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LIVING WITH CHILDHOOD CANCER - Family Members' Experiences and Needs

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# **LIVING WITH CHILDHOOD CANCER**

**Family Members' Experiences and Needs**

Maria Björk



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## ABSTRACT

The overall aim of this thesis was to elucidate family members' lived experiences and needs during a child's cancer trajectory and to describe how the illness and its treatment influence both individuals within the family and the family as a whole. Seventeen families with a child under the age of 13 and newly diagnosed with cancer were followed during the child's treatment trajectory by means of interviews and observations. Parents, patients and siblings seven years or older were interviewed at the time of diagnosis, during the treatment and after it was completed. Patients younger than seven were observed during their initial hospitalization. The interviews were analyzed with a hermeneutic phenomenological approach and the observations with content analysis. The results from the observations (Paper II) showed that the young children's needs during their initial hospitalization were described as a need to have the parent close by, a need to play and feel joy, a need for participation in care and treatment, a need for a good relationship with the staff and a need for physical and emotional satisfaction. The results from the interviews showed that, at time of diagnosis (Paper I) the families' lived experience was described as a broken life world and an immediate striving to survive. Their secure everyday life disappeared and was replaced by fear, chaos and loneliness. When striving to help the child and the family survive, family members endeavoured to feel hope and have a positive focus, to gain control and to feel close to other people. During treatment (Paper III) the families lived experience was described as focus on the ill child - an everyday struggle. Each day's focus was on the child and the families experienced it as a tough period which they struggled to come through. Only when the sick child's needs were satisfied, could the focus move to other parts of the family. Family members felt drained, locked up and isolated. Family life was experienced as disrupted and they struggled to retain normality and become experts. Perspectives on life changed; it was important to enjoy life and to be aware of sources of support. When treatment was completed (Paper IV) the families' lived experience was described as returning to a changed ordinary life - incorporating a trying and contradictory experience. The families felt relieved that the child's treatment was over but, at the same time they still experienced stresses and strains in life. Family members felt changed and especially the parents needed to focus on themselves in order to recover. The families wanted closeness but, from time to time, felt a loss of concern from others. The findings from this thesis can deepen the understanding of what it is like living with childhood cancer and of the needs of young children with cancer. By reflecting on the findings, paediatric oncology staff may become increasingly thoughtful and thereby better prepared to take care of family members of a child with cancer, including the sick children themselves.



## **ABBREVIATIONS**

ALL	Acute Lymphoblastic Leukaemia
CNS	Central Nervous System
HD	Hodgkin's Disease
NHL	Non-Hodgkin Lymphoma
PEG	Percutaneous Endoscopic Gastrostomy
FCC	Family Centred Care
SIOP	Société Internationale d'Oncologie Pédiatrique (The International Society of Paediatric Oncology)

## ORIGINAL PAPERS

This thesis for the doctoral degree is based on the following papers referred to in the text by their Roman numerals:

- I Björk M, Wiebe T, Hallström I. Striving to Survive: Families' Lived Experiences When a Child is Diagnosed With Cancer. *Journal of Pediatric Oncology Nursing* 2005, 22(5): 265-275
- II Björk M, Nordström B, Hallström I. Needs of Young Children With Cancer During Their Initial Hospitalization: An Observational Study. *Journal of Pediatric Oncology Nursing* 2006, 23(4): 210-219
- III Björk M, Wiebe T, Hallström I. An Everyday Struggle - Swedish Families' Lived Experiences During a Child's Cancer Treatment. Accepted for publication in *Journal of Pediatric Nursing*
- IV Björk M, Wiebe T, Nordström B, Hallström I. Returning To a Changed Ordinary Life - Families' Lived Experience After Completing a Child's Cancer Treatment. In manuscript

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## INTRODUCTION

Every year in Sweden, about 300 children up to the age of 14 years are diagnosed with childhood cancer (National Swedish Board of Health and Welfare, 2001). In the developed world, cancer affects 1 in 600 children before the age of 15. Even with improved childhood cancer treatments, the proportion of children who are diagnosed with cancer but cannot be saved makes it, for the developed world, the most common form of death caused by illness after the child's first birthday (Craft, 2000). However, since the early 1970s there has been a dramatic improvement in survival rates. Today 1 in 900 people aged 15 to 45 is a survivor of childhood cancer (Foley & Fergusson, 2002). The survival rate in Sweden exceeds 75 % (Gatta et al., 2003).

Even with a good prognosis of childhood cancer in Sweden, a childhood cancer diagnosis, treatment and hospitalization affects the life situation of the whole family (Berglund, Garwicz, Kreuger, & Åhström, 2007). It involves both a new physical realm and a psychological one, and it challenges the belief that life has some predictability, as for example that our children will grow up and leave home (Giammona & Malek, 2002). This thesis contributes to the understanding of how families experience living with childhood cancer and of the needs of young children with cancer.

## BACKGROUND

### **Childhood cancer**

Childhood cancer differs from adult cancer in that it mostly stems from the embryonal (foetal cells) tissues while adult cancers are mostly carcinomas involving epithelial tissues (Ruccione, 2002). In contrast to adult cancers, a childhood cancer mostly has a relatively brief latency, is minimally preventable and genetic alterations may play a major role in the pathogenesis. It is often difficult to diagnose childhood cancer early because the signs and symptoms are usually nonspecific and may mimic other more common childhood disorders (Steuber, 1997). Almost 80% of the patients have distant metastasis or a systemic disease when their cancer is detected as it usually arises from deep-seated tissues (Ruccione, 2002). The most common childhood cancer, about one third of cases, is leukaemias. Of the tumours arising from solid organs, brain tumours constitute the largest group with an incidence of approximately 25%, and other solid tumours i.e., lymphomas, nephroblastomas, neuroblastomas and osteosarcomas, constitute approximately 40 % (Dixon-Woods, Heney, & Young, 2005). The treatment varies in length from some months to two and a half years depending on the diagnosis.

### ***Leukaemia***

Leukaemia is a malignant proliferation of precursor cells occurring in the bone marrow. The leukaemia leads to a replacement of the normal bone marrow cells with malignant cells that enter the blood stream. About 80% of all leukaemias are acute

lymphoblastic leukaemia (ALL) (Dixon-Woods et al., 2005). Incidence rates for ALL vary across childhood but there is a peak between two and six years of age (Dixon-Woods et al., 2005). Today's treatment consists of intensive and prolonged chemotherapy (Dixon-Woods et al., 2005; Westlake, 2002) sometimes in combination with cranial radiation (Westlake, 2002). The shift from palliative to curative treatment came in the late 1960s (Westlake, 2002). The 5-year survival rate for ALL has increased dramatically to a current 85% in the Nordic countries (Gatta et al., 2003).

### **Brain tumour**

Among tumours in childhood, brain tumours are the second most common (Heideman, Packer, Albright, Freeman, & Rorke, 1997; Ryan-Murray & McElwain Petriccione, 2002) and the most common solid ones (Dixon-Woods et al., 2005). Central nervous system (CNS) tumours form a broad spectrum of diseases and their location is mostly intracranial (Heideman et al., 1997; Ryan-Murray & McElwain Petriccione, 2002). Only 4-10% of these tumours occur in the spinal cord and, in some literature, brain tumours are referred to as a CNS tumour (Ryan-Murray & McElwain Petriccione, 2002). During childhood there is a prominent peak in incidence during the first decade of life (Heideman et al., 1997). The treatment often consists of surgery in combination with radiation and/or chemotherapy (Ryan-Murray & McElwain Petriccione, 2002). Brain tumours can be either slow growing (low grade) and relatively benign, or faster growing with a poorer prognosis. The prognosis in cases of brain tumour is also dependent on their location (Dixon-Woods et al., 2005; Ryan-Murray & McElwain Petriccione, 2002). The 5-year survival rates for CNS tumours have not improved as dramatically as for many other types of childhood cancers (Ryan-Murray & McElwain Petriccione, 2002). However, in the Nordic countries, the 5-year survival rate for children with brain tumour is 73% (Gatta et al., 2003).

### **Solid tumours**

The third, remaining group are solid tumours. The commonest of these are in the lymphatic system 10% (Lymphoma), sympathetic nervous tissue 7% (Neuroblastoma), kidney 6% (Wilms' tumour), bones 5% (Osteosarcoma and Ewing sarcoma), muscle 4% (Rabdomyosarcoma), and a group of less common tumours (Dixon-Woods et al., 2005).

*Lymphomas* can be divided into two major groups; Hodgkin's disease (HD) and non-Hodgkin Lymphoma (NHL) (Dixon-Woods et al., 2005). Each of these malignancies arises from the lymphoid system (Dixon-Woods et al., 2005; Liebhauser, 2002; Ryan Hussong, 2002). HD is most common among adolescents (Dixon-Woods et al., 2005; Liebhauser, 2002) while NHL has a peak incidence between 7 to 11 years of age (Dixon-Woods et al., 2005; Ryan Hussong, 2002). HD is generally treated with chemotherapy in combination with radiotherapy and NHL is generally treated with chemotherapy (Ryan Hussong, 2002). In the 1960s few children with HD and NHL survived (Liebhauser, 2002; Ryan Hussong, 2002). Today in the Nordic countries, the

5-year survival for children with HD is nearly 94 % and for children with NHL nearly 80 % (Gatta et al., 2003).

*Neuroblastoma* arises from any area of the sympathetic chain including the adrenal medulla and sympathetic ganglia. About 60% of all neuroblastoma cases occur before the age of two and is rarely seen in children over the age of ten. The treatment is multimodal (Dadd, 2002) i.e. using different types of therapy such as surgery, radiation and chemotherapy. Depending on the biology of the disease, the prognosis for children under the age of one is excellent, with some children undergoing spontaneous regression. Children over the age of one often have radically worse prognosis (Dixon-Woods et al., 2005). However, the 5-year survival in the Nordic countries is 62% for all neuroblastoma cases (Gatta et al., 2003).

*Wilms' Tumour* is the commonest kidney tumour, with a peak incidence between two and three years of age (Drigan & Androkites, 2002). Chemotherapy in combination with surgery is undertaken to treat Wilms' tumour (Dixon-Woods et al., 2005). The prognosis has improved dramatically (Drigan & Androkites, 2002). In the Nordic countries, the 5-year survival for children with Wilms' tumour is about 92 % (Gatta et al., 2003).

*Osteosarcoma and Ewing's sarcoma*, are malignant tumours of the bone. They have a peak incidence between 10 and 20 years of age (Betcher, Simon, & McHard, 2002). The treatment for Osteosarcoma and Ewing's sarcoma consist of a combination of chemotherapy given before surgery as well as postoperatively. The surgery today usually offers limb salvage depending on the tumour localization (Betcher et al., 2002; Dixon-Woods et al., 2005). Those patients having Ewing's sarcoma are also offered radiation therapy (Betcher et al., 2002). Both these tumours are difficult to treat but the prognosis has increased during recent years (Dixon-Woods et al., 2005). The 5-year survival in Europe for children with osteosarcoma is 66 % and for children with Ewing's sarcoma it is 69 % (Gatta et al., 2003).

*Rabdomyosarcoma* (muscle tumour) is the most common soft tissue sarcoma (Zinger Kotsubo, 2002) and originates from primary embryonal muscle tissue (Dixon-Woods et al., 2005). It has two peak incidences, the first between two and five years of age and the second during adolescence (Dixon-Woods et al., 2005). To treat rabdomyosarcoma, a blend of surgery, radiotherapy and chemotherapy is used (Zinger Kotsubo, 2002). Over the last 25 years survival has improved and today's prognosis varies according to location and stage (Dixon-Woods et al., 2005), but in Europe 67% of these children survive 5 years (Gatta et al., 2003).

## **Childhood cancer treatment**

For a long time surgery was the only method of treating cancer. It was not until the late 1940s that children began to receive chemotherapy, but remissions were brief and the side effects devastating. Today's therapies are complex and intense and requires a

multidisciplinary team using a multimodal therapy (Dixon-Woods et al., 2005; Ruccione, 2002; Walker, Wells, Heiney, & Hymovich, 2002) including chemotherapy, radiation, surgery and less often stem-cell transplantation. However, one should keep in mind that 80 % of the world's children have little or no access to today's modern treatments as childhood cancer is not a priority area in low income countries (Craft, 2000).

### ***Short term side effects***

Today's treatment is often maximized which is associated with considerable toxicity to other organs of the body and can cause short-term side effects (Dixon-Woods et al., 2005). Hedström, Haglund, Skolin, & von Essen (2003) discovered that the most common causes of distress in a group of children and adolescents with cancer were treatment-related pain, nausea, and fatigue.

The pain can for example be caused by the procedures, the disease or the treatment. Pharmacological management of procedural pain should include analgesic and sedative agents, but behavioural methods such as tactile stimulation and relaxation techniques can also be used as well as parental participation and information. A blend of analgesics can be used for treating disease- or treatment-related pain. However, it is important for professionals to use age-appropriate assessment techniques when measuring pain, or, if the child is unable to report pain, the parent should be asked to assist its assessment through evaluation of changes in behaviour (Hockenberry & Kline, 2006).

Nausea and vomiting can become debilitating without effective prophylaxis (Sallan & Billett, 1997). Today there are useful and effective antiemetic drugs which are helpful to the sick child (Panzarella et al., 2002). However, despite effective antiemetic and pain treatment, children may have problems with their nutrition (Hockenberry-Eaton & Kline, 1997; Kreuger, 2000). Today additional nutrient solutions given through probes and percutaneous endoscopic gastrostomy (PEG) are often used (Kreuger, 2000).

Different types of fatigue exist in paediatric oncology patients (Davies, Whitsett, Bruce, & McCarthy, 2002) and it is described as one of the most distressing symptoms. Interventions such as for example physical activity and distraction techniques have been tested with various results (Hockenberry & Kline, 2006).

The treatment can also cause myelosuppression which means that the child becomes predisposed to infections, anaemia or bleeding (Hockenberry & Kline, 2006). Patients and their families are taught to avoid crowded areas and contact with sick people, especially when the neutrophil count is low as viruses, bacteria, fungi, and protozoa can cause infections in immune suppressed children (Kline, 2002).

### ***Late effects***

Late effects can be caused both by the childhood cancer as well as from its treatment (Bhatia, Blatt, & Meadows, 2006). Late effects can for example cause various organ dysfunctions, decreased fertility, neurocognitive sequelae, early mortality and second malignant neoplasm but also psychosocial and psychopathological late effects (Dixon-Woods et al., 2005). Follow-up care that is organized, systematic, and comprehensive, and includes physiological and psychosocial components are needed for all survivors (Hobbie, Ruccione, Harvey, & Moore, 2002). Gibson, Aslett, Levitt, & Richardson (2005) found that survivors wanted their follow up care to include a positive relationship with health care professionals, disease and treatment related information, and good communication with the professionals. They also wanted to know that their parents were supported and also that health care professionals had a good understanding of their disease and of their individual needs.

## **Paediatric Oncology Care**

Today in Sweden, the care of childhood cancer patients is centralized in six specialized paediatric oncology centres (Qvarnström, Rahm Hallberg, & Werkö, 2000). To be able to carry out today's advanced medical and nursing care, a multidisciplinary team with experienced and specially trained staff are required (Berglund et al., 2007; Walker et al., 2002). The need for a comprehensive view taking care of the whole family has been an important principle of paediatric oncology care in Sweden (Berglund et al., 2007; Qvarnström et al., 2000). At the paediatric oncology centres multidisciplinary teams include sibling supporters as well as consultant nurses in paediatric oncology who keep the child's and their siblings' schools informed about the illness and its treatment. The consultant nurses also work with the local hospitals (Qvarnström et al., 2000).

### ***Family Centred Care***

Parents play a crucial role in the child's hospital visits and treatment. Family centred care (FCC), is usually practiced (Shields, Pratt, Davis, & Hunter, 2007). Even though the concept of FCC has been encouraged and developed over time there is still no consensus about what it means in clinical practice (Hutchfield, 1999). Shields, Pratt and Hunter define FCC as "a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognized as care recipients" (Shields, Pratt, & Hunter, 2006 p. 1318). This is important since it is known that the whole family is affected when a child goes to hospital and the impact on all family members of the child's admission must be considered (Shields et al., 2007).

## **The family in the context of childhood illness**

There are different definitions about what a family is. Craft and Willadsen (1992, p. 519) define the family as “a social context of at least two persons characterized by a mutual attachment, caring, long-term commitment, and responsibility to provide individual growth, supportive relationships and health of members and of the unit and maintenance of the organization and systems during constant individual, family, and societal change”. A family can also be defined as a group consisting of those who say they belong to the family (Wright, Watson, & Bell, 1996).

The hospitalization of a sick child is considered to be a stressful time both for the child and the parents (Darbyshire, 1994). When a family member becomes severely ill the family members' experience can be that their physical existence, social identity and security are threatened as well as their basic aims of seeking a satisfying life (Cullberg & Lundin, 2006). A child in hospital is in great need of a parent (Shields, 2001). According to the attachment theory small children have a need to be near their parent when they are confronted with something frightening but also when they feel pain, are tired, their parent seems unapproachable or they find themselves in unknown situations such as a hospital environment (Bowlby, 1969, 1973, 1980). Research has shown (Bowlby, 1951; Robertson & Bowlby, 1952) that when there is no parent at hand at the hospital, the sick child tends to be obedient and silent. The child does not protest but accepts what doctors and nurses tell them to do. On the other hand, children tend to show their feelings when their parents are with them in hospital (Bowlby, 1951, 1973; Robertson & Bowlby, 1952). At threatening times both children and adults need to be close in order to protect and help each other (Ainsworth, 1991; Bowlby, 1988).

When a family member is ill, coping, strategies dealing with threats (Lazarus, 1966) such as illness, can be useful for both the family and the individuals and it helps the family to maintain and restore a balance between demands and resources as well as to lessen the intensity of perceived stressors (McCubbin & McCubbin, 1993). Sometimes also thoughts about life itself gradually change and new values can be gained (Kübler-Ross & Kessler, 2000). When people have been through a hard time together they often feel closer and this feeling tends to persist even after cessation of the threat or danger (Ainsworth, 1991). However, family members can react differently when a family member is ill; some may even go into denial which can stifle family communication about the illness (Danielson, Hamel-Bissell, & Winstead-Fry, 1993). From a clinical point of view it is important to support the efforts of the family to maintain their family identity while they are trying to incorporate new sickness routines into their daily life (Patterson & Garwick, 1994).

## **Family experiences of childhood cancer**

The main research area in childhood cancer during the 1970s and beginning of 1980s was about families losing a child. As a result of increasing survival the perspective changed to include exploration of how families cope with the challenges of cancer-



related events (Woodgate & Degner, 2003a). Within the last decade the focus has been on understanding how children and families live with cancer but there are mostly separate studies rather than studies building on each other (Qvarnström et al., 2000; Woodgate & Degner, 2003).

From the family's point of view, the childhood cancer trajectory can be viewed as a sequence of rough times including the distress and suffering that have to be faced (Woodgate & Degner, 2003a). The families' everyday life became affected (Clarke-Steffen, 1997; Márky, 1982; McGrath, Paton, & Huff, 2005; Scott-Findlay & Chalmers, 2001; Woodgate & Degner, 2003b; Yin & Twinn, 2004) and those living far from hospitals were forced to be separated from each other, sometimes for long periods (Scott-Findlay & Chalmers, 2001). In the beginning of the child's treatment the families experienced hope as well as fear (McGrath, Paton, & Huff, 2004). Feelings were contradictory even when treatment was completed. The family was relieved that treatment was over but also concerned about how they would manage the new situation (Ortiz & de Lima, 2007).

### ***The sick child***

When children were diagnosed with cancer they felt uncertainty as they lacked information about their disease (Stewart, 2003). They become fatigued as a result of the illness as well as of the treatment (Hicks, Bartholomew, Ward-Smith, & Hutto, 2003), they feel ill because of side effects of the treatment (Enskär, Carlsson, Golsäter, Hamrin, & Kreuger, 1997; Woodgate, Degner, & Yanofsky, 2003c), and they loose their hair (Hicks et al., 2003). It was important for the sick children to feel special but yet to be treated normally (Hockenberry-Eaton & Minick, 1994). During treatment the sick children found it important that the staff were socially competent, that they (the sick child) were amused and had something to do at hospital, and that their basic needs were satisfied (Enskär & von Essen, 2000). It was also important to get information about the disease and its treatment (Hockenberry-Eaton & Minick, 1994; Stewart, 2003). When the children knew what to expect of treatment this seemed to decrease their fear about painful procedures (Hockenberry-Eaton & Minick, 1994), but new situations could be experienced as scary (Stewart, 2003). However, when they had been undergoing treatment for a while they felt they had become used to the cancer and its treatment (Hockenberry-Eaton & Minick, 1994; Stewart, 2003). At the time of completion of treatment, children experienced both celebration and hope but also uncertainty and fear (Haase & Rostad, 1994).

### ***The siblings***

Siblings felt shock, fear and disbelief when their brother or sister was diagnosed with cancer and when treatment began they felt the loss of attention from their parents, of routines and of companionship with the sick child (Sloper, 2000; Woodgate, 2006). They felt that all family activities mainly were planned around the sick child and no longer around the family unit or the individual family members. The siblings felt it important to be able to help to take care of their sick sibling (Woodgate, 2006). They

followed their sick sibling's ups and downs, and everyday life varied from joy to a life filled with worries and anxiety (Nolbris, Enskär, & Hellström, 2007). Siblings found that support, information (Murray, 1998, 2002; Sloper, 2000) and being able to follow their own interests and activities helped them to deal with the situation, as did maintaining a positive outlook (Sloper, 2000). Although it was important to be with other significant people, for example friends, the time spent together with parents was found to be special to the siblings (Woodgate, 2006). They felt that their brother's or sister's cancer strengthened their family bonds and brought them closer together (Sloper, 2000; Woodgate, 2006). Yet, Woodgate (2006) found that the sibling's experience was a story of sadness even if the cancer had been treated successfully.

### ***The parents***

Parents reported feelings of shock, fear and disbelief on being told of their child's diagnosis (Patistea, Makrodimitri, & Panteli, 2000; Wills, 1999; Wong & Chan, 2006). They also associated cancer with death (Wills, 1999). Parents experienced the threat of losing the child, but also the threats of the side-effects of chemotherapy, invasive medical procedures and the fear of relapse (Yiu & Twinn, 2001). Although the situation was upsetting they experienced times of optimism (Patistea et al., 2000; Wong & Chan, 2006). Some parents also felt relieved as they had finally found out about what had been wrong with their child (Wills, 1999). Information was experienced as giving parents some sort of control over their situation and reducing their feelings of uncertainty (Yiu & Twinn, 2001). Parents searched for information about the disease, treatment and care (Wong & Chan, 2006; Yiu & Twinn, 2001). It was important for them to receive support if they were to manage the situation (Yiu & Twinn, 2001) and they received it from within the family, from their extended families and from staff, as well as from other families in the ward (Wills, 1999; Yiu & Twinn, 2001). However, parents experienced stress when there was a lack of continuity of care or inadequate psychological support from staff (Patistea et al., 2000). At time of completion of the treatment, many parents experienced anxiety and feared a possible relapse, they missed the security and safety associated with administering medicine to the child and they lost the close contact with the staff with whom they had shared a difficult and trying experience (Lewis & LaBarbera, 1983).

As described above, there are many studies within the area of paediatric oncology care. However, the articles usually describe separate studies within a limited area and for separate family members, rather than studies which add to each other (Qvarnström et al., 2000). There is also a lack of studies focusing on young children with cancer and their needs. Therefore, in this thesis, we chose to focus on the whole family, their needs and experiences, and in a longitudinal perspective.

## **AIMS**

The overall aim of the study was to elucidate family members' lived experiences and needs during a child's cancer trajectory and to describe how the illness and its treatment influence both individuals within the family and the family as a whole.

Specific aims were:

- To elucidate the family's lived experience when a child in the family was diagnosed with cancer (Paper I)
- To describe the needs of children with cancer under the age of seven, as expressed by their behaviour, body language, and verbal expression, through observation during their initial hospitalization (Paper II)
- To elucidate families' lived experience during a child's cancer treatment (Paper III)
- To illuminate families' lived experience after completing a child's cancer treatment (Paper IV)

## METHODS

### Design

This thesis includes four papers using two different qualitative methods for data collection and analysis. In Papers I, III and IV an inductive, longitudinal design was used with interviews that were analysed with a hermeneutic phenomenological approach. In Paper II, nonparticipant unstructured observations were used for data collection and analysed through content analysis.

#### ***Hermeneutic phenomenology***

Hermeneutic phenomenology as described by van Manen (1997b) was used in Papers I, III and IV as the aim was to elucidate in a longitudinal perspective, the families' experiences of living with childhood cancer (van Manen, 1997b). Hermeneutical phenomenological research develops personal insight and it contributes to a person's thoughtfulness as well as to their ability to act with consideration towards others. Further, it "aims at gaining a deeper understanding of the nature or meaning of our everyday experiences" (van Manen, 1997b, p. 9).

Hermeneutic phenomenology is mostly a writing activity in which, through the writing and rewriting process, the researcher thoughtfully brings the participants' lived experiences into the written word. Hermeneutic phenomenology tries to be attentive to both the descriptive (phenomenological) methodology and to the interpretative (hermeneutic) methodology (van Manen, 1997b). Husserl (1859-1939) was a philosopher and is acknowledged as the founder of phenomenology, had an epistemological focus (Mackey, 2005) which implied the idea to go to the things themselves in order to understand (Dahlberg, Drew, & Nyström, 2001). By contrast, the philosopher Heidegger (1889-1976) introduced interpretation as a concept and his philosophical concern was ontological. Heidegger wanted to understand the "being", e.g. what it means to be-in-the-world. He refers to phenomenology as a way to uncover the understanding of being as a hermeneutic, interpretative process compared to Husserl who wants to know and explain concepts in a descriptive process (Mackey, 2005).

#### ***Content analysis***

Content analysis at both manifest and latent levels (Baxter, 1991; Berg, 2001) was used to analyze the narrative text transcribed from the field notes gained during the observations in Paper II. Content analysis is a research method that, in a systematic and objective manner, makes valid inferences in order to describe and quantify specific phenomena (Downe-Wamboldt, 1992). Initially, content analysis dealt with objective, systematic and quantitative descriptions of manifest content of communication. It has since expanded to also include interpretations of latent content at various depths of interpretation (Baxter, 1991; Graneheim & Lundman, 2004). Berg (2001) emphasizes a blend of both manifest and latent levels in content analyses

whereby manifest content analysis limits the analysis to those elements that are physically present and countable i.e. to the surface structure present in the message. On the other hand, latent content analysis extends the analysis to a more interpretative reading of the symbolism underlying the physical data; that is to say that this analysis concentrates on the deep structural meaning conveyed by the message. Baxter's (1991) thematic analysis is an interpretative holistic analysis where a thread of meaning runs through the themes revealed from the data.

## **Setting**

The study originated from a Paediatric Oncology Centre within a University Hospital in the south of Sweden. Approximately 60 newly diagnosed children per year are admitted to the paediatric oncology unit. The catchment area includes a total population of approximately 1.8 million (SCB, 2008). The paediatric unit consists of a ward with 16 beds, a day-care unit and a consultant. There are eight local hospitals falling under the University Hospital and the children are treated at both the University Hospital and the local hospitals.

## **Participants**

During a ten month period in 2002, families with a child newly diagnosed with cancer were consecutively asked, within one month of diagnosis, to participate in the study.

The inclusion criteria were:

- The family had a child under the age of 13 diagnosed with cancer
- The child was diagnosed with cancer for the first time
- The family could speak and understand Swedish
- The treatment (surgery in combination with chemotherapy/radiation or chemotherapy/radiation alone) was initiated within one month of diagnosis

In Papers I, III and IV both parents were invited for an interview, as well as the sick children and any siblings aged seven years or more. In Paper II, sick children under the age of seven were observed.

If the sick child or both parents did not want to participate the whole family was excluded. If individual family members refused to participate, only they were excluded. In this thesis the families were asked who they considered to be family members (Wright et al., 1996) and these family members were then invited to participate in the study. Twenty-seven sick children fulfilled the inclusion criteria and their families were asked to participate. Ten families declined to take part mostly due to the stress of their situation. In three of these families the sick child declined and in seven families both parents declined to participate.

The families (parents and children over the age of seven) were interviewed at three data collection time points; at diagnosis (first interview, Paper I), during treatment

(second interview, Paper III) and after treatment was completed (third interview, Paper IV). Children under the age of seven were observed during the child's initial hospitalization (Paper II). The participants' treatment lasted for between three and 30 months. The first interview occurred between the children's first and fifth months (median two months) of treatment, whereas the last interviews were performed between two and eleven months (median four months) after treatment was complete. Figure 1 presents a flowchart showing the data collection at different times in the study. A description of the participants is shown in Table 1 and an overview of the interviews and observation time points is shown in Table 2.

During the study period five of the children died. Their family members were invited to an interview after the death. Of these families, two parents wanted to be interviewed and one wanted to write a story. None of these parents wanted siblings to participate. These interviews are not included in this study as these families had lived through a completely different experience. These interviews will be presented elsewhere.

At the time of the first interviews (Paper I), 17 families participated, comprising 17 mothers, 12 fathers, five sick children (of whom four were boys), and five siblings (three girls and two boys). The diagnoses for the interviewed sick children were leukaemia (3), brain tumour (1) and solid tumour (1). Twelve of the participating families had children under the age of seven. Those twelve children were not interviewed but were instead observed (Paper II). These children's diagnoses were leukaemia (6), brain tumour (3), and solid tumour (3).

At the time of the second interviews (Paper III), four families were excluded as their children had died. Three of these children had not yet reached the age of seven, the fourth was older. Additionally, two other families were excluded from the interviews, one because the child's treatment was rather short and the other because not enough time had elapsed since the first interview. Because of practical issues, two mothers declined to participate. In addition, one child under the age of seven at the start of the study had reached that age and was therefore interviewed. The net outcome was that the interviews covered nine mothers, nine fathers, four sick children (two girls and two boys) and four siblings (two girls and two boys) from a total of eleven families. The diagnoses for the children who were interviewed were leukaemia (2) and solid tumour (2). Seven families had children under the age of seven. Those seven children were not interviewed. Their diagnoses were leukaemia (4), brain tumour (2) and solid tumour (1).

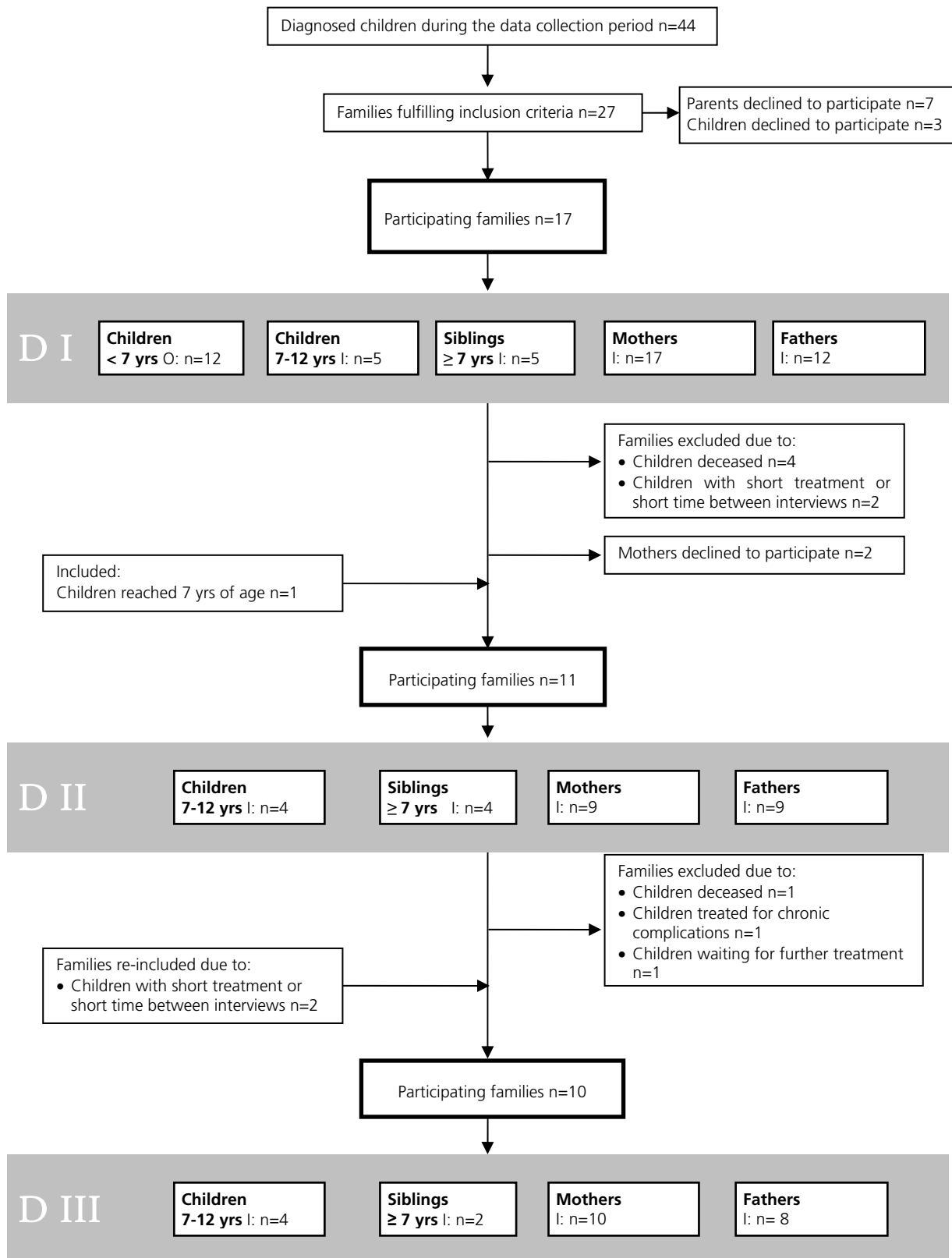
At the time of the third interviews (Paper IV), one family was excluded as their child (under the age of seven) had died. Two more families were excluded, in one case due to the child's chronic complications, in the other case because the child had completed the "standard treatment" but was waiting for further, as yet undecided, treatment. The two families excluded from the second interview because of the child's short treatment and because of that not enough time had elapsed since the first interview, were again included in the third interview. This resulted in ten families including ten mothers, eight fathers, four former sick children (two girls and two boys), and two siblings (one

girl and one boy) participating in the third interview. The diagnoses for the interviewed children were leukaemia (2) and solid tumour (2). Six participating families had children under the age of seven. Those six children were not interviewed. Their diagnoses were leukaemia (4) and brain tumour (2).

Of the 17 sick children, 12 (six girls and six boys) were under the age of seven and therefore included in the observational study (Paper II). The diagnoses of those were leukaemia (6), brain tumour (3), and solid tumour (3). Their ages ranged from 7 months to 6½ years (median 20 ½ months). Each child came from a two parent family and of these one had one parent born outside Sweden.

**Table 1.** Description of the participants in Papers I, III and IV

	Paper I	Paper III	Paper IV
Families (N)	17	11	10
Number of participants (n)	39	26	24
Single-parent family (n)	2	1	1
Number of children within the family (patient and siblings) range (median)	1-5 (2)	1-3 (3)	1-5 (3)
Parents born outside Sweden	4	2	2
Mother's age, range (median)	30-42 (35)	31-38 (35)	32-45 (37)
Father's age range (median)	31-45 (35)	32-42 (35)	34-40 (36)
Sick children's age range (median)	9-11 (11)	7-12 (10)	8-13 (11,5)
Sibling's age range (median)	7-16 (9)	7-10 (9)	10-12 (11)
Parental education (n)			
Nine-year compulsory-/Upper secondary school/ College/ University studies	2/14/6/7	0/10/3/5	1/10/3/4
Parent working/Parent at home (On sick leave or unemployed)	2/27	7/11	13/5



D I = Data collection time point I  
 D II = Data collection time point II  
 D III = Data collection time point III

I = Interview  
 O = Observation

**Figure 1.** Flowchart of data collection at different time points





Months after diagnosis	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36		
Family K	♀							♀													♀																	
	♂							♂													♂																	
	○									■																												
Family L				♀																																		
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				●							■	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-		
Family M	♀																																				♀	
	♂																																				♂	
	○																																				■	
Family N	♀																																					
	○	‡																																				
Family O	♀																																					
	♂																																					
	○																																					
Family P	♀																																					
	♂																																					
	○		‡																																			
Family Q	♀							♀																														
	●							●			■																											

- ♀ = Interview mother
- ♂ = Interview father
- = Observation child
- = Interview child
- = Interview sibling
- ‡ = Child deceased
- = Cancer treatment completed
- =Awaiting for yet not decided treatment or treated for chronic complications

## DATA COLLECTION

### *Interviews*

In Papers I, III and IV conversational interviews (van Manen, 1997b) were performed, all by MB. Before starting the study a pilot study with one family (two parents, one sick child and one sibling) was carried out to test the feasibility of the method, as well as to let the interviewer practice her skills. In order to create a good atmosphere and make the family members, especially the children, feel comfortable some time was spent with the family before the first interview, for example by playing Nintendo or party games.

The dates and places for the interviews were decided in agreement with the families. For the first interviews fifteen families chose to be interviewed in a separate room at the hospital while two wanted to be interviewed in their homes. For the second interviews ten families were interviewed in a separate room at the hospital and one wanted to be interviewed at home. For the last interviews, seven families were interviewed in a separate room at hospital and three families were interviewed at home.

The participants were invited to talk about their experiences and thoughts about living with childhood cancer at the time of diagnosis (Paper I), during treatment (Paper III) and after its completion (Paper IV). If the participants had difficulty describing their experiences, topics were introduced e.g. asking them to describe how life was at home and at the hospital. Follow-up questions were asked to help the participants describe more fully their experiences and to help them stay as close as possible to the experience as it was lived. Examples of follow up questions were “can you give me an example of a specific situation or event?”, “can you describe further?”, “how did you feel?”, “what did you think?”, “what did you need?” or “what happened next?” When interviewing the children, readily understandable language was used (Docherty & Sandelowski, 1999; Åstedt-Kurki, Paavilainen, & Lehti, 2001). If the child did not seem to understand the questions efforts were made to put them in another way. Durations of the interviews are shown in Table 3.

The interviews were performed individually, one person at a time, and lasted as long as the participant needed and wanted. Children were told that one of their parents could stay during the interview if they wanted to. For the second interview one sick child and one sibling took up that option. All interviews were audio taped and later transcribed. In connection with the first interview the parents were asked to fill in a questionnaire with demographic data including age, number of children, civil status, occupation, education as well as the child’s diagnosis, date of diagnosis and age of the sick child and siblings.

**Table 3.** Interview lengths

	Paper I	Paper III	Paper IV
Parents (median)	30-160 min (App. 60 min)	17-102 min (App. 60 min)	22-109 min (App. 70 min)
Sick children and siblings (median)	10-45 min (App. 20 min)	10-27 min (App. 20 min)	16-55 min (App. 20 min)

### **Observations**

In Paper II non participant observations, i.e. where the researcher (MB) was not involved in the caring process (Polit, Beck, & Hungler, 2001), of sick children under the age of seven were performed during the three months (median one month) after diagnosis. During this process the observer was dressed in street clothes to differentiate her from the staff, and she had no personal involvement with the sick children or the care on the ward. Observations with two children were carried out to test the feasibility of the method and to let the researcher practice the method before the first observation. Observations were planned to cover different activities and situations the children were going through during the course of a day at the hospital (Mays & Pope, 1996). They were performed in agreement with the parents, as well as with the children (if developmentally appropriate).

Observations were performed in the paediatric oncology ward, in the play therapy, in the X ray department, in radiation therapy, in the hospital dentist's office and during walks outside the hospital. One or both parents were with the child during the observation and some children had siblings or grandparents present as well as various staff members. Mobile positioning (Polit et al., 2001) was used, meaning that the observer followed the child throughout an activity or situation. During the observations the observer acted as discretely as possible. For example, if the activity took place in a room, the observer sat or stood in a corner quietly. Children and parents were able to initiate topics of conversation but the observer did not. Each child was observed for from 45 minutes to three hours, giving a total observation time of 26 hours. Each observation sequence lasted between 20 and 80 minutes. Field notes (systematic notes of events, behaviours, and words) were written immediately after each observation period in as detailed, concrete, objective and comprehensible a manner as possible. The observer's own actions were noted as well as the date and time of the observation (Neuman, 1997) The field notes were later transcribed into a narrative text. Observational data are shown in Table 4.

**Table 4.** Observational data

Age of the child	Accompanied by	Observation time
< 1 year	F, P	2 h 30 min
4 years	M, F, S, P	1 h 40 min
1,5 year	M, F, S, GP, P	1 h 35 min
1,5 year	M, F, P	2 h
3 years	M, F, P	2h 20 min
1 year	F, P	2 h 10 min
1,5 year	M, P	2 h 30 min
< 1 year	M, F, S, V, P	2 h
6,5 year	F, P	2h 30 min
1 year	M, F, P	3 h
4 year	M, P	2 h 50 min
5 year	F, P	45 min

M, mother; F, father; S, sibling; GP, grandparent; V, visitor; P, professionals

## DATA ANALYSIS

### Papers I, III and IV

In Papers I, III and IV a hermeneutic phenomenological analysis based on van Manen (1997b) was conducted. All analysis started with a naïve reading of the transcribed interviews to get an overall meaning of the participants' stories. In Paper I two of the authors (MB, IH) read all of the interviews, whereas for Papers III and IV the first author read all of the interviews and the other authors each read interviews from four different families. After the initial reading the authors in Paper IV discussed their overall understanding and identified preliminary themes during discussions before moving further in the analysis. In Paper I a detailed line-by-line approach was used (van Manen, 1997b) in which the first author looked at every sentence asking what it revealed about the phenomenon or experience being described. Phrases were underlined and tentative theme names were written in the margins of the text. After having identified significant statements, these were interpreted and organised into broad topical areas to illuminate their meaning and then the writing process started. In Papers III and IV a selective or highlighting approach was used. Phrases or statements that stood out and seemed to reveal something about the specific experience relevant to each specific study were underlined and separated from the text. The chosen statements were re-read and a summary of each was written underneath. All of the statements were then reorganised into structures of experience, clarifying the experience being described, and the writing process started. The writing process always started with the children's experiences in order not to lose them. During this process the analysis went from parts to the whole. The text was written and re-written and changes of themes were made after repeated discussions among the authors which

aimed at deepening the insights of the specific lived experiences that were under focus (van Manen, 1997b). The experience of the family as a unit was formed from the experiences contributed by each individual within the family.

## **Paper II**

The narrative text transcribed from the field notes was analyzed using content analysis (Baxter, 1991; Berg, 2001) at both manifest and latent levels, as emphasized by Berg (2001). Manifest content analysis was used when looking for the explicit meaning of the child's behaviour and verbal expression, such as when the child asked for something, but also when counting identified meaning units and code concepts. Latent content analysis was used when looking for the implicit meaning of the child's behaviour and body language as well as when finding the deep meaning conveyed in the observations.

The analysis was performed in six steps. The first involved multiple reviews, by the authors independently, of the transcribed narrative text to get an overall meaning. In the second step, words, sentences, or paragraphs that contained aspects of the child's behaviour, body language, or verbal expression relating to their need in the context were identified as meaning units (Graneheim & Lundman, 2004). Needs were assigned to meaning units in a broad sense, such as what the child needed, looked for, wanted, expressed, longed for, or missed. In total, 544 meaning units were identified independently by all three authors. In a third step, meaning units were discussed among the authors. Some meaning units were revised, and those that contained too little or inadequate information were excluded. In the further analysis, 442 meaning units were agreed on and carried forward. In the fourth step, meaning units were grouped together in conceptual clusters comprising variables constituting different kinds of needs and defined as code concepts (Berg, 2001), by the three authors independently. In the fifth step, code concepts were discussed and revised and finally 22 code concepts were agreed on. In the last and sixth step, the first author formed themes from code concepts that related to each other with a thread of meaning (Baxter, 1991), while the other two authors validated the themes and classifications.

## **PRE-UNDERSTANDING**

Pre-understanding is often referred to as our previous, non-critical, taken-for-granted knowledge important to understand data (Dahlberg et al., 2001; Nyström & Dahlberg, 2001). van Manen (1997b) says that it is important to make one's own understanding and beliefs explicit in order not to forget them, but to hold them at bay, so that we do not interpret the nature of the phenomenon before we actually come to an understanding of the significance of the phenomenological question. If we do not hold our pre-understanding at bay there is a risk that we obtain results that primarily reflect an image of something that already exists in our understanding (Nyström & Dahlberg, 2001).

The author of this thesis has several years of experience working as a paediatric oncology nurse at a children's hospital and is mother of one toddler and one pre-school child. BN is a doctor in psychology. She has extensive experience of working with children and families who are found to be in ordinary as well as in stressful circumstances. She also has experience of research with pre-school children and their families and is a mother of grown-up children. TW is a medical doctor in paediatric oncology with over 30 years of experience in this field and is a father of grown-up children. IH has been a paediatric nurse for 25 years and has extensive experience in carrying out research with children and families, and is a mother of grown-up children. Through discussions, all the authors tried, to make their pre-understandings explicit before entering the study as well as at the beginning of every paper. The understanding of the data was discussed and reflected upon throughout the study to increase the openness, and decrease the risk of letting the pre-understanding influence the interpretation of the families' lived experiences before arriving at specific descriptions.

## **ETHICAL CONSIDERATIONS**

When conducting research with human beings the research should be conducted according to accepted ethical guidelines and rules. This research was formally approved by the Research Ethics Committee at the Medical Faculty, Lund University, Sweden, (LU 476-01), and followed the principles of research ethics approved by the Medical Research Council (MFR, 2003). This means that the four ethical principles; respect for autonomy, beneficence, nonmaleficence and justice, were considered (Beauchamp & Childress, 2001; MFR, 2003).

Performing research with families including small children when a child is severely ill can involve ethical conflicts. Ethical questions and principles were considered in the following way. Two designated nurses gave written information to a consecutively series of families eligible for the study at a suitable time after the child's diagnosis was established. After the family had been contacted, parents, who gave written consent for their names to be forwarded, were contacted by the investigator. Children over the age of two were given age-related information about the study through informal chats whereas parents and children over the age of 12 were given written as well as oral information.

Since the study involved children (Polit et al., 2001) special considerations were made for inclusion. Giving informed consent means that the participant must understand that they have a choice as to whether to participate in the research or not, that they know that they have a right to withdraw at any time, with no explanation and without detriment to their care, as well as understanding what their participation means to them. Informed consent should not only be sought from the parent, but in addition from the child if he or she is able to give it (Greig & Taylor, 1999). Children develop their abstract thinking from about the age of 12, which enables them to give independent opinions and to perceive multidimensional situations (Merlo, Knudsen, Matusiewicz, Niebroj, & Vahakangas, 2007). Therefore, in this study informed

consent was obtained from children 12 years or older. Children younger than 12 years are dependent on the decisions of their parents to consent for research. However, in this study their verbal assent (willingness to participate) (Neill, 2005) was sought after they had been given age-appropriate information.

Before giving assent or informed consent to participate in the study, each family was given time to consider their possible participation. Before each interview session, the participants' consent as well as assent were repeated orally and the participants were informed that they could withdraw from the study whenever they wanted and do so without giving any explanation and without any effects on their future care. In addition, staff members at the paediatric oncology ward were informed about the study as were staff in other departments when the observation took place outside the paediatric oncology ward.

Each family member was told that they should say only what they wanted to in the interviews. All family members who were interviewed, and family members and professionals being observed, were guaranteed confidentiality, i.e. that findings could not be linked to specific persons and that no information should be forwarded to either staff members or family members. In addition, children were told that if they wanted to tell other people about what had been said in the interview, they could do so, but that the interviewer were not allowed to. If family members asked questions about the cancer or treatment during interviews they were recommended to ask these questions to the staff instead, so there would be no role confusion either for the participants or for the researcher. Observations were performed in agreement with parents and children (if developmentally appropriate). Family members were told that they were free to ask the observer to leave the room. This was done occasionally during visits to the lavatory and to make private telephone calls. After having performed interviews and observations regular debriefing was given to MB by the main supervisor.

Since an interview can cause difficult feelings, all interviewed family members were offered contact with supportive persons (psychologist, welfare officer, sibling supporter, paediatric oncology consultant nurse or their contact persons) after the interview. Several parents said that they had benefitted from being interviewed by having been listened to and given a considerable amount of time. Several of the parents suggested that these types of meeting should be a natural part of the care.

Dates and places for interviews and observations were made in agreement with each family. Those whose children died during the study time were offered an interview at a time suitable for them.

After the last interview, a box of chocolates was given to the family. It can be discussed whether one should give a gift or not and, if so, when (Neill, 2005). The gift did not compensate for the time and efforts the family had put into being included in the study but it was a way of thanking them once the study was completed.



## FINDINGS

Some of the most prominent findings from the data collection are described below.

### **A changed life world**

When the child was diagnosed with cancer (Paper I) the family felt that they were cast out into the unknown and that their life became intimidating. Fundamental feelings of security disappeared and family members felt more vulnerable when confronted with facts about the disease. Family members changed their perspectives on what was most important in life and set new priorities. The whole family was aware that the child had a possibly fatal disease and from time to time feared that it was incurable. However, optimism that the child would survive was the predominant feeling. Striving to feel hope and to have a positive focus helped the family to move forward.

Even though there were fundamental changes in the young sick children's life including hospitalization and treatments, they expressed a need to play and feel joy (Paper II). They wanted to have fun, to explore the world, to play with their siblings, and to have social contacts with other children and adults. The child's choice of play reflected their chronological and developmental age but also their physical ability and strength due to the disease. Children who were not visibly affected by the disease showed a need for more physical activities while severely ill children showed that they wanted to play and feel joy by pointing at toys and smiling.

During the period of treatment the families learned to appreciate things they earlier took for granted while they tried to focus on positive things (Paper III). It was important for both the sick children and the siblings to have fun, to play and to mess around with each other. Looking back, parents thought that the treatment period had passed quickly. On the other hand, a single day could be experienced as very long. They also often had thoughts about other families having a worse time than themselves.

Family members felt changed when the child's treatment was completed (Paper IV). The previously sick child felt that they had either become calmer and more self confident, or that they had become more compassionate. Siblings altered their feelings towards their brother/sister and thought they were as tiresome as before they became ill. Parents experienced that their perspectives on life had changed. They did not take so much for granted as before and trifling things did not become as big as previously. Now they wanted to slow down and have time to focus just on themselves and their relationships.

## **Family importance**

After the child had been diagnosed with cancer, family members experienced that their own family became more important (Paper I). The parents helped the child through medical procedures even though they were experienced as being painful and, indeed, as horrible and the child begged the parent to take them away. Siblings were often taken care of by other people e.g. grandparents or friends and missed both their sick brother/sister and their parents.

The young sick children showed a pronounced need to have one or both parents close by, both physically and emotionally (Paper II). They wanted to be comforted by their parents, and to have the parent as a facilitator and as a secure base. It seemed as if the parents' presence was a necessary condition for the children to express their needs as well as for them to receive optimal care.

It meant a lot for the entire family to be able to do things together during the child's treatment (Paper III). Common things like being together at home or having dinner together became important. The sick child was given priority but parents bore it in mind that siblings should not feel slighted because of the sick child. They did their best with regard to the siblings, however, from time to time the siblings experienced being divided from the rest of the family.

When treatment was completed (Paper IV) family members wanted to continue to prioritize their own family and they tried to retain the feeling of being close. Parents did not want to enter a stressful everyday life again but wanted to hold on to the values gained. However, family members felt that it was not always easy to retain this closeness, as parents sometimes worked more than before leaving less time for the own family.

## **An everyday struggle**

The family's ordinary life disappeared when the child was diagnosed with cancer (Paper I). The sick child felt ill, lost its hair and from time to time behaved in new ways due to side effects of the treatment. Siblings had to go to hospital to visit their sibling and parents and the sick children missed their normal activities and friends. The sick child was often in parents' and siblings' minds. Parents' experience of taking care of the sick child was that it was full time work. Appointments and practical matters had to be coordinated and they thought it was difficult to leave the sick child, even for short periods.

The young sick children (Paper II) had a need to participate in care and treatment, and they usually facilitated procedures by cooperating. However, when they were exposed to something in their care and treatment in which they did not want to participate, protests were made, irrespective of age.

Life during treatment (Paper III) was experienced as a taxing period which the family struggled to get through. The sick child found it tiresome being in hospital and receiving treatment and they felt locked in by their infusion suspension device. The sick child's port-a-cath impeded both the sick child and the sibling when they wanted to mess around. When the family was not able to go on vacations as they used to, siblings felt locked in by their sibling's disease. They also felt it as tiresome having to move between different places and people when their parents were at hospital. The working parent thought it was nice being back at work although it was often tiresome. The parent who was at home generally felt exhausted. They had to deal with the sick child, hospital visits, siblings and the household and looked forward to the other parent coming home from work to be able to recover their breath. Parents felt that they got too little time for themselves, together or alone and they found it difficult to set limits for the sick child as well as for the sibling. The child's liability to infections prevented the family from joining different activities. However, when the parents learned to interpret the child's blood tests, life became easier to handle.

Ordinary life became more normal when the child's treatment was completed (Paper IV), though, it was not the same normality as before the child became ill. The previously sick child thought it was taxing when they had to return to the hospital for controls and blood punctures. Siblings now felt they got more attention from their parents, in contrast to the previously sick child who now experienced getting less attention. Parents and siblings raised their demands and did not discriminate in favour of the previously sick child; from time to time this resulted in protests and whining. Parents felt overwhelmed by tiredness and emptiness and they found it difficult to work through their experience.

## **A swing between worry and relief**

On diagnosis the sick child and the siblings understood that it was a serious disease and experienced the illness as frightening and strange (Paper I). The sick child was afraid of not being cured but also that their siblings who knew that cancer was dangerous and sometimes fatal, would get it. Both the sick child and the siblings felt worried and sad. Parents felt an immediate threat of death when the child was diagnosed and they were afraid of losing their child. The family took one step at a time and the sick child's condition guided the family. When examinations or procedures were managed successfully, the sick child and parents felt relieved.

During treatment (Paper III), it did not appear that the sick children and their sibling felt as anxious as their parents, but they still felt sad from time to time when thinking about the illness or treatment. Siblings felt sad when they thought about their brother/sister going through painful procedures and when they made protests. On the other hand, parents felt anxiety for many things, such as when the child deviated from the protocol, had new drugs or displayed previous symptoms. They also felt anxiety that the healthy sibling might develop a serious illness. However, when family

members broadened their understanding, and when the sick child felt well, the anxiety eased.

Family members felt happy and relieved when the child had completed the treatment (Paper IV). Neither the previously sick children nor the siblings expressed anxiety for the disease returning, but parents did so. Parents were afraid that the disease would return when treatment ended and they worried about relapses and side effects of the treatment. This fear was present constantly, but in some families it was prominent. The anxiety was easily awakened when the child did not behave as usual, did not feel well or when a sick child from the ward suffered a relapse or died.

## **Striving to gain control**

To get through the chaotic and stressful situation (Paper I) the family strove to gain control. Children and siblings asked for information and gained increased control over the situation when they were involved in the care and when their thoughts were heard and valued. Parents tried to find information by reading and asking questions. They tried to regain control by finding new routines to give their life a structure they could hold on to. The sibling and, especially, the sick child wanted to be like other children. The sick child went to hospital school, ordinary school or day care when possible. Wearing a wig, or something that covered their head, also made the child look more like others.

The young sick children (Paper II) showed a need for information. To increase further their knowledge they asked for information or stayed in the room where conversations were held. If they did not know what was going to happen, they asked.

As treatment progressed (Paper III) the family experienced that having a child with cancer within the family had become an integral part of their lives. The entire family became experts on the child's symptoms and treatment. The sick child and the sibling knew much more about the illness and treatment, and this made them more calm and less sad. They did not want to talk much about the condition. Parents felt that they learned more about the disease and treatment, how to handle certain situations, what to expect and what they could make demands on which resulted in less confusion and fewer questions. However, they still felt that they needed both nursing and medical support to expand their understanding.

When treatment was completed (Paper IV) the previously sick child and their siblings enjoyed the present and felt hopeful for the future. On the other hand parents again found themselves in a new situation and they experienced being in uncharted territory. However, parents felt relaxed when they learned more.

## **A need for support**

To be able to manage life when the child was diagnosed with cancer (Paper I) the family became dependant upon other people, such as relatives and friends, who took care of them. When friends and relatives whom they expected to hear from did not contact them, they felt lonely. The sick children and the siblings thought it was important to feel close to family, friends and teachers at school.

The young sick children (Paper II) expressed a need to have their physical and emotional needs satisfied. The staff often took care of the basic medical needs whereas the parents gave a more all-encompassing care. The children for example needed help with going to the toilet, throwing up, taking a shower, and other such practical things, or when they wanted to eat. They also wanted to feel looked after and they expressed satisfaction when receiving a blanket or relieved when they were put in a comfortable position.

During the child's treatment (Paper III) the family experienced the need for support. The sick children felt happy when they got it from their family and friends. Siblings were happy when they got it from parents and friends. Parents often did not want to ask for support but appreciated when it was given, although they did not always take up the offers of help. They experienced frustration and sadness when people around the family did not understand the situation and its seriousness. From time to time friends and relatives feared giving the child infections, which resulted in fewer invitations.

When treatment was completed (Paper IV) the children and siblings wanted to feel close and supported by their friends and parents. Parents wanted to feel supported by friends, relatives and workmates. Some parents felt that their friends could contact them again once treatment was complete while others found that, in the absence of major news, their friends contacted them less frequently.

## **A need for a good relation to the professionals**

When the child was diagnosed (Paper I) the family members felt supported by the staff. The sick children and the siblings felt confident that the staff could cure the sick child while the parents felt that they had no choice but to trust the staff. They found themselves in a dependent situation and often did not want to disturb, complain or be bothersome by asking or mentioning things to the staff that they experienced as infuriating. Furthermore, they felt that their stress increased when staff members did not give consistent information or responses, or when the information was unclear. When the family had been on the ward for a while, parents felt that the staff did not pay as much attention to them as before and they felt lonely.

Additionally the young sick children expressed a need for a good relationship with the staff although their closest relation was with their parent (Paper II). They needed to

have social contacts with the staff, they smiled and talked to the staff and gave them hugs and kisses. They also expressed a need to play and to have fun together with the staff.

During treatment (Paper III) the sick children and their siblings felt happy when they received support from the staff. Parents felt it important that staff members knew them as they did not want to tell their story repeatedly. When the staff got to know the family, in the way contact persons did, the family felt even more supported. However, parents felt isolated from the staff when a meaningful dialogue did not occur between them and the professionals. This could happen when many different staff members cared for the child or when the staff worked under a lot of stress, and then the parents hesitated to ask questions. If they asked, they did not dare to ask follow-up questions.

When treatment was completed (Paper IV) the former sick child and the sibling missed the attention they had got from the staff, and the parents missed the ability to ask minor questions. Parents felt disappointed when the staff did not explicitly mark the ending of the treatment. They lacked a structured follow up. They found it was hard meeting new doctors all the time, and experienced not knowing where they belonged to or which hospital kept check on their child.

## **DISCUSSION**

### **Methodological considerations**

Children have a valuable contribution to make in matters that concern them and have rights to be consulted (Irwin & Johnson, 2005; Neill, 2005). In research as well as in clinical practice it has been common that proxies have been asked for their perception on children's experiences (Hart & Chesson, 1998) instead of asking the children themselves. Therefore it was important that the children diagnosed with cancer, as well as their siblings and parents were included in this study.

To evaluate qualitative data and findings to make sure that they are reflecting the trustworthiness of the data Lincoln and Guba (1985) suggested four criteria, credibility, confirmability, dependability and transferability. Credibility relates to whether the findings and interpretations are credible. Confirmability refers to whether the findings are grounded in the data. Dependability refers to the stability of the findings over time and over conditions, and transferability refers to the issue of whether the findings could be transferred to other contexts.

Different criteria are used to ensure quality in interpretative phenomenology. Openness, is concerned about whether the research process has been explicit throughout the study. Concreteness; relates to the usefulness for practice of the study findings, and resonance; relates to the effects the study findings have on a reader (de Witt & Ploeg, 2006). van Manen (1997a) suggests that it is important that the findings are written concretely, so the reader may experimentally recognize the lived reality

being described. van Manen (1997a, 1997b) also suggests that the findings should affect the reader and contribute to personal insight. The four fundamental life world themes or “existentials” - lived space, lived body, lived time and lived human relation, pervade the life worlds of all human beings (van Manen, 1997b). The findings are reflected in the discussion related to those four existentials to see further that the findings reveal different aspects of the participant’s life world.

To get a variation of participants, families were consecutively selected. Seventeen families were included initially in view of the possibility of exclusions due to deaths or relapses. The participants came from the south of Sweden which includes both urban and rural areas. In addition, children with different diagnoses and ages were included. Some of the children were less physically affected by their disease while others were severely ill and died weeks after the observation or interview. Siblings, mothers and fathers were in different age groups and with different educations, and there was a variation of types of family units and of nationalities. However, in the consecutive sample only ten sick children and siblings, over the age of seven were included. This is probably due to the fact that approximately 47% of the children diagnosed with cancer are under the age of seven and only 27 % are between 7 and 12 years old (National Swedish Board of Health and Welfare, 2005). Furthermore, some parents did not want siblings to participate in order to protect them from the whole cancer event. Adolescents newly diagnosed with cancer were not included, as adolescence is a special period in which the individual tries to find their own identity and freedom from their parents (Keenan, 2001).

Pilot interviews and observations were performed to test the feasibility of the data collection methods and to let the researcher practice her interview technique as well as her observational skills. Lessons learned from the pilot interviews were used to adjust the follow up questions and to adjust the language when interviewing children. The pilot observations increased the awareness of how the researcher could act in different observation situations. The pilot studies highlighted the importance of informing all family members that the researcher was solely that and was not involved as a nurse in the child’s care.

For practical reasons, from time to time it was not possible to do the interviews near to the times of diagnosis, or completion. However, studies have shown that memories including something very special seem to be remembered (Beyer, Berde, & Bournaki, 1991; Simkin, 1991). Families with a child who died before the data collection was completed were offered an interview after their child’s death. Dyregrov (2004) found that parents experienced it as positive to be allowed to tell their story in a research interview after their child had died. These interviews will be analysed separately and presented elsewhere.

A considerable amount of time was spent with the participants, which enhance the credibility of the study. Altogether, approximately 105 hours were spent with the families in interview time and in observation time. If it was possible, the researcher tried to meet the family, and especially the children, before the interviews and the

observations to establish a rapport (Irwin & Johnson, 2005; Neuman, 1997). Trust develops over time and a long-term relationship enhances the probability that the emerged data will be credible and meaningful (Sterling & Peterson, 2005).

Interviewing children can be potentially difficult. In this study only children of seven or older were interviewed, as younger children have limited communicative abilities (Greig & Taylor, 1999). When interviewing the children, language readily understandable by them was used as much as possible (Docherty & Sandelowski, 1999; Åstedt-Kurki et al., 2001). If the child did not understand what was said efforts were made to put the language in another way. However, the children were asked to speak freely, which sometimes led the conversation off topic (Irwin & Johnson, 2005). Children were interviewed separately, as they generally withhold emotion-laden information and sometimes try to protect parents from negative feelings (Docherty & Sandelowski, 1999). The children were told that they could have their parent present; two children did so.

Most of the parents felt it comforting talking to the interviewer and suggested that these types of sessions should be a natural part of the care. Sharing one's illness story can be healing within itself (Sterling & Peterson, 2005; Svavarsdottir, 2006), especially if the participant gets attention from one person who they believe to have a genuine and sincere interest in them over an extended period (Sterling & Peterson, 2005).

The observational method has broad applicability and is especially useful when doing research involving young children, as they are not always able to express themselves in words or not capable of articulating their actions, needs and/or feelings (Carnevale, Macdonald, Bluebond-Langner, & McKeever, 2008; Greig & Taylor, 1999; Polit et al., 2001). Instead their communication is shown in their actions and behaviour (Keenan, 2001). Therefore observations were used when investigating the needs of children under the age of seven. However, the issue of the researcher's bias, e.g. that the researcher sees what she/he wants to see based on their own interest and anticipation (Mays & Pope, 1996; Polit et al., 2001) often arises. The fact that the researcher was well acquainted with the ward and the staffs, as well as being the parent of a young child, could have had an effect on the observations made. For instance, some events could be experienced as so normal and obvious that they were not noted, others may have come close to the researcher in the view of her experience as a mother. The researcher was aware of this and therefore tried to be particularly careful and observant. In order not to lose information gained from the observations, field notes were written immediately after each session (Mays & Pope, 1996). During hospitalization, observations were carried out during only parts of the day. However, this requires a caveat that, during periods when not being observed, the child might have other needs from those in the periods when they were observed.

Another issue also often discussed is whether the researcher's presence may have a reactivity effect e.g. make the people who are being observed react differently from what they would have done without the observer being present (Neuman, 1997). By



creating an initial rapport each family became familiar with the researcher. During the observations the researcher tried to be as discrete as possible and did not initiate conversations but answered if she was spoken to. Schnelle, Ouslander, and Simmons (2006) found that being observed does not appear to influence behaviour.

The confirmability was enhanced by providing a clear description of each stage of the research process. Quotations were written in the text to show further that the findings were grounded in the data (Lincoln & Guba, 1985). Lincoln and Guba (1985) emphasize the performance of member's check which was done in Paper I where parents recognised the themes described and found them to be valid. Instead of member's check van Manen (1997b) suggests arranging a series of conversations. In this thesis, family members were interviewed at three data collection time points to enable them to reflect upon their lived experiences during their child's entire cancer course. The findings in all papers were considered and reflected upon during seminars with specialized nurses and during peer debriefings, as emphasized by van Manen (1997b). The results were found to be plausible and sensible.

With regard to dependability, researchers with different backgrounds independently familiarized themselves with the data. Interpretations and insights concerning what was under study were compared and discussed in an open dialogue between the researchers. However, the findings must be contemplated in a humble way. In relation to the findings from the interviews, van Manen says that one must be aware "that lived life is always more complex than any explication of meaning can reveal" (van Manen, 1997b, p. 18). Further he says that "a phenomenological description is always *one* interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even *richer* or *deeper* description" (van Manen, 1997b, p. 31). It might be that researchers with backgrounds different from ours could have reached another, but similar, result. The results could also have been different if other families had taken part in this study.

The context and the participants are described as carefully as possible in order to enhance transferability. One must contemplate that the study group consists of Swedish speaking families and those whose child has survived. van Manen (1997b) argues that the only generalization that can be made from phenomenological studies (Papers I, III and IV) is that they should never be generalized. On the other hand, Dahlberg et al. (2001) suggest that phenomenological results can be transferred to groups within the same context.

## **General discussions of the findings**

The "lived human relation" refers to the lived relation we maintain with others in the interpersonal space that we share with them (van Manen, 1997b). This dimension was illuminated in the family members' experience of the increased importance of the own family. At the time of the diagnosis the family experienced that their life world broke. They felt as if the family's existence was threatened, they lost their sense of security in

life and became vulnerable. This led to the family reflecting on their own family and the importance of it, and their family became more important than ever. Family members longed to spend time with each other and wanted to be gathered at home. Common things like spending time eating together and having nice evenings at home became important. Other researchers (Clarke-Steffen, 1997; Enskär et al., 1997; Woodgate & Degner, 2003a) have also found that the immediate family becomes more important when a child within the family is ill with cancer. This feeling may be explained in the attachment literature as, when a child or an adult senses something dangerous and threatening, they try to seek security and closeness. Parents mostly protect children and other members of the family protect each other (Ainsworth, 1991; Bowlby, 1988). It is well known that affectional bonds tend to be formed and strengthened under conditions of danger and threat, probably due to the fact that the caregiving and attachment systems are intended to provide protection and to satisfy different needs (Ainsworth, 1991).

The “lived space” refers to the felt space (van Manen, 1997b). The “lived space” was illuminated in family’s experience of finding themselves in a frightening and unsecure space when the child’s diagnosis had been given. When the cancer was diagnosed family members lost their foothold in life. Life became intimidating. The sick child and sibling felt fear and became worried and sad. Parents felt an immediate threat of death. Other studies have also found that the sick child became scared on being diagnosed with cancer (Hockenberry-Eaton & Minick, 1994), siblings and parents feel fear (Sloper, 2000), and parents feel fear and uncertainty when faced with the possible loss of the sick child (Yiu & Twinn, 2001). However, during and after the treatment was completed the sick child and siblings did not express themselves as being worried or anxious. They felt well informed which gave them some sort of control over their situation. On the other hand, studies have found that the sick children became scared when initial symptoms reappeared or new ones appeared (Woodgate et al., 2003c) or when they underwent routine post treatment examinations (Haase & Rostad, 1994). Nolbris, Enskär and Hellström (2007) found that siblings felt anxiety about losing their sibling. These findings do not really correspond with the findings from the present study. It might be that in the present study the parents, other family members and professionals provided the children with what they needed concerning knowledge and support, which made them feel less worried and more secure. Studies have shown that when the sick children receive information about their cancer it helps them to adjust to the diagnosis (Hockenberry-Eaton & Minick, 1994) and children who are well prepared seem to be more competent to cope with pain during procedures (Månsson, Björkhem, & Wiebe, 1993). Sloper (2000) found that when siblings got information about the illness, treatment and what was happening to their brother or sister it helped them make sense of the situation. However, if more children had been included in this study we might have come up with a different finding.

The “lived human relation” (van Manen, 1997b) was further illuminated in the sick children’s experience of being supported by and getting security from their parents. They wanted to have their parents close by, and they in turn helped the children through taxing procedures and treatments. Through the attachment literature it is

known that children have a need to be near their parents when they are confronted with something frightening, feel pain, are tired or they find themselves in unknown situations (Bowlby, 1969, 1973, 1980). This behaviour is partly a programmed pattern (Bowlby, 1969). The parents' importance for the sick child is found in other studies as well (Cleary et al., 1986; Enskär et al., 1997; Runeson, Hallström, Elander, & Herméren, 2002). However, it may appear that the parent has a huge task in providing comfort and security for their sick child in a situation which can be difficult for themselves. In addition, it is important that the staff do not force the parent into something they feel they cannot manage.

The "lived space" (van Manen, 1997b) was further illuminated in the siblings' feeling of being divided from the rest of the family. They had to move between different places to be looked after when parents were at hospital with the sick child. It appeared that siblings had a need to be able to stay in their own homes. Sloper (2000) found in her study that it was often the case that the siblings had to stay in other people's homes to be taken care of. Other studies have found that siblings felt a loss of attention and status when their sibling became ill (Murray, 1998; Sloper, 2000; Woodgate, 2006). They also felt less cared for as the sick sibling got more attention from their parents (Woodgate, 2006), but they often understood why their sibling was receiving more attention (Sloper, 2000). In this study parents were important to the siblings and supported them. They constantly had the siblings in mind. At hospital, siblings felt supported by the sibling supporter as well. Woodgate (2006) found, in her study, that what counted for siblings was time spent with the parent. Professionals need to have a holistic approach and support the parents so that they in turn can support the siblings in a positive way.

The "lived human relation" (van Manen, 1997b) was also illuminated in the family members' feelings towards the staff. The findings of this study suggest that the staff meant a lot to the family members. The children experienced feeling cared for by the staff during the entire treatment trajectory, but this was not always the case for the parents. They felt alone when a meaningful dialogue did not occur between them and the staff, as when for example the staff members were busy or when there were many different or new staff members. Heller and Solomon (2005) found that parents felt best cared for when there was continuity in the care, when they were seen by the staff and when the staff knew them and their child. On the other hand, Patterson, Garwick, Bennett, and Blum (1997) found that, as a result of poor interpersonal communication patterns such as avoidance, disrespect or insensitivity, parents thought that the staff appeared to be non-supportive. Wright and Leahey (2005a) describe that a common error when talking to families is that the staff members assume or speculate about things instead of asking the families about things that are not clear. Further, they argue it is important to listen to sickness stories as the family members have a need to express and communicate their experience.

The "lived body" refers to the fact that we are always bodily in the world (van Manen, 1997b). This dimension was illuminated in that the family members felt tired when the child was under treatment. The sick child sometimes felt exhausted after receiving

treatment and the siblings were tired of being forced to move between different places. The working parent felt good being back at work although they often felt tired when there. The parent who was at home generally felt exhausted. After treatment the parents particularly felt tired as only then did they have the time to realise how tired they were. If stress is present over a long time period it takes a lot of strength from the individual and they can feel exhaustion (National Swedish Board of Health and Welfare, 2003). Boman, Viksten, Kogner, and Samuelsson (2004) suggest that it is important to pay close psychosocial attention to families during the first years of diagnosis, and even after the end of treatment, in order to recognize the stresses parents are exposed to.

The “lived time” refers to subjective time as opposed to clock time (van Manen, 1997b). This dimension was clarified in that the parents experienced the entire treatment having progressed quite fast, even if a single day could have seemed very long. Parents felt disappointment when too little time and attention were given to indicate that the child’s tough treatment regime was finished, as this moment was experienced as crucial and important for the parents. When the recovery begins it may be useful for the family if the staff clearly indicates that treatment has ended so that the family can re-establish the patterns and roles that existed before illness (Danielson et al., 1993). Making a ritual about the ending of treatment may make the family proud and enhance the understanding of their situation (Wright & Leahey, 2005b). Therefore it can be of importance for the staff to mark the ending of the treatment and emphasize for the families that they are entering a new phase.

## CONCLUSIONS AND CLINICAL IMPLICATIONS

The results from this thesis indicate that the families' life world broke when the child was diagnosed with cancer, but that almost immediately after this they began to strive for survival. This applied mostly to the sick child, but it also included the survival of the entire family. This strong survival urge lasted throughout the entire cancer treatment. Parents became totally important to both the sick child and the siblings, and their own family became more important than ever. However, siblings often felt divided from the rest of the family. It was important for the family to get support throughout the child's treatment course and they wanted the staff to be attentive to them and their needs. Support and understanding about what was going to happen, as well as about the treatment and the disease, seemed to make family members, especially the sick children and their siblings, more secure and less worried.

The findings from this thesis can deepen the understanding of what it is like to be a family living with childhood cancer and of the needs of young children with cancer. By reflecting on the results, staff may become increasingly thoughtful and thereby better prepared to take care of all the family members including the sick children themselves. The findings led to some reflections when caring for children with cancer and their families. These are:

- Parents are important for their children. Therefore they need to be supported so that they in their turn are able to support the sick child and the rest of the family during the child's whole cancer course
- The importance of a good communication with the children in order to give and to obtain information as well as to prepare the sick child before procedures can not be emphasized enough
- When it is not possible for siblings to stay with the family, it may be of importance that they have the opportunity to stay in their familiar environment
- When caring for children with cancer and their families it is of importance to:
  - Establish an individual care plan in consultation with each family to include scheduled family meetings throughout the whole cancer course in order to give and to get adequate information about the illness, the treatment and all other issues concerning the illness
  - Have supportive conversations with the family as a whole as well as with family members individually, listening carefully to their experiences throughout the entire cancer course
  - Have one or two designated paediatric oncologists, as well as two designated nurses working with each family as primary carers throughout the entire cancer course
  - Pay extra attention to marking the end of the child's cancer treatment.

## **FURTHER RESEARCH**

The findings from this thesis revealed new research questions:

- Few studies have followed the same families over a long time. Further research is needed to illuminate these families' experiences years after the child's treatment was completed
- The families experienced that they were in a great need of support. Often grandparents gave support in practical ways, for example by taking care of the siblings. Thus, it would be of importance to ask grandparents how they experience their situation, as little is known in this area
- Further research is needed to identify the ongoing and perhaps changing needs of young children with cancer
- To further illuminate the lived experience of those families who lose a child to cancer, as well as those experiencing a relapse.
- To further illuminate non-Swedish speaking families' experience of living with childhood cancer
- To further illuminate adolescents' experience of living with cancer.

## SUMMARY IN SWEDISH

### Svensk sammanfattning

De senaste årtiondenas medicinska framsteg har radikalt förändrat perspektivet på barncancer. I Sverige diagnostiseras omkring 300 barn varje år i cancer och idag botas ungefär 75 % av dessa. Behandlingen pågår ofta under långa perioder och är påfrestande både för barnet och den övriga familjen. För att kunna bota krävs samordnade insatser av såväl medicinsk vård som omvårdnad. Medicinska behandlingsprogram utvärderas med hjälp av longitudinella multicenterstudier, medan omvårdnadsforskningen i nuläget efterfrågar studier som fokuserar på hela familjen i ett longitudinellt perspektiv.

Syftet med avhandlingen var därför att belysa hela familjens upplevelser och behov samt vilken inverkan ett barns cancersjukdom och behandling har på enskilda individer inom familjen och på familjen som helhet.

En longitudinell design valdes för att kunna följa hela familjen under barnets hela sjukdoms och behandlingsperiod. Familjer vars barn fått en cancerdiagnos tillfrågades inom en månad från diagnostillfället om de ville delta. Kriterier för att familjen kunde delta var att familjen hade ett barn med cancer som var under 13 år, att barnet diagnostiserats med cancer för första gången, att familjen kunde tala och förstå svenska och att behandling (kirurgi i kombination med kemoterapi/strålning eller enbart kemoterapi/strålning) påbörjades inom en månad från diagnos. Sjutton familjer inkluderades i studien. Barnens diagnoser var leukemi (9), hjärntumör (4) och solid tumör (4). Datainsamling skedde med hjälp av intervjuer med enskilda familjemedlemmar över sju år vid tre olika tillfällen; i samband med diagnos (artikel I), under behandling (artikel III) och efter avslutad behandling (artikel IV). Barn under sju år observerades i samband med den initiala sjukhusvistelsen (artikel II).

I artikel I intervjuades fem barn med cancer, fem syskon, 17 mödrar och 12 fäder och i artikel II observerades tolv barn. Observationer utfördes i samråd med barn och föräldrar och planerades för att täcka olika situationer under barnets sjukhusvistelse. Fältanteckningar skrevs ner efter varje observationsperiod. Dessa skrevs sedan om till en berättande text där barnets behov analyserades med hjälp av innehållsanalys på manifest och latent nivå. I artikel III intervjuades fyra barn med cancer, fyra syskon, nio mödrar och nio fäder från elva familjer. I artikel IV intervjuades fyra barn med cancer, två syskon, tio mödrar och åtta fäder från tio familjer. Intervjuerna analyserades utifrån en hermeneutisk fenomenologisk ansats.

Familjens upplevelser då ett barn i familjen insjuknade i cancer beskrevs som att familjens livsvärld föll itu. Allt som tidigare varit tryggt och välkänt försvann och ersattes av känslor av rädsla, osäkerhet, kaos och ensamhet. I samma stund som familjernas livsvärld brast påbörjades nästan omedelbart och intuitivt en strävan att skapa en ny livsvärld med ett nytt ramverk för att underlätta familjens strävan att överleva både situationen samt barnets sjukdom.

De små barnens behov under den initiala sjukhusvistelsen uttrycktes som ”behov av att ha föräldern nära”, ”behov av att leka och känna glädje”, ”behov av att vara delaktig i vård och behandling”, ”behov av att ha en god relation med personalen” och ”behov av fysisk och emotionell tillfredsställelse”. Några av behoven kan relateras till cancerbehandlingen medan andra uttrycker behov som alla barn kan sägas ha. Det mest framstående behovet var att ha föräldern nära. Föräldrarnas närvaro och tillgänglighet gjorde barnen trygga så att de kunde uttrycka andra behov.

Under behandlingen upplevde familjen det som att det var ett ständigt kämpande att få vardagen att fungera och familjemedlemmarna kände sig trötta, splittrade, låsta och isolerade. Varje dag utgick ifrån det sjuka barnets behov. Om det fanns tid kvar delades den med syskon, föräldrarna enskilt och till sist föräldrarna som par. För att underlätta tillvaron då familjen befann sig i mitten av behandlingen försökte familjen att återfå någon form av normalitet, enskilda familjemedlemmar upplevde att de blivit experter på barnets symptom, på sjukdomen och på behandlingen. Deras syn på tillvaron förändrades.

Efter avslutad behandling upplevde familjen att de behövde införliva det som de gått igenom i sitt nuvarande liv. Alla familjemedlemmar kände en lättnad över att behandlingen var över men ibland upplevde de fortfarande prövningar. De hade behov av närhet både inom och utanför familjen samtidigt som de ibland saknade den omtanke och omsorg de känt under barnets behandling.

Resultatet från denna avhandling visar på att familjen har en stark strävan att ta sig igenom hela behandlingen och att barnet ska överleva sin cancersjukdom. Den egna familjens betydelse ökar i samband med att ett barn i familjen insjuknar i cancer. Den uppnådda känsla man fått av den egna familjens betydelse var något familjen ville bibehålla även efter avslutad behandling. Det verkar också som att föräldrarnas närvaro var avgörande för att kunna ge barnen en optimal vård.

Genom att få kunskap om hela familjens och enskilda individers upplevelser och behov kan vårdrutiner utvecklas och välbefinnandet hos barn med cancer och för familjen som helhet därmed förbättras.



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