is easier to maintain, like... if a glass is broken there’s that good thing that we can fit more stuff into the dishwasher (laughs).” 1.1.5.*

*Preparing for the future* is maintaining the equilibrium in the family and such maturing through hardships that is needed when a serious disease brings about unexpected elements of insecurity or adversities. Moreover, *understanding emotions* is, for its part, characteristic of maintaining the equilibrium and of maturing that takes place in the course of being ill among the family. The family members' spiritual growing and becoming aware of the emotions of others are, in a way, positive effects of being ill. For example, the spouse may grow spiritually along with the patient's being ill and learn to express his/her feelings in more open a manner than before.

## **Looking after Oneself**

Looking after oneself (Appendix 24) is connected to maturing through hardships. It is characterised by *cherishing health* because looking after one's physical health and well-being is now central in the everyday life of the family. For instance, being careful to avoid tiring oneself excessively by working too hard and avoiding unnecessary stress become central objectives in the family's life. *Rearranging commitments* is included in looking after oneself, and, for its part, it facilitates adjusting to life with the disease. Suffering from a disease teaches, e.g., refusing commitments outside the family and shifting confidential posts or social responsibilities to others in order to achieve the well-being of oneself and the family.

Looking after oneself includes also *appreciating recuperating* that facilitates the family's adjusting to life with a serious disease. Although suffering from a disease is difficult, the family appreciates the promoting of the patient's recovery. Therefore, e.g., participating in adaptation training courses and other comprehensive means of looking after oneself are considered important. A mother with cancer told about her appreciating of recuperating as follows:

*"I've allowed myself some luxuries and I've done needlework and played piano and I go regularly for walks, which probably I haven't done before, so this certain type of selfishness has arisen, and that's yet another way to survive."* 5.2.13.

## **Accepting the Circumstances**

Accepting the circumstances (Appendix 24) is interrelated with maturing through hardships. Despite the changing of life due to suffering from a serious disease, satisfaction and gratefulness may be seen in the family for the possibilities they still have as they continue their life together. *Rejoicing for extra time* is involved in accepting the circumstances since the family members perceive it as important that they are not suddenly losing a family member. Fighting either against the disease or as a convalescent is essential for the family members in respect of maturing through hardships that takes place along with being ill. The extra time provided by being ill offers many possibilities for the family, such as time for thinking about important issues and going through them either alone or with family members. Furthermore, *valuing life* is included in accepting the

circumstances during the course of being ill. It means respecting the remaining lifespan and living in balance with the disease, not as much waiting for recovering.

*Realising the possibilities* is a part of the family's accepting the circumstances and contributes to maturing through difficulties. Even if failing of the parent's health is inevitable, the parent's receiving help and treatments as well as relieving the pains is perceived as a possibility among the family. Losing the parent without treatment would be dramatic for the family members, and it could further exacerbate their life in a difficult situation. A spouse recounted the family's realising the possibilities as follows:

*"Well, in this situation in a way... you think about things quite differently, and now that this continuation treatment has already lasted a month after the operation. Like you have adapted and come what may, it wouldn't really be so dramatic when you think about it like what if... is a few days there and comes, like now the life ends. It is dramatic when you haven't prepared for it at all, like now we've had a month to weigh the options and get used to the idea so that you either make it and life continues happily [or you do not]. The family's been doing quite well and... but if the operation hadn't been so successful and one would have... well, died..." 1.2.5.*

## 5.5 Submitting to the Disease in a Family of a Parent with Cancer

Motto: *"The disease has remained a part of our lives."*

Submitting to the disease is connected to stabilising of life in a family of a parent with cancer. It is actualised in facing of hardships and assuming an attitude towards the future. When stabilising of life refers to the powerless, dejected and passive facing of hardships and manner of assuming an attitude towards the future is negative, hopeless, anxious, fearful and doubtful, the family submits to the disease on the level of both feelings and actions. During the process of submitting, the life of the family stabilises through attaching itself more and more strongly to the adverse reputation of the disease and the difficult circumstances the disease has brought about. Submitting to the disease becomes evident in the lives of the parent and his/her family as a process of psychosocial behaviour, which begins with life coming to a standstill and succumbing to fear and progresses through being burdened by concerns and life turning more difficult to getting caught in being ill. (Figure 6).

<b>STABILISING OF LIFE</b>		<b>FACING OF HARDSHIPS IN THE FAMILY</b>
		Powerlessness Dejection Passivity
		<b>Criteria:</b>
<b>ASSUMING AN ATTITUDE TOWARDS THE FUTURE IN THE FAMILY</b>	Negativity Hopelessness Anxiety Fearfulness Uncertainty	<b>Submitting to the disease:</b> 1. Life coming to a standstill 2. Succumbing to fear 3. Being burdened by concerns 4. Life turning more difficult 5. Getting caught in being ill

**Figure 6.** The process of submitting to the disease in the family of a parent with cancer.

Submitting to the disease in the family of the parent with cancer begins with *life coming to a standstill*, which is essentially related to the dejected manner of facing hardships and assuming a hopeless attitude towards the future. In stabilising of life, it is closely followed by *succumbing to fear*, which is also involved in the powerless facing of hardships and assuming a doubtful attitude towards the future. *Being burdened by concerns* enhances submitting to the disease and interconnects both with the passive facing of hardships and assuming an anxious attitude towards the future. *Life turning more difficult* is connected both with the powerless facing of hardships and assuming a fearful, even negative, attitude towards the future. Furthermore, the powerlessness, dejection and passivity in facing of hardships experienced by the parent and his/her family in conjunction with feelings of negativity, hopelessness, anxiety, fearfulness and doubtfulness when assuming an attitude towards the future are connected to *getting caught in being ill* as the family is submitting to the disease. (Figure 6, Table 12).

**Table 12.** The stages and their categories of submitting to the disease in a family with a parent with cancer.

The subcore category	The stages of the subcore category	The categories of the stages of the subcore category
Submitting to the disease	1. Life coming to a standstill	Being paralysed by falling ill Being appalled by the adverse reputation of the disease Being upset by the gravity of the disease
	2. Succumbing to fear	Dreading the treatments Being afraid of being ill Fearing the reactions of the immediate circle
	3. Being burdened by concerns	Realising the criticality of the condition Accumulating of hardships
	4. Life turning more difficult	Everyday life becoming burdensome Intimate relationship drifting into a crisis Family members' becoming depressed Breaking down of the immediate circle
	5. Getting caught in being ill	Staying in the shadow of the disease Becoming exhausted of the disease Submitting to the destiny Life's filling with the disease

### 5.5.1 *Life Coming to a Standstill*

Life coming to a standstill begins the process of submitting to the disease in the family of the parent with cancer, when the family members are shocked to hear about the parent falling ill and even experience feelings of panic and fear of death. Life coming to a standstill comprises feelings and actions connected to *being paralysed by falling ill*, *being appalled by the adverse reputation of the disease* and *being upset by the gravity of the disease* (Table 12, Appendix 25). When the family members, in a manner of speaking, freeze to the adverse reputation of cancer and falling ill, they feel as if their entire life is coming to a standstill due to feelings of shock caused by the grave nature of the disease.

Then, an atmosphere of giving up and surrendering prevails in the family as they submit to the disease which is especially enhanced by uncertainty about the nature of the disease and fearfulness towards it. Life coming to a standstill in the family of the parent with cancer is included in stabilising of life, and it is essentially connected with the dejected facing of hardships and assuming a hopeless attitude towards the future.

### **Being Paralysed by Falling Ill**

Being paralysed by falling ill, which is linked with life coming to a standstill, (Appendix 25) is characterised by *being shocked by falling ill* that is the first reaction from the family members upon hearing of the parent's falling ill. The situation is at its worst directly before the final moment of diagnosis when the uppermost thought in the minds of the family members concerns the nature of the tumour: is it benign or malignant. Being shocked by falling ill is repeated upon hearing the potential advancing of the disease. It is startling to hear about a person falling ill with cancer since it is felt to be an unjust disease due to its bad reputation.

*Internalising falling ill* is one of the properties of being paralysed by falling ill. It refers to assimilating to the situation of the parent first among the closest family members in order to facilitate discussing it in a wider circle, *e.g.*, with the entire family and immediate relatives. The patient may strive towards internalising his/her falling ill also by first deliberating about it in private before s/he is able to speak about it even with his/her spouse. Internalising falling ill is required in that, *e.g.*, while going to the hospital a person may feel him/herself quite healthy, upon returning s/he is, in a way, a patient "labelled" with a cancer diagnosis.

A further aspect of being paralysed by falling ill is *taking falling ill as a warning*. Perceiving falling ill as a warning of something even worse also inspires developing of positive feelings and, therefore, facilitates accepting the disease as a part of the family's life. On the other hand, freezing at falling ill, taking it as a sort of a warning, brings about alleviating of the family's shock-like situation. A father with cancer told the following about taking falling ill as a warning:

*"To say something about the disease from my viewpoint: of course since I've been healthy so far and always thought that it's alright, I'll go on the same way and that the pace shouldn't slow down, not at this point anyway. In that way, it's healthy, having to stop since when I'm planning for the future and doing things, I know how to spare myself and think while making those plans, that somebody else in the firm should be able to run the business as I'm necessarily no longer capable of being responsible for everything myself. These are sort of warnings."* 5.2.9.

### **Being Appalled by the Adverse Reputation of the Disease**

Being appalled by the adverse reputation of the disease (Appendix 25) is interlinked with life coming to a standstill, which promotes submitting to the

disease amongst the family members. Being appalled by the adverse reputation of the disease is like *hearing bad news* that one cannot believe to be true. Falling ill with cancer is such bad news that one wants to shut one's ears in order to avoid hearing about it since it is the most serious diagnosis for one's symptoms. *Keeping silent about the disease*, which is characteristic of being appalled by the adverse reputation of the disease, takes place due to the fact that telling the bad news to outsiders is perceived as difficult. Talking about the disease is regarded as crossing a high threshold, and one is reluctant to do it. The ill parent prefers keeping the disease to him/herself and avoiding talking about it to outsiders. Being appalled by the adverse reputation of the disease also entails *resenting gossiping about the disease* because the fast spreading of the knowledge among acquaintances and discussing the family's situation is felt as unpleasant.

The family's images of suffering from cancer may be very negative, so *reminiscing about the deceased among the immediate relatives* is involved in being appalled by the adverse reputation of the disease. Recalling the gravity of the disease takes place when the family reflects upon the fate of those who have succumbed to cancer in the past, whereby perishing of their own family member seems inevitable. Furthermore, being appalled by the adverse reputation of the disease includes *doubting the recovering* from cancer. Regarding recovering from cancer as impossible is still common since cancer is considered a very notorious disease. Maintaining of the negative reputation of cancer is persistent despite the availability of information about different forms of treatment. Below is the view of one spouse on doubting his wife's recovering from cancer:

*"I always had the thought, straight after the first operation, when it was all so... everything was to be in order, surely there couldn't be anything and no postoperative treatments. I've been pondering the whole time whether it can be true. I didn't, sort of, believe it, that wouldn't a thing like this..., that the cancer had disappeared... that wouldn't there still be consequences, as there were, and all the time I had this thought that it may break out again." 10.1.7.*

## **Being Upset by the Gravity of the Disease**

Being upset by the gravity of the disease (Appendix 25) is linked to life coming to a standstill, and it refers to *panicking* by the family members. Being upset by the disease and sliding into panic increase fear and anxiety in the family. A further property of being upset by the gravity of the disease is *experiencing moments of weakness*, when life drifting into a crisis and emphasising of the negative effects of the disease prevail and are felt inevitable in the family. Moreover, being upset by the gravity of the disease entails *recurrent awakening to the disease*, which means realising the disease during the process of being ill repeatedly. When the disease is diagnosed, the awakening is at its strongest. The operation phase reawakens the patient and the family members and causes recalling of the gravity of the disease. As the treatments continue, the awakening is concrete and recalling the disease is intense. During the follow-up examinations, the awakening repeatedly evokes recalling the disease and leads to profound deliberating about the disease.

Being upset by the gravity of the disease also entails *experiencing fear of death*, which is common in the life of the parent with cancer and his/her family. It is characterised by fear of death invading the discussions and dreams of the family and emerging of insomnia, as well as keeping silent about death. A clear indication of this is, *e.g.*, the children's willingness to talk about the potential death of their parent and the fears related to it. A mother with cancer used following words to describe experiencing fear of death:

*"But I've got to admit that now and again I've spent sleepless nights, like, if I start thinking about it in the evening and so on, then I may stay awake till long after midnight... it's still like... its nothing else but fear of death... a certain kind of panic and anxiety... oppressive feeling and it's not nice at all."* 5.2.6.

The parent and the family members may be *deliberating about the way to die* which is entailed in being upset by the gravity of the disease. They contemplate, *e.g.*, whether the ill parent's last moments are very painful or agonised or if s/he has to suffer some other way before death.

### 5.5.2 Succumbing to Fear

In the family's process of submitting to the disease, life coming to a standstill is followed by succumbing to fear, when different kinds of feelings of anxiety spread from one family member to another. Succumbing to fear comprises feelings and actions connected to *dreading the treatments, being afraid of being ill and fearing the reactions of the immediate circle* in the family of the parent with cancer (Table 12, Appendix 26). As dreading the different treatments spreads in the family and being ill as such is felt as a source of concerns, the family members are comprehensively overcome by fear. Then, the atmosphere in the family is dominated by a dread directed towards the disease itself, receiving treatments for it and living with it, which contributes to succumbing to fear. Succumbing to fear is involved in stabilising of life and ties in with both the powerless and dejected facing of hardships and assuming a doubtful attitude towards the future.

### **Dreading the Treatments**

Succumbing to fear includes dreading the treatments (Appendix 26). It entails *fearing the forms of treatment*, which tinges the lives of the parent and his/her family. Further factors enhancing succumbing to fear are dreading the side-effects of the treatments and their permanent effects as well as finding the taxing effect of the treatments on the patient's strength odd. Doubting the actual efficiency of the treatments contributes to arousing of fears. Dreading the treatments is also characterised by *fearing the meeting of the treatment limit*, for instance, in connection with radiation therapy and cytostatic treatment, when there is fear of reaching the maximum number of treatments before the final defeating of the disease. Furthermore, a factor peculiar to dreading the treatments

is *fearing the follow-up examinations*, which is succumbing to fear that fatigues as the follow-up examinations draw near. It may be manifested among the family members in anxiety, insomnia and nervousness. The following is an example of a wife with cancer of fearing the follow-up examinations:

*“Now, I was worried when I had stomach-ache here on the left side after the operation, in March, I thought it had spread all the way over there. I was absolutely scared. I was really scared of the ultrasound again then before the new operation. My co-worker came with me as my spouse didn’t; he thought he couldn’t take it.” 10.1.8.*

### **Being Afraid of Being Ill**

Being afraid of being ill (Appendix 26) is essentially connected with succumbing to fear and submitting to the disease since it is characterised by *anticipating the disease’s becoming aggravated*. Additionally, dreading the disease spreading or reoccurring are daily thoughts in the family of the parent with cancer. Being aware of the insidiousness of the disease and being concerned about where the disease will break out next tie in closely with their lives. *Realising the heredity of the disease* causes anxiety among the family. Intensifying of being afraid of being ill is manifested, *e.g.*, in *spreading of the feeling of fear* from one family member to another. It is expressed, *e.g.*, by children’s succumbing to fear and ensuing behaviour typical to their age. Children’s being concerned about the condition of the parent suffering from cancer and being frightened by the parents’ anxiety as well as the children assuming a fearful attitude towards their mother’s or father’s disease are indications of spreading of the feeling of fear.

Being afraid of being ill involves also *becoming stressed by fear*, which involves the manifestation of physical or mental stress symptoms caused by being ill irrespective of whether the family has prior experience of suffering from a severe disease. For the family, learning of tolerating pain appears impossible; rather, it entails succumbed by on-going stress in their life.

*Fearing mental collapsing*, which is characteristic of being afraid of being ill, is also possible when being ill becomes overwhelming. Potential mental collapsing of the parent or one of the family members is invoking fear towards being ill. A further characteristic of being afraid of being ill is *lacking confidence in recovering*, which, in the family, leads to developing and strengthening of an atmosphere that is mingled with fear. It is supported by the potential lack of results of recovering or lack of trust in them and finding the situation hopeless. A spouse reflected upon lacking confidence in recovering while his wife was ill:

*“The recovery, it’s not so concrete, [like] when you have a splinter in your finger and it’s taken off and then it’s taken care of and you see it. When you treat that kind [of a disease] with radiation therapy, then you don’t actually know what is happening there, if anything.” 7.2.2.*

### **Fearing the Reactions of the Immediate Circle**

Fearing the reactions of the immediate circle (Appendix 26) is interrelated to succumbing to fear and submitting to the disease. *Being afraid of being blamed*

entails fearing the reactions of the immediate circle; fearing the outsiders' criticism of the family or fearing the disapproving, even moralising attitudes towards the family member's falling ill. A concrete manifestation of fearing the reactions of the immediate circle is *being afraid of being rejected*. Then, the family feels fear of having to go through loneliness and isolating due to the disease. A further characteristic of fearing the reactions of the immediate circle is *being afraid of labelling* with the disease. It resembles fearing of being sentenced to death. For instance, the parents may fear that their children are being labelled with dying or losing a parent. Moreover, being afraid of labelling with the disease may include fearing of becoming embittered or being branded through cancer or, *e.g.*, of being ashamed of being ill. A father with cancer told the following:

*"It was quite odd, what I've read about this disease and talked about it, in the beginning you're ashamed of the disease. You want to hide it so that you wouldn't tell much to any outsider and you wouldn't want to discuss it with them at all."* 8.1.13.

### 5.5.3 Being Burdened by Concerns

In the family's process of submitting to the disease, succumbing to fear is followed by being burdened by concerns, whereby the disease has become a permanent burden to the life of the family members. Along with being burdened by concerns, the life of the parent and the family members becomes more difficult and stabilises in submitting to the disease. Being burdened by concerns comprises feelings and actions connected to *realising the criticality of the condition* and *accumulating of hardships* in the family of the parent with cancer (Table 12, Appendix 27). When the family becomes aware of the weakening in the parent's condition, the family members feel that concerns and hardships are nearly overwhelming. Then, powerlessness and passivity in evicting troubles and uncertainty towards the future emerge among the family. Being burdened by concerns is involved in stabilising of life and ties in with the passive facing of hardships and assuming an anxious attitude towards the future.

### **Realising the Criticality of the Condition**

Realising the criticality of the condition (Appendix 27) is interrelated with being burdened by concerns, when changing of the lives of the family members and submitting to the disease are gaining ground in the family's atmosphere. A characteristic of realising the criticality of the parent's condition is *sensing the gravity of the disease*, whereby, *e.g.*, the children are apt to recognise the concern, grief and anxiety in the mother or father. They realise the gravity of the disease and react to it. This causes changing in the atmosphere in the entire family.

Additionally, realising the criticality of the parent's condition includes *reacting strongly to the disease*, which is illustrated by the child refusing to go to

day care or his/her turning to the healthy parent, a grandparent or, *e.g.*, the private caretaker more than before as well as pining for the ill parent during the treatments. Below are the comments of one couple on sensing the gravity of the parent's disease and reacting strongly to the disease.

*Wife with cancer: "The children can definitely sense it."*

*Husband: "Of course, in the way that it's been rather hard, on the other hand, that..."*

*Wife with cancer: "And when I was having the operation, the smaller child... it was absolutely awful when they couldn't bring the child to see me in the hospital, because there was the feeling of rejection, that mommy stayed there. It was horrible to hear the screaming, so we decided to do so that I rang from the hospital and talked with both of them over the phone."*

5.1.1.

A further characteristic of realising the criticality of the parent's condition in the family and in its immediate circle is *becoming stressed by falling ill*, whereby knowledge about the disease brings about feelings of being burdened by concerns in the family. It is manifested in exhaustion and life turning meaningless. In addition to the patient's family, his/her own parents feel that their child's falling ill is difficult and stressful. The parents' feelings of stress caused by the potential fear of losing the child may emerge as feelings of heavy concern and be even greater than the actual situation of the patient would give cause for. Being concerned by the patient's parents may contribute to creating an extra load of stress for his/her family.

## **Accumulating of Hardships**

Accumulating of hardships in the family (Appendix 27) ties in with being burdened by concerns. It is characterised by *becoming concerned about the patient's condition*, which is a part of the everyday lives of both the parent him/herself and his/her close ones. Concerns about the patient's condition may vary very much in nature and connect to the family's different actions in several ways. Being concerned about changes in the patient's condition, *e.g.* an inflammation of the wound, loss of appetite and increasing fatigue is burdensome for the family. Accumulating of hardships also entails *becoming anxious about the well-being of the close ones* because becoming concerned about the children's condition or the spouse's health and the strength of all family members give food for thought for the parent him/herself as well as other family members. Moreover, another family member's falling ill or the disease showing symptoms later in others and, *e.g.*, being concerned about the children's habit of smoking trouble them. In addition to the own family, becoming anxious about the well-being of the close ones extends to other members of the immediate circle, which is exemplified in worrying about how the grandparents are getting by. Below is an example provided by a father with cancer regarding becoming anxious about the well-being of the close ones:

*"There's worrying about the child smoking and hoping that the own child would quit as there's this disease in the family. One shouldn't toy with health."* 9.3.2.

Furthermore, accumulating of hardships among the family members involves *doubting the efficiency of the treatments*, which is characteristic of being burdened by concerns and submitting to the disease. Doubting the relief brought about by the treatments adds to the accumulating of hardships in the family. Similarly, *e.g.*, transferring the patient from one hospital to another and being concerned about the efficiency of the treatment given in the new hospital adds another cause of anxiety and causes accumulating of hardships and stressing in their lives.

A further characteristic of accumulating of hardships is being concerned about work issues, which enhances life being burdened by concerns. Work issues becoming more difficult, *e.g.*, when treatments or the sick leave are prolonged or when complications arise causes worry amongst the family members. Accumulating of hardships also involves *being concerned about the economic situation* of the family, which increases the burden on the family in addition to the family member's falling ill. Increasing of the expenses caused by being ill, petering out of the earned income or, *e.g.*, paying off a large bank loan during the time of being ill may cause being concerned about the economic situation in the family.

#### *5.5.4 Life Turning More Difficult*

Life turning more difficult complicates the everyday life of the parent and his/her family members and attaches the life of the family to submitting to the disease. A part of the process of submitting to the disease, life turning more difficult comprises feelings and actions related to *everyday life becoming burdensome, intimate relationship drifting into a crisis, family members' becoming depressed and breaking down of the immediate circle* in the family of the parent with cancer (Table 12, Appendix 28). When the everyday life of the family becomes burdensome and the relationship between the parent and his/her spouse faces the crisis caused by the disease, the life of the family turns more difficult and the family members become depressed and even the entire immediate circle experiences feelings of dejection. This is manifested in the family as passivity and hopelessness as well as submitting to the disease. Life turning more difficult is involved in the stabilising of life and ties in with facing of hardships in a powerless manner as well as assuming a fearful, even negative attitude towards the future.

#### **Everyday Life Becoming Burdensome**

Everyday life becoming burdensome is interrelated with life turning more difficult for the parent and his/her family members during the course of being ill (Appendix 28). It is characterised by *receiving too much information*, whereby anxiety over the information about the disease and treating it as well as receiving that information appear overwhelming. Moreover, making one's own decisions

on different treatment alternatives seems difficult. However, little by little, returning to oral and written information about the disease is possible and internalising it may begin. Additionally, everyday life becoming burdensome entails *becoming stressed by child care* that consumes the parent's resources. During the parent's being ill, transferring the main responsibility for child care to the healthy parent may cause tiring of the latter one as well.

A further characteristic of everyday life becoming burdensome is *becoming stressed by housework*, which is influenced by the increase in participating in the housework on behalf of the family members and giving up their free time and hobbies for the benefit of the family. Moreover, looking after the siblings and taking care of their everyday life is trying for the older children. The increasing amount of work for the family members is also affected by the home care of the patient.

Furthermore, everyday life becoming burdensome is manifested in family members' *becoming impatient*, whereby their threshold of being provoked lowers. For instance, becoming tired of the children's whining, shouting at the children or even feeling hatred towards other family members are signs of lowering of the threshold of being provoked and everyday life becoming burdensome. The following is an example given by a mother with cancer of becoming impatient:

*"Yes, at our house the 'quota of shouting' is quite well covered by now." 5.2.15.*

Gossiping about the disease and becoming annoyed at the outsiders' comments tinge the life of the family, when *being annoyed at the news value of the disease* is involved in everyday life becoming burdensome and the family's life turning more difficult. Becoming exasperated over curious questions about the disease and the outsiders' wallowing in the adverse reputation of the disease, as well as fomenting the fear annoy the family members.

## **Intimate Relationship Drifting into a Crisis**

One aspect related to the life turning more difficult taking place during the parent's being ill is intimate relationship drifting into a crisis (Appendix 28), which is characterised by *ensuing of guilt* due to the falling ill of the parent. On the other hand, in addition to ensuing of guilt, the intimate relationship drifting into a crisis encompasses *owing a debt of gratitude* due to the patient's obtaining a special position through the disease since tiring in paying attention to the spouse and decreasing of one's own personal time cause the life turning more difficult for the spouses. A further factor of intimate relationship drifting into a crisis is *supporting becoming more difficult*, creating a supportive atmosphere becoming more trying and the spouses' hiding of feelings and falling silent. The following is the view of a father with cancer on supporting becoming more difficult:

*"Yes, the support from the family, it's important, but I think that if that kind of basic structure didn't already exist between the spouses, that is, having this kind of functioning, somehow satisfying, (laughs), well-functioning system already there, then I think that this kind of*

*disease can't... creating one could be terribly hard. Your eyes aren't necessarily opened to that kind of thing all of a sudden; they should've been opened already when healthy."* 8.1.12.

*Understating the symptoms* of the patient is involved in the patient's becoming stressed and intimate relationship drifting into a crisis. Understating the side-effects of the treatments, hindering the patient from resting or criticising the lacking input in housework are manifestations of an uncomprehending attitude towards the patient and encumber the intimate relationship. Further reasons for the relationship between the spouses turning difficult include the manner of thinking becoming cynical, an uncomprehending attitude towards the partner's concerns, offending each other and feeling as an outsider. This may be illustrated by the spouse assuming an understating attitude towards the disease-centred thoughts of the patient or fears with regard to the patient going through the symptoms or growing weaker without noticing the patient's depression due to the disease.

*Becoming stressed by threats* from the outsiders and having a fright at the assessment coming from the immediate circle of the family may also cause intimate relationship drifting into a crisis. Being offended at talks about rejecting the patient or leaving the family results in life turning more difficult, and the spouses experience it as an overwhelming additional problem.

Furthermore, *weakening of the patient's self-esteem* is characteristic of intimate relationship drifting into a crisis. Deliberating about the effects regarding sexuality brought about by the disease and doubting the spouse's feelings have a weakening effect on the patient's self-esteem and thereby contribute in intimate relationship drifting into a crisis. Changing of the sexual or physical body image of the patient due to operations, cytostatic and hormonal treatments and radiation therapy is taxing for him/her even if the changes caused by the disease or the treatments would not be a problem for the spouse. A wife with cancer gave the following the view on pondering on the connection between the breast removal and weakening of self-esteem:

*"Well, at first it felt like, at first I didn't think about it, but then during the autumn... It's for me, like, [an issue of] my own being as a woman and, of course, in a way, it has influenced the things between us. I've been thinking whether my man can accept me as I am."* 6.2.4.

## **Family Members' Becoming Depressed**

Family members' becoming depressed (Appendix 28) ties in with life turning more difficult. It is characterised by *being dejected by the disease* and it is manifested in the spouse's suffering from stress or the children's tiring, in addition to the fact that being ill is causing anxiety for the parent him/herself. One property of family members' becoming depressed is *becoming anxious about the disease getting the upper hand*, which includes a feeling of the disease spreading everywhere. Moreover, appearing of bad days and feelings of dejecting become familiar to the family members encumbering their lives. Then, feelings of dejecting and hopelessness are characteristic of the atmosphere in the family.

Moreover, family members' becoming depressed entails *spreading of the feeling of being ill* to all family members thus complicating their lives. Particularly in a family with a feeling of togetherness, the spreading of the feeling of being ill to all family members may be possible; therefore it is a factor causing grief to all of them. When everyone in the family feels ill, decreasing of support offered by the family members to each other and increasing of anxiety will ensue. A mother with cancer told the following about spreading of the feeling of being ill:

*"If you think about our family, we are, if I had to describe our family, [I'd say that] we're, in a way, very close, and in another way, we like to keep to ourselves, so that we are this kind of a real core family and then, like, when one part of the family has fallen ill, it's a bit like infecting the others with it as well."* 5.2.14.

### **Breaking down of the Immediate Circle**

Breaking down of the immediate circle (Appendix 28) is connected with life turning more difficult, and it entails *feeling the ruthlessness of the disease*. It involves breaking down of the immediate circle, when the relatives acknowledge the possibility of falling ill for their part as well. A feeling of the disease ruthlessly choosing its victim causes anxiety. A further factor is *losing contact* due to the close ones' resources dwindling away or due to fear and anxiety. Moreover, breaking down of the immediate circle entails *being discouraged by the disease* among the relatives. In a way, the immediate circle experiences being ill with the same cancer as the parent, which is manifested in, e.g., the grandparents' assuming a fearful attitude towards the patient and the treatment causing anxiety among them as well. The situation may also change to the patient being the supporter for his/her immediate circle and paying attention to the relatives' level of getting by becomes the responsibility of the parent and the family members, in addition to paying attention to their own strength. Here is an example of a father with cancer of being discouraged by the disease as it manifested in his mother:

*"Certainly, mother may have some spent sleepless nights worrying about these treatments and other things given to me here, like: couldn't this or that be done differently. Then, I coolly said that we've got to trust the doctor as we don't know much about these things ourselves so that it's better to remain calm, and I tried to calm her down a bit."* 4.3.11.

#### **5.5.5 Getting Caught in Being Ill**

Getting caught in being ill attaches the parent and his/her family to the circumstances of being ill and ties them to submitting to the disease. Getting caught in being ill comprises feelings and actions connected to *staying in the shadow of the disease, becoming exhausted of the disease, submitting to destiny and life's filling with the disease* in the family of the parent with cancer (Table 12, Appendix 29). When the family, in a way, cling to being ill and when the

family members grow tired, the family undergoes getting caught in being ill, when the disease takes control over the everyday life of the family members and submitting to the disease deepens. Among the family, this is manifested in life's filling with the disease. The powerlessness, dejection and passivity in facing of hardships felt by the parent and his/her family in connection with feelings of negativity, hopelessness, anxiety, fearfulness and doubtfulness in assuming an attitude towards the future are aspects of getting caught in being ill when life is stabilising in the family that is submitting to the disease.

## **Staying in the Shadow of the Disease**

Staying in the shadow of the disease (Appendix 29) ties in with getting caught in being ill. It is characterised by *endless deliberating about the reasons for falling ill* since the family members are constantly concerned about the forming and breaking out of the disease. Additionally, staying in the shadow of the disease includes *constant monitoring of the condition* of the patient, which contributes in the relentless recalling of the disease. An increasing factor is, *e.g.*, incessantly keeping an eye on the after-effects of the treatments and paying attention to them while monitoring the patient's condition. Moreover, *being disappointed at sympathy* shown by outsiders is involved in staying in the shadow of the disease. Condolences perhaps intended as a compliment instead promote getting caught in being ill, and the show of sympathy does not help the family, instead, it is perceived as an aspect reminding them of the disease. A father with cancer recounted this in the following manner:

*"I don't like those people who pat me on the back and can't talk about anything else than the disease. 'Hang in there' doesn't encourage me and I don't need any sympathy. All the time, you have to explain your disease." 12.1.3.*

## **Becoming Exhausted of the Disease**

Becoming exhausted of the disease (Appendix 29) is interlinked with getting caught in being ill, and it is characterised by *growing tired of feeling weak*, when the parent and his/her family do not feel that the parent's condition is improving despite the treatments. Furthermore, it involves *being frustrated about recovering*, when neither trusting in the information about the treatments, in the change in life nor even in one's own professional competence is helping. It is felt that the disconsolate feelings cannot be repressed. Moreover, growing tired of going to the hospital is possible.

A further factor of becoming exhausted of the disease is being *disappointed in complaining* since it seems that lamenting or grumbling by the parent or the family members is not helping them. On the contrary, constant complaining is felt to exacerbate the entire situation. *Growing tired of talking* about the disease and *avoiding others* manifest the state of exhaustion the family is going through. The family members no longer have strength to talk about the disease with anyone and growing frustrated about the support received from the immediate

circle and outsiders causes them to start avoiding others. Moreover, becoming exhausted of the disease entails *growing tired of the role of a patient*, when the immediate circle either intentionally or unintentionally remind the family members constantly about the disease and expect that the family suffer from the disease more than they do at the moment.

Further, becoming exhausted of the disease entails *deliberating about committing to the family*. The family life's turning burdensome during the patient's being ill brings up thoughts in the minds of the patient and his/her spouse about whether to leave the family or to continue committing to it. Below, this is exemplified by the view of a mother with cancer:

*"And it's true that in the situation, when the other falls ill, no matter with what kind of illness, the relationship works that way that you inevitably think about whether I really care for him/her or is it only that you're in an ecstasy of feelings or you've had a wrong image. It'll certainly be some kind of a test. In many situations, the relationship doesn't last because of this sort of thing. Then, it is always a further factor of stress in that. You really have to consider this thing as well."* 6.3.10.

## **Submitting to Destiny**

Submitting to destiny (Appendix 29) ties in with getting caught in being ill. It is characterised by *waning of mental strength*. The parent or the family members feel that all activity directed towards defeating the disease is pointless and they are afraid of becoming depressed when they notice decline in their mental strength. Furthermore, *being discouraged by a metastasis* appears to tie them to the destiny brought about by being ill, which involves lacking of resilience and manifesting of dejection or anxiousness and tearfulness. A mother with cancer described being discouraged by a metastasis as follows:

*"But now, when this metastasis appeared, now I'm feeling somehow resigned, that now I must live with this, and that's all. I admit, I'm a bit impatient. I don't have the patience to, sort of, listen about all sorts of things. Like last night about spending money, when I gave my daughter so much money, I said that now, listen, I don't have time to listen to nagging about that kind of thing and about the daughter spending, I said please, shut up."* 10.1.12.

A further property of submitting to destiny is *disappearing of self-evident facts* in life. Then, detecting the irrevocable changes in the family caused by the parent's being ill complicates the lives of all family members. Being upset by the parent's incapacity for work, weakening of the treatments' effects and waning of mental strength remove matters which before have been taken for granted. At this point, increasing of the feeling of surrendering and of fear of losing a family member seems real and inevitable. Therefore, being aware of the realities of being ill and grieving over them, as well as submitting to destiny are forcing the family to live on the disease's terms.

During the course of being ill, the parent and the family members are faced with rethinking of personal matters that have previously been axiomatic. For instance, work or hobbies are not taken for granted in the changed situation of the family. Moreover, recovering is not regarded as certain or a self-evident fact

of life. Instead, maintaining of health is paid attention to. The family may even prepare themselves for the possibility of the disease's recurring. A spouse told the following about disappearing of self-evident facts, which took place during his wife's being ill:

*"What I've concretely learned about this is that you've got to remember that health is not to be taken for granted. It's something you should be grateful for."* 6.2.11.

## **Life's Filling with the Disease**

Life's filling with the disease (Appendix 29) is linked with getting caught in being ill. It is characterised by *being trapped by the disease*. When being ill dominates the thoughts and the daily life of the parent and his/her family members, they feel that the disease is the most central thing in their life, detaching from which, even for a moment, is impossible. The family members undergo becoming tired of the disease, because being ill attracts the attention of the family completely and exhausts the family. Being ill has become a burden to the family. The following is an example given by one couple concerning being trapped by the disease:

*Husband: "It's the thing, on the other hand, when you've got, all the time... in a way, you're fed up with the cancer and treatments. It may be therapeutic in some way, but always everything's about the cancer, you're in the middle of it all the time."*

*Wife with cancer: "We're getting fed up with the whole cancer. After last summer, we've been to nowhere, visited nobody except for the appointments at the cancer ward, so that we're a bit tired of that."* 5.2.6.

Additionally, life's filling with the disease entails *losing strength*. Weakening of the condition reminds one about the unyielding nature and the power of the disease. Not only is the parent's strength weakening, but also the other family members undergo increasing of the feeling of powerlessness. Moreover, the *disease tightening its grasp* is involved in life's filling with the disease, whereby the family is faced with the disease tightening its grasp and getting caught in being ill more closely than before.

## **5.6 Summary of the theory of family survivorship**

The substantive theory of family survivorship involves families' living with a parent with cancer and consists of the process of stabilising of life which followed a shock among family members. The core category of stabilising of life with its subcore categories, detaching from the disease, fighting against the disease, adjusting to live with the disease and submitting to the disease constitute the typology of the family's psychosocial behaviour and explains the variation of behaviour in the family. Stabilising of life of a family with cancer either follows the behaviour in accordance with the subcore categories and their processes or varies between the four behavioural patterns.

The dimensions of stabilising of life, facing of hardships and assuming an attitude towards the future relate to the feelings and actions prevailing in the family. The variation of stabilising of life is manifested in the family based on different criteria depending on whether facing of hardships and the associated feelings and actions are life-embracing, persistent and active or powerless, dejected and passive, and whether assuming an attitude towards the future and the feelings and actions related to it are positive, hopeful, meaningful, balanced and trusting or negative, hopeless, anxious, fearful and doubtful.

Based on these criteria, stabilising of life through its typology makes the theory of family survivorship significant since it explains the variation of behaviour in a family with cancer which varies both in facing of hardships and assuming an attitude towards the future and may be utilised by health and social care professional in assessing the family's survivorship.

# 6 SYNTHESIZING THE RELEVANT LITERATURE ON THE SUBSTANTIVE THEORY OF THE FAMILY SURVIVORSHIP

In this chapter, I present the overview and the synthesising function of the substantive theory of family survivorship and its core category of stabilising of life with the subcore categories, detaching from the disease, fighting against the disease, adjusting to live with the disease and submitting to the disease, to literature through the constant comparison done during the phases of memo sorting and theoretical writing. Hereby, the following sections will discuss the manner in which this substantive theory (6.1) and its concepts (6.2-6.6) locate in the research related to cancer on an individual basis together with family research since cancer in one family member influences also all other family members in a family unit due to its emerged character as a family disease.

## 6.1 Family Survivorship with Cancer

### **Stabilising of Life with Cancer in a Family**

According to Cooley and Moriarty (1997), many deductive studies have identified the impact of an adult's cancer diagnosis and treatment on the functioning of the family and their importance in relation to the patient's and the family's adjustment to cancer. However, these studies have used preconceived theoretical frameworks, such as the family system theory, the circumplex model of family systems, the resiliency model of family stress, adjustment and adaptation, the social-ecological-psychological theory and a developmental model, not an inductive approach to study families living with cancer. In addition, many researchers have found that a family member's cancer diagnosis is the family's concern and affects the entire family (Cooley and Moriarty 1997, Shepard *et al.* 1999), as well as that there is a link between a patient's feelings of helplessness or hopelessness in the face of cancer and inappropriate communication among the family members (Inoue *et al.* 2003). There is also evidence that the cancer diagnosis of an adult family member is a shock to the

entire family (*cf.* Hietaranta and Jokinen 1989, Clarke-Steffen 1997, Oktay 1998, Baum 2000, Johnson 2000, Chesler and Parry 2001, Echlin and Rees 2002, Mellon 2002, Wideheim et al. 2002) and may even cause posttraumatic stress disorder (Kangas *et al.* 2002, Perry and Azad 1999) among family members.

This inductive substantive theory of family survivorship has the core category of stabilising of life as a response to the shock with two subcore categories: facing of hardships in the family and assuming an attitude towards the future in a family. This substantive theory of family survivorship and its typology of stabilising of life include some similar characters to the family survivorship model (Mellon and Northouse 2001, Mellon 2002), which has been derived from the resilience model of family stress, adjustment and adaptation according to McCubbin and McCubbin (1991, 1996) and influence the quality of life in the family with cancer. According to Mellon and Northouse's family survivorship model (2001, 2002), the illness survival stressors relate negatively to the family's understanding of cancer. These illness survival stressors include concurrent family stressors, fear of recurrence, and somatic concerns. Furthermore, family resources, such as the resoluteness of the family and social support for the family, relate positively to the family's understanding of cancer. Moreover, the family's understanding of cancer relates positively to the family's quality of life and mediates the effect of the illness survival stressors and the family resources. (Mellon and Northouse 2001, Mellon 2002.) Therefore, the family's quality of life is strongly related to facing of hardships and assuming an attitude towards the future in the family, which are the two dimensions of stabilising of life. Thus, the outcome variable of the family's quality of life in the family survivorship model by Mellon and Northouse (2001, Mellon 2002) has some similarities with this substantive theory of family survivorship and its typology of stabilising of life, although this inductive theory has its own unique and powerful character.

Families perceive stabilising of life as the core category in the substantive theory of family survivorship. Stabilising of life in a family of a parent suffering from cancer has similarities with the theory of reconstructing reality in a family of a child with recently diagnosed cancer according to Clarke-Steffen (1997). The families view reconstructing reality as creating a new normalcy while normalising their lives. During the transition of living with childhood cancer, the families are using strategies of managing the flow of information, reorganising roles, evaluating and shifting priorities, changing the future orientation, assigning meaning to the disease and managing the therapeutic regimen. (Clarke-Steffen 1997.) Hence, the character of the process is involved in reconstructing reality as well as in stabilising of life in order to continue living in the family with cancer.

Stabilising of life in a family is closely connected to normalising of life on an individual basis, as stated by Killoran *et al.* (2002), when long-term survivors of metastatic cancer attempt to normalise their lives through the process of self-transformation. It is characterised by viewing the diagnosis as insignificant; questioning the diagnosis or disbelieving the severity of disease; not worrying;

not questioning the cause for the disease; and explaining the recovery in terms of faith in medicine, spirituality and personal volition. (Killoran *et al.* 2002.) Stabilising of life is also closely related to the process of transforming personal tragedy on an individual basis through different phases identified as encountering darkness, converting darkness, encountering light, and reflecting light among breast cancer patients (Taylor 2000). The similarity between the family's stabilising of life and the individual's normalising of life through transformation is the character of the process, although stabilising of life has its own character in the typology as well.

In this research, the typology of stabilising of life consists of detaching, fighting, adjusting and submitting. The typology of stabilising of life in a family with cancer is now compared to the typology of functioning of the family during the palliative phase of cancer according to Kissane *et al.* (1994). The cohesiveness, expressiveness and conflict are the parameters in differentiating adaptive families from those coping poorly and those whose members develop psychological morbidity. The members of supportive families with high cohesiveness have a low level of psychological morbidity and function competently in the social world. Accordingly, supportive families have similarities with the families behaving in a detaching manner during stabilising of life. Supportive families as well as conflict-resolving families have low psychosocial morbidity, while ordinary families with intermediate levels of cohesion, expressiveness and conflict experience somewhat higher psychosocial morbidity. Therefore, the character of conflict-resolving and ordinary families resembles the character of families behaving in an adjusting manner during stabilising of life because their number of conflicts, differences of opinion and negative feelings is tolerable. Furthermore, hostile families with a great number of conflicts have the highest levels of psychological morbidity and poorest levels of social adjustment and have some similarities with the families behaving in a fighting manner during stabilising of life. On the other hand, sullen families having some conflicts, poor cohesion and limited expressiveness resemble the families behaving in a submitting manner during stabilising of life. (Kissane *et al.* 1994.)

### **Facing of Hardships in the Family**

Facing of hardships in the family is one of the subcore categories of stabilising of life, and its properties are life-embracing attitude, persistence and activity, or powerlessness, dejection and passivity concerning feelings and actions. This subcore category is consistent with the model of functioning of the family consisting of the mother with newly diagnosed breast cancer, her partner and young school-aged children, as stated by Lewis *et al.* (1993). According to the model, more frequently experienced demands posed by the disease are associated with higher levels of the parents' depression having a negative effect on the marriage. Moreover, when the marriage is less well-adjusted, it affects the family's coping behaviour negatively. Functioning of the household, on the other

hand, is positively affected by heightened coping activity and by higher levels of marital adjustment. Furthermore, the children are functioning better when the healthy parents interact with them more frequently and their families cope more often with their problems. (Lewis *et al.* 1993.) Therefore, facing of hardships varies according to feelings and actions in the family.

However, cancer patients with unsupportive partners may be at risk to suffer from difficulties with the cognitive processing of the cancer experience and from psychological distress (Manne and Glassman 2000). On the other hand, couples facing breast cancer also experience uncertain assessments, adjustment problems associated with the disease, and find that their marital and family functioning is greatly weakened. In addition, couples experiencing great distress or a high number of role problems at the time of diagnosis are likely to remain greatly distressed later on. (Northouse *et al.* 1998, Northouse *et al.* 2001.) Similarly, both colon cancer patients and their spouses perceive decline in their family functioning and social support, but also in emotional distress over time (Northouse *et al.* 2000). Hence, those results support this theory that facing difficulties among couples with cancer may happen powerlessly, passively and with dejection.

Ways of facing of hardships in the family as a core category of stabilising of life is also consistent with the ways children appraise and cope with their parent's cancer according to Compas *et al.* (1996). The use of emotion-focused coping efforts, and efforts to avoid thinking about the parent's cancer are related to greater symptoms of anxiety-depression. Furthermore, the use of emotion-focused coping and avoidance increase with age, suggesting that older children are employing relatively ineffective coping strategies. (Compas *et al.* 1996.) Thus, the families' stabilising of life in confronting a parent's cancer is very much related to the emotion-focused coping in addition to having its own unique character. Similarly, children and adolescents with cancer describe the experience of living with cancer as an unsettled state of mind (Yeh 2002) and are at risk to encounter some behavioural adjustment problems, particularly anxiety, somatisation, adaptability, attention, and withdrawal (Moore *et al.* 2003), which are closely related to powerlessness, passivity and dejection pertaining to feelings and actions in facing difficulties on an individual basis.

### **Assuming an Attitude towards the Future in the Family**

Assuming an attitude towards the future in the family is another subcore category of stabilising of life, and has properties such as favourableness, hopefulness, meaningfulness, balance and trust, or negativity, hopelessness, anxiety, fearfulness and doubtfulness regarding feelings and actions. The subcore category of assuming an attitude towards the future in the family is consistent with the experience of suffering of children with cancer and their families according to Woodgate and Degner (2003). The emphasising of the beliefs and expectations of these families is involved in suffering and results in ignored, unrelieved or uncontrolled cancer symptoms. Despite suffering, the children and

their families accept the symptoms as an integral part of overcoming cancer without expecting complete relief from them. (Woodgate and Degner 2003.) Consequentially, their attitudes towards the future are hopeless according to this theory of family survivorship.

Significant others experience deep unrelieved suffering when living with women with breast cancer and adopt a negative attitude towards the future. They even consider themselves prisoners of the situation involving uncertainty and powerlessness when standing by the women. Therefore, they are torn between their own suffering and their desire to alleviate the women's suffering. (Lindholm *et al.* 2002.) Moreover, the cancer patients and their spouses are both somewhat distressed when the patients' psychological distress is a consequence of the level of intrusion and the spouse's psychosocial distress and cohesion, while the spouse's distress follows intrusion, gender, and the patient's distress (Baider *et al.* 1998). Thus, couples with cancer may perceive the future in negative light. In addition, coping among couples with cancer relates to problem-focused and emotion-focused behaviour according to the dyad model of coping. Hence, patients use more strategies involving problem-focused coping than their spouses, and the dyads' emotion-focused coping is associated with the patients' distress and adjustment. (Ben-Zur *et al.* 2001.) Dyads are also searching for meaning in the disease that would lessen its threat (Germino *et al.* 1995) in order to assume either a positive or a negative attitude towards the future in the family.

Attitudes towards the future become manifested in families with cancer when mothers with metastasised breast cancer perceive relatively less maternal preoccupation in comparison with mothers with a first occurrence of non-metastasised breast cancer. Accordingly, more severely ill mothers experience less poor parenting and fewer externalised symptoms in their children compared with less severely ill mothers and their children. Furthermore, more severely ill mothers' children manage better than those of less severely ill mothers. (Sigal *et al.* 2003.) In this fashion, in the family with cancer, the severity of the disease influences the manner of assuming an attitude towards the future.

## 6.2 Detaching from Cancer in a Family

### **Maintaining Hope**

Maintaining hope is essential in detaching from cancer in the family with a family member who is suffering from cancer. Hope itself can be viewed as an emotion, an experience or a need when the distinction is made between generalised and particularised hope (Kylmä and Vehviläinen-Julkunen 1997). Hope is also regarded as a variable contributing positively to the experience of the cancer patient's quality of life (Rustøen 1995). Cancer patients may perceive hope as objective or subjective, as a burden or a resource. Additionally, it is representing an evaluation of the empirical states of affairs or the wish for the

desired outcomes and is a warrant for action or an excuse for inaction. Hope is attributed both to the patient and to the caregiver, to individuals and to situations. Moreover, it is vulnerable and enduring, as well as focused on the present or on the future. (Elliott and Olver 2002.) To a cancer patient, experiencing hope does not always mean healing or getting well physically. On the contrary, it may mean individually feeling good or better, having no pains or continuing life together with his/her immediate circle. (Lindvall 2001.) It is significant that the patient's psychological and social well-being is very much affected by pain (Sarvimäki *et al.* 2003) and pain can act as a mechanism regulating the distance and closeness among family members (Smith and Friedemann 1999). Thus, the dimensions of hope among cancer patients are not only emotional, but also goal-related, contextual, cognitive and temporal, as well as related to trust and to abandonment (Lindvall 1998). Various sources, such as religious beliefs, family, relatives, friends and relations to the hospital staff, as well as knowledge of continuing the treatment are inspiring hope in cancer patients (Lindvall 1995, 1997). Accordingly, maintaining hope allows patients and their family members to believe in something, *e.g.*, in a higher power or in their own possibilities to influence the course and the quality of their lives, which is mobilising their energy (Rustøen and Wiklund 2000). Furthermore, according to von Roenn and von Gunter (2003), setting goals to maintaining hope entails asking the patient and his/her family what they already know about the disease; exploring what they are expecting or hoping for in the future in living with the disease; suggesting realistic goals for living with the disease; responding empathically to their emotions that will arise; making a plan; and reviewing and revising the goals periodically with the family.

Maintaining hope with its category of thinking optimistically is meaningful in the family with cancer also on an individual basis. Personality characteristics, such as optimism, hope, self-esteem and resilience (Oktay 1998) relate to detaching from the cancer. Optimism associates with less delay and anxiety in seeking care as well as with expectations of desirable outcomes of seeking care (Lauver and Tak 1995). In addition, hopefulness and optimism are helpful strategies for coping with the cancer treatments (Wengström *et al.* 2001). In addition, the cancer patients' family caregivers at home (Borneman *et al.* 2002), people with a first recurrence of cancer (Herth 2000) and dying cancer patients (Yates 1993) benefit from enhancing hope as an optimistic attitude since optimism acts as a resource that may not only preserve mental health in the context of traumatic or life-threatening events but be protective of physical health as well (Taylor *et al.* 2000).

## **Living Trustingly**

Living trustingly and, especially, its category of prevailing of equilibrium are central in detaching from cancer in the family. Balance in the sense of harmony is regarded as an inner strength arising from connectedness with the family and friends, from partnership with health care professionals and reinterpretation of

the disease, and from self-reliance, which are aspects of the cancer patients' empowerment process (Mok 2001). Balancing the lives gives explanation to couples' living with a recurrent breast cancer according to Lewis and Deal (1995), and involves the processes of managing the women's everyday illness, surviving, healing and preparing for death through balancing. Moreover, it is perceived as normalising and surviving between the disease experiences and the cancer patients' disease management (Thulesius 2003), especially in end-of-life cancer care (Thulesius *et al.* 2003). Further, Cohen and Ley (2000) discovered that fear, related to a predominant reality when undergoing bone marrow transplantation, is balanced with hope for survival. Thus, decreasing fear due to fear of death, fear of unknown, loss of control, fear of discharge and fear of recurrence is balanced with increasing hope in the cancer patient's family. Moreover, balancing among survivors of thyroid cancer portends demands of cancer surveillance against day-to-day living which have a major influence on the perceptions of their quality of life (Dow *et al.* 1997). Balancing has also gains and losses with two dimensions of the quality of life versus biomedical expertise in the patients' and their families' reflections in making decisions about where best to undergo treatment (Bakker *et al.* 2001). Furthermore, patients with colorectal cancer and their relatives perceive the treatment as striking the right balance between rapid access to specialist treatment for all and good communication of bad news and test results (Bain *et al.* 2002). In addition, women with recurrent breast cancer need to balance themselves between being needed and perhaps not existing, balancing between demands, a will to be strong and allowing themselves to be ill and balancing between telling the truth and protecting the children from the truth (Billhult and Segesten 2003).

### **Changing of the Concept of Self**

Changing of the concept of self changes the family members' life in detaching from cancer in the family with a cancer patient. Spiritual growing as increasing openness is one of its categories. More open discussion within the cancer patient's family increases positive rehabilitation outcomes, such as less uncertainty, fewer negative feelings, higher self-esteem, as well as fewer psychological and physical complaints (Mesters *et al.* 1997). In addition, it increases support from family members to each other and discussion between the partners. Changing of the concept of self may be considered as a change in the self-image as a man and as a parent in the family of a male blood cancer patient. This change consists of transition in self-image, dealing with the changed role of the father, attempts to gain control and balance emotions, sharing knowledge, meeting challenges in family life, and striving for the family's well-being. (Elmberger *et al.* 2002.) Moreover, childhood cancer as a potentially life-changing experience for fathers may promote change by challenging the fathers to adopt new identities, requiring new social role behaviour, and providing the opportunity for new and different relationships with the surrounding social structures and institutions (Chesler and Parry 2001). On an individual basis, the

notion of change among women having radiation therapy involves facing the changing lifestyles and the unfamiliar clinical situations forcing changed routines. On a deeper level, the notion of change entails facing changed values and perceptions of their life patterns and perhaps radically changed views of their own mortality. (Johnson 1999.) Moreover, self-transformation as a factor in the self-esteem and the well-being of breast cancer patients may be changing their concept of self (Cohen *et al.* 1998, Carpenter *et al.* 1999).

## **Progressing of Recovery**

Progressing of recovery is a turning point towards better in the process of detaching from cancer in the family of a family member with cancer. Its category of becoming motivated in self-care is essential. According to Richardson and Ream (1997), self-care behaviours among chemotherapy patients involve modifications in activity and rest patterns, alterations of sleep-wake patterns, psychological strategies, social interventions, preservation of normalcy, nutrition interventions, relief to symptoms and comfort measures. Self-care motivation is high among women who participate in mammography screening, since they have greater benefits and health motivation, fewer barriers to screening and shorter duration of time since the last mammogram in comparison with those who do not participate in screenings at all (Holm *et al.* 1999). However, women attending the mammogram after receiving a reminder have lack of time and doubts about the necessity of screening, and the time or the place for the screening is inconvenient for them (Grönroos 2002). Not attending the screening programmes is also related to avoidance, fear, and denial (Sheikh and Ogden 1998), which are signs of low self-care motivation.

Progressing of recovery with its category of restoring the zest of life on an individual basis brings forth satisfaction with life among adults with chronic leukaemia. To these people, satisfaction with life is composed of self-esteem, interpersonal relationships, performance ability and social ability. (Berterö 1996, Berterö *et al.* 1997a.) Satisfaction with life is closely connected to the quality of life, *e.g.*, for adults with acute leukaemia. For them, satisfaction with life means having a positive attitude towards life with the dimensions of interpersonal relationships and autonomy, which have the qualities of security, support, respect, information, and conversation. (Berterö and Ek 1993, Berterö 1996.) This is important since the cancer diagnosis has psychological effects, such as stress and the reduced quality of life, in addition to behavioural compliance and changed health behaviours in terms of diet, exercising and smoking, as well as biological responses to the immune system and the endocrine system (Andersen 2002).

Progressing of recovery and its category of facilitating of life appear to be supporting each other. Support in the sense of social support may be regarded as emotional, instrumental, informational, and evaluative (Langford *et al.* 1997). Social support affects the physical health and disease by protecting the individual from the potentially harmful effects of stress (Lehto-Järnstedt 2001) and

influences positively the quality of life (Courtens *et al.* 1996). For instance, relatives' most important way of taking part in the cancer patients' care is supporting the patient emotionally instead of providing concrete care and participating in the decision-making concerning the patient's care (Eriksson and Lauri 2000b). However, cancer patients may experience problems in obtaining social support due to intense fears and stigma associated with the disease (Krishnasamy 1996).

Facilitating of life involves offering and receiving support in a family where a young adult has cancer. It is certain "family work", the nature of which comprises establishing a caring partnership; acknowledging the possibility of death; putting the disease in its place; looking towards the future; and recognising the roles of others in supporting the young adult (Lyman 1995). Furthermore, emotional support, as well as amusement, normal family life, participation, social competence, and time are essential aspects of care for siblings of children treated for cancer (Savela 2000, von Essen and Enskär 2003, Barrera *et al.* 2004). Resources of social support for children with cancer are family, other children with cancer, healthy friends, and significant adults (Ishibashi 2001), and for adults with cancer, *e.g.*, family and friends, health care personnel and fellow patients (Isaksen *et al.* 2003). Supportive marital relationship is important for the psychosocial adjustment of the couple (Foy and Rose 2001) and for the entire family with cancer (Omne-Ponten *et al.* 1995). Satisfaction with the partner's helping relationship is also associated with psychological well-being. Although women have a good helping relationship with another person, it does not compensate for a problematic helping relationship with the partner, since good communication with the partner is characterised by high empathy and low withdrawal (Pistrang and Barker 1995). However, the spouses and the family have only a minor effect on coping with cancer according to Lehto-Järnstedt (2000), since for women, the most influential sources of support are friends, whereas for men, they are acquaintances and other patients. Therefore, support among patients receiving radiation therapy, for instance, is regarded as an interpersonal process which involves encountering support, recognising support and feeling supported (Hinds and Moyer 1997).

## **Continuing the Habituated Life**

Continuing the habituated life facilitates detaching from cancer in the family. Continuing the habituated life may resemble shielding and being shielded (Hilton and Gustavson 2002) in a situation where children are aware of their mother's suffering from cancer and are at the same time very dependent of her due to their age (Hilton and Elfert 1996). The children protect themselves from their own thoughts and feelings as well as from others by shielding. Being shielded, on the other hand, is what others do in order to protect the children in the situation. Shielding and being shielded have components of knowing and

understanding, acknowledging and feeling, sharing, and shifting as well as helping. (Hilton and Gustavson 2002.)

Continuing the habituated life is like getting back to normal according to Hilton (1993). It involves taking care of the cancer by dealing with uncertainty, waiting for appointments and treatments, hearing, facing and living with the cancer diagnosis in the family. Additionally, it concerns feeling not informed, making decisions regarding the treatment, being concerned about one's health care and its provision, and accompanying the physical and the psychological effects of treatments. Moreover, getting back to normal involves resorting to functional family patterns, such as emotional response issues, family's communication patterns, family's support behaviours, major marital discords, making household arrangements and disrupted plans, shifting priorities and loss of control. Likewise, getting back to normal includes coping with other major concerns, *e.g.*, with work issues, financial concerns, health concerns of the family, concerns related to friends, and managing overload. (Hilton 1993, 1994.)

Accordingly, getting back to normal is a safe, desirable and stable state in the family with an adult cancer patient. Strategies for getting back to normal (Hilton 1996) include, *e.g.*, regarding the family as normal but dealing with a difficult situation, maintaining or returning to usual patterns as quickly as possible, minimising disruptiveness, de-emphasising, hiding, and minimising the changes and demands in the patient role, reframing negatives to be more positive and putting the cancer behind. Several factors influence the manner in which the family uses strategies in the normalisation process (Deatrick *et al.* 1999), for instance, the patient's and the family's perspectives of cancer; visibility, intrusiveness or disruptiveness of the cancer symptoms and effects of the treatment; flexibility and adaptability of the family; the family's experience with the disease; the family's life stage, as well as the congruency of the family members' views. (Hilton 1996.) On the other hand, continuing the habituated life in relationships and at work is considered as reducing the threat to identity; maintaining changes in identity; finding support in facing uncertainty and mortality; supporting a healthy identity; supporting autonomy and independence; finding support in facing isolation and overcoming stigma; finding support for sexual identity; and finding support in relationships among breast cancer patients (Lugton 1997). Therefore, the dynamics of the family's recovery after returning to normal is perceived, for example, by family caregivers after bone marrow transplantation as regaining normality, supporting the family members, facilitating life, changing the roles, burdening the caregivers and regaining life satisfaction (Boyle *et al.* 2000).

Continuing the habituated life resembles becoming ill and getting well among cancer survivors by avoiding individual blame, providing the possibility of positive influence and allowing for individual successes (Tishelman 1997). The change in the image and the experience of cancer has been dramatic during the last decade since today cancer is often curable due to early detection and effective treatments. Neither fear nor death is an automatic aspect of the cancer experience. Nowadays, the patients are better able to put the experience in

perspective with his/her everyday life as well. (Linden 1995.) Returning to normal life as soon as possible is, *e.g.*, among young people with cancer, one of their main coping strategies in addition to emotional support given by the family and belief in recovery (Kyngas *et al.* 2001), while adult cancer patients rather use the coping strategies of defending, blaming, rationalising, turning to others and taking direct action (Fitzsimmons *et al.* 1999).

## 6.3 Fighting against Cancer in a Family

### **Deliberating about Falling Ill**

Deliberating about falling ill is a primary feature of fighting against cancer in the family with a family member who is suffering from cancer. Becoming confused by the disease as a category of deliberating about falling ill may involve confronting oneself in a situation of an overall severe crisis. It manifests itself in experiencing feelings of distress, restrictions and limited or lacking support. For instance, spouses of patients with acute leukaemia and highly malignant lymphoma may confront the crisis of that kind in three different ways depending on the spouses' personal resources and on the way the spouse and the patient relate to each other. Therefore, the couple can act with contentment as a unit and independently on equal terms, or with discontentment separately with the spouse in a subordinate position. (Persson *et al.* 1998.) After observing their type of behaviour, the couple and the entire family may be helped.

Deliberating about falling ill may also manifest itself as an awareness of increased openness of women with breast cancer to their own needs and desires which is an important resource in healing and rehabilitative process. It is necessary in fighting against the disease and involves a hidden potential for health (Arman 2003, Arman and Rehnsfeldt 2002). The woman's inner struggle may be considered as moving from actions toward healthier living through renewed values and priorities in life to the existential level by finding meaning in the experience for her life and the lives of her immediate circle (Arman and Rehnsfeldt 2003).

### **Rebelling against the Change in Life**

Rebelling against the change in life involves gathering up all resources and fighting against cancer in the family. For example, transforming the exhausting-to-energising process in being a good parent in the face of cancer comprises finding the meaning and looking to the future (Elmberger *et al.* 2000) in order to be able to fight against the disease. On the other hand, the fighting spirit refers to minimising the disease (Osborne *et al.* 1999) where persistence helps. It is needed in rebelling against the change in life and in preparing for worse. Struggling to gain meaning through the uncertainty among cancer patients

consists of changes of emotions; relying on support through relationships; learning new ways of being in the world; reflections of self in the world and gaining understanding by putting uncertainty into the perspective of life (Nelson 1996), as well as, learning together with family members to live with cancer (Friesen *et al.* 2002). Searching for meaning among long-term survivors of malignant melanoma, on the other hand, consists of an identifiable cause for their cancer and a quiet reassessment of life (Dirksen 1995).

When a mother is living with life-threatening cancer, rebelling against the change in life is like struggling towards a balance between confronting her own needs and those of their family. This struggle comprises reactions and changes due to the process of diagnosis and treatment; changes in contextual issues; changes in the mother's role and relationships; communication and discussion; coping; and appraisal of support. (Fitch *et al.* 1999.) Moreover, among men with prostate cancer and their spouses, rebelling against the change in life involves a daily struggle to balance enduring uncertainty, living with the effects of treatment, coping with changes and needing help (Harden *et al.* 2002).

## **Overcoming Adversities**

Overcoming adversities is an expression of strength in fighting against cancer in the family with a cancer patient. As a category of overcoming adversities, taking responsibility of one's own treatment is evident in the patient participation in care and in decision-making which are manifested either as contributing to the decision-making or as expressing one's views on the treatment options (Sainio *et al.* 2001b). Patient participation in the decision-making is nevertheless quite passive, since patients prefer to leave the decisions to health care professionals (Juvonen and Lauri 1994). However, health care professionals play an important role in the patient participation in the decision-making (Sainio and Lauri 2003) since patients define participation in the decision-making in terms of asking questions, obtaining or providing information and choosing from or presenting different alternatives (Sainio *et al.* 2001a), while family members play an important role in the selection of the patient's doctors, treatment or even hospitals (Zhang and Siminoff 2003). Accordingly, men with prostate cancer and their partners are an example of patient participation in preferring to play an active role in the decision-making in addition to having a very active attitude toward seeking information at the time of diagnosis (Davison *et al.* 2002).

Although cancer patients have different opinions on patient participation, ranging from the immediate decision-making to receiving information, the patient's activity, good physical health and good interaction with the health care professionals seem to promote it. Then again, insufficient information, poor physical and mental health, high age, short time since diagnosis and an unsatisfactory relationship with the health professionals restrict patient participation in decision-making. (Sainio 2002.) Patient participation also involves using a broad spectrum of own activities to aid the recovery instead of leaving the treatment solely to medicine as some women do during radiation

therapy treatment according to Wengström *et al.* (2001). For instance, attitudes towards complementary therapies among patients with breast and prostate cancer vary as a way of taking responsibility of one's own treatment. Patients possibly believe that people suffering from cancer may benefit from them, although they do not think that these therapies actually cure cancer. (Salmenperä *et al.* 2001.) On the other hand, complementary therapies are chosen for providing something specific that patients cannot get in conventional care (Carlsson *et al.* 2001) in order to overcome cancer. Therefore, the use of complementary therapies may be regarded among breast cancer patients as helping relationships with others to become more valuable, improving their self-confidence and experience of strength, and enriching life (Arman *et al.* 2001) in order to help them to overcome the disease.

Creating a fighting morale as a category of overcoming adversities means a spirit of "not giving in" according to Jensen, Bäck-Pettersson and Segesten (2000), since it comprises finding something important to live for and gaining insights about the life itself. This struggle to live is viewed among women with breast cancer as accepting the challenge to go on living; working actively on the healing process; finding something important to live for; gaining insights about the life itself; experiencing awareness and avoidance; and introducing radical changes to life (Jensen *et al.* 2000). Adopting a fighting spirit and expressing emotions are associated with psychological adjustment to advanced breast cancer (Classen *et al.* 1996). Maintaining a fighting spirit also involves having knowledge about cancer, having experience of cancer among family or friends, and eliminating negative affectivity about cancer (Irving *et al.* 1998). Thus, the fighting spirit includes not only minimising the disease but also having a positive orientation towards it (Osborne *et al.* 1999) so that life-embracing attitude and activeness are truly needed.

In addition, the category of processing the worries included in overcoming adversities encompasses fighting against cancer, as exemplified by a struggle between bone marrow transplantation patients' bodies and minds according to Shuster *et al.* (1996). This dialect is not a simple struggle where the physical body with a physical disease is interfering with the social and spiritual part of the person. Rather, it involves struggling against the worries of physiological functioning, alertness, attitude, social relationships, and spirituality, since the body is both the source of the problem and the cure to it through bone marrow transplantation. (Shuster *et al.* 1996.)

## **Preparing for Worse**

Preparing for worse in fighting against cancer in the family involves the family members' preparing themselves for the after-effects of the treatments and for the deterioration of the patient's present condition. This is quite similar to struggling to live while waiting to die, as experienced by chronically ill men according to Charmaz (1995). The struggle is an identity dilemma of awakening to death after a life-threatening crisis, of accommodating to uncertainty in realising that the

crisis has lasting consequences for life, of defining illness and disability, and of preserving self to maintain a sense of coherence while experiencing loss and change. (Charmaz 1995.) As a category of preparing for worse, getting accustomed to the after-effects of the treatments entails experiencing micturition problems, indwelling catheter treatment and consequences in sexual life among men with prostate cancer. The consequences of physical deterioration and fear of ridicule radically affect men's autonomy and quality of life and change their life continuum. (Jakobsson *et al.* 2000.)

Moreover, preparing for a decline in the patients' condition is a category of preparing for worse. It involves being aware of inherited cancer in the family with a history of breast cancer according to McAllister *et al.* (1998). This awareness among men and fathers in families of inherited breast cancer entails fearing the development of inherited cancer in themselves as well as being concerned that their existing or potential daughters might be at risk. Genetic counselling for these families is needed since men are often excluded from family conversations about breast cancer. (McAllister *et al.* 1998.) Furthermore, genetic counselling is needed for women of suspected hereditary breast and ovarian cancer families for balancing the benefit of positive illusions with the delivery of statistical probabilities of risk (Andersen *et al.* 2003, Kenen *et al.* 2003). On the other hand, counselling of young, high-risk women should include assessments of the concerns and clinical signs of breast cancer, since total symptoms and younger age predict greater concerns of breast cancer than the perceived risk and the family history of breast cancer (Loescher 2003).

## **Ensuring the Functionality**

Ensuring the functionality enables fighting against cancer in the family of a family member with cancer. As a category of ensuring the functionality, securing the future is parallel to guarding against uncertainty in the family of a newly diagnosed cancer patient according to Plant (1995). Guarding against uncertainty consists of reconstructing the future, having "residual separateness" from protecting the patient, not disclosing the disease to outsiders, dictating coping solely according to the patient, bearing unacknowledged burden, supervising activities, and monitoring (Plant 1995). Moreover, securing the future involves taking time for oneself, maintaining a sense of humour and focusing on the present in the family with cancer (Lowdermilk and Germino 2000). Humour may also be a meaningful coping factor for cancer patients (Johnson 2002). Further, winning the disease after fighting is linked to having a positive attitude towards getting better, when the meaning of the cancer for patients is either a challenge, a value, an enemy, a loss, a weakness, a punishment, a strategy, a relief or a warning (Luker *et al.* 1996b). A positive attitude towards life is perceived also as an important resource among young cancer patients together with the willingness to fight; belief in person's own resources; belief in God; and earlier life experiences (Kygäs *et al.* 2000).

Ensuring the functionality is interlinked to bearing responsibility for the family, which involves communication between parents and children about maternal breast cancer according to Barnes *et al.* (2000). Even if the children are not told about the illness they soon become aware of the change in the atmosphere at home and in their parent's health. Reasons for wanting to obtain information are belief in communicating, desire to maintain the children's trust, and communication expected to alleviate the children's distress, whereas reasons for withholding information from children are to avoid facing questions about cancer and death, to prevent the children's distress, not expecting the children's understanding, and to preserve special family times. (Barnes *et al.* 2000.)

Bearing responsibility for ensuring the functionality also takes place when the helped is turning into the helper as in case of including children in the breast cancer experience of the mother as stated by Shands *et al.* (2000). This comprises talking about the breast cancer, explaining the treatment and care, providing experiences and doing things to help the children fight against the disease. Furthermore, it means assuming the educator's role towards the children about the cancer instead of an interactive, emotive-expressive parenting role. Moreover, it involves using technical and biomedical language rather than checking on the children's understanding of what they have been told, not eliciting the children's concerns, and exposing the children to emotionally laden or potentially frightening images, words or experiences. (Shands *et al.* 2000.) As well as clear communication, bearing responsibility for the family with cancer refers to having a great deal of mutuality and good flexibility in the family (Murtonen *et al.* 1998) which are essential dimensions of the family dynamics (Friedemann 1989, 1995). These obligations seem to be left largely to the unaided parents in terms of what information should be given to children, at what stage and in what manner, while taking the parents' views and feelings into account (Kroll *et al.* 1998).

## 6.4 Adjusting to Life with Cancer in a Family

### **Clarifying of Facts**

Clarifying of facts involves assuming a serious attitude towards treatment and realising the limited scope of future in the process of adjusting to life with cancer in the family with a family member who is suffering from cancer. As a category of clarifying of facts, becoming clear about the nature of the disease is present in the families' devastated perspective on living with a highly malignant brain tumour regarding the onset of disease and understanding the diagnosis as stated by Wideheim *et al.* (2002) when the family members are shielding one another, living in the present and avoiding talking about the future. They are also anxious and have a fear of losing the ill family member. Patients are observing symptoms, reacting to the diagnosis and having recognition of death.

Simultaneously, the next of kin are observing the deviant behaviour of the patient and distancing themselves from the diagnosis after hearing about it, in order to protect each other, in addition to having recognition of death. The ill family members' daily life consists of living with limitations and receiving support, while the next of kin are searching for an answer confirming that the patient is going to survive. Moreover, they are feeling burdened and trying to create a sense of security for the family, as well as being aware of the risk of becoming ill themselves. (Wideheim *et al.* 2002.) Nowadays, the need of adjusting to the risk of inherited cancer has become more common as the number of genes associated with inherited cancer continues to grow. Genetic testing for cancer susceptibility is causing depressive symptoms, functional impairment and test-related distress. (Lerman *et al.* 2002, Bleiker *et al.* 2003, Hutson 2003.) Adjustment to the risk of breast cancer, for instance, takes place through the process of living with the breast cancer experience of one's relative, developing a perception of one's personal risk of breast cancer, and coming to terms with the risk of breast cancer by putting it "in its place" through information, support and communication within the family (Chalmers *et al.* 1996). Becoming clear of the nature of the disease is also perceived among daughters of women suffering from breast cancer since they have a higher sense of coherence and are more actively involved in the medical setting, requesting more medical information than women whose mothers do not have breast cancer (Gilbar and Borovik 1998).

Clarifying of facts appears in families with a child's cancer as they experience significantly more emotional distress than families in the general community during the period immediately following the diagnosis. However, this emotional distress caused by having cancer stabilises during the first year to a level comparable with that found in families in the general community. (Sawyer *et al.* 1997.) Clarifying of facts among survivors of acute leukaemia and highly malignant lymphoma emerges as living with energy loss, overwhelming fatigue and nutritional problems during the treatment phase. Reduced psychological and sexual energy, existential problems and sensitivity to infections as long-term effects persist in remission, as does living in realities, which is also a category of clarifying of facts. (Persson *et al.* 1997.)

## **Resorting to Help**

Resorting to help entails looking for relief in the difficult situation in adjusting to life with cancer in the family. It contains feeling relieved for human contacts, which is not limited to spouses and other family members as also close friends and health care professionals are valuable sources of help in the form of social support (Fridfinnsdottir 1997, Jussila 2000, Wengström *et al.* 2001, Landmark *et al.* 2002). Additionally, the encouragement of peers and support groups or self-help groups (Adamsen 2002) consisting of, *e.g.*, other women who have suffered from breast cancer, are beneficial for patients' social well-being (Ferrell *et al.* 1997) and adjustment since the perceived needs of the patients are greatest in the psychological and informational areas (Samarel *et al.* 1998, Sanson-Fisher *et al.*

2000). Storytelling has been found to be a good method of adjusting to the cancer affecting four domains of existence, namely, cognitive, affective, interpersonal and personal. Thus, the abilities of transmitting knowledge, instilling hope, creating communality and connectedness and bringing about personal insight are benefits of storytelling as found by cancer patients. (Chelf *et al.* 2000.)

Resorting to help with its category of learning about the philosophy of life is parallel to Käppeli's (2000) results that religiousness has great potential as a resource of strength and hope for cancer patients. For instance, most of the patients suffering from incurable cancer as well as their family members are not experiencing fear of death since they believe in the existence of God and the afterlife (Kuuppelomäki 1996a, 1996b, 2000). According to Taylor (2003), cancer patients and their family caregivers have needs associated with an Ultimate Other; needs for positivity, gratitude and hope; needs to give and receive love; needs to review beliefs; needs to create meaning and find purpose; needs to be religious; and needs to prepare for the death (Taylor 2003). However, the cancer experience is not shared in the same way by patients and family caregivers because patients with expressed faith identify fewer psychosocial needs than those without faith, and family caregivers with expressed faith identify more needs than those without faith in relation to support from family and other people (Soothill *et al.* 2002).

The typology of the patients' religious motives for seeking for a meaning in adjusting to cancer includes stories of retaliation and return, stories about combating, stories of mercy, apocalyptic stories and stories of mystical transfiguration. This typology is utilised among Jewish and Christian patients. (Käppeli 2000.) There is an agreement on increasing awareness of the patient's personal spiritual and cultural values and beliefs, and gaining knowledge about the diverse religious traditions in cancer care (Taylor 2001, Chan *et al.* 2001). There is also an agreement on the importance of providing spiritual support to family members, although nursing staff rarely discusses spiritual issues with them or offers them spiritual support (Kuuppelomäki 2002). However, it is important to recognise the patient's individual spirituality in the nursing process (Åstedt-Kurki 1992, 1995, Albaugh 2003), and according to Highfield (1992), the nursing staff might really be able to use their knowledge to identify patients at risk of spiritual distress, since issues related to religion and spirituality have been studied to a great extent in oncology nursing (Flannelly *et al.* 2002). Interestingly, religious beliefs also contain doubts, or religiosity is not at all an important aspect of living with cancer, or the cancer experience has not changed the patients' religiosity during their illness (Landmark *et al.* 2001).

As a category of resorting to help, calming down due to professional help takes place, *e.g.*, among women with breast cancer and their family members in the form of a substantial need for information. The families often prefer verbal forms of information from health care professionals, particularly around the time of diagnosis. Especially women need information through their entire journey through breast cancer from the initial diagnosis period through the treatment

phase to remission and recovery, although the needs change with time since the diagnosis and with treatment-related events. (Rees and Bath 2000, Salminen *et al.* 2003.) Further, women with breast cancer and their spouses have a number of concerns regarding spousal information. While some spouses actively seek information, some avoid it. Some women and their spouses who have similar needs for information commonly engage in information disclosure. On the other hand, some partners have different needs for information and communicate infrequently about the topic of breast cancer. In addition, the information needs of spouses are often ignored by health care professionals, and spouses feel uncomfortable with seeking information. (Rees *et al.* 1998.)

Resorting to help entails seeking information about the prognosis, the stage of the disease, the treatment options, and the side-effects which are the highest information preferences among men with prostate cancer and their partners. Men perceive information on sexuality more important than the partners, while the partners rank information on home self-care higher than men. Couples with sons also rank information of heredity risk very high. (Davison *et al.* 2002.) Information about the likelihood of recovery, the spread of the disease and the treatment options are the most important items of information at the time of diagnosis. Others include the risk to the family, the side-effects of the treatment, the impact on the family, self-care and the effect on social life and sexual attractiveness (Luker *et al.* 1995). Even 21 months after the diagnosis, women still want information about the likelihood of recovery but also about the risks of family members falling ill with breast cancer (Luker *et al.* 1996a). Furthermore, children and adolescents suffering from cancer express an interest in receiving more information and pay attention to what, when and how to tell about the disease (Ishibashi 2001). As the 13-month experiment of support and education intervention reported by Samarel, Tulman and Fawcett (2002) illustrates, an individual telephone support could provide an effective alternative for delivering information and support through support groups. As expected, the fact is that patients suffer from a huge lack of information, especially concerning the prognosis, the alternatives to the treatment and the effect of the cancer or the treatment (Juvonen and Lauri 1994). Among cancer patients, information is sought after due to its positive impact on the patients' feelings and attitudes as well as its help in coping with the situation (Sainio 2002) and its positive impact on patient-spouse dialogue (Chaitchik *et al.* 1992). The strongest associations with patients searching for or receiving information are the length of time since the diagnosis, the employment status, the physical condition and the mood (Sainio and Eriksson 2003).

## **Returning to Life**

Returning to life comprises concretely experiencing that living with the disease is possible in adjusting to life with cancer in the family of a family member with cancer. According to Landmark *et al.* (2001), returning to life is comparable to having the will to live and struggle for life among newly diagnosed female breast

cancer patients when they are seeking for a meaning in their suffering and changing attitudes towards different values in their life. The women's will to live consists of different levels of life expectations, such as fight against death, future life, religious beliefs and doubts as well as increased awareness of life values. They are also aware of contrasts between health and suffering and, in spite of uncertainty and confusion, they choose the will to live. (Landmark *et al.* 2001.) Returning to life may also vary on an individual basis inside the family since school-age children and adolescents of a parent suffering from cancer may show significantly more behavioural problems than may be expected (Birenbaum *et al.* 1999, Huizinga *et al.* 2003). Parents either see little or no evidence of emotional distress or disruptive behaviour in their children regardless of the child's age or sex, or of whether the mother or the father has cancer. Then again, the children's opinions may differ significantly from those of their parents as, *e.g.*, adolescent girls have the most symptoms of anxiety, depression and aggressive behaviour. Therefore, health care professionals should assist parents in accustoming to changes in life and in recognising and coping with their children's distress, if needed. (Welch *et al.* 1996.)

### **Intensifying of Togetherness**

Intensifying of togetherness is a strong feeling in adjusting to life with cancer in the family. Families are relatively enduring and not readily discarded in response to a parent's disease (Stetz *et al.* 1994). Even in distressed marriages, the spouses of women at a high risk of breast cancer are more involved and have more influence in the patients' decision-making than the relatives (Coyne and Anderson 1999), which demonstrates the category of strengthening of the intimate relationship. Prostate cancer patients and their partners perceive as well that their marital relationship has remained the same or improved since the diagnosis, although a few men report negative changes (Lavery and Clarke 1999). Further, *e.g.*, a breast cancer diagnosis challenges the women's basic assumptions about themselves and the social world, which has an important impact on their relationships (Holmberg *et al.* 2001). Some of those changes in relationships are positive and lead to intensifying of togetherness. However, they also frequently threaten the psychosocial well-being of the women suffering from cancer and that of her partner according to Holmberg *et al.* (2001) since patients treated for breast and gynaecologic malignancies and their spouses face a potential assault on the patient's bodily image, gender role functioning, sexual functioning and fertility (Bruner and Boyd 1998). The fact is that physical and menopausal symptoms are more frequent among breast cancer patients than among healthy women, and their health-related quality of life and sexual functioning are comparable to those of healthy women (Ganz *et al.* 1998). Unifying of the family is a category of intensifying of togetherness and it involves, on the other hand, pattern recognition which entails finding meaning in the patterns of the family and making a shift from separated individuals within the family to trustful and caring relationships (Endo *et al.* 2000).

## **Maturing through Hardships**

Maturing through hardships enables adjusting to life with cancer in the family with a cancer patient. Maturing through hardships shares the properties of the active process of making the most of the moment according to Davis Kirsch *et al.* (2003) in which the parents are preparing the children for the present and the future. They are creating new opportunities for togetherness within the family in order to minimise the intrusion of breast cancer into their family life. Additionally, they are creating new opportunities in the family which promote positive atmosphere among family members (Davis Kirsch *et al.* 2003). Moreover, they are seeking support, making decisions, talking with children, making alternative childcare arrangements and trying to be supportive towards all family members (Hymovich 1993). In addition, accepting the circumstances as a category of maturing through hardships resembles a demanding but gratifying and challenging process according to Gates and Lackey (1998) when youngsters are caring for a parent suffering from cancer. At the same time, caring for a parent is burdensome, since the youngsters' caregiving activities, such as personal care, medical care, household care and spending time with the adult, take time from playing, studying and private pursuits, although their school time is protected. (Gates and Lackey 1998.)

## **6.5 Submitting to Cancer in a Family**

### **Life Coming to a Standstill**

Life coming to a standstill involves feeling panic and fear of death after hearing about the disease and in submitting to cancer in the family with a family member who is suffering from cancer. Life coming to a standstill may be described as a paternal experience of family stress among fathers when their child is receiving chemotherapy or radiation therapy, and it consists of paternal perception of uncertainty and paternal anxiety (Mu *et al.* 2002). Being paralysed by falling ill is included in life coming to a standstill, and it is comparable to adopting a patient role. For instance, if patients undergoing radiation therapy assume that role, it results in a feeling of not being in control, although they attend the treatment on an outpatient basis and are required to manage their own care (Lesley 2001).

Life coming to a standstill contains being appalled by the adverse reputation of the disease which occurs also among couples, in which women with recurrent breast cancer suffer more emotional distress than their husbands, and in which both have a similar number of psychosocial role problems according to Northouse *et al.* (1995b). The majority of women in this type of couples are very surprised that their cancer has recurred and feel that the period of time

surrounding the recurrence is more stressful than the time when their cancer was first diagnosed. On the other hand, the majority of husbands are only somewhat surprised by the recurrence and perceive the time of initial diagnosis as more stressful than the time of recurrence. (Northouse *et al.* 1995b.) Further, spouses who feel anxiety and depression have problems they never talk about, physical symptoms, or feelings of anger. They neither feel supported by family nor friends irrespective of the patients' sex, age, diagnosis, treatment or the performance status. (Glasdam *et al.* 1996.) Moreover, on an individual basis, being appalled by the adverse reputation of the disease has similarities to experiencing anxiety, fear, helplessness, depression, uncertainty and hopelessness in grasping the meaning of the disease (Poncar 1994).

## **Succumbing to Fear**

Succumbing to fear involves spreading feelings of anxiety in submitting to cancer in the family. Cancer is explained in terms of feelings of fear and death, and the process of symptom recognition includes also a fear of finding out the truth through screening programmes (Sheikh and Ogden 1998). Succumbing to fear is closely related to a feeling of uncertainty of different forms, such as not feeling secure, being in doubt, not being in control and being undecided as experienced by leukaemia patients (Berterö *et al.* 1997b). The nature of uncertainty makes cancer and life difficult to get through as experienced by the children with cancer and their families. According to them, uncertainty comprises also everything else that comes with the "rough spots" in the family, more than living with the unknown, knowing what to expect, and expecting the unexpected. (Woodgate and Degner 2002.) Therefore, the sense of uncertainty caused by disease is a very negative feeling which the patient wants to get rid of (Iire 1999). Additionally, uncertainty is one manner in which the people in the remission or the recovery phase of cancer experience existential changes, the others being vulnerability, isolation, discomfort, and redefinition (Halldorsdottir and Hamrin 1996).

Succumbing to fear and, especially, its category of dreading the treatments takes place clearly among outpatients receiving radiation therapy (Karhu-Hämäläinen and Eriksson 2001, Kekäläinen 2002). At the beginning of the radiation therapy, these patients show only a few physical symptoms and emotional distress while at the end, the distressing symptoms are fatigue, local skin reactions, problems with bowel and urine function and lack of sexual desire (Karhu-Hämäläinen 2002, Ekfors and Petersson 2004). Nevertheless, young women with breast cancer may experience their quality of life declining from the start of the radiation therapy up to the midpoint with gradual improving six months later (Dow and Lafferty 2000). As fatigue is having a negative impact on the patients' daily lives (Langeveld *et al.* 2000) and as one of the most common side-effects accompanying radiation therapy is considered to be a troublesome condition, it is the carefully structured balance between activity and rest that is more beneficial to these patients than mere rest (Flinton and Pettet 1999).

Medical oncology outpatients experience a wide range of physical and psychosocial problems which appear interrelated, and therefore, *e.g.*, treating physical symptoms may help reduce the patients' levels of psychosocial problems (Newell *et al.* 1999).

### **Being Burdened by Concerns**

Being burdened by concerns entails being involved in a permanent concern in submitting to cancer in the family with a cancer patient. For example, the children's being concerned and confused as a result of their mothers' breast cancer diagnosis includes concerns about their mothers, their families, and themselves since it is unclear to them what is happening at the time and what would happen next. Hence, children are feeling concerns that the mother is going to die and feeling confused and concerned that something bad would happen. Additionally, they are concerned about the family and others as well as several other matters: when the mother does not look good; that their mother would change; if the family would have to cut back financially; about talking to others; and if they would get cancer. Children are not only attempting to make sense of what they hear, but of what they see themselves. (Zahlis 2001.) Mothers have also intense concerns and a fear of breast cancer for their daughters, which is a greater concern to the women than their own health (Ferrell *et al.* 1997).

Being burdened by concerns includes realising the criticality of the condition as a category, which may be perceived clearly in the family systems model of post-traumatic stress response of childhood cancer according to Stuber *et al.* (1994). The link between the survivor's post-traumatic stress symptoms and those of his/her parents is through the mother to the survivor's subjective assessment of the intensity of the cancer treatment. The father is communicating with the child through the mother, which is the only link between the mother's and the father's post-traumatic stress symptoms. Thus, the mother is the key person in the system by influencing both her husband's likelihood of experiencing post-traumatic stress symptoms and her child's inclination to appraise his/her cancer treatment as having been severe. Further, the mother tends to be the primary caretaker of her ill child and, thereby, a key person in that sense as well. (Stuber *et al.* 1994.) Moreover, the survivors of childhood cancer themselves may suffer from post-traumatic stress which is related to the poor quality of their life and increased psychological distress (Meeske *et al.* 2001). Realising the criticality of the condition may be perceived also in the impact an adult child's cancer has on the parent, as Ora and Ronit state (2000), when the parent has more symptoms of depression than the adult child, although cancer creates a highly stressful situation for both. In addition, the parents receive less assistance and support from their ill adult child than the child receives from the parents. Health care professionals do not pay attention to the parents, either. (Ora and Ronit 2000.)

Realising the criticality of the condition is also displayed in partners' understanding of the breast and prostate cancer experience according to Carlson

*et al.* (2001). Female partners hold a more accurate understanding of their husbands' experience with prostate cancer than male partners do of their wives' breast cancer experience. Furthermore, the husbands tend to overestimate the breast cancer patients' self-reported levels of distress. Moreover, patient and partner perceptions regarding social support in the relationship and the cancer experience are more similar in couples with prostate cancer than in couples with breast cancer. (Carlson *et al.* 2001.) Realising the criticality of the condition is also connected to emotional distress reported by women and husbands prior to a breast biopsy when women undergo rather high levels of emotional distress and significantly more distress than their husbands (Northouse *et al.* 1995a).

Being burdened by concerns is involved with accumulating of hardships which resembles the depression burden experienced by women receiving treatment for breast cancer, as stated by Badger *et al.* (2001). Their depression burden is significantly connected to severity and the number of side-effects, the burdens of fatigue, difficulties in concentrating and anxiety. Therefore, there is interplay of depression burden and fatigue burden in women suffering from breast cancer, as well as the importance of depression as a contributor to the total side-effect experience. (Badger *et al.* 2001.)

### **Life Turning more Difficult**

Life turning more difficult complicates the everyday life in the process of submitting to cancer in the family of a family member with cancer. It entails everyday life becoming burdensome which is similar to the influence of cancer on the family functioning (Cooley and Moriarty 1997) which consists of parental mood, marital and parental quality and family coping (Lewis and Hammond 1996). Mothers and fathers regard that the impact of the early stage of breast cancer on the functioning of their families with adolescents has illness-related effects, such as higher levels of maternal depressive mood, poorer marital adjustment and lower parenting quality. The more illness-related pressure the parents perceive, the greater difficulties the family experience. It is also remarkable that lower parenting quality experienced by the adolescents is causing lower self-esteem for them. Furthermore, lower marital adjustment experienced by the husbands is dependent on transferring illness-related tension into the evaluation of their marriages. (Lewis and Hammond 1996.) Everyday life becoming burdensome is also parallel to the potential mechanisms accounting for a relationship between parental physical illness and child functioning as stated by Armistead *et al.* (1995), which contains disruption of parenting, parental depression, interparental conflict and parental divorce. Disruption of parenting means reducing parental support for the child, having fewer efforts in disciplining, neglecting of child due to reorganisation of family around illness, changing family routines and staying absent parentally. (Armistead *et al.* 1995.)

Life turning more difficult is involved with intimate relationship drifting into a crisis which may be described as experiencing negativity from the spouses by

the women with a high risk of breast cancer, which has a great influence on their well-being (Coyne and Anderson 1999). Intimate relationship drifting into a crisis may be similar to the diagnosis of breast cancer exacerbating existing problems and serving as a cause for separation in partner relationships of breast cancer patients already earlier fraught with conflict. Reasons for this contain an inability of the couple to discuss mutually the feelings of each partner about grief, loss and potential death, changes in the usual manner of conflict resolution resulting from each partner's efforts to protect the other, and the women's negative perceptions of their femininity and feelings of competence. (Holmberg *et al.* 2001.) Alterations due to surgery, chemotherapy or radiation therapy may result in physical changes as well as changes in bodily image and a decreased sense of well-being among the survivors of breast and prostate cancer. Hence, patients and partners have sexual concerns concerning their bodily image, gender roles, patterns of affection, social and family roles and genital sex. Erectile functioning and the capacity to enjoy sexual activity and to satisfy the sexual partner are the main concerns to men deciding for treatment options for prostate cancer. Sexual identity and female attractiveness, as well as pain and suffering are women's concerns related to cancer. Women feel also emotional vulnerability and negative changes in their current sexual functioning during cancer treatments. (Hughes 2000.) According to Navon and Morag (2003), the partners' supportive attitude and the patients' attempts to stage resilience may lead to the maintenance of pre-treatment relationship in the advanced prostate cancer patients' relationships. Patients' rejection by their partners and resignation to this difficulty may result in disruption of spousal ties but the disruption may also be revoked by the patients. (Navon and Morag 2003.)

Life turning more difficult entails family members becoming depressed which ties in with having anxiety, depression and stress symptoms which identify members at risk of psychological maladjustment in families with adult cancer patients, spouses and their children in the time of the patients' diagnoses. Distress of the patients and family members is related to appraisals of the seriousness and stressfulness of cancer but not to the objective characteristics of the disease. Although patients and spouses do not differ in anxiety and depression or in stress-response symptoms, they differ in dealing with children depending on their age and sex as well as on the sex of the patient. (Compas *et al.* 1994.) Passive coping manners differ as well among healthy women without a family history of breast cancer compared with healthy women with such history, and they also would benefit from individualised coping training programmes (Kim *et al.* 2003). Moreover, breaking down of the immediate circle is included in life turning more difficult which is similar to relationship changes within women's social networks due to negative changes in self-perception. Relationship changes include friends' withdrawal and inappropriate comments, concerns of family members about genetic factors relating to breast cancer, others' interference with attempts of the women and their partners to cope with the crisis and the lack of a positive, supportive working environment (Holmberg *et al.* 2001).

## Getting Caught in Being Ill

Getting caught in being ill refers to attaching the family to the circumstances of illness and tying the family members into submitting to cancer in the family. Among patients with advanced cancer, having cancer has been perceived as a hostile takeover with four types relating to the chronological appearances. These are: the onset of primary tumours, takeovers by treatments and treatment side-effects, takeovers by spread of cancer, and takeovers by death (West 1995). Getting caught in being ill may be like grieving over losses or issues that may never be reached due to changes in the patient's life (Aakala *et al.* 2000). Getting caught in being ill is also illustrated in having negative effects on the quality of life as, *e.g.*, for women suffering from recurrent breast cancer and for their family members. These detrimental effects on quality of life, such as symptom-related distress, concerns, hopelessness and negative appraisal of illness or caregiving are more common among them than among breast cancer patients in general, whereas self-efficacy, social support, and family resoluteness would have positive effects on the quality of their lives. (Northouse *et al.* 2002a.)

Getting caught in being ill is involved with staying in the shadow of the disease which may be exemplified by patients suffering from head and neck cancer becoming depressed. The stage of the tumour, sex, depressive symptoms, openness to discuss the cancer in the family, available assessment support, receiving emotional support, tumour-related symptoms and the size of the informal social network are variables used in determining accurately which patients could become depressed in six months to three years after treatment. (de Leeuw *et al.* 2001.) Moreover, transition to becoming a leukaemia patient resembles staying in the shadow of the disease by putting up barriers that increase patient isolation (Berterö 1998).

Getting caught in being ill and its category of becoming exhausted of the disease may be described as patients' suffering from incurable cancer with three different dimensions: physical, psychological and social. Physical suffering is caused by the illness itself and its treatments, psychological suffering by the psychological changes associated with the disease and the imminence of death, and social suffering by general deterioration and by fearing infections causing the withdrawal. (Kuuppelomäki and Lauri 1998a, Kuuppelomäki 1998.) Becoming exhausted of the disease also occurs among patients receiving radiation treatment for cancers of head and neck, when the quality of life is measured after one month of treatment, during the last week of treatment and one month after treatment. Physical and functional symptoms, head- and neck-specific concerns and depression had increased between one month of treatment and during the last week of treatment. However, there was some improvement between each measuring, except for depression, during the last week of treatment and one month after treatment, although the improvement was not permanent. (Rose and Yates 2001.) Getting caught in being ill entails life's filling with the disease which may be illustrated in experiencing individual anticipatory grief

patterns in the family. Women feel more anger, hostility and despair than men. Moreover, adult children feel anger and hostility. Emotive coping and hope account for despair, somatisation and loss of control. Anticipatory grief is a multidimensional phenomenon with death anxiety, despair, anger, hostility and somatic distress being common across different individuals in the family of a terminal cancer patient. (Chapman and Pepler 1998.)

## 6.6 Summary of Stabilising of Life in a Family with Cancer

The substantive theory of family survivorship and its core category of stabilising of life with the subcore categories, detaching from the disease, fighting against the disease, adjusting to live with the disease and submitting to the disease, provides an overview and has a synthesizing function of the relevant literature on dealing with a family member with cancer in a family. This substantive theory is located in the research related to family survivorship with cancer (Appendix 30), detaching from cancer in a family (Appendix 31), fighting against cancer in a family (Appendix 32), adjusting to live with cancer in a family (Appendix 33) and submitting to cancer in a family (Appendix 34) together with research related to cancer on an individual basis since cancer in one family member influences also all other family members in a family unit due to its emerged character as a family disease.

Based on synthesizing the relevant literature, stabilising of life has similarities and differences with the core categories related to the other grounded theories of families living with cancer (Table 13). The main difference and uniqueness of the core category of this substantive theory of family survivorship compared to those of the other grounded theories are the nature of a typology containing the processes of living in a family with cancer which emerged as the theoretical codes.

**Table 13.** The core categories of the other grounded theories of families living with cancer.

<b>Core category</b>	<b>Researcher/s, year, country</b>
Making the most of the moment	Davis Kirch, 2003, USA
Suffering	Woodgate and Degner, 2003, Canada
Learning to live with cancer	Friesen <i>et al.</i> , 2002, Canada
Experiencing uncertainty	Woodgate and Degner, 2002, Canada
Reconstructing reality	Clarke-Steffen, 1997, USA
Getting back to normal	Hilton, 1996, Canada
Balancing our lives	Lewis and Deal, 1995, USA
Guarding against uncertainty	Plant, 1995, UK
Sharing meaning	Hilton, 1994, Canada

Making the most of the moment as an active process in which the parents engage to minimise the intrusion of cancer in their family life (Davis Kirch 2003), getting back to normal (Hilton 1996), and balancing our lives (Lewis and Deal 1995) is adjacent to stabilising of life in detaching from the disease in a family since they all emphasise active and positive behaviour in order to keep the disease a background issue in the family life. Guarding against uncertainty (Plant 1995) resembles stabilising of life in fighting against the disease in a family of this theory because both of them contain active but fearful behaviour towards struggling against the disease in the family.

Learning to live with cancer (Friesen *et al.* 2002), reconstructing reality (Clarke-Steffen 1997), and sharing meaning (Hilton 1994) bear a resemblance to stabilising of life in adjusting to live with the disease in a family since they include passive but hopeful behaviour on the level of both feelings and actions among family members. Suffering (Woodgate and Degner 2003) and experiencing uncertainty (Woodgate and Degner 2002) are quite similar to stabilising of life through submitting to the disease in a family because they both contain powerless and uncertain behaviour which attaches the family more and more strongly to the circumstances which the disease has brought about. Despite of these similarities to the other core categories, stabilising of life through its typology makes the theory of family survivorship significant since it explains the variation of behaviour in a family living with cancer for which the other grounded theories on families living with cancer do not account.

# 7 DISCUSSION

## 7.1 Evaluation of the Discovery Process of the Grounded Theory

### **Selection of the Research Methodology**

According to the grounded theory methodology, the social world is empirically integrated, not logically modelled. The social world is also structured and involves actions and interactions which are integrated into other actions and interactions in the structures wherever and constantly. The research interest of this study was to discover the social integration while generating concepts in the form of categories and their properties which explain what is occurring in the social world of families in which one of the parents is suffering from cancer. Thus, the grounded theory methodology fitted well into this research as the purpose was to develop a substantive theory of living in a family with a parent with cancer. (Glaser and Strauss 1967, Glaser 1978, 1992, Glaser 1995b, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

Since according to the grounded theory methodology, the social world is empirically integrated as well as multivariate and always in motion as living in a family with a parent with cancer may be, the only way to track this phenomenon conceptually was to pick up categories and their properties at any moment and to constantly write memos. Thereby, the integration was going to emerge. I trusted in the emergence due to its grab and conceptual empowerment because the grounded theory methodology generates the social and psychological processes involved in the fundamental latent patterns of the participants' behaviour in the substantive area. That is why uncertainty and tolerating confusion were needed for being open to the emergence and I had to trust that existing social organisation of social life was going to be discovered. (Glaser and Strauss 1967, Glaser 1978, 1992, Glaser 1995b, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

Although the grounded theory methodology is a general research methodology and works with any qualitative and/or quantitative data which exist for generating a theory (Glaser 1999), theoretical sampling of this research consisted only of qualitative data. Unifying it to, *e.g.*, phenomenology, ethnography, action research, post-positivism or even positivism should have distorted true emergence required for the generation of the theory because they would have brought in evidentiary principles which do not belong to the

grounded theory methodology (Stern 1995). Instead, this methodology is open to all theoretical codes which are emergent and earn their way into the theory. Hence, the grounded theory methodology is empirical, not logical, and seeks to find out what is going on by allowing the emergence to take place. Based on these background assumptions, the grounded theory methodology was selected for the research methodology of this research. (Glaser and Strauss 1967, Glaser 1978, 1992, Glaser 1995b, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

## **Theoretical Sampling**

I started the theoretical sampling in an area of research interest, living with a parent with cancer in a family instead of with a professionally preconceived problem, *e.g.*, coping with a parent's cancer in a family. Therefore, my research area contained a life-cycle interest, as grounded theory studies usually do. I had no preconceived view of the problems the participants may confront in the research or the manners in which they were going to solve their problems or main concerns. I let the problem and its continued resolving emerge since the research issue was to discover a core category and a substantive theory which account for what I was going to find as participants' main concern. Therefore, forcing would have derailed and failed this purpose. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

This substantive theory was not logically deduced from the literature or based on any systematic research. Instead, the focus was on induction from observations of participants' views on this substantive area. Theoretical sampling included carefully grounded deduction from inducted categories, where to next seek data for comparison, probabilities of where to go next and for what kind of data there is to be found for inducing further to the growing theory. Thus, I excluded the deductions and the inferences of what should or might have been going on. Induction meant that I started finding out what was going on, conceptualised it and generated hypotheses as relations between the concepts. Through theoretical sampling, I started deducting where more data could be found. As I collected more data, previous data and conceptualisation were corrected and verified. Therefore, deduction was closely based on grounded concepts which were constantly corrected by inductive comparison. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2002a, 2003.)

Because the grounded theory methodology generates hypotheses from data and in no way tests theories found in other literature, it was appropriate to deliberately avoid a literature review in the studied substantive area at the beginning of the research. This dictum is brought about by the concepts not to contaminate, constrain, inhibit, stifle or to concern otherwise the researcher's effort to discover emergent concepts and hypotheses, properties and theoretical codes from the data that truly fit, are relevant and work. I commenced the study with a totally open mind as best as I could. I increased my level of sensitivity to

enable catching what will emerge. I did not go blank or give up my knowledge entirely, but I was sensitive towards all my learning, which made me alert to any possibility of emergence and how to formulate it conceptually. I brought back the literature starting in the sorting stage when I was not avoiding its conceptual grab and awed descriptions. I was constantly reading literature in other substantive areas to keep up and to increase my sensitivity towards theory, its way of conceptualisation and theoretical codes. Entering the field without prior knowledge and convincing oneself that what will be discovered is yet unknown is a skill. It developed over time as I saw how well it worked, how rich the genuine discovery was and how my knowledge did not disappear but helped me to generate concepts through sensitivity. As I let the data speak for itself, my knowledge made me sensitive towards how to conceptualise it through constant comparisons without controlling preconceptions. Constant comparisons checked out and verified the concepts and patterns. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2002a, 2003.)

### **Coding, Memoing and Writing**

As I based this research on emergence, I assumed that the memos would have to be integrated on their own through my inductive reasoning, which could catch the integration of the social organisation. Thus, I did not integrate the social world of the family into any certain outlines, *e.g.*, coping theories, since the social organisation was occurring regardless of whether I had a prior modelled theory as a framework or not. Therefore, I trusted in the discovery and avoided all preconceived theories, and the really capturing moment was when the social integration was emerging through tedious coding and the theory was maturing. (Glaser and Strauss 1967, Glaser 1978, 1992, Glaser 1995b, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

The use of the grounded theory methodology generated a general, conceptual problem, not a problem of an aggregate or a unit. Any specific unit may simply embody an instance of the problem; as a result, the continual resolution is applied to it. Hence, this grounded theory has conceptual generality, not generality in terms of a unit, *e.g.*, patients, spouses or children. Forcing notions of using face sheet data, structural interviews, unit populations or resorting to full descriptive portrayal or assuming thereby that all is relevant are not allowed. As a consequence, categories had to earn their way into the theory through working and relevance. (Glaser and Strauss 1967, Glaser 1978, 1992, Glaser 1995b, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2002c, 2003.)

My analytic decisions during this research process became analytic rules for this emergent theory generation and construction and were important to keep track of (Appendix 9). They detailed operations and delimited and selected the use of data, illustration balance and concepts as well as detailed specific foci, chapters and sections. Analytic rules were related to generating the theory and were emergent and not proliferated beyond control to force the generation. They also emerged, were not forcing and were followed with sensitivity. (Glaser and

Strauss 1967, Glaser 1978, 1992, Glaser 1995b, Lowe 1996, Starrin et. al. 1997, Glaser 1998, 2001, 2003.)

## 7.2 Evaluation of the Discovered Substantive Theory

The purpose of this research was to explore families' living with a parent with cancer and to develop a substantive theory to explain how families solve the main concern in their lives. The theory was developed to fit in the real world, work in predictions and explanations, be relevant to the people concerned and be readily modifiable. Thus, the substantive theory would transcend and have implications to a formal theory invariably. I will now evaluate the adequacy and theoretical credibility of the emerged substantive theory of family survivorship against the fit, workability, relevance and modifiability criteria of the grounded theory (Glaser and Strauss 1967, Glaser 1978, 1992, 1998, 2001, 2003).

*Fit* considers the question whether the concepts adequately reflect and express the pattern in the data which it purports to conceptualise (Glaser and Strauss 1967, Glaser 1978, 1998). Accordingly, I generated the substantive theory systematically on the basis of the data by comparing whether the excerpts of raw data incorporated in my explanation of the pathway through the data to the emerged theory. The constant comparison process of concepts was continued until the incorporation of more incidents did not reveal any new categories. The theoretical sampling used also benefited the validating of the concepts and testing whether they fit in the data until they had saturated. Additionally, I paid attention to the fact that all new ideas written in the memos emerged and had emergent fit into the theory instead of using preconceived theories or professional interests. Hereby, the data could speak for itself.

*Workability* relates to the ability of the concepts and the way they are related to hypotheses sufficiently accounting for how the main concern of participants in a substantive area is continually resolved (Glaser and Strauss 1967, Glaser 1978, 1998). The workability of this emerged theory was secured by resisting description and ensured by generating concepts through theoretical sampling in order to find out what was taking place in families with a parent with cancer. Especially, workability was reached by the systematic memoing and the constant comparative method so that the emerged concepts accounted for how the main concern of families with a parent with cancer was continually solved. Workability was needed in order to make the emerged theory reach its explanatory power in explaining the families' patterns of behaviour and would thus be relevant to the substantive area.

*Relevance* explains the importance of the theory and evokes an instant "grab" foremost to the people in the substantive area as well as others since a workable theory is also relevant (Glaser and Strauss 1967, Glaser 1978, 1998). The relevance of this substantive theory was ascertained by avoiding preconceived theories, deduction from other theories and conjectured thoughts or professional

interests as this substantive theory gained relevance by allowing the main problem of stabilising of life and the processes for solving it to emerge. Hence, this theory was not forced or preconceived, but its relevance was discovered on the basis of the data by allowing the core problem and its solving processes to emerge. Conversations with participants and participant observation yielded authentic data for coding and enhanced the relevance. Hereby, the handling of confronting a parent's cancer in a family sits explicitly within the theory. Therefore, this substantive theory could evoke an instant grab to the families' life in the substantive area, the work and education of health and social care professionals, and future studies by the researchers.

*Modifiability* encompasses the capacity for the theory to accommodate new concepts as they are revealed because the generation of a grounded theory is an ever-modifying process (Glaser and Strauss 1967, Glaser 1978, 1998). I secured the modifiability of this emerged theory of family survivorship by paying attention to the emerged generation of concepts and to their being outside of the scope of place, people and time (Glaser 1995b, 2002c) since psychosocial life is ever-changing in families. Consequently, this saturated theory would be capable of including new concepts from the data which will be generated after the completion. The prospective new data would then be treated as one more incident and, through further constant comparisons, this substantive theory could grow to include another new category or categories.

## 7.3 Ethical Viewpoints of the Discovery Process of the Grounded Theory

### **Ethical Starting Points**

This potentially sensitive research of families living with cancer required discretion already from the planning phase, not only during the phase of recruiting informants for joint couple conversations (Moriarty 1990, Anderson and Anderson 1999, Morris 2001) and for participant observations (Johnson 1992, Moore and Savage 2002). This research is sensitive because the character of cancer and the condition of a family with cancer affect the lives of the patient and all family members. Cancer is still generally seen as a life-threatening disease, and possibility of losing a spouse and a parent to that disease might be present constantly in families with cancer. For that reason, this potentially sensitive family research needed paying thorough ethical attention in each research stage by maintaining a balance between high standard ethical action of family research and the goals of thorough data collection, analysis and reporting. (*cf.* Demi and Warren 1995, Gibson 1996, Paavilainen *et al.* 1998, Liaschenko and Underwood 2001, Horowitz *et al.* 2002, Maijala *et al.* 2002a, Maijala *et al.* 2002b.)

## **Gaining Access**

I gained access for meeting the informants for conversations by requesting formal research permission from the Oulu University Hospital and the Medical Faculty of the Oulu University based on the legislation (Medical Research Act 488/1999, Medical Research Decree 986/1999) regulating medical-related research in Finland. After receiving the formal permissions from the head of Oncology Clinic of the Oulu University Hospital (dated March 20, 1998) and from the Ethical Committee of the Medical Faculty in the Oulu University (dated April 27, 1998), I had a meeting with the personnel of the outpatient clinic and the radiation therapy department of the Oncology Clinic in the Oulu University Hospital since I recruited participant couples with the assistance of nurses at the outpatient clinic and radiographers at the radiation therapy department. I described the eligibility criteria of informants for this research to the personnel and gave them the participant information sheet (Appendix 6). It contained a general description of the research and its ethical aspects. In addition, there was contact information of a nurse in case the participants needed help and support and my contact information in case they wanted further information. Thereby, the informants learned about their human rights-related participation in this research, such as autonomy, non-maleficence, beneficence and justice (Munhall 1988, Vehviläinen-Julkunen 1993, Firby 1995, Garity 1995, Merrell and Williams 1995, Holloway and Wheeler 1995, Vehviläinen-Julkunen 1997, Kylmä *et al.* 1999, Burns and Grove 2001).

## **Recruiting Participants**

The nurses and the radiographers conducted the initiative recruiting of informants for this research and suggested me as a source for information about this research, approached these patients as potential participants by describing the research to them and by asking their permission for me to meet them in order to gain more information about this research. The patients received the information sheet and my answers to their questions concerning the essential ideas and the different phases of the research so that they could discuss the participation with their spouse. During their next hospital visit, I discussed with the couples and ascertained that they were aware of the guarantee of their voluntariness and anonymity throughout the research process. They were also let know that the taped conversation transcripts for this doctoral dissertation would be typed in verbatim without their names by a qualified radiographer and that the tapes would be stored in a locked place and later destroyed. Further, they were informed of the fact that they could decide a mutually accepted place and time for the conversations. Finally, I asked the patients' and their spouses' permission for this research, and they signed the informed consent forms (Appendix 7).

I gained access for observing the families during the boarding course of psychosocial rehabilitation by receiving the permission from the Cancer Society of Northern Finland. The attending families were informed beforehand about my

role as a staff member and as an observer for this research purpose. Their permission for the use of that kind of data collection method during the boarding course of psychosocial rehabilitation was obtained in advance by the head of the course. In the beginning of the boarding course of psychosocial rehabilitation, I repeated the general information of this research. The attending families were informed of the fact that I was going to write the observational memos and field notes and leave their names out, and that their anonymity was guaranteed all through the writing phase of the dissertation, after which the field notes were to be destroyed. All participants reported that they were aware of their human rights concerning the participation in this research and agreed with my combined role as a staff member and an observer. Moreover, everyone gave their individual permissions for me to do observations.

### **Implementing the Grounded Theory Methodology**

Further ethical considerations rose from the perspective of the grounded theory methodology (Kylmä *et al.* 1999, Chiang and Williams 2001). As data collection and data analysis took place simultaneously in the grounded theory research, and as the research was designed to remain open for generating concepts while keeping preconceptions to minimum, the participants could not be fully informed at the very beginning of the research process, which posed a challenge to me (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin *et al.* 1997, Glaser 1998, 2001, 2003).

Other ethical considerations from the methodological perspective of the grounded theory research related to enduring the unknown and paying attention to constant comparisons, delimiting the interchangeability of indices, saturation, other delimiting, latent patterned relevance, theoretical completeness, theoretical coding when it emerged, theoretical sampling, constant comparisons again, densification levels, discontinuing full descriptive coverage, maintaining the conceptual level, as well as putting in and sorting jots, bits, scripts and paragraphs in the memos. I was able to avoid preconceiving the sorting integration and trusted in the emergence of theoretical code as an organiser of the theory. Additionally, the informants as collaborators wanted to continue conversations up to the saturation of this substantive theory. (Glaser and Strauss 1967, Glaser 1978, 1992, Lowe 1996, Starrin *et al.* 1997, Glaser 1998, 2001, 2003.) I neither adopted (Glaser 2001), *e.g.*, simply the constant comparative method but used the entire package of the grounded theory methodology, nor did I adopt (Glaser 2001), *e.g.*, deduction to the grounded theory methodology nor remodelled the analysis, *e.g.*, towards descriptive qualitative data analysis (Glaser 2001) or towards constructivist orientation (Glaser 2002b), although coding and memoing occasionally seemed tedious. Instead, I paid attention to the difference between conceptualisation and description and between preconceived concepts, problems or frameworks disturbing the data and the emergence of concepts, problems and theoretical codes (Glaser 2002a, 2003).

## 7.4 Possibilities for Using the Discovered Substantive Theory

The purpose of this research was to explore families' living with a parent with cancer and to develop a substantive theory to explain how families solve the main concern in their lives. This resulting theory is a middle range theory (Meleis 1992, Glaser 1998, Liehr and Smith 1999) and provides researchers, health and social care professionals and educators with a greater understanding of perspectives on families' living with cancer. In addition, the general implication of the theory of family survivorship is useful with all other serious diseases and, modified, with less serious diseases and accidents which families confront suddenly and which are life-threatening. In short, stabilising of life may be applied more widely and not only to families who are living with a member with cancer.

The discovered theory of family survivorship with a parent with cancer may be used in *developing the health and social care of families* and in *developing the education of health and social care professionals*. There have recently occurred many developments in individual cancer care for patients (*cf.* Pålsson and Norberg 1995, Corner 1997, Lauri and Mäkinen 1998, Lauri and Sainio 1998, Lauri *et al.* 1998, Jarrett and Payne 2000, Jussila *et al.* 2000, 2001, Andersen 2002, Lauri *et al.* 2002), also from the viewpoint of families and relatives (*cf.* de Lucio *et al.* 2000, Cunningham *et al.* 2003), and further, also from the perspectives of interprofessional co-operation and interprofessional education (*cf.* Hammick and Robertshaw 1999, Hammick and Stone 2003). Regardless of these attempts, there still are areas requiring development in the individual cancer patients' health care (*cf.* Suominen 1994, Berterö *et al.* 1996, Kuuppelomäki and Lauri 1998b, Thorne 1999, Hanson Frost *et al.* 2000, Widmark-Petersson *et al.* 2000, Dow 2003). Moreover, there is lack of caring for cancer patients and their entire families or their relatives (*cf.* Eriksson 1996, Frost *et al.* 1997, Attree 2001, Davis *et al.* 2003, Dow 2003), especially, from the point of view of the interprofessional health and social care and of the health and social care professionals' interprofessional education.

This substantive theory of living in a family of a parent suffering from cancer offers possibilities to promote the stabilising of life in the cancer patients' families by *developing the health and social care of families*. After experiencing a shock due to a family member's falling ill, life in a family begins to stabilise through detaching, fighting, adjusting and submitting. During this stabilising process, the families need help and advice from the health and social care professionals. Pasacreata, Barg, Nuamah and McCorkle (2000) have reported about a family caregiver cancer education programme carried out in Pennsylvania. It focused on symptom management, psychosocial support and resource identification, and it improved the family caregivers' own lives. After attending the programme, the perception of burden did not worsen albeit the caregiving tasks had become more intense. Moreover, the attendants were well-

informed and confident about caregiving after the programme. (Pasacrete *et al.* 2000.) Furthermore, later, a family-based FOCUS programme on the care of women with recurrent breast cancer has been established in the Midwest region of the USA. It discussed the involvement of family, optimistic attitude, effectiveness of coping, reduction of uncertainty and symptom management, and its participants have reported that they were very satisfied with it (Northouse *et al.* 2002b).

In addition, in Australia, the education programme on living with cancer (Roberts *et al.* 2002, Todd *et al.* 2002) has focused both on the individuals diagnosed with cancer and on their families and friends providing the participants with adequate information and support. The findings of a research comprising information received from attendants after participating in the education showed significant improvement in the families' coping abilities, knowledge and the relationships with significant others and with health care professionals. Furthermore, in South Carolina, an intervention programme for children whose parents or grandparents are suffering from cancer (Heiney and Lesesne 1996) was set up in order to increase understanding about cancer and to promote more positive communication regarding the diagnosis within the family. The results of the research conducted among the children taking part in the programme showed that the programme was valuable for the attendants since it gave them the possibility to reflect and express their feelings and to receive information of the disease. Correspondingly, this substantive theory of living in a family with a parent with cancer emerged in this research may be used in developing the contents of family-oriented education programmes in Finland.

The theory of family survivorship in a family with a parent with cancer established in this research presents a challenge to develop the health and social care of families since, for example, the symptoms of significant distress of a healthy child whose parent has been diagnosed with cancer are often overlooked (Johnson 1997). Children may have behavioural problems during the acute stage of their parent's disease and problems that may persist for longer, such as anxiety, sleeping disorders and compulsive behaviour (Huizinga *et al.* 2003). There is also evidence that psychosocial interventions for patients (Meyer and Mark 1995) and their families reduce emotional distress, improve the quality of life, decrease cancer-related pain, lessen anticipatory nausea and vomiting associated with chemotherapy, improve immune parameters and facilitate familial adjustment to the diagnosis and to the treatment of cancer (Fawzy *et al.* 1998). On the other hand, families with cancer frequently report that their needs for information and support are not being met to their satisfaction and there is evidence of prolonged stress and overt psychological morbidity among them (Flanagan 2001). Therefore, *health and social care of families* with cancer should contain elements of the theory of family survivorship and its core category of stabilising of life.

The substantive theory of living in a family with a parent suffering from cancer may be used also in *developing interprofessional education for health and social care professionals* since learning between professions improves

collaboration in practice (Barr *et al.* 1999). It is notable that, in many countries in Europe, there already is an attempt to promote learning to live with cancer in a family from the point of view of interprofessional co-operation with the Training Trainers course which is a pan-European programme (Grahm *et al.* 1999). Paying attention to the interdisciplinary approach in the oncology care continuum from prevention, diagnosis and treatment to end of life in hospital and hospice care settings is needed (Cartwright-Alcarese *et al.* 2003) – already in the education stage of health and social care professionals. It is noteworthy that an interdisciplinary team in Philadelphia is already using an assessment tool in screening families of newly diagnosed paediatric oncology patients for identifying families at potential risk to high-level distress during treatment and for justifying appropriate levels of psychosocial care for them (Kazak *et al.* 2001, 2003). An assessment tool based on this substantive theory of family survivorship would be needed also in Finland for assessing families of a parent suffering from cancer and for carrying out interprofessional care. Since it is evident that interdisciplinary planning is needed, *e.g.*, regarding the disclosure of diagnostic information for the cancer families (Dunniece and Slevin 2000) *interprofessional education for health and social care professionals* would be beneficial from the perspective of stabilising of life in a family of an adult cancer patient.

## 7.5 Suggestions for Future Research

This research examined the main concern of families living with cancer, *i.e.*, stabilising the impact of the disease on their lives, and studied a substantive theory explaining how they are solving the main concern in their lives. This substantive theory presents many challenges for further research on the health and social care of families and the education of health and social care professionals. Since there are only a few studies concerning the families' life with a family member's cancer in Finland, there is a real need for further research in this field. Moreover, research is needed because nowadays more and more cancer patients and their families are actively seeking information, knowledge and support on their own. Suggestions are as follows:

1. The concepts of this substantive theory of family survivorship in a family with a parent with cancer might be used as a basis for the development of an assessment tool regarding the stabilising of life. This assessment tool might be used in health and social care for screening families with cancer patients since it is important to identify families at potential risk belonging to the typology of stabilising of life in order to justify appropriate levels of health and social care for them.

2. The substantive theory of family survivorship may present a basis for the development of a quantitative research instrument which would be helpful in quantitative research in order to measure the typology of stabilising of life among families with a parent with cancer. The results of this quantitative research would be used in planning, carrying out and evaluating health and social care for those families.

3. The established substantive theory of family survivorship should be expanded to a broader spectrum of sudden and life-threatening family problems covering more than diseases. Theoretical sampling should be extended to other types or any kind of problems which families may confront in their lives. These could be economical, financial, cultural and social events which cause a shock and could start the process of stabilising of life. That kind of substantive theory would yield a broader perspective to stabilising of life in a family.

4. The established substantive theory of family survivorship might also be generated to a general, formal theory (Glaser and Strauss 1971, Glaser 1978) which fits in the real world, works in predictions and explanations, is relevant to the people concerned and is readily modifiable. A formal theory of survivorship could be generated by linking this substantive theory both to other substantive theories and to other research data through comparative analysis. A formal theory would then be developed into an integrated formal theory through elaborating relevant conceptual categories, through conceptual properties of categories, through hypotheses relating to these concepts and through emerged theoretical code or codes. (Glaser and Strauss 1971, Glaser 1978.) Thus, the formal theory of survivorship with its core category of stabilising of life would give a wider perspective to reacting to a shock in human life.

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Oulu, August 2004

Aino-Liisa Jussila

# APPENDICES

## APPENDIX 1. Research related to the character of cancer in a family.

Re-searcher/s, Year, Country	The purpose	Research methodology, Data, Data collection method	Main results
Arman <i>et al.</i> 2002 Finland	To study the suffering experience of women with breast cancer as described by those women and their significant others.	A phenomenological analysis, 17 women and 16 significant others, N=33, 49 individual interviews.	”The field of force” in cancer suffering includes subthemes: the ”doubled” suffering, an enduring surrounding and relief from the suffering, the suffering opens questions about life and meaning, the suffering body, and suffering related to healthcare.
Ferrell <i>et al.</i> 2002 USA	To explore quality of life (QOL) in family caregivers of ovarian cancer patients to better define their needs for support.	Content analysis, Family members’ written correspondences, N=1100, sent to a newsletter, <i>Conversations!: The International Newsletter for those Fighting Ovarian Cancer.</i>	Comments by family caregivers reflected little concern for their own physical wellbeing, but focused on the psychological, social, and spiritual aspects of their experiences. Correspondence on the psychological effects of caregiving demonstrated poor QOL stemming from feelings of lack of control and helplessness. Family caregivers lacked support, were given to feelings of isolation, and experienced anxiety regarding the genetic nature of the disease. Spiritual wellbeing was particularly important to them, as they drew strength from their faith and were able to find positive meaning in their experiences.
Miller <i>et al.</i> 2000 UK	To explore cancer attitudes among public and health care professionals.	Meta-analysis of Cancer Attitude Survey (Haley 1968), Cancer Attitude Questionnaire	Despite treatment advances, cancer remains one of the most feared of all diseases, not only among the public but also among oncology health care professionals. However, the practice

		(Hoffmeister 1976), Cancer Belief Scales (Burns 1981), and Cancer Perceptions Vignettes (Slevin <i>et al.</i> 1991, Bremnes <i>et al.</i> 1995, Hailey and Lador 1990, Solodky <i>et al.</i> 1986).	of measuring attitudes is difficult. The link between attitudes and behaviour and also public and professional attitudes towards cancer were discussed. Results give recommendations for the measurement of cancer attitudes in the future.
Richer and Ezer 2000 Canada	To clarify the conceptual definitions of beliefs and meanings.	Concept analysis, Cancer literature.	The terms of beliefs and meanings refer to three different but related phenomena; personal beliefs, existential meaning, and situational meaning, in the context of experiences and culture.
Aro <i>et al.</i> 1999 Finland	To examine the image of cancer and attitudes towards cancer patients among Finnish people.	Statistical analysis, Finnish people, N=1232, Questionnaire.	The image of cancer among the Finnish public is negative, among older people it is even more negative than among younger people. Thus it causes fear of death. Recovery, its character of intensifying togetherness in families and its character of changing values were the main attitudes towards cancer among the Finnish public.
Utley 1999 USA	To discover the different meanings of cancer for older women who are long-term survivors of breast cancer.	The heuristic inquiry, Female survivors, N=8, Interviews; three life history interviews with each participant.	Three meanings of cancer emerged: cancer as sickness and death, cancer as an obstacle, and cancer as transforming.
Taylor 1995 USA	To clarify the conceptual definition of "search for meaning".	Concept analysis, Cancer research studies, N=24.	The meaning of cancer contains casual explanations, responsibility, and significance: reprioritisation of goals, changed lifestyles and values, increased appreciation for nature and others, and spiritual development.
Kristjansson and Ashcroft 1994 Canada	To provide a review of the literature on cancer and the family.	Content analysis of clinical papers, research studies and theoretical writings between 1970-1991, N=200.	Four major dimensions of family cancer experience were identified: developmental stage of the family, cancer illness trajectory, family responses to cancer, and health-care provider behaviour.

**APPENDIX 2. Research related to the condition of a family with cancer.**

<b>Researcher/s, Year, Country</b>	<b>The purpose</b>	<b>Research methodology, Data, Data collection method</b>	<b>Main results</b>
Yin and Twinn 2004 Hong Kong	To explore the effects of cancer on an ill child, parents, and siblings during different stages of the disease.	Content analysis, 13 families; 13 parents, 10 ill children and 11 siblings, N=34, 23 individual and family interviews.	The effects of childhood cancer on Hong Kong Chinese families are: knowing and understanding of the nature of the disease, being truthful about the disease, responding the disease, changing family relationships, and changing the family life during different stages of the disease.
Chien <i>et al.</i> 2003 Taiwan	To evaluate the quality of life among primary caregivers of Taiwanese children with brain tumours and to examine the factors associated with their quality of life.	Statistical analysis, The primary caregivers; 26 mothers, three fathers, and one grandmother, N=30, Questionnaire.	The scores in the physical health and psychological domains for caregivers of children with brain tumours were lower than the norm scores for healthy adults. Caregivers of boys had higher scores in social relationships. Caregivers of children within 5 years of the brain tumour had higher scores in the physical health domain. The child's treatment stage was associated with caregiver scores in the physical health and psychological domains. The caregiver's psychological domain was negatively affected by a low educational level. The health status of caregivers was positively associated with their quality of life in physical health, psychological status, social relationships, and environmental domains.
Helseth and Ulfset 2003 Norway	To explore the well-being and coping of young children during the period of cancer of their parents.	A phenomenological-hermeneutical analysis, 10 families; 20 parents with 11 children, N=31, 56 individual interviews.	Four major themes emerged: illness ruling in the family, reactions over and under the surface, many efforts to manage the situation, and feeling good most of the time. By going "in and out" of the situation, both literally and emotionally, the children cope with the situation and maintain a balance in life. The children reported "feeling good", but they put a lot of effort into it, and their quality of life appeared to be fragile. Their well-being was especially vulnerable at the time of the diagnosis and when the illness situation changed.
Hill <i>et al.</i>	To examine the	Statistical	Adult survivors were more likely than

2003 UK	role of relationships with parents as a possible mediating factor of psychosocial functioning among adult survivors of childhood cancer.	analysis, 102 adult survivors of childhood cancers and 102 matched controls aged 19-30 years, N=204, Standardised interview.	controls to have impaired close relationships, and poorer day-to-day coping. Lower encouragement from fathers and greater involvement with mothers were each independently associated with impaired close relationships outside the family. This association was evident across the sample and in the cancer survivor group. It was much stronger among young adult females. Lower paternal encouragement was also associated with poor day-to-day coping, and this association was stronger in young men. There was little evidence that quality of relationships with parents mediated the link between childhood cancer and adult psychosocial functioning.
Chalmers <i>et al.</i> 2002 Canada	To describe the information and support needs of women whose primary relative has breast cancer.	Statistical analysis, Female relatives, N=261, Questionnaire.	The women perceived that their information and support needs were not well met. Highly rated needs were related to information about personal risk of breast cancer, to risk factors for breast cancer and to early detection measures.
Eriksson and Lauri 2000a Finland	To find out what cancer patients' relatives think about the actions of health care professionals in providing informational and emotional support.	Statistical analysis, Relatives of cancer patients, N=168, Questionnaire.	The importance of informing relatives about the patient's illness was clearly highlighted. However, less than one-third of the relatives said they received much information. Relatives' need for emotional support was clearly at a lower level than their need for information. Even so, only very little support was provided in relation to relatives' needs.
Fleeman <i>et al.</i> 2000 USA	To determine the needs of children with brain tumours and their parents and siblings during the different stages of illness.	Content analysis, 7 families; 7 ill children, 24 parents / adult caregivers, 19 siblings, N=50, 11 focus groups.	Four categories were identified as important: interaction with healthcare providers, medical information/education, healthcare utilisation and treatment, and psychosocial issues. The needs of family members differed at various stages of the illness.

**APPENDIX 3. Research related to family caregiving in the context of cancer.**

<b>Re-searcher/s, Year, Country</b>	<b>The purpose</b>	<b>Research methodology, Data, Data collection method</b>	<b>Main results</b>
Carter 2003 USA	To describe sleep quality and depressive symptoms over time in family caregivers of patients with advanced cancer.	Statistical analysis, Family caregivers, N=10, 10 weeks study period, Questionnaire and for 3 days during weeks 1, 5, and 10: sleep log books + an Actigraph sleep watch.	Individual caregiver sleep and depression plots showed large variance over time. Discrepancies were noted between the Actigraph sleep watch for the measurements of sleep patterns and sleep quality latency, duration, and efficiency scores. Sleep and depressive symptoms fluctuated widely over time, and sleep quality and depressive symptoms were affected by several internal and external factors such as patient disease status, patient symptoms, and caregiver anxiety. Self-reports of sleep and depression appeared to underestimate problems.
Proot <i>et al.</i> 2003 The Netherlands	To explore the family caregivers' experiences, needs for home care, and which health services they receive.	Grounded theory, Family caregivers, N=13, Interview.	Vulnerability was characteristic of caring for a terminally ill person at home and required continuous balancing between care burden and capacity to cope. Factors having the potential to increase the caregiver's vulnerability were care burden, restricted activities, fear, insecurity, loneliness, facing death, and lack of support. Continuing previous activities, hope, keeping control, satisfaction and good support were factors which decreased the caregiver's vulnerability. The family caregivers' needs for professional home care included the dimensions of instrumental, emotional and informational support. Availability of care, aids, and continuity of care were essential to enable terminally ill people to stay home.
Wennman-Larsen and Tishelmann, 2001 Sweden	To explore how family caregivers reason about their expectations of providing end-of-life care at home for a relative with	Content analysis, Family caregivers, N=11, Interview.	Role transition in becoming a family caregiver and the transition to a new life situation of the caregiver were the main areas. Caregivers described themselves as the persons primarily bearing responsibility and providing care for their dying relative. They had many concerns about their own

	cancer.		situation, especially after the death of the relative. Professional support for care-related tasks and hope for other areas were expected sources of help to the concerns.
Bakas <i>et al.</i> 2001 USA	To describe family caregivers' perceptions of time spent and difficulty experienced with performing specific caregiving tasks for patients with lung cancer, and to compare adult child and spousal caregivers in relation to time and difficulty of tasks.	Statistical analysis, Family caregivers, N=78, Structured interview.	The most time-consuming tasks for adult children and spouses were providing emotional support, transportation, and monitoring symptoms. The most difficult duties were emotional support, behavioural management, monitoring symptoms, and household tasks. Time and difficulty of tasks did not differ significantly between adult child and spousal caregiving.
Ayres 2000a and 2000b USA	To investigate the meaning in accounts of family caregiving.	Hermeneutic and narrative analyses, 36 caregivers and their 44 care recipients, N=80, Semi-structured interview.	The narratives of family caregiving were stories of ideal lives, stories of normal or ordinary lives, and stories of lives compromised by caregivers. Caregivers' process of making meaning included expectations, explanations, and strategies.
Schumacher <i>et al.</i> 2000 USA	To develop the concept of family caregiving skill.	Grounded theory, 30 patients and their 29 primary caregivers, N=59, 130 individual interviews.	Family caregiving skill was defined as the ability to engage effectively and smoothly in the processes of monitoring, interpreting, making decisions, taking action, providing hands-on care, making adjustments, accessing resources, working together with the care receiver, and negotiating with the health care system. Family caregiving skill was a blend of previously developed skills, such as problem-solving, organisational and interpersonal skills, and newly developed skills for illness management. It also was involved integrating knowledge about the ill person, including identity, concerns, and personal history, with knowledge about the specifics of illness care, and - it developed over time and with experience.

Allen <i>et al.</i> 1999 USA	To identify factors associated with nominating one's spouse as caregiver in a crisis situation related to cancer and to evaluate the usefulness of helper selection theories in understanding the caregiver selection process.	Statistical analysis, Married women and married men with advanced stage cancer, N=353, Questionnaire.	Wives are only one third as likely as husbands to select their spouses as caregivers, and spouses who name their mates as confidants are three times more likely than those who do not to also name them as caregivers. Although gender role norms are key to caregiver selection, the intimacy inherent in caregiving role renders an emotionally close marriage an important criterion to the selection of spouse as caregiver.
Chan and Chang 1999a Hong Kong	To understand the perceived difficulty in managing caregiver tasks among family caregivers of terminally ill cancer patients.	Statistical analysis, Family caregivers, N=29, Questionnaire.	The level of difficulty in handling the direct care, intrapersonal tasks, and interpersonal ties were similar. The individual tasks identified as extremely difficult include compensation of personal time, updating knowledge of reimbursement mechanism, and emotionally accepting the likelihood of a progressive downward course of illness. The caregivers who had a shorter duration of caregiving experience perceived significantly greater difficulty in direct care, intrapersonal tasks, and overall tasks. Thus counselling and support are needed.
Chan and Chang 1999b Hong Kong	To examine family caregivers' experiences of stress symptoms and its relationship with perceived difficulty in managing caregiver tasks.	Statistical analysis, Family caregivers, N=26, Questionnaire.	More stress symptoms were experienced by caregivers who had reported increased difficulty in managing caregiver tasks. Psychological stress symptoms, rather than physical symptoms, overwhelmed most of the caregivers. There were significantly more negative responses to stress by caregivers who had a shorter duration of experience in providing care.
Williams <i>on et al.</i> 1998 USA	To examine active restriction and prior relationship history as contributors to mental health outcomes in spousal caregiving.	Statistical analysis, 75 cancer patients and their 75 spousal caregivers, N=150, Questionnaire.	If the relationship had been mutual in the past, activity restriction was predicted by intimacy and affectional loss, and in turn predicted caregiver depressed affect. Among caregivers in less mutual relationships, activity restriction was predicted by severity of patient symptoms, and in turn predicted resentment of care recipients and the caregiving role.

**APPENDIX 4. Research related to a family with cancer as a patient.**

<b>Researcher/s, Year, Country</b>	<b>The purpose</b>	<b>Research methodology, Data, Data collection method</b>	<b>Main results</b>
Grinyer 2004 UK	To discover what practices and procedures make the cancer journey easier or more difficult to manage for parents in the medical setting.	Narrative method, Parents of 28 families, N=56, Narratives.	Interaction with health professionals have a far-reaching effect on patients' experience. If parents feel excluded, or uninformed about procedures, or believe that their son or daughter is receiving less than optimum care, this results in feelings of helplessness and frustration.
Kristjanson <i>et al.</i> 2004 Canada	To elicit detailed descriptions of adolescents' information and support in response to their mothers' breast cancer.	Grounded theory, Adolescents, N=31, 27 semi-structured interview and two focus groups.	Most of the adolescents reported that their needs were poorly met both within and outside the family. Support needs were described in terms of types, sources, forms, and effects. Information needs were described according to content, sources, the importance of timing, and the ways that information was communicated. The emotional impact of breast cancer on adolescents was significant. Assessment of the needs of adolescents and their families was minimal. Specific interventions are needed to address children of cancer patient.
Persson <i>et al.</i> 2004 Sweden	To illuminate spouses' perceptions of living with a partner who had been diagnosed with rectal cancer followed by surgery resulting in a stoma.	Content analysis, Spouses, N=9, Two focus groups with two meetings.	Five themes emerged: difficulties of being involved, living with uncertainty, learning to live in a new way, the altered body, and the search for explanations. There were feelings of anxiety about the partner's serious condition and the possible spread of cancer. After the rehabilitation period, the stoma influenced the spouses' lives in many ways but they coped with the problems together with their partners and helped them adapt to their changed circumstances.
Zebrack <i>et al.</i> 2004 USA	To evaluate and compare psychological	Statistical analysis, 1101 survivors	Higher levels of distress among survivors and siblings were associated with female sex, low household income, lower educational

	outcomes in long-term survivors of pediatric brain cancer and siblings of childhood cancer survivors, and to identify significant correlates of psychological distress.	and 2817 siblings, N=3918, Questionnaire.	attainment, being unmarried, not being employed in the past 12 months, and poor physical health status. Cancer treatment does not appear to contribute directly to increased psychological distress. Instead, distress appears to be associated with diminished social functioning that may be related to cancer type or treatment.
Ferrell <i>et al.</i> 2003 USA	To examine the roles of oncology nurses improving quality of care for cancer survivors.	Literature review, Relevant textbooks, journals, different key documents.	Ten critical content areas of cancer survivorship were used: description of population of cancer survivors, primary care, short- and long-term complications, prevention of secondary cancers, detecting recurrent and secondary cancers, treatment of recurrent cancers, quality-of-life issues, rehabilitative services, palliative and end-of-life care, and quality of care. Oncology nursing has had significant contributions over the past two decades to the area of cancer survivorship, especially in patient care and family support.
Echlin and Rees 2002 UK	To identify the information needs and information-seeking behaviours of men with prostate cancer and their partners.	Literature review, Relevant papers (the information needs or information-seeking behaviours of men with prostate cancer and/or their partners) published between 1990 and 2000, A literature search using	Men with prostate cancer have distinct information needs and information-seeking behaviours throughout their cancer journeys. Although there is considerable variation in the amount and type of information that men require, the majority of men with prostate cancer are satisfied with the information they receive. Although partners of men with prostate cancer have needs for information, these needs are often unmet. Partners undergo an information-seeking pattern that is comparable with, if not more active than, patients' information-seeking behaviours.

		Medline, CINAHL, PsychLIT, BIDS.	
Feldman- Stewart <i>et al.</i> 2001 Canada	To determine the questions that family members of recently diagnosed early-stage prostate cancer patients want addressed and to compare their information priorities with the patient's priorities.	Statistical analysis, 38 patients and 22 family members, N=60, Questionnaire.	Many families of patients with early-stage prostate cancer want a large amount of information. However, exactly which questions are important to an individual varies a great deal from one family member to another. Patient information needs do not generally predict the family's needs very well. Thus, answering a patient's questions may not necessarily answer his family's questions. With such wide variation between family members, to ensure that each family member receives the information needed or desired, one could resort to a strategy of providing all information to everyone. The other strategy is to be as efficient and as effective as possible, and start by addressing the core questions that the majority of the family members want to be answered.
Åstedt-Kurki <i>et al.</i> 1999b Finland	To find out how families experience the hospitalisation of one family member and to chart the participation of the family in the treatment of the hospitalised family member.	Statistical analysis, Family members, N=70, Questionnaire.	There were a variety of negative sentiments in families, such as worry, fear, shock, anxiety and depression at the hospitalisation of their family member. The families also expressed approval, relief, and faith in the help given. Nearly 80% of the families' statements dealt with emotional responses. Changes in the everyday life were also reported. Hospital visits gave a rhythm to family life. There were changes in the sharing of housework and taking care of affairs, and relationships within the family. Family members felt loneliness, fear, and longing. Helping the patient in hospital involved functions like participation in nursing care. Only 20% of statements dealt with emotional support for the patient.
Benson and Britten 1996 UK	To discover cancer patients' views about disclosure of information to their family,	Content analysis, Patients, N=30, Semi-structured	Subjects favoured openness with their family but most rejected unconditional disclosure of information without their consent and their family influencing what information they would be given. They valued respect for their autonomy more highly than beneficence and

	<p>their family's influence over the information given them, and their preferences for doctors' behaviour if they and their family disagree, as a complement to applied ethical theory.</p>	<p>interview.</p>	<p>considered that their own needs took priority over those of their family.</p>
<p>Arraras <i>et al.</i> 1995 Spain</p>	<p>To assess the knowledge status of patients on the oncology ward, to determine the opinion of lay people with no direct experience of cancer about the provision of diagnostic information, and to compare data from these samples.</p>	<p>Statistical analysis, 89 patients and 78 lay people, N=167, Questionnaire.</p>	<p>Two factors were found to be predictive of knowing status among the patient group, including primary tumour site, and family's wish for the diagnosis to be withheld. Age and educational level were found to be predictive of attitudes towards "truth telling" among the general population sample. These results indicate a clear wish for greater knowledge among "potential" patients. Although the family will certainly continue to play a central role in health care, there are early signs of the desired trend towards greater diagnostic disclosure by families.</p>
<p>Nelson <i>et al.</i> 1994 UK</p>	<p>To determine whether the children of cancer patients experience problems and anxieties related to the parent's diagnosis and treatment.</p>	<p>Statistical analysis, Adolescents, N=24, Semi-structured interview and self-report questionnaire.</p>	<p>Some of the children experienced problems and anxieties related to their parents' cancers that affected their school lives, sports and leisure activities, family lives, and relationships. Factors with high anxiety score were: inability to discuss the patients' illness with parents, having to spend less time with friends, having to spend less time on sports and leisure activities, deterioration in schoolwork, and continuing anxiety over the parent's illness.</p>

**APPENDIX 5. Research related to caring for a family with cancer.**

<b>Researcher/s, Year, Country</b>	<b>The purpose</b>	<b>Research methodology, Data, Data collection method</b>	<b>Main results</b>
Uitterhoeve <i>et al.</i> 2003 The Netherlands	To describe the problem areas in the care of patients who are receiving chemotherapy as perceived by patients and professional caregivers, and to explore differences between their perceptions.	Statistical analysis, 120 patients, 42 medical specialists, 68 oncology nurses, N=230, Questionnaire.	Patients were satisfied with the medical and nursing care they received. Professional caregivers perceived the experience of patients with chemotherapy differently than patients, <i>eg.</i> patients perceive chemotherapy as reassuring that something is being done, whereas caregivers think that patients experience chemotherapy as something to fear or be anxious or uncertain about. It seemed that professional caregivers are more prone to act upon the medical-technical aspects of the treatment than to act on psychosocial side of the treatment.
Åstedt-Kurki <i>et al.</i> 2001b Finland	To generate knowledge of the interaction between an adult patient's family members and nursing staff from the staff's perspective.	Statistical analysis and content analysis, Staff members, N=155, Questionnaire.	Staff members perceived interaction with the patient's relatives as fairly important, and the interaction most often denoted personal discussion with relatives on the ward in the evenings. Only one-third felt that it is possible to interact with relatives at any time of the day. Discussions with significant others often took place in the patient's presence, and the staff felt that it was important. Sometimes discussions, such as the relatives' own coping or the patient's poor condition, took place in the patient's absence. Discussions primarily pertained the patient's condition, discharge from hospital and planning of continued treatment. The majority reported that the opportunity for discussion was offered by staff. The patient's positive attitude towards discussion with the family and family members' own interest facilitated interaction.
Åstedt-Kurki <i>et al.</i> 2001c Finland	To ascertain health care providers' perspectives about interaction with patients' family	Statistical analysis, Health care providers, N=320, Questionnaire.	The interaction with the patient's family was seen to be important. Family members were primarily seen as informants of the patient's condition and family condition, and the interaction was marked by dissemination of information. The support provided by family

	members.		members to the patient was also seen as important. The interaction with hospital staff was mainly initiated by a family member.
Eriksson 2001 Finland	To find out what cancer patient's relatives regard as important factors of patient care.	Statistical analysis, Relatives, N=168, Questionnaire.	The relatives regarded both the content of care and the way in which it was provided as important. The most important factors were the professional skill and trustworthiness of staff members and the safety of care. Relatives regarded information about the patient's prognosis as less necessary than information about the patient's cancer, treatment and its side-effects. Relatives were generally pleased with the standards of care received by patients. Satisfaction with the actions of health care professionals was highest on the dimensions of professionalism, professional skill, and friendliness.
Eriksson and Lauri 2000b Finland	To find out how important it is for relatives to take part in cancer patients' care and to what extent they do take part.	Statistical analysis, Relatives, N=168, Questionnaire.	The most important aspect of relatives' participation was supporting the patient emotionally. Providing concrete care and participation in decision-making were both considered less important. Relatives did not take part in discussions about care, nor were they informed about such a possibility.
Radwin 2000 USA	To analyse theoretically oncology patients' perceptions of the attributes and outcomes of quality nursing care.	Grounded theory, Patients, N=22, Interview.	Excellent care was characterised by professional knowledge, continuity, attentiveness, co-ordination, partnership, individualisation, relationship, and caring. Quality nursing care included increased fortitude and a sense of well-being with its constituents of trust, optimism, and authenticity. These indicate how oncology patients experience "being well cared for".
Rustøen <i>et al.</i> 2000 Norway	To describe what domains in quality of life were considered most or least important by patients with newly diagnosed cancer and the change of the importance during a 9-month period.	Statistical analysis, Patients, N=131, Questionnaire.	Items related to family matters were rated as most important, while faith in God was reported to be of least important. The patients fluctuated somewhat in terms of what was most important to them during the study period. The most unstable items tended to be less important over time. Results showed significant differences in the importance of quality of life domains according to gender, age, educational level and cohabitation.

Rustøyen <i>et al.</i> 1999 Norway	To examine which domains of quality of life are most strongly affected in patients with newly diagnosed cancer, and to examine if quality of life was related to gender, age, educational level, cohabitation, time since diagnosis, treatment or type of cancer.	Statistical analysis, Patients, N=131, Questionnaire.	Those cohabiting had significantly higher quality of life compared with those living alone. The younger group living alone had significantly lower quality of life than the older groups living alone. Although age was only significantly associated with quality of life in one sub-scale, the elderly people reported their quality of life to be better in almost all sub-scales. Time since diagnosis was not associated with quality of life, while treatment was associated with quality of life. Gender and educational level were only associated with one or two domains in quality of life.
Åstedt-Kurki <i>et al.</i> 1997 Finland	To explore the experiences of family members in their role of relative in a situation where a next of kin has been admitted to hospital.	Statistical analysis, Family members, N=70, Questionnaire.	Family members spent a lot of time with their relatives in hospital. Families had received most support in the form of information about the patient's care and treatment. Family members' opportunities to talk with doctors were poor, but about half of respondents were able to meet nurses and talk with them. Almost half of the family members needed help from nurses and over one third from the doctors. Family members' experiences of visiting the hospital were good.
Eriksson 1996 Finland	To chart the perceptions of relatives and nurses regarding the importance and realisation of actions by health care professionals which promote the adjustment of cancer patients' relatives, and to clarify the adjustment of relatives to their present life situation.	Statistical analysis, 168 relatives and 143 nurses, N=311, Questionnaire.	It was important to give information related to the patient's illness to relatives. They did receive very little information. Relatives' need for emotional support was clearly smaller than their need for information. There was very little support provided in relation to relatives' needs. Relatives mostly participated in the patient's care by supporting the patient emotionally. Performing concrete care activities and participating in decision making on the patient's care were noticeably more rare. These were also considered less important than supporting patient emotionally. Both relatives and nurses felt that the content of the health care professionals' action and their way of performing the action were important in the patient's care, and they were realised well. Relatives total adjustment was moderate.

## **APPENDIX 6. The information sheet.**

### **Dear participant,**

I would like to ask you to take part in a study on families' living with a parent with cancer for a doctoral dissertation. The results will be utilised in developing the care of the families.

I would like to interview you and your spouse three to four times during the different phases of being ill. The interviews will be taped. The raw data will be dealt with in strict confidence. The results will be published so that individual informants, their opinions or families cannot be recognised. The writer of this study has obtained the permission from the head of the Oncology Clinic of the Oulu University Hospital, Professor Taina Turpeenniemi-Hujanen, and the Ethical Committee of the Medical Faculty in the Oulu University. Your decision of either participating in this study or refusing will have no effect on the quality of your treatment or the attitudes of the hospital personnel towards you. The interviews will not be played or their contents disclosed to the personnel. Your participation is entirely voluntary.

I sincerely hope that you will take part in this study and thereby in developing the care of the patients and their families.

Should you want further information, please contact Professor Päivi Åstedt-Kurki, University of Tampere (details).

### **Thanking you in anticipation for your co-operation.**

---

Aino-Liisa Jussila  
(details)

**APPENDIX 7. The consent form.**

**CONSENT TO STUDY**

I agree to participate in the study on Families' Living with a Parent with Cancer during the Different Phases of Being Ill.

I am aware of the purpose and the implementation of the study as well as of the matters relating to treating the raw data.

Furthermore, I am aware that my privacy will remain intact and that I may withdraw from the study at will.

Place \_\_\_\_\_ Date \_\_\_\_\_

\_\_\_\_\_  
Signature.

## **APPENDIX 8. An example of conversation themes with the family 1.**

### **The 1<sup>st</sup> conversation; Themes:**

- Appearing of symptoms, as well as the viewpoint of the spouse and the children on the appearing of symptoms
- The patient's state / the state of the spouse and the children at the moment
- Integrating the family's life and the disease

### **The 2<sup>nd</sup> conversation; Themes:**

- The patient's state / the state of the spouse and the children at the moment
- Changes in the patient's state / the state of the spouse and the children since the previous conversation
- Integrating the family's life and the disease

### **The 3<sup>rd</sup> conversation; Selective coding conversation; Themes:**

- The patient's state / the state of the spouse and the children at the moment
- Changes in the patient's state / the state of the spouse and the children since the previous conversation
- Integrating the family's life and the disease
- Maintaining of hope
- Living trustingly
- Changing of the concept of self
- Progressing of recovery
- Continuing the habituated life

### **The 4<sup>th</sup> conversation; Selective coding conversation continues; Themes:**

- The patient's state / the state of the spouse and the children at the moment
- Changes in the patient's state / the state of the spouse and the children since the previous conversation
- Maintaining of hope:                      Awakening of hopes of recovering  
  Dispelling concerns  
  Thinking optimistically
- Living trustingly:                         Prevailing of equilibrium  
  Evicting concerns  
  Trusting in the future
- Changing of the concept of self:        Changing of life values  
  Spiritual growing  
  Reinforcing self-esteem
- Progressing of recovery:                 Becoming motivated in self care  
  Increasing of treatment satisfaction  
  Restoring the zest of life  
  Facilitating of life
- Continuing the habituated life:         Resuming the former life  
  Maintaining the same relationships  
  Continuing with everyday routines

## **APPENDIX 9. The analytic rules.**

1. Start sorting from the beginning.
2. Sort categories and properties only as they relate to the basis of the core category of stabilising of life. Write memos at the same time and sort them.
3. Pay attention to theoretical codes and figure out the relation of a concept to the core category. Write memos about theoretical codes and sort them.
4. Stop sorting and write memos as necessary.
5. Integrate memos by asking each of them "Where does this fit in?"
6. If a memo does not fit, do not force.
7. Sort memos as soon as it is possible.
8. Map out the relationships among the categories as they emerge.
9. Create a mechanics of sorting for reaching theoretical completeness.
10. Look for the "big picture" of what is going on in families with a parent with cancer concerning stabilising of life.

## APPENDIX 10. The categories and the properties of maintaining of hope.

The stage of the subcore category	The categories	The properties of the categories
Maintaining of hope	Awakening of hopes of recovering	Being aware of the recovering Living on the patient's terms Being encouraged by the treatment results Trusting in the improved reputation of cancer
	Dispelling concerns	Gradual advancing Viewing the future positively Trusting in the shared life Life becoming brighter Using humour Anticipating the future
	Thinking optimistically	Pulling through honourably Trusting in recovering Searching for positive aspects Turning negative aspects into positive Distinguishing between great and small problems Avoiding of grieving in advance Emphasising of optimism

## APPENDIX 11. The categories and the properties of living trustingly.

The stage of the subcore category	The categories	The properties of the categories
Living trustingly	Prevailing of equilibrium	Trusting in the treatments Living the day “to the full” Maintaining the mental balance Occasionally forgetting the disease Disappearing of the disease’s sensation value Receiving future from God
	Evicting concerns	Minimalising the time for consideration Detaching from the circumstances of being ill Focusing thoughts and attention elsewhere Avoiding of isolating
	Trusting in the future	Yielding of conceding Trusting in recovering Increasing of gratitude Seeing past the present

**APPENDIX 12. The categories and the properties of changing of the concept of self.**

The stage of the subcore category	The categories	The properties of the categories
Changing of the concept of self	Changing of life values	Concentrating on the family Looking after one's health Clarifying of the outlook on life
	Spiritual growing	Becoming independent Increasing of openness Realising the uniqueness of health Increasing empathy Learning humility Assuming a more relaxed attitude towards life Searching for the purpose of being ill
	Reinforcing of self-esteem	Replanning life Managing in everyday life Realising a dream

**APPENDIX 13. The categories and the properties of progressing of recovery.**

The stage of the subcore category	The categories	The properties of the categories
Progressing of recovery	Becoming motivated in self care	Appreciating the treatment Avoiding exertion Tending to side-effects Comparing forms of treatment Taking care of personal well-being
	Increasing of treatment satisfaction	Consoling in the early diagnosis of the disease Being aware of the importance of screenings Consoling in the immediate starting of treatments Being relieved for receiving treatment Emphasising positive treatment results Giving positive feedback
	Restoring the zest of life	Improving of physical condition Sensing the recovery Getting past of being ill Becoming interested in everyday matters Regaining concentration skills Keeping up high spirits Striving to get away from the disease
	Facilitating of life	Surviving for the sake of the close ones Getting by with support Comforting in speaking

**APPENDIX 14. The categories and the properties of continuing the habituated life.**

The stage of the subcore category	The categories	The properties of the categories
Continuing the habituated life	Resuming the former life	Overcoming the worst phase Managing to avoid loss Managing to avoid late side-effects Normalising of life Sparing the family members from difficulties
	Maintaining the same relationships	Maintaining an intimate relationship Maintaining the same family connections Maintaining the same attitudes by the close ones
	Continuing with everyday routines	Taking part in everyday life Filling the life with activities Keeping the life stable Continuing the former life

**APPENDIX 15. The categories and the properties of deliberating about falling ill.**

The stage of the subcore category	The categories	The properties of the categories
Deliberating about falling ill	Becoming confused by the disease	Becoming surprised by the disease Lacking the feeling of being ill Assuming an uncomprehending attitude towards the disease
	Seeking for reasons for falling ill	Pondering on the factors causing the disease Grieving over falling ill Posing questions

**APPENDIX 16. The categories and the properties of rebelling against the change in life.**

The stage of the subcore category	The categories	The properties of the categories
Rebelling against the change in life	<p>Deliberating about the life becoming more difficult</p> <p>Criticising the treatment</p>	<p>Envyng health</p> <p>Struggling against falling ill</p> <p>Doubting one’s own decisions</p> <p>Feeling guilty about falling ill</p> <p>Questioning the necessity of treatment</p> <p>Criticising the timing of the treatment</p> <p>Criticising the chosen line of treatment</p> <p>Expressing wishes for changes in the treatment</p> <p>Criticising the actions of the health care personnel</p> <p>Complaining about the lack of complementary therapy</p>

**APPENDIX 17. The categories and the properties of overcoming adversities.**

The stage of the subcore category	The categories	The properties of the categories
Overcoming adversities	Taking responsibility of one's own treatment	Acting in the limits of endurance Seeking different treatment alternatives Turning to complementary therapy
	Creating a fighting morale	Clarifying the common goal Inspiring togetherness Maintaining the unity Wishing for an understanding and helpful attitude
	Processing the worries	Hoping for another diagnosis Blocking the bad news in advance Erasing problems independently
	Blocking out the disease	Appreciating the certainty of healing Blocking out the possibility of the recurrence Preventing the disease from taking the upper hand

**APPENDIX 18. The categories and the properties of preparing for worse.**

The stage of the subcore category	The categories	The properties of the categories
Preparing for worse	Getting accustomed to the after-effects of the treatments	Becoming conscious of hormonal changes Getting accustomed incapacitation Adapting to the changes in self-image
	Preparing for a decline in the patient's condition	Anticipating mental collapse Foreseeing the failing of health Realising the recurrence possibility of the disease

**APPENDIX 19. The categories and the properties of ensuring the functionality.**

The stage of the subcore category	The categories	The properties of the categories
Ensuring the functionality	Securing the future	Combining treatments, childcare and work Emphasising the coping of the children Worrying over the children's lives Preparing for the death of the patient
	Bearing responsibility	Caring for the coping of the family members The helped turning into the helper Preventing the anxiety of the family members Providing for the family
	Protecting the close ones	Avoiding complaining Sparing the family members from emotional upset Keeping the disease secret Refusing pity
	Rationalising the facing	Focusing on the essentials of disease Avoiding to think about falling ill Preventing the fear of death
	Adopting a new way of spending time	Altering the family members' participation in everyday life Increasing co-operation Giving time for the family members

**APPENDIX 20. The categories and the properties of clarifying of facts.**

The stage of the subcore category	The categories	The properties of the categories
Clarifying of facts	Becoming clear of the nature of the disease	Taking the treatment seriously Investing in bravery Becoming serious in face of the disease
	Living in realities	Conforming to the disease Acknowledging the limited scope of future Living according to the situation Being annoyed at excessive optimism Reserving time for adjusting

**APPENDIX 21. The categories and the properties of resorting to help.**

The stage of the subcore category	The categories	The properties of the categories
Resorting to help	Feeling relieved for human contacts	Receiving help Cheering up through friendship Feeling encouraged by fellow sufferers
	Leaning on the philosophy of life	Relying on faith Conversing with higher powers
	Gathering up the family's resources	Leaning on individual strengths Laying stress on empathy Striving for the unity of the family
	Calming down due to professional help	Trusting in knowledge Negotiating about the treatments Finding relief in reasoning

## APPENDIX 22. The categories and the properties of returning to life.

The stage of the subcore category	The categories	The properties of the categories
Returning to life	Accustoming to changes in life	Accepting the emerging of hardships Experiencing the fluctuating of feelings Processing the changing of everyday life
	Being perplexed by the ending treatment	Becoming exhausted of the of the treatments Experiencing insecurity Receiving a new life
	Attaching to the present	Living in the present day Ignoring the disease Striving for tomorrow Acting like a robot Proceeding from treatment to treatment
	Processing being ill	Processing the reputation of the disease Receiving the facts Comparing with fellow sufferers Monitoring the recuperating

## APPENDIX 23. The categories and the properties of intensifying of togetherness.

The stage of the subcore category	The categories	The properties of the categories
Intensifying of togetherness	Strengthening of the intimate relationship	Showing affection Deliberating about the changes regarding sexuality Deepening of love
	Unifying of the family	Strengthening of family ties Adjusting to a new way of life Harmonising decision-making
	Coming closer of the immediate circle	Restoring the former situation Giving assistance Showing attention

## **APPENDIX 24. The categories and the properties of maturing through hardships.**

The stage of the subcore category	The categories	The properties of the categories
Maturing through hardships	Maintaining the equilibrium	Emphasising important issues Striving for inner harmony Preparing for the future Understanding emotions
	Looking after oneself	Cherishing health Rearranging commitments Appreciating recuperating
	Accepting the circumstances	Rejoicing for extra time Valuing life Realising the possibilities

## **APPENDIX 25. The categories and the properties of life coming to a standstill.**

The stage of the subcore category	The categories	The properties of the categories
Life coming to a standstill	Being paralysed by falling ill	Being shocked by falling ill Internalising falling ill Taking falling ill as a warning
	Being appalled by the adverse reputation of the disease	Hearing bad news Keeping silent about the disease Resenting gossiping about the disease Reminiscing about the deceased among the immediate relatives Doubting the recovering
	Being upset by the gravity of the disease	Panicking Experiencing moments of weakness Recurrent awakening to the disease Experiencing fear of death Deliberating about the way to die

## APPENDIX 26. The categories and the properties of succumbing to fear.

The stage of the subcore category	The categories	The properties of the categories
Succumbing to fear	Dreading the treatments	Fearing the forms of treatment Fearing the meeting of the treatment limit Fearing the follow-up examinations
	Being afraid of being ill	Anticipating the disease's becoming aggravated Realising the heredity of the disease Spreading of the feeling of fear Becoming stressed by fear Fearing mental collapsing Lacking confidence in recovering
	Fearing the reactions of the immediate circle	Being afraid of being blamed Being afraid of being rejected Being afraid of labelling

## APPENDIX 27. The categories and the properties of being burdened by concerns.

The stage of the subcore category	The categories	The properties of the categories
Being burdened by concerns	Realising the criticality of the condition	Sensing the gravity of the disease Reacting strongly to the disease Becoming stressed by falling ill
	Accumulating of hardships	Becoming concerned about the patient's condition Becoming anxious about the well-being of the close ones Doubting the efficiency of the treatments Being concerned about work issues Being concerned about the economic situation

**APPENDIX 28. The categories and the properties of life turning more difficult.**

The stage of the subcore category	The categories	The properties of the categories
Life turning more difficult	Everyday life becoming burdensome	Receiving too much information Becoming stressed by child care Becoming stressed by housework Becoming impatient Being annoyed at the news value of the disease
	Intimate relationship drifting into a crisis	Ensuing of guilt Owing a debt of gratitude Supporting becoming more difficult Understating the symptoms Becoming stressed by threats Weakening of self-esteem
	Family members' becoming depressed	Being dejected by the disease Becoming anxious about the disease getting the upper hand Spreading of the feeling of being ill
	Breaking down of the immediate circle	Feeling the ruthlessness of the disease Losing contact Being discouraged by the disease

**APPENDIX 29. The categories and the properties of getting caught in being ill.**

The stage of the subcore category	The categories	The properties of the categories
Getting caught in being ill	Staying in the shadow of the disease	Endless deliberating about the reasons for falling ill Constant monitoring of the condition Being disappointed at sympathy
	Becoming exhausted of the disease	Growing tired of feeling weak Being frustrated about recovering Being disappointed at complaining Growing tired of talking Avoiding others Growing tired of the role of the patient Deliberating about committing to the family
	Submitting to destiny	Waning of mental strength Being discouraged by a metastasis Disappearing of self-evident facts
	Life's filling with the disease	Being trapped by the disease Losing strength Disease tightening its grasp

**APPENDIX 30. Research related to family survivorship with cancer.**

<b>Researcher/s, Year, Country</b>	<b>The purpose</b>	<b>Research methodology, Data, Data collection method</b>	<b>Main results</b>
Inoue <i>et al.</i> 2003 Japan	To investigate the relationship between breast cancer patients' coping response to the diagnosis of cancer and family functioning.	Statistical analysis, 46 families; dyads of parents, N=92, Questionnaire.	Patients' perception of poor family functioning in the area of communication correlated with high helplessness/hopelessness score, whereas patients' high education was correlated with low fighting spirit score. There is a link between a patient's attitude of helplessness or hopelessness in the face of cancer and inappropriate communication among family members.
Moore <i>et al.</i> 2003 USA	To describe behavioural adjustment in children and adolescents with acute lymphoblastic leukemia and to determine whether behavioural adjustment is correlated with cognitive and academic abilities.	Statistical analysis, 47 families; triads of an ill child and the parents, N=141, Questionnaire.	Parent ratings for somatization, adaptability, attention problems, withdrawal, anxiety, social skills, and depression; and self-report ratings for anxiety and attitude to school were in the at-risk range. Treatment-related experiences such as body image alterations and mental and emotional problems were associated with problematic behaviours, including depression, somatization, withdrawal, and social stress.
Sigal <i>et al.</i> 2003 Canada	To test the hypothesis that differences between sicker and not-so-sick women in their preoccupation with their illness and	Statistical analysis, 87 families; dyads of 42 women with metastasised breast cancer and 45 with non-metastasised cancer, and their 87 children,	Sicker mothers reported relatively less preoccupation. They and their children reported less poor parenting and fewer externalising symptoms in the children. Regression analyses revealed further differences between the groups. Less preoccupation with their illness and less poor parenting behaviour by sicker mothers may explain why their children seem to fare better than those not-so-sicker mothers.

	parenting behaviour can explain why some investigators find that children of breast cancer patients fare better than controls and other investigators find the reverse.	N=174, Questionnaire.	
Woodgate and Degner 2003 Canada	To describe the childhood cancer symptom course experienced by children with cancer from the perspectives of the children and their families.	Grounded theory, 39 families; participant observation of 960 hours, 15 families; 230 individual and family interviews with ill children, mothers, fathers and siblings.	Underpinning of all beliefs and expectations was the experience of suffering. Beliefs and expectations contributed to and were a direct result of cancer symptoms that were ignored, unrelieved, or uncontrolled. Children and families had definite beliefs and expectations about the cancer symptom experiences, including short-term pain for long-term gain, you never get used to them, “they all suck”, “it sort of helps”, and they are all the same but they are all different. Although cancer symptoms resulted in suffering by children and families, they accepted the symptoms as an integral part of overcoming cancer and never expected complete symptom relief.
Lindholm <i>et al.</i> 2002 Finland	To describe how significant others experience being close to a woman suffering from breast cancer.	A phenomenological analysis, 17 women, 16 significant others, N=33, 48 individual interviews.	The significant others experience deep often unrelieved suffering. They consider themselves prisoners of a situation of uncertainty and powerlessness when standing by the women. They are torn between their own suffering and their desire to alleviate the woman’s suffering. A vicious circle of mutual protection intensifies the suffering of the significant other, while actively sharing the suffering brings relief. The gravity of the situation creates as ethical urge in the significant other to assume responsibility for life in common with the women.

<p>Mellon 2002 USA</p>	<p>To explore the meaning of the illness to the family and to the family quality of life (QOL) for survivors and family members and to describe similarities and differences between survivors' and members' meaning of the illness and family QOL.</p>	<p>Content analysis, 123 families; dyads of a survivor and a family member, N=246, Questionnaire.</p>	<p>The positive dimension of survivorship in meaning of the illness and family QOL were seen for patients and family members, although long-term stressors also were reported. More similarities than differences in meaning and QOL were noted between survivors and family members. Similarities in meaning of the illness were: devastation or shock at time of diagnosis, taking care of cancer, not thinking or talking about it too much, and reliance on faith. Similarities in family QOL were: valuing and living life to the fullest, no lasting negative effect on QOL, increasing family closeness, and living with other stressors. Overlaps in meaning of the illness and family QOL were: going on after cancer, concerns for cancer in the family, worrying about cancer coming back, difficulty living through cancer, and taking care of our health. Differences in meaning of the illness and family QOL were: receiving support from family, friends, and health care professionals, dealing with long-term physical concerns, worry and distress for family, showing concern and keeping feelings to self, and coming together as a family.</p>
<p>Ben-Zur <i>et al.</i> 2001 Israel</p>	<p>To investigate the similarities and differences in patterns of psychological distress, psychosocial adjustment, and coping on the part of both the patients and their spouses, and to examine the patient's</p>	<p>Statistical analysis, 73 families; 73 dyads of couples, N=146, Questionnaire.</p>	<p>The patients' distress was greater than their spouses', but a similar level of psychosocial adjustment was reported. The patients used more strategies involving problem-focused coping than their spouses. The use of emotional-focused coping, which included ventilation and avoidance strategies, was highly related to distress and poor adjustment on the part of the patient. The spouses' emotional-focused coping and distress were related to that of the patients. Dyad emotional-focused coping measures were highly associated with the patients' distress and adjustments.</p>

	adjustment in relation to both her and her spouse's use of problem- and emotion-focused coping strategies.		
Mellon and Northouse 2001 USA	To examine the quality of life of the family as a unit during the long-term survivor phase of illness and to test the family model of factors that may influence family quality of life.	Statistical analysis, 123 families; dyads of a survivor and a family member, N=246, Questionnaire.	The family survivorship model explained 63% of the variance in family QOL, with the strongest predictors being concurrent family stressors, family social support, family member fear recurrence, family meaning of the illness, and patient employment status.
Northouse <i>et al.</i> 2001 USA	To identify predictors of women's and husbands' psychosocial adjustment to breast disease during the first year following diagnosis.	Statistical analysis, 131 couples; 58 couples with a cancer diagnosis and 73 with a benign breast disease, N=262, A series of three questionnaire.	The strongest predictor of adjustment for women were severity of the illness and hopelessness and for husbands, their own baseline level of adjustment. Husbands' and wives' levels of adjustment at 1 year had a significant direct effect on each other's adjustment.
Northouse <i>et al.</i> 2000 USA	To provide a comprehensive assessment of patients' and spouses' adjustment to colon cancer, starting at the time of	Statistical analysis, 56 couples, N=112, Questionnaire.	Spouses reported significantly more emotional distress and less social support than patients. Gender differences were found, with women reporting more distress, more role problems, and less marital satisfaction, regardless of whether they were patients or spouses. Both patients and spouses reported decreases in their family functioning and social support, but also

	diagnosis and continuing to one year post surgery.		decreases in emotional distress over time. The strongest predictors of patients' role adjustment problems were hopelessness and spouses' role problems. The strongest predictors of spouses' role problems were spouses' own baseline role problems and level of marital satisfaction. Interventions need to start early in the course of illness, be family-focused, and identify the couples at risk of poorer adjustment to colon cancer.
Baider <i>et al.</i> 1998 Israel	To explore long-term adaptation, psychological distress and the influence of gender on the adjustment of patients and their spouses to cancer.	Statistical analysis, 133 couples, N=266, Questionnaire.	Patients and spouses were moderately distressed. The patient's psychological distress was explained by the level of intrusion, by the spouse's psychological distress and cohesion which had a protective effect. The spouse's distress was explained by intrusion, gender and, to some extent, by the patient's distress, but cohesion had no influence.
Northouse <i>et al.</i> 1998 USA	To provide a comprehensive assessment of couples' adjustment to breast cancer starting at the time of diagnosis and continuing to 1 year later.	Statistical analysis, 131 couples; 58 couples with a cancer diagnosis and 73 with a benign breast disease, N=262, A series of three questionnaire.	Couples facing breast cancer reported greater decreases in their marital and family functioning, more uncertain appraisals, and more adjustment problems associated with the illness. There was a high degree of correspondence between the levels of adjustment reported by women with breast cancer and their husbands over time. Couples who reported high distress or a high number of role problems at diagnosis were likely to remain highly distressed at 60 days and 1 year. There is the importance of assisting couples, not just patients, to manage the adjustment difficulties associated with breast cancer.
Clarke-Steffen 1997 USA	To describe strategies used by the family in response to childhood cancer and to relate those strategies to	Grounded theory, 7 families; 7 mothers, 7 fathers, 6 ill children (a 2-year-old did not participate), 12 siblings,	The family engaged the process of reconstructing reality by using strategies of managing the flow of information, reorganising roles, evaluating and shifting priorities, challenging future orientation, assessing meaning to the illness, and managing the therapeutic regimen. The common goal for the families was creating a

	two different conceptual frameworks.	N=32, A series of two individual and one family interviews.	new normal, or normalising their lives.
Kissane <i>et al.</i> 1994 Australia	To assess family functioning of palliative care patients and to group into classes by a computer-based taxonomic programme.	Statistical analysis, 102 families; 102 patients, 84 spouses, 179 children, N=365, Questionnaire.	One third of families were named supportive for their high cohesiveness, a further 21% resolved conflict effectively, both of these classes contained low psychological morbidity. Two classes were dysfunctional: hostile families (6%) were distinguished by high conflict while sullen families (9%) displayed moderate conflict, poor cohesion and limited expressiveness. These two classes had significantly higher levels of psychological morbidity and poorer social functioning. The remaining class (31%) had intermediate levels of cohesion, expressiveness and conflict (termed ordinary) yet more moderate psychosocial morbidity.

**APPENDIX 31. Research related to detaching from cancer in a family.**

<b>Researcher/s, Year, Country</b>	<b>The purpose</b>	<b>Research methodology, Data, Data collection method</b>	<b>Main results</b>
Isaksen <i>et al.</i> 2003 Norway	To evaluate the satisfaction with the help and support received by patients with cancer and their relatives from family friends, health personnel, and fellow patients.	Statistical analysis, 536 patients and their 473 close relatives, N=1009, Questionnaire.	The patients receive more support and information than their close relatives. The patients were generally more satisfied with the support. The relatives seemed to underestimate the help and support provided to the patients. The patients and their close relatives, family and friends proved to be important sources of support.
Boyle <i>et al.</i> 2000 USA	To identify and distinguish primary caregivers' and adult bone marrow transplantation survivors' perceptions of their quality of life beyond the acute phase of hospitalisation.	Content analysis and statistical analysis, 36 families; 36 dyads of a survivor and a family member, N=72, Individual interview and questionnaire.	Normalcy regained sense of the usual or customary; return to a state of routine as before transplantation, per their personal view of "normal". Family support was availability of family assistance post-transplant; being the sustainer to the survivor; receiving help from others. Role changes were changes in duty expectations and responsibilities as well as in intrafamilial relationships. Caregiving burden meant additional duties, work, stress assumed by the caregiver related to the survivor's illness and/or recovery. Satisfaction was being content with how life overall was transpiring.
Savela 2000 Finland	To examine the coping requirements, means and resources of parents with children with cancer.	Statistical analysis and content analysis, 54 families, N=54, Questionnaire.	The parents considered it more difficult to rear a child with cancer than a healthy child, but coped well with the rearing. Parents' relationship and social relations changed during the child's illness. Parents used emotionally oriented, problem-oriented and palliative means of coping. They wanted more support from the health care personnel.
Hilton 1996 Canada	To examine the process of normalisation as it emerged from a study of	Grounded theory, 41 women and their spouses, 14	Getting back to normal, defined as a safe, desirable, and stable state, was important for these families. Strategies used to get back to normal included seeing their families as normal, maintaining or returning to usual

	families coping with early stage breast cancer.	single parents, N=96, A series of five semi-structured family, couple and individual interviews.	patterns quickly, minimising disruptiveness, de-emphasising sick role demands, reframing negatives, and putting the cancer behind them. Factors influencing the process were family perspective of cancer, visibility or disruptiveness of symptoms of and treatments for cancer, family flexibility, experience with illness, life stage, and congruency of views.
Omne-Ponten <i>et al.</i> 1995 Sweden	To investigate to what extent there is an association and agreement between the married couple's assessment of the impact of breast cancer disease and its treatment, and to what extent the husband's assessment at four months could to be a predictor of the patient's psychosocial adjustment 13 months after the diagnosis.	Statistical analysis, 56 couples, N=112, A series of two semi-structured individual interviews.	The husband's assessment of the marital relationship was significantly related to the patient's psychosocial outcome at 13 months. The spouses' degree of agreement did not vary with the type of surgery. Agreement increased over time irrespective of whether the adjustment was assessed to be better or worse. A supportive marital relationship is important for psychosocial adjustment.
Lewis and Deal 1995 USA	To examine the married couple's experience with cancer recurrence from each partner's own perspective, to describe their mood and marital quality, and to develop	Grounded theory, 15 couples, N=30, Structured couple interview and questionnaire.	Balancing our lives explained how couples lived with the breast cancer recurrence. Couples activity worked to balance their lives by keeping the breast cancer as a background issue. Although couples talked about managing the daily realities of the woman's breast cancer, not dwelling on the cancer and moving ahead and healing themselves was most important. Balancing out lives involved the couples in four processes: managing the woman's everyday illness, surviving, healing, and preparing for death. One or both members of 60% of the couples scored outside the

	an initial explanatory theory of the couple's lived experience with breast cancer recurrence.		normative range on either depressed mood or marital adjustment.
Hilton 1994 Canada	To explore family communication pattern in coping with early breast cancer.	Grounded theory, 41 couples, N=82, A series of five semi-structured couple interviews and questionnaire.	Sharing meaning was a central strategy for families. Through sharing meaning they become, and stayed, informed about events and issues how other family members were coping and feeling. By sharing meaning this allowed members to be in sync with one another, to show their concern and support, to make and carry out decisions, and to enhance family adjustment and satisfaction. The sharing meaning process took place both verbally and nonverbally and followed several patterns influenced by prior sharing patterns in both the birth and present family, by gender, and by beliefs about sharing. The need to talk varied over time and with circumstances and was influenced by the imminence of treatment or of follow-up issues such as upcoming appointments or media events.

**APPENDIX 32. Research related to fighting against cancer in a family.**

<b>Researcher/s, Year, Country</b>	<b>The purpose</b>	<b>Research methodology, Data, Data collection method</b>	<b>Main results</b>
Zhang and Siminoff 2003 USA	To examine family disagreements about treatment decisions for patients with advanced lung cancer.	Content analysis, 37 patients and 40 family caregivers of 26 families, N=77, 83 individual interviews, a focus group of 13 people with four meetings.	Family disagreements about treatment decisions for patients with advanced lung cancer are common and include a wide range of issues. Family members play an important role in the selection of patients' doctors, hospitals, treatment options, and provisions of care.
Davison <i>et al.</i> 2002 Canada	To identify and compare information and decision preferences of men with prostate cancer and their partners at the time of diagnosis.	Statistical analysis, 80 couples, N=160, Questionnaire.	Men had a preference to play either an active or a collaborative role in decision making with their physician and partners. The majority of partners wanted to play a collaborative role in treatment decision making. Couples identified prognosis, stage of disease, treatment options, and side effects as the top four information preferences. Men ranked information on sexuality more important than partners, and partners ranked information on home self-care higher than men. Men who had sons, a positive family history, and lower levels of education ranked heredity risk significantly higher. Profiles of information categories did not differ according to role preferences of either men or partners.
Friesen <i>et al.</i> 2002 Canada	To describe the experience of families when an adult family member is diagnosed with cancer.	Grounded theory, 8 families; 23 adults and 7 children, N=30, Individual interview.	Information was gathered, interpreted, and shared in the process of learning to live with cancer. Families learned together by reviewing the past, gathering and sharing information, and sharing their experiences of living with someone undergoing treatment for cancer. By revealing their own personal perspectives, patients taught their families about their illness experiences and what constituted effective support.

Harden <i>et al.</i> 2002 USA	To explore the experiences of couples living with prostate cancer, the impact of the illness on their quality of life, their ability to manage symptoms, and their suggestions for interventions that would help them to improve their daily experiences.	Statistical analysis and content analysis, 22 men and 20 spouse-caregivers, N=42, Questionnaire and six focus groups with one meeting.	Themes of enduring uncertainty, living with treatment effects, coping with changes, and needing help emerged as themes, which reflect the physical and psychological impact of living with prostate cancer. Participants had a need for information and support. They felt unprepared to manage treatment effects. Symptoms had a broad effect on couples, and the illness itself had positive and negative effects on them.
Murtonen <i>et al.</i> 1998 Finland	To describe family dynamics of families with cancer on the basis of Barnhill's framework for healthy family systems.	Statistical analysis, 96 dyads of a patient and a relative, N=192, Questionnaire.	The cancer of a family member did not impair family functioning, but that family dynamics were considered quite good. There were no statistical significant differences between cancer patients and relatives on any of the family dynamics dimensions. Older relatives reported more enmeshment and rigidity than did younger relatives, whereas the latter reported more role conflict than older relatives. Relatives who were men reported more enmeshment than women, whereas women reported more role conflict. Relatives of two-member families reported more rigidity than relatives with a larger family. Patients who reported a serious illness in the family described more mutuality, better flexibility, and clearer communication than patients who did not report such an illness. Relatives, who mentioned a serious illness reported more mutuality and flexibility.
Plant 1995 UK	To explore the experiences	Grounded theory, 20 patients	Reconstructing the future as a way of guarding against uncertainty had a range of differences, where residual separateness meant that the

	of a patient with newly diagnosed cancer and their relatives.	and 26 relatives, N=46, Individual interview.	relatives often felt that they had to somehow carry the burden on their own grief and protect the patients from it. Non-disclosers had a joint strategy of dealing with the illness together by not talking about cancer. The patient's way meant the forms of coping dictated by the patient even when they were said to be mutual. In the less "close" relationships the relative often had to bear as even more unacknowledged burden. Supervision of activities involved attempting to prevent the patient from dwelling on what had happened to them by encouraging him/her to think about or do other things. Monitoring appeared when the patients attempted to assert their independence and would not allow any more direct help from the relatives.
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**APPENDIX 33. Research related to adjusting to life with cancer in a family.**

<b>Researcher /s, Year, Country</b>	<b>The purpose</b>	<b>Research methodology, Data, Data collection method</b>	<b>Main results</b>
Davis Kirsh <i>et al.</i> 2003 USA	To assess the mothers' with breast cancer and fathers' perceptions of the influence of the home-based intervention programme on the quality of mother-child relationships after the intervention.	Grounded theory, 4 families; Parents, N=8, Individual interview.	Making the most of the moment explicated the active process which the intervention affected and in which the parents engaged to minimise the intrusion of breast cancer into their family life. Fathers defined making the most of the moment as the mother's effort to assimilate the pre-cancer routine with newly discovered ways to appreciate self, communicate and interact with the child, and maintain an enhanced and durable relationship. Mothers defined making the most of the moment as vigorous work on an individual level, on an internal level, and in interactions with their children by learning about cancer and by discussing sensitive topics. They also discovered new things about themselves and children and they grew closer in the process of sharing these experiences. Mothers described needing to carefully evaluate what was discussed as well as when and where the discussion occurred in an effort to keep their children safe from untoward fears or worries. However, mothers also expressed positive reactions from their children as a result of having sensitive discussions of cancer-related issues and a shared understanding of the family's experience.
Huizinga <i>et al.</i> 2003 The Netherlands	To explore the psychosocial functioning of children who have a parent treated for cancer and the variables that may relate to the development	Content analysis and statistical analysis, 14 families; 14 parents and 15 children, N=29, Semi-structured interview and questionnaire.	Parents reported problems on a borderline and clinically elevated level in one third of the children, and three of seven children self-reported problems on these levels. Parents reported temporary behavioural problems in most children during the acute stage of their parents' illness. Anxiety, sleeping disorders, and compulsive behaviour, presented for longer. Parents reported that their children had more problems than the children themselves reported. Children of families with poor family functioning were more vulnerable. Extremely high adaptation and extremely low family

	of emotional and behavioural problems.		cohesion seemed related to the prevalence of emotional and behavioural problems in the children.
Salminen <i>et al.</i> 2003 Finland	To investigate breast cancer patients' and their spouses' need for information on the disease.	Statistical analysis, 96 patients and 72 spouses, N=168, Questionnaire.	Higher education, younger age and shorter time since diagnosis indicated stronger need for information. Both patients and spouses desired more information mainly from the physician. More information was needed on prognosis, cancer as a disease, its influence on daily life, and on the effect of treatments.
Wideheim <i>et al.</i> 2002 Sweden	To describe what living with a highly malignant brain tumour is like from a family perspective.	Content analysis, 3 families; 3 patient, and 5 next of kin, N=8, 15 individual interviews.	When a highly malignant brain tumour is diagnosed, the effect on the family is devastating and there is a state of crisis, distancing, and a sense of helplessness. Family members live from day to day in a state of constant anxiety and fear of losing the patient. The affliction limits the patient's capacity regarding activities of daily life, which increases the burden of the next of kin. They attempt to cope with their grief by occupying themselves with practical tasks and activities that they believe are meaningful. The family members have only good words to say about their encounter with healthcare staff and about the information given. Negative information that the family have not asked for can cause a long period of frustration and anxiety, and they believe that their hope has been taken away from them.
Woodgate and Degner 2002 Canada	To increase the understanding of the uncertainty experienced by the children with cancer and their families.	Grounded theory, 39 families; participant observation of 960 hours, 15 families; 230 individual and family interviews with ill children, mothers, fathers and siblings.	Uncertainty is present throughout the cancer trajectory and even after the child has successfully completed the cancer-treatment course. In addition to "not knowing", uncertainty involves dimensions of indecisiveness, self-doubt, and a lack of security. Experiencing the "what ifs" is common to the experience of uncertainty. Certainty is not always a desired state, since both uncertainty and certainty can cause a lot of distress. Coming to know what to expect and taking 1 day at a time are two strategies

			that help to reduce a sense of uncertainty in children and families and help them to cope. Many difficult events or experiences especially the children's cancer-symptoms contribute to the feeling of uncertainty.
Holmberg <i>et al.</i> 2001 USA	To explore the impact of breast cancer and its treatments on the relationships and roles of women with breast cancer.	Content analysis, 4 single, 6 partnered women and 5 partners, N=15, Individual interview and three focus groups with one meeting.	Partner relationships troubled before the diagnosis as well as those characterised by mutual caring faced challenges and negative changes. In an effort to protect each other, communication within the partner dyad become less open, and there were changes in the usual manner of conflict resolution. Un-partnered women appeared to be more vulnerable to problems of negative adjustment, largely because of relationship issues. Participants confirmed the need for a comprehensive intervention to facilitate coping with issues relative to relationships, intimacy, and sexuality.
Birembaum <i>et al.</i> 1999 USA	To describe school-age children's and adolescents' adjustment to parental cancer.	Statistical analysis, 66 families; 66 patients, 54 partners, 31 children and 84 adolescents, N=235, Questionnaire.	School-age children and adolescents of a parent with cancer have significantly more behavioural problems than were expected. The significant agreement among raters is of a modest magnitude but as strong as rater agreement reported in the literature. Thus most of school-age children and adolescents of a parent with cancer are well-adjusted, but a significant subset of youngsters is at risk for behavioural problems.
Lavery and Clarke 1999 Australia	To assess the coping and marital adjustment of prostate cancer patients and their spouses.	Content analysis, 12 couples, N=24, Semi-structured individual interview.	Relative to spouses, patients employed a wider range of individual strategies, and used them more frequently. With regard to interpersonal coping, spouses were more actively engaged in meeting the demands of illness than were patients, whereas patients employed more protective buffering than partners by avoiding discussions about their cancer or by denying their anxieties and concerns regarding it. The majority of patients reported that their marital relationships had remained the same or had improved since their diagnoses, although a few men reported negative changes. Of those couples who had been sexually active prior to diagnosis, all reported negative changes arising

			from the patients' impotence brought about by their treatment for prostate cancer.
Rees <i>et al.</i> 1998 UK	To explore the key information concerns of spouses of women with breast cancer from the patients' and spouses' perspectives.	Statistical analysis and content analysis, 30 women and 9 spouses, N=39, Questionnaire and four focus groups with one meeting.	There are a number of key concerns for both women with breast cancer and their spouses regarding spousal information. The information needs of spouses are highly individualistic and should be treated as such. The information needs of spouses are often ignored by health care professionals. Many spouses feel uncomfortable approaching health care professionals for information. The patient is often seen as the most important, potential source of information for spouses.
Sawyer <i>et al.</i> 1997 Australia	To follow prospectively the psychological adjustment of young children, parents, and families during the first 2 years after the children's diagnosis of cancer.	Statistical analysis, 38 families of a child with cancer and 39 families in the general community, Parents and children, N=222, Questionnaires at baseline, one year and two years after diagnosis.	Children with cancer and their parents experienced significantly more emotional distress than children and parents in the community during the period immediately after diagnosis. However, the number of problems declined during the first year after the children's diagnosis and stabilised at a level comparable with that found among children and parents in the general community.
Welch <i>et al.</i> 1996 USA	To examine psychological adjustment of adolescent and preadolescent boys and girls whose mother or father recently received a diagnosis of cancer.	Statistical analysis, 76 families; 54 patients, 36 spouses, 55 adolescents and 34 preadolescents, N=179, Questionnaire.	Parents' reports indicated little or no evidence of emotional distress or disruptive behaviour in their children regardless of the child's age or sex, or whether the mother or father was ill. Children's reports differed significantly from those of their parents, with adolescent girls reporting the highest levels of symptoms of anxiety/depression and aggressive behaviour. Children's reports of their emotional distress declined from an initial assessment 10 weeks after their parents' diagnosis to a follow-up 4 months later, whereas parents' reports of their children's distress did not change with time.

**APPENDIX 34. Research related to submitting to cancer in a family.**

<b>Researcher/s, Year, Country</b>	<b>The purpose</b>	<b>Research methodology, Data, Data collection method</b>	<b>Main results</b>
Northouse <i>et al.</i> 2002 USA	To assess women's and family members' quality of life within 1 month after recurrence of breast cancer, and its effects on quality-of-life.	Statistical analysis, 189 dyads of a woman and a family member, N=378, Questionnaire.	Women reported significant impairments in physical, functional, and emotional well-being. Family members reported significant impairment in their own emotional well-being. Structural equation modelling revealed that self-efficacy, social support, and family hardiness had positive effects on quality of life, whereas symptom distress, concerns, hopelessness, and negative appraisal of illness or caregiving had detrimental effects. Study variables accounted for a sizeable amount of variance in women's and family members' physical and mental dimensions of quality of life.
Carlson <i>et al.</i> 2001 Canada	To examine partners' understanding of patients' experience with prostate or breast cancer and to assess the congruence between patient and partner perceptions regarding social support and the cancer experience.	Statistical analysis, 23 couples, N=46, Questionnaire and semi-structured individual interview.	Female partners possessed a more accurate understanding of their husbands' experience with prostate cancer than male partners had of women's breast cancer experience. These men tended to overestimate the breast cancer patients' self-reported levels of distress. Patient and partner perceptions regarding social support in the relationship and the cancer experience were also more congruent in prostate couples than in breast couples. Patients were well adjusted and felt understood by their partners and satisfied with the support their partners provided.
Ora and Ronit 2000 Israel	To describe the relationship between adult cancer patients' adjustment to their illness and	Statistical analysis, 41 dyads of a parent and an ill adult child, N=82,	The parents displayed more depression symptoms than the children. A significant positive correlation between depression, anxiety, and grand severity index (GSI) symptoms of the ill adult child and of the parent, and a similar

	that of their parents.	Questionnaire.	correlation between domestic environment, extended family relations, and total adjustment, and family support. A significant, but negative correlation was found between interpersonal relationships, paranoid ideation, psychotism, and the GSI symptoms, and family support. The parents reported receiving less assistance and support from their ill adult child than the child reported receiving from the parents.
Lewis and Hammond 1996 USA	To examine the impact of early stage breast cancer on the functioning of families with adolescents.	Statistical analysis, 70 couples and their 70 adolescents, N=210, Questionnaire.	The illness-related demands that mothers and fathers saw impinging on their family predicted higher levels of maternal depressive mood, poorer marital adjustment, and lower parenting quality. When parenting quality was lower, the adolescent scored lower on self-esteem. Family professionals can help couples gain cognitive behavioural control over their perceived illness-related demands, help husbands avoid transferring illness-related tension into their appraisal of the marriage, and help adolescents appropriately interpret parenting behaviour.
Northouse <i>et al.</i> 1995a USA	To describe the emotional distress of women and husbands prior to the women's breast biopsy and to identify factors to their levels of distress.	Statistical analysis, 300 women and 265 husbands, N=565, Questionnaire.	Women reported moderately high levels of emotional distress and significantly more distress than their husbands. Concurrent stress, lower education, hopelessness, and uncertainty explained the most variance in women's distress, while concurrent stress, hopelessness, and family functioning explained the most variance in husbands' distress.
Northouse <i>et al.</i> 1995b USA	To compare psychosocial adjustment of women with recurrent breast cancer to that of their husbands.	Statistical analysis, 81 women and 74 husbands, N=155, Questionnaire.	Women with recurrent breast cancer reported more emotional distress than their husbands, but both had a similar number of psychosocial role problems. Women and husbands differed in the amount of support and uncertainty they reported but not in the levels of symptom distress or hopelessness they

			perceived. Women, in contrast to their husbands, expressed more surprise than their cancer recurred and found the recurrent phase of illness more distressing than the initial diagnosis.
Stuber <i>et al.</i> 1994 USA	To describe the utility of a family systems model in understanding the aetiology and maintenance of post-traumatic stress symptoms in childhood cancer survivors and their parents.	Statistical analysis, Parents of 30 childhood cancer survivors, N=47, Questionnaire.	Neither diagnostic category, nor time since completion of treatment significantly correlated with severity of post-traumatic stress symptoms reported by parents. Although there was a significant correlation between symptom severity of mothers and fathers, neither mothers' nor fathers' scores were significantly correlated with the survivors'. Maternal symptoms were significantly correlated with mothers' trait anxiety, survivors' appraisal of treatment intensity, and with duration of treatment.
Compas <i>et al.</i> 1994 USA	To assess anxiety/depression and stress response symptoms in adult cancer patients, spouses, and their children near the patients' diagnoses to identify family members at risk for psychosocial maladjustment.	Statistical analysis, 117 patients, 76 spouses and 110 children, N=303, Questionnaire.	Patients' and family members' distress was related to appraisals of the seriousness and stressfulness of the cancer but not related to objective characteristics of the disease. Patients and spouses did not differ in anxiety/depression or in stress-response symptoms. Both stress-response and anxiety/depression symptoms differed in children as a function of age, sex of child, and sex of patient. Adolescent girls whose mothers had cancer were the most significantly distressed.